

The Stigmatisation of Black South African Women around HIV  
and AIDS with Special Reference to the Machibisa and  
Esibusisweni Lutheran Congregations  
(1996-2005)

By

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**Declaration**

I, Xolelwa Mshubeki a candidate of Masters in Theology (History of Christianity) in the School of Religion and Theology, University of KwaZulu-Natal, Pietermaritzburg, hereby declare that except for the quotations specifically indicated in this thesis, and such help as I have acknowledged, this is wholly my original work and that it has not been submitted at any institute for the fulfilment of another degree.

Student..........

I acknowledge that this thesis is ready for submission

Supervisor.....

## **Table of Contents**

|                            |   |
|----------------------------|---|
| Acknowledgement            | 5 |
| Abstract                   | 6 |
| Acronyms and Abbreviations | 7 |

### **Chapter 1**

#### **Introduction**

|                                |    |
|--------------------------------|----|
| 1.1 Introduction               | 8  |
| 1.2 Objectives of the Study    | 8  |
| 1.3 Research Question          | 9  |
| 1.4 Research Hypothesis        | 9  |
| 1.5 Research Methodology       | 9  |
| 1.5.1 Oral History Methodology | 9  |
| 1.5.2 Secondary Sources        | 10 |
| 1.6 Theoretical Framework      | 10 |
| 1.7 Literature Review          | 12 |
| 1.8 Limitations                | 14 |
| 1.9 Conclusion                 | 14 |

### **Chapter 2**

#### **A Brief History of HIV and AIDS in South Africa**

|  |    |
|--|----|
| 2.1 Introduction   | 16 |
| 2.2 The Arrival and Spread of HIV and AIDS in South Africa         | 16 |
| 2.3 The Occurrence of and Response to HIV and AIDS in South Africa | 17 |
| 2.4 HIV and AIDS in South Africa from 1982-1995                    | 18 |
| 2.5 HIV and AIDS in South Africa from 1996-2004                    | 19 |
| 2.6 HIV and AIDS in South Africa from 2005-2006                    | 21 |
| 2.7 Conclusion   | 22 |

## **Chapter 3**

### **A Theoretical Discussion of the Concept of Stigma**

|   |    |
|---|----|
| 3.1 Introduction  | 23 |
| 3.2 What is Stigma?   | 23 |
| 3.2.1 Stigma of Deformity   | 24 |
| 3.2.2 Sexual Stigma   | 24 |
| 3.2.2.1 Homosexual Stigma   | 25 |
| 3.2.2.2 Homosexual Stigma in the Pre-Colonial Society                                       | 26 |
| 3.2.2.3 Christianity and Heterosexual Stigma  | 27 |
| 3.3 Contemporary Analysis of Stigma   | 28 |
| 3.4 The Stigma of HIV and AIDS  | 32 |
| 3.4.1 Indicators of HIV and AIDS-related Stigma   | 36 |
| 3.4.2 Sexuality and Stigma of HIV and AIDS  | 39 |
| 3.4.2.1 Stigmatisation of Women with regard to HIV and AIDS                                 | 39 |
| 3.4.2.2 Factors that leads to Stigmatization of Women                                       | 39 |
| 3.4.3 Gender-based Stigma   | 41 |
| 3.4.3.1 Use of Language   | 43 |
| 3.4.4 Death and the Stigma of HIV and AIDS  | 47 |
| 3.4.5 Witchcraft and Stigma of HIV and AIDS   | 50 |
| 3.5 Differences and Similarities of HIV and AIDS-related Stigma and the Stigma of Deformity | 51 |
| 3.7 Conclusion  | 52 |

## **Chapter 4**

### **A Brief Historical Overview of the Machibisa and Esibusisweni Lutheran Congregations**

|  |    |
|--|----|
| 4.1 Introduction   | 54 |
| 4.2 A Brief Historical Background of ELCSA                     | 55 |
| 4.3 Background of the Machibisa and Esibusisweni Congregations | 55 |
| 4.4 The Machibisa Lutheran Congregation                        | 56 |
| 4.4.1 History of the Machibisa Congregation                    | 56 |
| 4.4.2 Ecumenical Relations                                     | 57 |
| 4.5 Esibusisweni Lutheran Congregation                         | 57 |

|  |    |
|--|----|
| 4.5.1 History of the Esibusisweni Congregation | 57 |
| 4.5.2 Ecumenical Relations                     | 59 |
| 4.6 Conclusion                                 | 60 |

## **Chapter 5**

### **The Presentation of Findings and Analysis**

|   |    |
|---|----|
| 5.1 Introduction  | 61 |
| 5.2 The Machibisa Congregation  | 61 |
| 5.2.1 The Background of the Interviewees  | 62 |
| 5.2.2 The Research in the Machibisa Congregation  | 63 |
| 5.2.3 The HIV and AIDS Programme of the Machibisa Congregation  | 64 |
| 5.2.4 Disclosure in the Machibisa Congregation  | 65 |
| 5.2.5 Stigma in the Machibisa Congregation between 1995 and 2005<br>(males and females)                         | 66 |
| 5.2.6 Gender-based destigmatisation in the Machibisa Congregation   | 68 |
| 5.2.7 HIV and AIDS in the Machibisa Congregation  | 69 |
| 5.2.8 The Role of the Media in HIV and AIDS-related Stigma in the Machibisa<br>Congregation                     | 70 |
| 5.2.9 Plans of the Machibisa Congregation of HIV and AIDS Programme to Combat<br>Stigma                         | 71 |
| 5.3 Esibusisweni Lutheran Congregation  | 71 |
| 5.3.1 Profile of the Interviewees   | 71 |
| 5.3.2 The Research Process in the Esibusisweni Congregation   | 72 |
| 5.3.3 The HIV and AIDS Programme of the Esibusisweni Congregation   | 73 |
| 5.3.4 The HIV and AIDS support Group of the Esibusisweni Congregation   | 74 |
| 5.3.5 Disclosing HIV and AIDS status in the Esibusisweni Congregation   | 75 |
| 5.3.6 Holy Communion and HIV and AIDS-related Stigma in the Esibusisweni<br>Congregation                        | 77 |
| 5.3.7 HIV and AIDS-related Stigma in the Esibusisweni Congregation between 1995<br>and 2005 (males and females) | 80 |
| 5.3.8 The Experiences of HIV Positive Women in living with "Spoiled Identities"                                 |    |
| 5.3.9 Stigma and Culture  | 81 |
| 5.3.10 Stigma and the Bible   | 82 |
| 5.3.11 Conclusion   | 86 |

**Chapter 6**  
**Recommendations and Conclusion**

|   |    |
|---|----|
| 6.1 Recommendation                        | 87 |
| 6.2 Conclusion                            | 88 |
| <b>Appendix of LUCSA's Plan of Action</b> | 91 |
| <b>Bibliography</b>                       | 93 |

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**Abstract**

HIV and AIDS have historically been associated with homosexuality and promiscuity (especially among blacks), evoking blame and stigma. The implication of sex in the spread of HIV and AIDS complicates matters as traditional ideas of pollution and contamination are evoked. These attitudes translate into a lack of support for people infected with and affected by HIV and AIDS. Moreover, such attitudes result in the stigmatisation of those people, leaving them with a poor self-image. Stigmatisation also leads to secrecy and non-disclosure of the disease allowing it to spread rapidly. This thesis deals with the issue of stigmatisation due to HIV and AIDS, looking specifically at the two congregations of the Evangelical Lutheran Church in Southern Africa (ELCSA) in KwaZulu-Natal province.

## **Acronyms and Abbreviations**

|        |  |
|--------|--|
| ARV    | Antiretroviral                                 |
| AIDS   | Acquired Immune Deficiency Syndrome            |
| COSATU | Congress of South African Trade Unions         |
| ELCSA  | Evangelical Lutheran Church in Southern Africa |
| HIV    | Human Immunodeficiency Virus                   |
| HBTS   | Highveld Blood Transfusion Service             |
| LUCSA  | Lutheran Communion in Southern Africa          |
| LWF    | Lutheran World Federation                      |
| MEC    | Minister of Education and Culture              |
| IMC    | Inter-Ministerial Committee                    |
| NACOSA | National AIDS Convention of South Africa       |
| STD    | Sexually Transmitted Disease                   |
| SED    | South Eastern Diocese                          |
| TAC    | Treatment Action Campaign                      |
| UNAIDS | Joint United Nations Programme on AIDS         |

## **Chapter 1**

### **Introduction**

#### **1.1 Introduction**

This dissertation looks at the stigmatisation of black South African women regarding HIV and AIDS during the period 1996-2005, using the Machibisa and the Esibusisweni Lutheran congregations as a case study. Through this period (1995-2006) HIV and AIDS became visible as a pandemic in South Africa and South Africans became increasingly aware of the disease. The Machibisa congregation is part of the Pietermaritzburg-South Lutheran Parish in Pietermaritzburg, and the Esibusisweni congregation is part of the Ntuzuma Lutheran Parish, in Durban, both in KwaZulu-Natal province. Most members of these two congregations are Zulu. The two congregations fall under the South Eastern Diocese (SED), which is part of the Evangelical Lutheran Church in Southern Africa (ELCSA). The detailed historical background of the two congregations will be discussed in chapter four.

My decision to focus on this subject developed out of my interest in gender studies and because of my frequent visits to the Machibisa and Esibusisweni congregations. In addition, the experience of working as a student work at the Sinomlando Centre in the Memory Box Programme with women who are foster-mothers for HIV positive children made me aware that women are more stigmatised than men. The Sinomlando Centre is a centre for oral history and the Memory Box Program helps families affected by HIV and AIDS to record their stories as the way of enhancing resilience in the orphaned or soon-to-be-orphaned children. I refer in particular to an HIV positive woman whom I interviewed, she told me about how she was stigmatised both in the church and the community.

#### **1.2 Objectives of the Study**

The first objective of the study was to throw more light on the issue of the HIV and AIDS-related stigma in the Christian church in general, by examining the issue of stigmatisation in the two specific congregations. The second objective was to look at some of the practical demonstrations of stigmatisation of women in the two congregations.

### **1.3 Research Question**

The research question of this study is whether the Lutheran church, in the Machibisa and Esibusweni congregations, has been able to reduce the stigmatisation of women infected by HIV and AIDS. To answer this question, the research was guided by the following questions: What is the level of stigmatisation in Machibisa and Esibusweni Lutheran congregations? What have been the initiatives of the two congregations in the last ten years to reduce stigma? How successful have the two congregations been in bringing about gender-based de-stigmatisation? On the other hand, in what ways have the teachings of the two congregations contributed to gender-based stigmatisation? Are there any insights that can be drawn from the involvement of other faith-based organisations in the area of gender-based de-stigmatisation, which can be applied to these two congregations?

### **1.4 The Research Hypothesis**

The hypothesis of this study is that the teachings of the two congregations on HIV and AIDS have not been gender-sensitive and that women are more stigmatised than men. The hypothesis of the study is based on Kanyoro's theoretical framework on feminist cultural hermeneutics within African Women's Theology, which she describes as a key to African women's liberation.<sup>1</sup> It offers an opportunity to scrutinize culture and theologically discuss oppressive practices for the well being of women.

### **1.5 Research Methodology**

Oral and secondary sources have been employed in this study, with one complementing the other. In particular, chapter 5 relies mainly on oral sources.

#### **1.5.1 Oral History Methodology**

In chapter five, I have used the oral history methodology, as mentioned previously, as well as in chapter four. In chapter four, I have used oral interviews to obtain information about the historical background of the two Lutheran congregations. In chapter five, I have used oral interviews to acquire data concerning the life and experiences of the women sampled in relation to HIV and AIDS-related stigma. I have also used this methodology to determine the perception of HIV and AIDS-related

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<sup>1</sup> Kanyoro, M. *Introducing Feminist Cultural Hermeneutics: An African Perspective* Cleveland: The Pilgrim Press 2002 p. 20

stigma by other people in the community. These are the two ministers from the Machibisa and Esibusweni congregations, and also the chairperson of the AIDS Programme in the Machibisa congregation. In each congregation, different questionnaires were used for the minister, the chairperson of the AIDS Programme and HIV positive women (Esibusweni congregation). Structured open-ended questions were used. The interviews were individually conducted.

In the Machibisa congregation, the minister and the chairperson of the AIDS Programme committee were interviewed. None of the HIV positive people was prepared to disclose publicly his or her status and therefore no HIV positive people were interviewed. External evidence from both the minister and the chairperson of the AIDS Programme has been used to identify indicators of stigma in the congregation. The minister and the chairperson of the AIDS Programme of the Machibisa congregation also asked for their names not to be revealed in the dissertation.

In the Esibusweni congregation, the minister, the chairperson of the HIV and AIDS support group and nine HIV positive women were interviewed. The HIV positive women interviewed asked that their names not to be revealed in the dissertation. The HIV positive women interviewed were chosen randomly. The study employed the story-telling method, involving the HIV positive women talking about their experiences of stigma, societal and church treatment for HIV positive women.

### **1.5.2 Secondary Sources**

The secondary sources consisted of published books, unpublished articles, unpublished thesis and journal articles relevant to the topic. They contributed to a great deal in the discussion of the stigmatisation of black HIV positive women. They were analysed and compared with the interview results, to support the findings and place them within a broader context.

### **1.6 Theoretical framework**

Since this study is based on the stigmatisation of black South African women in the area of HIV and AIDS with special reference to the Machibisa and Esibusweni Lutheran Congregations between the periods 1996 to 2005, its conceptual framework is feminist cultural hermeneutics in the discipline of History of Christianity. The study

focused on the Lutheran congregations; therefore, Musimbi Kanyoro and other feminist theologians' views of the church will be used as part of the analysis when assessing the stigmatisation of women on HIV and AIDS.<sup>2</sup> The stigmatisation of women on HIV and AIDS is the result of patriarchy. Patriarchy involves men's domination and women's subordination.<sup>3</sup> Since any effort to help HIV positive women can be hindered by patriarchal structures, this research will investigate how the two Lutheran congregations ought to combat HIV and AIDS within a patriarchal setting.

The Bible also contains some passages that bear evidence of patriarchal influence. One has to bear in mind that while the Bible was written by men, they were from patriarchal cultures, and more importantly, it contains the Gospel, which leads to our salvation, and understood in our culture.<sup>4</sup> In Islam for example, women are given a lower status than that given to men. Men therefore use the Koran to justify patriarchal domination. The Koran, however, does not support the exploitation of women although it is used that way.<sup>5</sup> An examination of such religious beliefs and practices will be done with the view to seeing how the Lutheran church should correct such religious biases against women.

The African feminist cultural hermeneutics focuses on the importance of culture and religion, and how it fuels the construction of gender roles between men and women in societies. Cultural hermeneutics exposes the inequalities between women and men. It examines critically the gender imbalances between men and women in the church and in the society. It therefore aims to give a voice to those who are silenced. African feminists such as; Isabel Phiri, Mercy Oduyoye have come to realise that culture as well as the Bible are composed of patriarchy. Kanyoro points out that, culture can only be critiqued "when vulnerability of all participants is transparent"<sup>6</sup>. The Bible has great influence especially in its interpretation on the conduct of women in society. Sarojini Nadar, an African woman theologian, contends that:

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<sup>2</sup> Kanyoro, M. *Introducing Feminist Cultural Hermeneutics: An African Perspective* Cleveland: The Pilgrim Press 2002 p.18

<sup>3</sup> Haddad, B "Reflection on the Church and HIV/AIDS: South Africa" in *Theology Today* Vol. 62 2005 p. 32

<sup>4</sup> Phiri, I. "Domestic Violence in Christian in Christian Homes: A Durban Case Study", in Phiri, I. (ed) *Journal of Constructive Theology* Vol. 6 2000 p.85

<sup>5</sup> Haddad, B. "Reflection on the Church and HIV/AIDS in South Africa" in in *Theology Today* Vol. 62 2005 p. 33

<sup>6</sup> Kanyoro, M. *Introducing Feminist Cultural Hermeneutics: An African Perspective* Cleveland: The Pilgrim Press 2002 p. 22

Interpretation is a dynamic process, and, therefore, meaning should not be fossilized. Meaning should be evolving constantly. If biblical texts are used in the modern age as a basis for teaching and preaching, particularly because they are thought to contain examples of right living ..., then we cannot be satisfied with accepting characters as mere literary constructs simply because they come to us via an artistic medium.<sup>7</sup>

Using African women feminist cultural hermeneutics will serve as a tool for analysing culture and religion.

It is further stated that the “feminist reinterpretations challenge us to move away from endorsing the oppression of women in the text and in the society”<sup>8</sup>. It is further noted that the “feminist theological praxis suggests that telling and listening to the stories of those who are suffering, discriminated against, or oppressed is an essential starting point for counteracting silence, denial and stigma”<sup>9</sup>

### **1.7 Literature Review**

In an article written by Philippe Denise, on sexuality and AIDS, he starts by narrating a story that shows how a family set-up can allow or prevent the spread of HIV and AIDS, and how HIV and AIDS affect families.<sup>10</sup> Children grow up without sex education and consequently have wrong information or myths about sex. This wrong information or myths about sex, may lead to early sexual experiences, and possibly HIV infection. Silence on HIV and AIDS is the rule in most South African families in KwaZulu-Natal.<sup>11</sup> This may be the reason why most teenagers are reluctant to go for voluntary HIV and AIDS test and counselling.

Denis also points out that education on sexuality may be appropriate, because it could help both men and women to see the dangers arising from unprotected sex and

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<sup>7</sup> Nadar, S. “A South African Indian Womanist Reading of the Character of Ruth”, in Dube M. (ed.). *Other Ways of Reading: African Women and the Bible* Geneva: WCC Publications 2001 p.162-163

<sup>8</sup> Dube, M. “Adinkra! Four Hearts Joined Together: On Becoming Healing-Teachers of African Indigenous Religions in HIV and AIDS Prevention”, in Phiri, I. and Nadar, S. (eds) *African Women, Religion, and Health: Essays in Honor of Mercy Amba Ezwudziwa Oduyoye* Pietermaritzburg: Cluster Publications 2006 p. 62

<sup>9</sup> Ackermann, D. “Tamar’s Cry: Re-Reading and Ancient Text in the Midst of HIV and AIDS Pandemic”, in Dube, M. and Kanyoro, M. (eds). *Grant Me Justice! HIV/AIDS and Gender Readings of the Bible* Pietermaritzburg: Cluster Publications 2004 p.59

<sup>10</sup> Denis, P. “Sexuality and AIDS in South Africa” in *Journal of Theology for Southern Africa Vol.115* 2003 p.15

<sup>11</sup> Denis, P. “Sexuality and AIDS in South Africa” in *Journal of Theology for Southern Africa Vol.115* 2003 p.15

unfaithfulness in marriage. Furthermore, he mentioned HIV and AIDS as being a gender issue.<sup>12</sup> Therefore, it is important for both the church and society to address the issue of sexuality in order to give light on how sex should be handled, in view of HIV and AIDS.

The actions of society are related to the issue that "AIDS is a gendered pandemic. As such requires gender analysis to unravel the complex relationship between culture, gender, and religion and how this unholy trinity contributes to fuelling the pandemic".<sup>13</sup> The idea that there is a dominant figure in the treatment of HIV and AIDS shows that the other part is oppressed. HIV and AIDS is a gendered pandemic because more women are vulnerable to infection than men. According to Mabunda, "culturally, the differences between males and females were and are still widely assumed to be natural and hence not amenable to change".<sup>14</sup> Studies have shown that: "the fact that a man is far more likely than a woman to initiate, dominate and control sexual interactions and reductive decision-making creates a tremendous barrier to women being able to adopt HIV risk-reducing behaviour".<sup>15</sup>

Women are seen to be vulnerable when it comes to HIV and AIDS infection because "even where women are informed on how to avoid HIV infection, the need for reproduction and their traditionally subordinate role within the family and society, combined with their economic dependence on men, may prevent them from refusing unwanted, and often risky sexual intercourse".<sup>16</sup> The oppression in this case is the ability to prevent women to make decisions for themselves on their bodies. Musa Dube agrees to this when she states:

The process of national self-distancing has been deadly, since it gave HIV/AIDS sufficient time to spread before the community mobilized to be active in their prevention. The point here is that most African nations have

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<sup>12</sup> Denis, P. "Sexuality and AIDS in South Africa" in *Journal of Theology for Southern Africa Vol.115* 2003 p.16

<sup>13</sup> Ackermann, D. "Tamar's Cry: Re-reading and Ancient Text in the Midst of an HIV and AIDS Pandemic", in Dube, M. and Kanyoro, M. (eds) *Grant Me Justice! HIV/AIDS and Gender Readings of the Bible* Pietermaritzburg: Cluster Publications 2004 p.61

<sup>14</sup> Mabunda, P. and Lephala, M. "Patriarchal Practices and their Effects in Black Societies, and the Role of Women Teachers in Empowering Illiterate Women", in Malherbe, J. Kleijwegt, M and Koen, E. (eds) *Women, Society and Constrain* Pretoria: Unisa Press 2000 p.121

<sup>15</sup> "Commonwealth Secretariate", *Gender Mainstreaming in HIV/AIDS: Taking a Multisectoral Approach*. London: Marlborough House. 2002 p. 26

<sup>16</sup> "Commonwealth Secretariate", *Gender Mainstreaming in HIV/AIDS: Taking a Multisectoral Approach* London: Marlborough House. 2002 p. 27

not allowed themselves of the official name HIV and AIDS in African languages that would speak to African people, who are among the hardest hit by this pandemic.<sup>17</sup>

Education and information on HIV and AIDS need to be taught to both men and women in their own languages to enable them understand and know their rights fully. This will help them to pass on the information to their children and friends. Further discussion on gendered stigma appears in chapter three with the research of Denis Ackerman in her paper on “HIV and AIDS –Related Stigma Challenging Faith Communities.”

### **1.8 Limitations**

The fact that I visited the Machibisa congregation frequently was an obstacle to the HIV positive women being interviewed. The familiarity resulting from the visits could have made them think that disclosing their HIV positive status to me would lead to stigmatisation as I attend Sunday services with them. The second obstacle was the fact that I am a university student and in many cases people are suspicious of the motives of university students when conducting research.

In the Esibusisweni congregation, one of the obstacles to getting the intended number of HIV positive women for the interviews is that some of them only disclosed to the minister and they do not want other congregants to know about their status. Secondly, some of the members of the HIV and AIDS Support Group from the Esibusisweni congregation are not members of the Lutheran church. However, the people who are in charge of the support group are members of the Esibusisweni congregation.

### **1.9 Conclusion**

Chapter one is an introductory chapter of the thesis. Its main focus is to give a brief outline of what will be discussed in the dissertation. The chapter has outlined the background of the study, which comprises two Lutheran congregations with people affected and infected with HIV and AIDS. The awareness of the presence of stigma brought by my experience of working with the Sinomlando Centre motivated me to do the research in the two congregations. The objectives of the study are spelled out, the

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<sup>17</sup> Dube, M. “Re-reading the Bible: Biblical Hermeneutics and Social Justice” in Katongole, E. (ed). *African Theology Today* Scranton: University of Scranton Press 2000 p. 69

research question posed, the research hypothesis created, the limitations of the study described and the research methodology outlined.



## Chapter 2

### A Brief History of HIV and AIDS in South Africa

#### 2.1 Introduction

HIV and AIDS have a long history in South Africa, like other sexually transmitted diseases (STD), such as syphilis. This chapter will give a brief history of HIV and AIDS in South Africa. It will look at the arrival and the spread of HIV and AIDS in South Africa and will examine the response to the virus from 1982 to 2006

#### 2.2 The Arrival and Dispersion of HIV and AIDS in South Africa

HIV and AIDS had found a well developed system of migrant labour in the country to be “very facilitating environment and means for entrenchment in the African population at large, via its concentration on young men in the cities (many in single-sex hostels) far from their wives or families for months, and in its subsequent dispersal of these men (many now unwittingly HIV positive) back to their families in rural areas during holidays, or at the end of their contracts.”<sup>18</sup> As the director of Medical Research Council’s HIVENET Project put it, “the social dislocation and family disruption induced by the migrant labour system...create the right condition for rapid transmission of sexually transmitted infections, including HIV and AIDS”<sup>19</sup>

Some people believe that the diamond and gold rushes of the late nineteenth century “heralded the spread of STDs and endemic syphilis...into the interior from the coast”.<sup>20</sup> According to Jochelson, it was migrant mineworkers from Malawi who brought HIV and AIDS to South Africa. Therefore, the movement of mineworkers, into and within South Africa, has long been a key factor in the spread of the HIV and AIDS epidemic in modern South African history.<sup>21</sup>

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<sup>18</sup> Phillips, H. “AIDS in the Context of South Africa’s Epidemic History: Preliminary Historical Thoughts”, in *South African Historical Journal*. Vol. 45 November 2001 p. 12

<sup>19</sup> Karim, Q. “Trends in HIV and AIDS Infection: Beyond Current Statistics”, in *South African Journal of International Affairs*. Vol.7. 2000 p.15

<sup>20</sup> Jochelson, K. “Sexually Transmitted Diseases in the Nineteenth and Twentieth Century –South Africa”, in Setel, P. et al (eds) *Histories of Sexually Transmitted Diseases and HIV and AIDS in Sub-Saharan Africa* London: Greenwood Press. 1999 p. 219

<sup>21</sup> Phillips, H. “AIDS in the Context of South Africa’s Epidemic History: Preliminary Historical Thoughts”, in *South African Historical Journal*. Vol. 45 November 2001 p. 13

### 2.3 The Occurrence and Response on HIV and AIDS in South Africa

In 1982 HIV and AIDS was first discovered in South Africa. From then, the disease continued to spread, invoking various responses from various sectors of the South African society. The response on HIV and AIDS in South Africa has parallels with the response to the earlier epidemics. Blaming others (the homosexuals) for the spread of the disease has long history in South Africa's epidemic history, as Phillips put it, in "threatening epidemics, blaming others for bringing the disease has been the standard human response ever since history begun."<sup>22</sup> For example, in 429 BC, Athenians blamed the Peloponnesians for the plague, which decimated their city. In 1349, the Jews were blamed by the Germans for the Black Death. The spread of small-pox in Cape Town, in 1858 and 1882 was blamed on "dirty Malays" by the whites.<sup>23</sup>

In the same way, the bubonic plague in 1901 was attributed by many whites to "unhygienic" Africans. When HIV and AIDS appeared in the 1980s, "various sectors of prejudiced South African population similarly explained it in terms of their pet aversions."<sup>24</sup> In South Africa, gay white men were blamed by the heterosexuals for introducing HIV and AIDS into the country and spreading it through what one Dutch Reformed Church minister labeled as their "devious form of sexuality" and what one specialist from Groote Schuur Hospital called "the perverted practices of promiscuous homosexuality"<sup>25</sup>.

From the late 1980s, HIV and AIDS in South Africa became more common among heterosexuals, especially among Africans. Racist white accusations turned in the direction of Africans. An anonymous pamphlet circulated in 1989 urged whites to have their black domestic workers tested regularly for HIV test to "safeguard their families"<sup>26</sup> Acting in regard to these stereotypes, in 1990, the director of the Highveld Blood Transfusion Service (HBTS) decided that blood should no longer be taken from Africans and coloureds, asserting that blacks and coloureds were likely to be HIV

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<sup>22</sup> Phillips, H. "AIDS in the Context of South Africa's Epidemic History: Preliminary Historical Thoughts", in *South African Historical Journal Vol. 45* November 2001 p.14

<sup>23</sup> Davids, A. "The Revolt of the Malays: A Case Study of the Reactions of Cape Muslims to the Small Pox Epidemics of the Nineteenth Century Cape Town", in Saunders, C. et al (eds) *Studies in History of Cape Town Vol. 5* Cape Town: David Phillips Publishers. 1985 p.60

<sup>24</sup> Crewe, M. *AIDS in South Africa: Myth and Reality*. London: Lion Publishers 1992 p.14.

<sup>25</sup> Crewe, M. *AIDS in South Africa: Myth and Reality*. London: Lion Publishers 1992 p.14.

<sup>26</sup> "South African Institute of Race Relations", *Race Relations Survey*. Johannesburg: SAIRR 1986 p. 75

positive.<sup>27</sup> In the early 1990s, some young black activist believed that “AIDS was a plot by the white government to convince black people to have less sex, and therefore fewer children, lampooned the acronym AIDS as meaning, Afrikaner Invention to Deprive us Sex”<sup>28</sup> Other Africans interpreted HIV and AIDS to be the result of witchcraft.

Later, in the 1990s, in response to HIV and AIDS, some companies laid down a rule that in future, all applicants for life insurance in South Africa should take an HIV test before applying for the insurance. If the results proved positive, their applications were to be rejected. The Congress of South African Trade Union (COSATU) commented that such approaches showed that the maximizing profit was what the industry thought about first.<sup>29</sup>

#### **2.4 HIV and AIDS in South Africa from 1982-1995**

As mentioned previously, in 1982, the discovery of HIV and AIDS resulted in the first two official AIDS deaths to be recorded in South Africa. In 1987, the Chamber of Mines in South Africa identified one hundred and thirty employees with HIV and AIDS. Alarmed by the potential threat posed by “foreign” mine workers, the South African government passed regulations denying non-citizens with the HI virus entry into the country. HIV positive non-citizens were to be deported.<sup>30</sup> In 1988, the spokesperson for Health in South Africa, Dr Marius Barnard, asked that HIV “carriers” be isolated. In the same year (1988), the government launched an AIDS awareness campaign. In 1990, the first antenatal surveys for HIV test were carried out, and 0,7% of pregnant women tested positive.<sup>31</sup> In 1992, the National AIDS Convention of South Africa (NACOSA) was formed to begin developing a national strategy to deal with AIDS. The former minister of health, Dr Nkosazana Zuma accepted the NACOSA strategy in 1994, as the foundation of the government’s plan of action.<sup>32</sup>

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<sup>27</sup> “South African Institute of Race Relations”, *Race Relations Survey* Johannesburg: SAIRR 1986 p. 75

<sup>28</sup> Phillips, H. “AIDS in the Context of South Africa’s Epidemic History: Preliminary Historical Thoughts”, in *South African Historical Journal Vol. 45* November 2001 p.14

<sup>29</sup> “South African Institute of Race Relations”, *Race Relations Survey* Johannesburg: SAIRR 1986 p. 76

<sup>30</sup> “Natal Witness”, *Timeline of AIDS in South Africa*. 1 December 2004 p. 4

<sup>31</sup> “Natal Witness”, *Timeline of AIDS in South Africa*. 1 December 2004 p. 4

<sup>32</sup> “Natal Witness”, *Timeline of AIDS in South Africa*. 1 December 2004 p. 4

The number of AIDS cases escalated rapidly, reaching 8,784 reported cases by November 1995, made up of 3,941 adult males, 3,873 adult females, and 909 children. The annual national surveys of women attending antenatal clinics revealed that the prevalence among women had increased from 0.73% in 1990, to 10.44% by 1995.<sup>33</sup> Based on this survey, it was estimated that more than 1,8 million people were infected with HIV by the end of 1995, of which 719, 862 were males, 986,133 were females, and 40,557 were infants. Two patterns of transmission became apparent. In the white population, HIV was initially concentrated on the homosexual males, although gradually cases were found in the heterosexual population. Among Africans, HIV had been concentrated predominantly on heterosexuals.<sup>34</sup>

## **2.5 HIV and AIDS in South Africa from 1996-2004**

In 1996, NACOSA held a consultation on AIDS for members of Parliament, but only fourteen members attended. In 1997, a South African inter-ministerial committee on HIV and AIDS was established. In 2000, President Thabo Mbeki established a presidential advisory panel on AIDS, consisting of both orthodox and “dissident” scientists.<sup>35</sup> In the same year (2000), South Africa hosted an International AIDS Conference in Durban.<sup>36</sup> In 2001, Treatment Action Campaign (TAC), Dr Haroon Saloojee and the Children’s Rights Centre, “filed a motion in the Pretoria High Court”.<sup>37</sup> They intended to compel the health minister and provincial MECs to make Nevirapine available to all pregnant women who give birth in state hospitals. In 2002, the cabinet decided that anti-retroviral (ARVs) should be made available to all rape survivors and that the government should examine ways to introduce ARVs into public health.<sup>38</sup> In 2003, TAC launched its civil disobedience campaign, and the cabinet gave a go-ahead to a comprehensive AIDS treatment plan that was to offer free ARVs in all districts of the country.<sup>39</sup>

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<sup>33</sup> Jochelson, K. “Sexually Transmitted Diseases in the Nineteenth and Twentieth Century –South Africa” in Setel, P. et al (eds) *Histories of Sexually Transmitted Diseases and HIV and AIDS in Sub-Saharan Africa*. London: Greenwood Press 1999 p. 233.

<sup>34</sup> Jochelson, K. “Sexually Transmitted Diseases in the Nineteenth and Twentieth Century –South Africa”, in Setel, P. et al (eds) *Histories of Sexually Transmitted Diseases and HIV and AIDS in Sub-Saharan Africa*. London: Greenwood Press 1999 p. 233

<sup>35</sup> “Natal Witness”, *Timeline of AIDS in South Africa*. 1 December 2004 p. 5

<sup>36</sup> “Natal Witness”, *Timeline of AIDS in South Africa*. 1 December 2004 p. 5

<sup>37</sup> Ibid

<sup>38</sup> Ibid

<sup>39</sup> Ibid

The statistics released in September 2004 by the Department of Health on the HIV and AIDS pandemic in South Africa reveal that 5,6 million people (out of a population of 46 million) are HIV positive, and that about 3,1 million of these are women. The largest percentage of infected people is KwaZulu Natal, the province that is home to 37,5% of all HIV positive people in the country.<sup>40</sup> Some of the factors contributing to this high infection rate are the large numbers of migrant labourers, men who migrate to Johannesburg in search of jobs. Another factor is that a main transport route runs through the middle of KwaZulu-Natal and therefore there are many truck drivers passing through the province. Many women sleep with them in exchange for money. In most cases the use of a condom is very rare.<sup>41</sup>

The highest HIV/AIDS incidence is in urban informal areas (26,4%) and the lowest on farms (11,3%). According to Daniela Gennrich this may be because informal areas are less stable as communities than farm labourer communities, which tend to be more settled. Women are the most vulnerable group. Some black South African women are reluctant to disclose their status because of the fear of being isolated and stigmatized.<sup>42</sup> For example, Gugu Dlamini, an HIV positive woman from Durban, after disclosing her HIV status via the media in December 1998, was identified by a mob, stoned and stabbed to death. She thus became one of the first AIDS martyrs in South Africa. HIV and AIDS is nourished by silence. Fear of stigmatisation amongst women who believe that they are HIV positive has been found to be a barrier to accessing VCT (Voluntary Counselling and Testing).<sup>43</sup> Stigmatisation encourages people to deny and hide the real extent of the problem, simply so that they themselves can avoid the blame and its consequences.

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<sup>40</sup> Gennrich, D. (ed) *The Church in the HIV + World*. Cluster Publications: Pietermaritzburg 2004 p. 8.

<sup>41</sup> Gennrich, D. (ed) *The Church in the HIV + World*. Cluster Publications: Pietermaritzburg 2004 p. 8.

<sup>42</sup> Gennrich, D. 2004 p. 9

<sup>43</sup> Ntsimane, R. "To Disclose or not to Disclose: An Appraisal of the Memory Box Project as a Safe Space for Disclosure of HIV Positive Status", in *Journal of Theology for Southern Africa Vol.2* 2006 p.4

## 2.6 HIV and AIDS in South Africa from 2005-2006

Based on the sample of women attending 399 antenatal clinics across all nine provinces, the South Africa Health Study estimated that 16,510 women were living with HIV in 2005. The provinces with highest HIV rates were KwaZulu-Natal, Mpumalanga and Gauteng.<sup>44</sup>

In 2006, the South African government was criticized both domestically and internationally for its slow response on HIV and AIDS. Some of those criticisms were directed to Dr Manto Tshabalala-Msimang, a minister of health who has been nicknamed “Dr Beetroot” because of her focus on promoting the nutritional value of beetroot, garlic and lemon in the diet of people living with HIV and AIDS.<sup>45</sup>

Stephen Lewis, the general secretary for HIV and AIDS in Africa, in his address at the International AIDS Conference in Canada, August 2006 said, “South Africa is the only country in Africa whose government continues to propound theories more worthy of lunatic fringe than of a compassionate state”.<sup>46</sup> COSATU pushed the government to do more on HIV and AIDS.<sup>47</sup> The spokesperson of COSATU, Patrick Craven agreed with a letter from eighty-one scientist and academics to President Thabo Mbeki. They wrote, “good nutrition is important for all HIV positive people, but garlic, lemons and potatoes are not alternative to effective medication...”<sup>48</sup>

As a response to the criticisms, at the cabinet meeting on the 7<sup>th</sup> of September 2006, the deputy president Phumzile Mlambo-Ngcuka was assigned to oversee a new Inter-Ministerial Committee (IMC) on HIV and AIDS of cabinet ministers “to strengthen the implementation of a comprehensive HIV and AIDS Programme, improve co-ordination and communication and communication, and to monitor the implementation”.<sup>49</sup> The government confirmed that the minister of health would continue to lead the implementations of the government’s comprehensive plans on HIV and AIDS.<sup>50</sup>

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<sup>44</sup> <http://www.avert.org/aidssouthafrica.htm> accessed 1 December 2006

<sup>45</sup> “Mail & Guardian”, *Manto on AIDS: Fruit, Veggies not an Alternative to Medicine*. 26 September 2006 p.3

<sup>46</sup> <http://www.avert.org/aidssouthafrica.htm> accessed 1 December 2006

<sup>47</sup> <http://www.avert.org/aidssouthafrica.htm> accessed 1 December 2006

<sup>48</sup> <http://www.aidstruth.org>. accessed 3 December 2006

<sup>49</sup> <http://www.avert.org/aidssouthafrica.htm> accessed 1 December 2006

<sup>50</sup> <http://www.avert.org/aidssouthafrica.htm> accessed 1 December 2006

## **2.7 Conclusion**

This chapter gave a brief history of HIV and AIDS in South Africa. It looked at the arrival and dispersion of HIV and AIDS in South Africa. It has been shown that migrant labour provided a facilitating environment for the spread of HIV and AIDS. Furthermore, it examined the response of HIV and AIDS in South Africa, from 1982 to 2006. The response paralleled the response to the earlier epidemics. Blaming others for the spread of the disease was typical in South Africa's epidemic history. Various interpretations and discriminatory approaches typified the response. There was evidence that HIV and AIDS prevalence continued escalating. However, more women were infected than men. There were two main forms of transmission – homosexual and heterosexual. The government responses aimed at coping with the rise in HIV and AIDS prevalence. The international community expressed varied views on the HIV and AIDS pandemic in South Africa.

## Chapter 3

### A Theoretical Discussion on the Concept of Stigma

#### 3.1 Introduction

Stigma has been identified as one of the contributing factors to the spread of HIV and AIDS.<sup>51</sup> This chapter discusses stigma as a concept. There are many different focii of stigma, for example, epilepsy, sexuality and deformity. In this chapter, however, I have chosen to focus on stigma of deformity and sexually related stigmas. Firstly, my reason to focus on the stigma of deformity is because in South Africa, there are some people who are stigmatizing “disabled people”.

Secondly, my reason to focus on sexually related stigmas is because sexuality is the main route of HIV transmission in South Africa. The moment a person tests HIV positive, that person is regarded to have lived a “wayward” or “immoral” life. As a result, sexuality is sometimes seen as evil or bad.

The purpose of this chapter is to identify some of the causes that have shaped the hostility and rejection that stigmatised HIV positive individual’s experience. Understanding the history of stigma and its consequences for affected individuals and communities can help in developing better measures for combating and reducing stigma. This chapter also identifies and discusses indicators of stigma among HIV positive people. These indicators shall inform the interviews discussed in chapter four.

#### 3.2 What is Stigma?

The word “stigma” is derived from the Greek word referring to a tattoo mark. The tattoo mark was made on the skin of people who were devoted to certain services by putting a hot iron on particular parts of the body, such as the arms.<sup>52</sup> Later this message was somewhat secularized, “to designate the marking of an individual as a slave or criminal”<sup>53</sup>. Even in its early history, the concept of stigma was not static, but influenced by the social changes of the given epoch. Today the term stigma is used

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<sup>51</sup> Gennrich, D. (ed) *The Church in the HIV + World*. Cluster Publication: Pietermaritzburg 2004 p. 9

<sup>52</sup> Whitehead, E. “Historical Developments of Stigma”, in Mason, T. *Stigma and Social Exclusion in Health Care*. London: Routledge 2001 p. 17

<sup>53</sup> Whitehead, E. “Historical Developments of Stigma”, in Mason, T. *Stigma and Social Exclusion in Health Care*. London: Routledge 2001 p. 18

differently. It is applied more to disgrace and it has a negative connotation. In the contemporary time, a society's beliefs and attitudes continue to influence the meaning of stigma. The "profound and dramatic world events that shake the foundations of a society, cause its individual to re-consider, reflect, and re-priorities what is considered as really important to their individual communities"<sup>54</sup>. There are also strong cultural differences in what is considered as stigma, as well as regional variations within wider social contexts. However, it is not only the derivation of the word that is of interest, but also the accompanying semantics by which we come to know what it means to be stigmatized.

### **3.2.1 Stigma of Deformity**

Goffman in his book, *Stigma: Notes on the Management of Spoiled Identity* opens with a letter written by a sixteen-year-old girl, born with a congenital defect. This letter had been sent to an "agony aunt", and it was published in a magazine. It expressed the girl's sadness, loneliness and personal hurt for herself and her family due to an abnormality causing a "serious facial disfigurement". This letter reflects the profound stigmatizing impact of a congenital abnormality. Although this letter was written over thirty-five years ago, it captures a sense of stigma, which still has relevance today.<sup>55</sup>

The acceptance of a certain form of behaviour, a particular ethnic group or a specific physical abnormality in a certain society depends on the development of a society's cultural heritage, which may be determined by key historical and societal landmarks creating the values of that society.<sup>56</sup> The origin of such stigmatisation lies in the group feeling threatened by people who are perceived to undermine and contaminate the larger society. Such reaction can be regarded as arising from the fear of the unknown.

Historically, children born with abnormalities or who are disabled and their families were stigmatised. In Greek society, physical deformity was seen as a sign of divine punishment. Likewise, in Roman civilization, statutes instructed the head of a certain family to kill a child with physical deformity.<sup>57</sup> Garland writes that "in some sections of

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<sup>54</sup> Whitehead, E. 2001 p. 19

<sup>55</sup> Goffman, E. *Stigma: Notes on the Management of Spoiled Identity* London: Penguin 1990 p.7

<sup>56</sup> Whitehead, E. 2001 p. 18

<sup>57</sup> Whitehead, E. "Historical Developments of Stigma", in Mason, T. *Stigma and Social Exclusion in Health Care*. London: Routledge 2001 p. 52

Roman society, most notably the higher social classes, this law was not always followed, suggesting a sympathetic and compassionate response”.<sup>58</sup> It seems that important factors influencing reactions to the disabled in these early civilizations included concerns about the functional economic ability of the individual.

In medieval times, children with disabilities were viewed as devil’s substitutes for human children, with the perception that the parents of the disabled children were involved with black magic. Even the great protestant reformer Martin Luther, considered the disabled children as the devil’s incarnates and recommended that they should be killed.<sup>59</sup> Some societies still regard children with disabilities as incapable and a burden to a society. Children with disabilities experience exclusion from a very young age. Non-disabled children in turn, learn that exclusion of children with disabilities is the norm and therefore acceptable. These early experiences reinforce acceptance of segregation in later life.

The stigma of deformity is still present in many societies. When I grew up I used to hear some people saying that being disabled is a punishment for sin. They would say that those disabled should be thrown into bushes, because they were symbols of sin. However, now the South African government is supporting the disabled people in fighting for the right to be regarded as “normal” people.

### **3.2.2 Sexual Stigma**

There are different types of sexuality, such as bisexuality, homosexuality and heterosexuality. The most common ones in South Africa are homosexual and heterosexual sexuality. For example, a heterosexual person may be stigmatized as a result of having a baby out of wedlock or for not having a husband. In addition, some married people are also stigmatised because they have too many children. Therefore, they are given names like “producer of babies”. In this section, I will discuss sexually-related stigma as it concerns homosexuality and heterosexuality.

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<sup>58</sup> Garland, R. *The Eye of the Beholder: Deformity and Disability in the Graeco-Roman World*. London: Duckworth 1995 p. 70

<sup>59</sup>Whitehead, E. 2001 p. 52

### 3.2.2.1 Homosexual Stigma

Sexuality is frequently associated with heterosexuality. Attitudes of many of the world religions towards sexuality can be positive and affirming. However, there are instances of the opposite too. This is especially so when sexuality is other than heterosexual.<sup>60</sup> Such negativity forms and perpetuates the stigma of sexuality. In the early church, stigma was influential in the formation of Western civilization. For example, there were numerous examples of stigma attached with being a woman. Labour pains during childbirth were seen as a punishment for wrongdoings. Women were treated as having rights unequal to those of men. The condemnation of men who were thought to be feminine (homosexual) came in part from this gender inequality.<sup>61</sup> This condemnation occurred even when “the man had no choice in the matter, such as after having been raped by conquering soldiers in an act of utter brutality and humiliation”.<sup>62</sup> At the dawn of the new millennium the origins of stigmatisation continue to be as deeply rooted in the very fabric of society as they have ever been.<sup>63</sup>

In Africa, homosexuals struggle to affirm their identity because they have often been expected to deny their sexuality for the sake of surviving in the society. The subject of homosexuality is a huge taboo. Some Africans who are in same-sex relationships are not open to their families, because of the fear of being stigmatised. To many Africans, homosexuality is an abuse of traditional values. In South Africa, there are many people who see homosexuality as an abuse of traditional values, for example, the former deputy president of South Africa, Mr. Jacob Zuma. During the Heritage Day celebration in Durban, on the 24<sup>th</sup> of September 2006, Zuma said, “When I was growing up, an *ungqingili* (a gay person) would not have stood in front of me, I would knock him down”.<sup>64</sup> This angered the gays and lesbians of the country. Later, Zuma apologised. He said that he did not intend to have this interpreted as a condemnation of

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<sup>60</sup> Evans, D. “The Stigma of Sexuality: Concealability and Course”, in Mason, T. *Stigma and Social Exclusion in Health Care*. London: Routledge 2001 p. 105

<sup>61</sup> Evans, D. “The Stigma of Sexuality: Concealability and Course”, in Mason, T. *Stigma and Social Exclusion in Health Care*. London: Routledge, 2001 p. 105

<sup>62</sup> Evans, D. “The Stigma of Sexuality: Concealability and Course”, in Mason, T. *Stigma and Social Exclusion in Health Care*. London: Routledge, 2001 p. 106

<sup>63</sup> Evans, D. “The Stigma of Sexuality: Concealability and Course”, in Mason, T. *Stigma and Social Exclusion in Health Care*. London: Routledge, 2001 p. 106

<sup>64</sup> “The Witness”, *Zuma Sorry for Gay Insults* 29 September 2006 p.1

gays and lesbians. Instead, he meant that the communal upbringing of children was able to assist parents in noticing children with a different sexual orientation.<sup>65</sup>

It might be possible that Zuma was really condemning homosexuals, but because of the fear of losing support and the fact that he is a public figure or a politician, he had to apologise. In Africa, some black people see homosexuality as a sign of western sexual corruption and immorality. Some people see homosexuals as outcasts, bringing terrible shame to their family name and harming the family's value and reputation. Some homosexuals go underground, leading to a lack of self-esteem, increased insecurity and sometimes loneliness. It is not only the homosexuals that are stigmatised, but also the heterosexuals, for example, unmarried mothers with many children.

### **3.2.2.2 Heterosexual Stigma in the Pre-Colonial Society**

Pre-colonial cultures in Southern Africa were open about sexuality. Children learned about the mechanics of sex from the early age and played sexually explicit games. In many Southern African societies a form of non-penetrative "thigh sex" was the accepted practice for unmarried youths. Although there were strict rules around custodial rights, sex was not rule-bound. In other words, sex outside marriage would only be a problem once it resulted in pregnancy.<sup>66</sup> Extra-marital pregnancy was a problem, not because sex was sinful, but because of the custodial complication it created. Girls who became pregnant lost a great deal of their value in terms of bride wealth transaction.<sup>67</sup> Unmarried mothers were "shamed and even ostracized by their peers".<sup>68</sup> Unmarried mothers were absorbed in their fathers' households and allocated lands. Parental anger at the pregnant woman rarely persisted once the fines were paid, especially if the illegitimate child was a girl.<sup>69</sup>

Pitje described forms of sexual play amongst young children, which were ignored by the parents. For example, he noted that, "Pedi children usually sleep in the same room with their parents and can be no doubt early instructed in sexual matters. They cannot

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<sup>65</sup> "The Witness", *Zuma Sorry for Gay Insults* 29 September 2006 p. 1

<sup>66</sup> Delius, P. and Glaser, C. "The Myths of Polygamy: A History of Extra-Marital and Multi-Partnership Sex in South Africa", in *South African Historical Journal Vol. 50*. 2004 p. 86

<sup>67</sup> Ibid

<sup>68</sup> Ibid

<sup>69</sup> Ibid

help seeing sexual performance of their parents".<sup>70</sup> Many adults discussed sexual matters in the presence of their children. "Not only do they learn about sex from such indiscreet conversation but they also listen to quarrels in which whole lists of sexual obscenities and technicalities are recited".<sup>71</sup>

In the pre-colonial society, legitimate sexual activity was by no means confined to marriage. For example, there is a substantial evidence of a class of women, known as *amankazana* among the Xhosas and *amadikazi* in the Pondo tradition, who engaged in regular sexual relationships with (usually married) men. Some of these women are widows, runaways from abusive marriages and some are unmarried mothers.<sup>72</sup> Although they had a lower status than married women, "they were by no means social pariahs."<sup>73</sup> This was an acceptable life path for those who were not married. No one expected them to remain celibate. Attitude towards sex outside marriage and sex with many partners was not entirely stigma-free in pre-colonial society, but it was relatively tolerated in comparison to post-colonial society in the nineteenth century.<sup>74</sup>

### **3.2.2.3 Christianity and Heterosexual Stigma**

Some people believe that Christianity brought shame or stigma to the sexual act to Southern Africa. There were some Christian teachings that were not accepted by some of the Christian converts because they demanded from them too much of a cultural compromise, for example, monogamy and fidelity. This led some men to be discrete about their extra-marital affairs. Adulterous and unmarried women were disgraced, even excommunicated by the churches, while male adultery was overlooked.<sup>75</sup> Pregnancy before marriage was also not acceptable. The pregnant girl was required to start her Christian teaching from the beginning and publicly request forgiveness from the congregation after serving a period of probation. If she refused to do this, the church withheld baptism for the illegitimate child. Later, if the young woman wanted to get married, she was often denied a church marriage.<sup>76</sup>

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<sup>70</sup> Pitje, G. *Traditional and Modern Forms of Male Education amongst the Pedi and Cognate Tribes* University of South Africa: Unpublished Masters Thesis 1948 p. 65

<sup>71</sup> Hunter, M. *Reaction to Conquest* London: Oxford University Press, 1936 p. 235

<sup>72</sup> Hunter, M. 1936 p. 236

<sup>73</sup> Hunter, M. 1936 p. 236

<sup>74</sup> Hunter, M. 1936 p. 236

<sup>75</sup> Vilakazi, A. *Zulu Transformation: A Study of Dynamics of Social Change* Pietermaritzburg: University of Natal Press 1962 p. 62

<sup>76</sup> Vilakazi, A. 1962 p. 62

An association of married Christian women (*manyano*) was the enforcer of morality in sexual matters. With their effective internal policing mechanisms, “they imposed a powerful sense of shame around sexual misdemeanor”.<sup>77</sup> The *manyanos* also enforced prohibition against “white weddings” for those who had borne a child before marriage. Instead, they had to bear the shame of marrying in pink or blue dress.<sup>78</sup> Therefore, the existing stigma that I will discuss in the following paragraph has historical roots.

### 3.3 Contemporary Analysis of Stigma

The contemporary sociological analysis of stigma has its origin in the work of Goffman, who in turn was influenced by other sociological authors, such as Durkheim.<sup>79</sup> When the first edition of Goffman’s work *Stigma: Notes on the Management of Spoiled Identity* was published in 1963, “both academics and the lay readers were for the first time provided with a comprehensive sociological map of the concept of stigma techniques”.<sup>80</sup> It is difficult to encapsulate an absolute definition of stigma, but Goffman offers an excellent starting point on which to base further sociological exploration:

While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind in the extreme if a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted discounted one. Such an attribute is stigma.<sup>81</sup>

This extract shows how the individual can socially emerge as different. Goffman’s concern is to understand how and why some members of the society choose to stigmatize others. This can provoke the readers, irrespective of their sociological background, to critically consider the dynamics of stigma from either an experiential or a theoretical perspective.

In Goffman’s book, there are significant examples that clearly express the characteristics of stigma. These significant examples are personal experiences from

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<sup>77</sup> Gaistkell, D. “Housewives, Maids or Mothers: Some Contradictions in the Domesticity for Christian Women in Johannesburg 1903-1939”, in *Journal of African History* Vol.4 1983 p. 341

<sup>78</sup> Gaistkell, D. 1983 p. 341

<sup>79</sup> Goffman, E. *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin 1968 p. 82

<sup>80</sup> Whitehead, E. “Historical Developments of Stigma”, in Mason, T. *Stigma and Social Exclusion in Health Care* London: Routledge 2001 p. 20

<sup>81</sup> Goffman, E. 1968 p. 12

stigmatized individuals, and they ground the book “in the life world of the marginalized others.”<sup>82</sup> Goffman give the following example.

I [Goffman] met a man with whom I had been at school. He was, of course, a gay himself, and took it for granted that I was too. I was surprised and rather impressed. He did not look in the least like the popular idea of a homosexual, being masculine, well built, and neatly dressed. This was something new to me. Although I was perfectly prepared to admit that love could exist between men, I had always been slightly repelled by the obvious homosexuals whom I had met because of their vanity, their affected manner and careless chatter. This, it now appeared, formed only a small part of the homosexual world, although the most noticeable one...<sup>83</sup>

The gay person in Goffman’s example illustrates the difference as a dilemmatic relation within the concept of stigmatisation. The gay person understands that he will be stigmatised as different, and yet within the notion of being different he wishes to be seen as “normal” within his own group. Understanding social exclusion and its analysis as a major thread of social interaction of contemporary society is of fundamental importance. Goffman provides the framework to address the issue of why some individuals experience the perception of stigma. According to Goffman’s analysis, “when a person becomes a perpetrator of stigmatisation towards others, that individual will experience a number of emotional reactions”.<sup>84</sup> Those individuals who stigmatise others believe them to be of less value.<sup>85</sup> Although Goffman did not develop a sophisticated analysis of the power relations within institutional and social structures, however, his work provided a basis on which others could develop.

Another influential contribution comes from Edward Jones and his colleagues, whose work post-dates Goffman by twenty years. Edward Jones and the other sociological authors on *Social Stigma: The Psychology of Marked Relationships* have made a significant contribution to the understanding of the nature and social impact of stigmatised individuals.<sup>86</sup> They write, “the personal experiences of marginalised individuals are very much associated with emotional feelings of depression, anger, and

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<sup>82</sup> Goffman, E. 1968 p. 52

<sup>83</sup> Goffman, E. 1968 p. 53

<sup>84</sup> Whitehead, E. “Historical Developments of Stigma”, in Mason, T. *Stigma and Social Exclusion in Health Care* London: Routledge 2001 p. 21

<sup>85</sup> Whitehead, E. 2001 p. 22

<sup>86</sup> Whitehead, E. 2001 p. 22

humiliation".<sup>87</sup> The value of Jones' contribution is to show the relationship between societal values and the perceptions of the marginalised individual as a devalued person. Therefore, as perceived by vulnerable individuals, it is a feeling of stigma, which in this context deals with the personal responses of fear, anger and depression. The emotional impact of these feelings, "whether or not explicitly evoked by the societal response to the stigma, is implicitly felt as a corollary of those social expectations".<sup>88</sup> The result of this, according to Jones, is the development of the mental strategy to deal with the social implications of the stigma.<sup>89</sup>

Another effect of stigma on the individual can be low self-esteem. Self-esteem is a "summary evaluation of the attributes of the self or the extent to which individuals are satisfied or pleased with themselves".<sup>90</sup> High self-esteem is when the individuals feel positively about themselves and feel that they are worthy, whereas low-self esteem suggest negative feelings about the individual, dissatisfaction, and lack of respect or rejection of the individual.<sup>91</sup> Stigma is likely to have influence on self-esteem for a number of reasons. For example, stigmatising an attribute of an individual is likely to lead to lowered self-esteem because the average evaluation of the attributes comprising the individual will change. Negative feelings about one attribute of an individual often create an overall negativity towards the individual. A consideration of the influence of stigma on self-esteem is critical, because self-esteem is related to coping. Stigma establishes a barrier between the stigmatiser and the stigmatised.<sup>92</sup> For the stigmatised individuals, social contact with the stigmatisers may become stressful. As a result, stigmatised individuals are likely to feel uncertain about many of their thoughts.

Society categorises people according to the attributes that are felt to be ordinary and natural for members of the society. For example, when a stranger comes into a certain society, the first appearances are likely to enable the society to anticipate his or her category and attributes. The category and attribute that a stranger could be proved to

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<sup>87</sup> Jones, E. et al *Social Stigma: The Psychology of Marked Relationships* New York: W.H. Freeman 1984 p. 70

<sup>88</sup> Jones, E. et al 1984 p. 71

<sup>89</sup> Jones, E. et al 1984 p. 130

<sup>90</sup> Jones, E. et al 1984 p. 131

<sup>91</sup> Jones, E. et al 1984 p. 132

<sup>92</sup> Goffman, E. 1968 p. 15

posses will be called his or her “actual social identity”.<sup>93</sup> This can be compared to what is happening to people who are HIV positive. The next paragraph discusses the stigmatisation of HIV and AIDS.

### **3.4 The Stigma of HIV and AIDS**

South Africa has a history of segregation along racial lines. The tendency to divide between “us” and “them” seems to be playing itself out in the dynamics of HIV and AIDS.<sup>94</sup> This propensity gives rise to the stigmatisation that is so pervasive in HIV and AIDS discourse, together with the moral tone that surrounds it.<sup>95</sup>

From the start of the AIDS epidemic, stigma has contributed to the transmission of HIV and has greatly increased the negative impact of the epidemic. As Philippe Denis noted, “in spite of all the campaigns, people living with HIV and AIDS continue to suffer stigma and discrimination.”<sup>96</sup> Therefore, in order to identify potential solutions to HIV and AIDS related stigma, as it affects people living with HIV and AIDS, it is necessary to understand what facilitates stigma. In 1988, Gregory Herek and Eric Glunt described the public reaction to AIDS in the United States as an “epidemic of stigma”.<sup>97</sup> This figure of speech has turned out to be more appropriate than one would wish for, in many ways, the stigma of HIV and AIDS has had an even wider reach and a greater effect than the virus itself.

The suffering of people living with HIV and AIDS has been intensified by the stigma that surrounds the disease. HIV and AIDS became a disease of already marginalised or stigmatised groups, such as gay men, commercial sex workers and drug users.<sup>98</sup> In the initial era of the epidemic in most countries, HIV infection spread through the sexual networks of these stigmatised groups.<sup>99</sup> These marginalised groups were already stigmatised by the society, and this prejudice was carried over, and strengthened, when

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<sup>93</sup> Goffman, E. 1968 p. 15

<sup>94</sup> <http://www.avert.org/aidssouthafrica.htm> accessed 1 December 2006

<sup>95</sup> <http://www.avert.org/aidssouthafrica.htm> accessed 1 December 2006

<sup>96</sup> Denis, P. “Sexuality and AIDS in South Africa” in *Journal of Theology for Southern Africa Vol. 115* March 2003 p. 64

<sup>97</sup> Herek, G. and Glunt, E. *An Epidemic of Stigma: Public Reaction to AIDS* Washington: HIV and AIDS Legal Network 1988 p. 43

<sup>98</sup> Singhal, A. *Combating AIDS: Communication Strategies in Action* New Dehli: Sage Publishers 2003 p. 251

<sup>99</sup> Ibid

such individuals became identified as “carriers” of HIV and AIDS. This “double stigma”<sup>100</sup> of AIDS stemmed from the identification of AIDS as a serious illness and sexually transmitted disease. This gave rise to a common fear that by associating with people living with HIV and AIDS, individuals might put themselves at risk.<sup>101</sup>

Goffman’s work on stigma and its management is concerned with the everyday interaction of what he calls the “normals” and the “deviant”.<sup>102</sup> His work focuses on the management of the self in social situations. Goffman argues that, “there are conditions, especially those that involve some sort of potential stigmatisation, that interfere with rituals of everyday interaction”.<sup>103</sup> In keeping with Goffman’s theories, HIV positive people anticipate being judged and stigmatised, and will thus seek ways to protect themselves. HIV and AIDS, as a sickness that attacks the body, bring forth stereotypes on how those who are infected look.

HIV and AIDS also trigger reactions that interfere with normal social interaction between those who are infected and those who are not. Alcorn concurs that the imagery that surrounds any disease may shed light on how it is constructed in the popular imagination.<sup>104</sup> Moreover, stigma also reflects social status and according to Williams, “stigma is really a special kind of relationship between attribute and stereotype, where the stigmatised are assigned an inferior status relative to the rest of the society”. The stigmatising attributes trigger a chain of secondary consequences, such as fear of contamination.

The stigma of HIV and AIDS is also reflected in metaphoric language.<sup>105</sup> As the United Nations Programme on HIV and AIDS (UNAIDS) puts it, “since the beginning of the epidemic, the powerful metaphors associating HIV and AIDS with death, guilt, punishment, crime, horror and “otherness” have compounded and legitimated stigmatisation.”<sup>106</sup> In this way the stigma of AIDS is deeply rooted within the values of

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<sup>100</sup> Singhal, A. *Combating AIDS: Communication Strategies in Action* New Delhi: Sage Publishers 2003 p. 251

<sup>101</sup> Ibid

<sup>102</sup> Goffman, E. 1968 p. 69

<sup>103</sup> Goffman, E. 1968 p. 70

<sup>104</sup> Alcorn, K. “Illness, Metaphor and AIDS” in Aggleton, P. and Homans H. (eds) *Social Aspects of AIDS* London: The Falmer Press 1988 p. 136

<sup>105</sup> Ibid

<sup>106</sup> “HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful

everyday life. Sontag in *AIDS and Metaphors* examines the nature of stigma through a historical analysis of how illnesses have been perceived. She argues that it is not the mortality rate of the disease that engenders fear in the population. Stigma is rather the impact of the disease on the individual. According to Sontag, it is the disease that disfigures the face that is prone to being stigmatised.<sup>107</sup> Sontag's perception of stigma may be associated with the existing perception about HIV and AIDS. Like syphilis and other STDs, HIV and AIDS invoke the use of metaphors that give the epidemic a significance that it does not merit. HIV and AIDS is used by some people as a metaphor for sin and punishment. There are also "township metaphors" that are used when talking about HIV and AIDS. For example, one of my interviewees said:

In township lingo, AIDS is called *amagama amathathu*, meaning the three words. *Amagama amathathu* or three words was derived from HIV, which have three letters. It is also called *Z3* or *phamokate*. *Z3* is a model of a car, its linkage to HIV and AIDS refer to the number three in *Z3*. *Phamokate* was derived from a television Tswana drama on HIV and AIDS, where the main character had HIV and AIDS and subsequently died of AIDS.<sup>108</sup>

Furthermore, the interviewee said that there are experiences whereby whole conversations about HIV positive people went on in some communities using this language (metaphoric language). HIV positive people were not meant to understand these "conversations".<sup>109</sup> This constitutes a form of emotional violence.

Goffman asserts that, "within any historically situated social category, there are rituals that govern human interaction".<sup>110</sup> The interaction becomes stilted and difficult for both parties if these are interfered with. Moreover, in every such category, there are stereotypes of what the person ought to be or look like.<sup>111</sup> As an illness, HIV and AIDS is loaded with socio-cultural meaning because it is associated with anti-social attributes, such as an HIV positive person "signifies death."

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Programme", Geneva: UNAIDS 2005 p. 7

<sup>107</sup> Sontag, S. *AIDS and its Metaphors* London: Penguin Publishers 1989 p. 78

<sup>108</sup> An interview with an HIV positive woman from the Esibusweni Lutheran Congregation, Interview translated from Zulu to English language, 14 August 2006 in Durban.

<sup>109</sup> An interview with an HIV positive woman from the Esibusweni Lutheran Congregation, Interview translated from Zulu to English language, 14 August 2006 in Durban.

<sup>110</sup> Goffman, 1968 p. 88

<sup>111</sup> Herek, G. and Glunt, E. *An Epidemic of Stigma: Public Reaction to AIDS* Washington: HIV and AIDS Legal Network 1988 p. 50

Pierret says that, "owing to its (HIV and AIDS) transmissibility, and the cognitive representations surrounding it, AIDS turned out to be an illness that threatens the person's relationship".<sup>112</sup> In the same vein, Goldin noted that "in recent years the stigma has tended to define the bearer, rather than the sign carried by the bearer, and the bearer becomes known by the disease carried"<sup>113</sup> This becomes what Goffman calls the "total identity" of the individual. The concept of the "known-aboutness" of a disease links closely to the question of disclosure. A person's condition may be known about without them having disclosed it.<sup>114</sup>

In Goffman's terms, an individual whose stigmatising attribute is not yet known is discreditable to others. In such a situation, the individual may devise means to control the information about their condition. Goffman's work is devoted to the everyday interaction between what he calls "normal" and the "deviant"<sup>115</sup> Goffman's insights are indispensable to the understanding of the everyday challenges that HIV positive people face. Central to these challenges is the preoccupation with protecting one's identity as a "normal" person, one who does not have a deadly disease. All efforts and energy become focused on protecting this knowledge and watching carefully for changes in the behaviour of others.

For example, one HIV positive woman whom I interviewed had to disclose her status to her children. As a result, she was very vigilant in looking for signs that showed that they might know about her medical condition. She would listen carefully to their conversations, steer these conversations to areas that might reveal whether they knew or not and would then breathe a sigh of relief when such signs were not there. She had become very paranoid about people finding out about her HIV status. This is what she said:

As long as I have not told them [about her HIV status], I will not allow them to talk to me about it. They [her children] are now fighting against other people about this. [Allegations that she was HIV positive]<sup>116</sup>

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<sup>112</sup> Pierret, J. "Everyday Life with HIV and AIDS: Surveys in Social Sciences", in *Journal of Social Sciences and Medicine Volume 6* 2000 p.1589

<sup>113</sup> Goldin, C. "Stigmatisation and AIDS: Critical Issues in Public Health", in *Journal of Social Sciences and Medicine Volume 9* 1994 p.1359

<sup>114</sup> Goffman, 1968 p. 88

<sup>115</sup> Goffman, 1968 p. 88

<sup>116</sup> An interview with an HIV positive woman from the Esibusisweni Lutheran Congregation, Interview translated from Zulu to English language, 14 August 2006 in Durban.

In this instance, the interviewee was talking about her children. This attitude was however generalized to other people. According to my interviewee, she did not stay in one place. She moved from place to place as soon as she thought that people she was staying with suspected that she was HIV positive. Although my interviewee was determined to hide her medical status from her friends and family, her behaviour may also, ironically, have contributed towards their realisation that she was HIV positive. Her tendency to move frequently and to closely observe those around her would not have gone unnoticed in the vigilant "township gossip system". In a quest to safeguard HIV and AIDS status, the individual may avoid contact with others lest his or her secret was discovered. This means that she or he would effectively experience a social death before the physical one. Following Goffman's thoughts on stigma, this is because of the fear of being stigmatised. There are attitudes, behaviours or discourses that could be taken as signs of stigma. These are discussed in the next section as indicators of HIV and AIDS-related stigma.

### **3.4.1 Indicators of HIV and AIDS-related Stigma**

Stigma manifests itself externally or internally, and has different effects. External stigma "refers to actual experience of discrimination".<sup>117</sup> This includes the experience of domination, oppression and exclusion. It sometimes leads to violence against an HIV positive person. Internal stigma is the shame associated with HIV and AIDS and HIV positive people's fear of being discriminated against."<sup>118</sup> It can be a mechanism to protect oneself from external stigma and can result in the refusal or reluctance to disclose ones HIV positive status or the denial of HIV and AIDS.

HIV and AIDS related stigma has often been identified as a primary barrier to HIV prevention as well as the provision of treatment, care and support.<sup>119</sup> This is because of the belief that HIV and AIDS is somehow associated with the disgrace and shame that leads to further discrimination. This, in turn, leads to violation of the human rights of people living with HIV and AIDS.<sup>120</sup>

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<sup>117</sup> "Fighting HIV-Related Intolerance: Exposing the Links between Racism, Stigma and Discrimination", Geneva: UNAIDS July 2001 p. 1

<sup>118</sup> "Fighting HIV-Related Intolerance: Exposing the Links between Racism, Stigma and Discrimination", Geneva: UNAIDS July 2001 p. 1

<sup>119</sup> Bond, V. et al *The Dimension and Wider Context of HIV/AIDS Stigma Resulting Stigma in Southern Africa* Stockholm: Swedish International Development Co-operation 2002 p. 34

<sup>120</sup> Gennrich, D. 2004 p. 1

HIV and AIDS stigma reduction is now a key objective of many HIV and AIDS Programmes, such as health education, church and community empowerment.<sup>121</sup> However, indicators are needed to monitor changes and progress during implementations and also to provide tangible evidence for evaluation of the outcomes and the efforts to combat stigma.

As much as it is difficult to identify stigma in a society, there are particular behaviours that indicate the presence of stigmatisation. An individual would be considered stigmatised if these indicators are present in his or her life experiences. These are not exclusively AIDS-related, but a combination of several would highly suggest the presence of stigma.

The first indicator of stigma is broken relationships and the difficulty to sustain a healthy relationship. The external prejudice by society leads to lack of trust and the breakdown of relationship. Sometimes the members of the society initiate the breakdown of relationships.<sup>122</sup> These include relatives, church members, and religious leaders. If an HIV positive person suddenly differs with his relatives and friends following their awareness of the person's status, then that could be taken as an indicator of the presence of stigmatisation in that community.<sup>123</sup> The failure to initiate normal healthy relationships with business partners and neighbours could also indicate the presence of stigma in a society. Therefore, in this research the presence of broken relationships or the inability to sustain healthy relationships shall be considered as an indicator of stigma.<sup>124</sup>

The second indicator is rejection. Sometimes persons that are HIV positive often find themselves unable to participate in social events as well as other societal functions. For instance, they may not be invited to wedding banquets, birthday parties and church anniversaries due to their HIV status. In a church context, they may even be excluded

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<sup>121</sup> Parker, R. and Aggleton, P. "HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action", in *Journal of Social Science and Medicine Vol. 57* 2003 p. 13

<sup>122</sup> Parker, R. and Aggleton, P. "HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action", in *Journal of Social Science and Medicine Vol. 57* 2003 p. 14

<sup>123</sup> Ibid

<sup>124</sup> Ibid

from the Holy Communion, the choir and church leadership positions.<sup>125</sup> Sometimes HIV positive people are also rejected by being asked to leave their places of residence or social setting after publicly disclosing their HIV positive status. Whenever these kinds of rejections are found directly or indirectly associated with one's HIV status, then such could be taken as an indicator of the presence of stigma in the society.

The third indicator is self-exclusion. Due to external pressure on HIV positive people in a form of rejection, they tend to lack self-esteem. They keep to themselves and close out external interventions.<sup>126</sup> Sometimes they choose not to seek out services or opportunities associated with HIV and AIDS because of the fear of being stigmatised.<sup>127</sup> For example, some of them choose not to apply for jobs because of the fear of being stigmatised if their HIV positive status is known.

The fourth indicator is fear of disclosure. For some HIV positive people, disclosing their status is a difficult challenge, as they are sometimes concerned about the consequences for themselves and those close to them.<sup>128</sup> As a result, some HIV positive people do not disclose to others the news of their HIV status. An individual can feel obliged to disclose their status to three individual sets of people: his or her parents; neighbours; colleagues at work and other social acquaintances.<sup>129</sup> Moreover, the negative connotations and blame that accompany HIV and AIDS infection as the result of sexual immorality makes it difficult for HIV positive people to disclose their status.<sup>130</sup> Therefore, this could also be found as an indicator of the presence of stigma in a society or church. Although images associated with HIV and AIDS vary, they are patterned so as to ensure that HIV and AIDS-related stigma plays into, and reinforces social inequalities.<sup>131</sup>

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<sup>125</sup> Bond, V. et al *The Dimension and Wider Context of HIV/AIDS Stigma Resulting Stigma in Southern Africa* Stockholm: Swedish International Development Co-operation 2002 p. 34

<sup>126</sup> Bond, V. et al *The Dimension and Wider Context of HIV/AIDS Stigma Resulting Stigma in Southern Africa* Stockholm: Swedish International Development Co-operation 2002 p. 35

<sup>127</sup> Ibid

<sup>128</sup> Bond, V. et al *The Dimension and Wider Context of HIV/AIDS Stigma Resulting Stigma in Southern Africa* Stockholm: Swedish International Development Co-operation 2002 p. 36

<sup>129</sup> Ibid

<sup>130</sup> Ibid

<sup>131</sup> For a theoretical elaboration of the linkages between stigma and the reproduction of social difference, see Parker R and Aggleton P, "HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action" in *Journal of Social Science and Medicine Vol. 57* 2003 p. 13-24

### **3.4.2 Sexuality and Stigma of HIV and AIDS**

With regards to the spread of HIV and AIDS, sexual transmission has received more condemnation than any other means of transmission. Religious laws and societal value taboos have been webbed around the subject of sexuality. For example, Wolf pointed out that in Malawi, some traditional healers associated AIDS with *kanyara*, “a wasting disease caused by pollution through sexual contact soon after menstruation or giving birth”.<sup>132</sup> Therefore, HIV and AIDS is not only seen as the result of sexual promiscuity, it is also understood to be the outcome of breaches of sexual taboos. These forms of explanation of HIV and AIDS contributed to the level of stigma, especially on women.

#### **3.4.2.1 Stigmatisation of Women in HIV and AIDS**

Focusing on the stigmatisation of women does not mean that men are not stigmatised. However, women are more stigmatised than men because of gender imbalances. It is necessary to look at the power imbalances that hinder a right relationship between the genders, which must be broken down. These imbalances include culture, gender and sexual inequalities. Sanders pointed out that, “Customs and practices which promote a cycle of illness and death must not be preserved. Gender values and disempowerment of women give men a false sense of power and one killing our youth”<sup>133</sup>

#### **3.4.2 Factors that leads to Stigmatisation of women in South Africa**

According to a research done by Qakisa, “on average, 1 in 4 sexually active people is HIV positive and statistics from more than 400 clinics across the South Africa show that 25% of women attending antenatal clinics are HIV positive.”<sup>134</sup> The biological make-up of women and their lack of power to determine where and how sex takes place puts them at high risk of infection. Mpine Qakisa also added that:

The poverty and powerlessness of women in South Africa make them increasingly vulnerable to AIDS. Furthermore, inequality based on apartheid policies and cultural beliefs or expectations heighten women’s vulnerability to HIV infection. In many South African cultures women and girls do not have

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<sup>132</sup> Wolf, A. *AIDS or Kanyara? Concepts of Sexuality and the Discourse of Morality in Malawi* Unpublished paper presented at AIDS Context Conference, Johannesburg: University of Witwatersrand, April 2001 p. 2

<sup>133</sup> Sanders, F. “Gender is not Synonymous with Sex”, in *AIDS Bulletin Vol. 93* September 2000 p.16

<sup>134</sup> Qakisa, M. “The Media Representation of Women and HIV/AIDS: How it Affects Preventive Messages”, in *Missionalia Vol. 2* August 2001 p. 306

power to negotiate safer sex because of their lower social and economic status. A majority of HIV positive women get the virus at home, not on the streets.<sup>135</sup>

However, it is now common knowledge that, with HIV and AIDS, it is not the condition itself that hurts most (because many other diseases and conditions lead to serious suffering and death), but “the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV positive people have to deal with.”<sup>136</sup>

The impact of HIV and AIDS on South Africa women is particularly acute. There are important differences between men and women in the underlying stigma of the pandemic in our societies. This stems from gender differences between men and women in their respective roles, responsibilities and access to resources and decision-making. The inequity that women and girls suffer as a result of HIV and AID serves as a result of a “barometer” of their general status in the society and the discrimination they encounter in all fields, including health, education and employment.”<sup>137</sup>

Despite the realities of the patterns of infection, gender stereotypes allow women to be blamed for the spread of HIV. Men are often reported to be infected by sex workers (prostitutes) or casual girlfriends, who may be blamed by men and, unfortunately, some women alike, while less blame tends to fall on men who have multiple partners. People who know little about HIV and AIDS associate it with “loose women” rather than believing themselves to be at risk of the spread of the disease. Some Christians still hold firm to the belief that it comes from promiscuous women.<sup>138</sup> In early work on stigma, the concept was meant to refer to a whole spectrum of people “who are regarded negatively, for having violated rules, others for being the sort of people they are or having traits that are not highly valued”<sup>139</sup>

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<sup>135</sup> Qakisa, M. “The Media Representation of Women and HIV/AIDS: How it Affects Preventive Messages” in *Missionalia Vol. 2* August 2001 p. 306

<sup>136</sup> Ibid.

<sup>137</sup> “Commonwealth Secretariate”, *Gender Mainstreaming in HIV/AIDS: Taking a Multisectoral Approach* London: Marlborough House 2002 p. 26

<sup>138</sup> Haddad, B “Reflection on the Church and HIV/AIDS: South Africa”, in *Theology Today Vol. 62* 2005 p. 13

<sup>139</sup> Ibid

In South Africa, HIV and AIDS-related stigmatisation is closely linked to sexual stigmatisation, particularly gender-related stigma. Very often, the source of gender-related stigma is linked to what is considered proper and improper behaviour, especially those related to issues of sexuality.<sup>140</sup> Despite the significant amount of epidemiological data revealing high rates of infection among married women due to their unfaithful husbands, the predominantly male public continues to portray “loose women” with multiple sexual partners as the root cause of the HIV pandemic.<sup>141</sup> Such a misconstrued notion continues to endanger the lives of women.<sup>142</sup> A comprehensive understanding of why women are highly stigmatised in this respect can only emerge if this process is understood in relation to power and domination of men. Stigmatisation functions at the point of intersection of power, culture and differences between men and women.<sup>143</sup>

### 3.4.3 Gender -based Stigma

Denis Ackerman asserts that, “focusing on stigma can undermine the productive debate on how to deal with HIV and AIDS.”<sup>144</sup> If the concept stigma becomes “an umbrella concept under which all debates resort, it can divert attention from responsibility to address the realities of transmission”.<sup>145</sup> If we only speak about stigma, that can shift the focus from the reality that the infection is the result of certain types of behaviours.<sup>146</sup>

However, HIV and AIDS, “finds particularly fertile grounds within the groups that are already stigmatised.”,<sup>147</sup> for example, women and widows and this is called gender-based stigma. “Gendered-based stigma feeds pre-existing stigma, imprisoning people in

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<sup>140</sup>Haddad, B “Reflection on the Church and HIV/AIDS: South Africa”, in *Theology Today* Vol. 62 2005 p. 13

<sup>141</sup> Ibid

<sup>142</sup> Haddad, B “Reflection on the Church and HIV/AIDS: South Africa”, in *Theology Today* Vol. 62 2005 p. 14

<sup>143</sup> Ibid

<sup>144</sup> Ackerman, D. *HIV and AIDS –Related Stigma Challenging Faith Communities: A Feminist Theological Response* Unpublished paper presented at an International Colloquial in Stellenbosch, 5 July 2006 p. 2

<sup>145</sup> Ackerman, D. *HIV and AIDS –Related Stigma Challenging faith, Communities: A Feminist Theological Response* Unpublished paper presented at an International Colloquial in Stellenbosch, 5 July 2006, p. 2

<sup>146</sup> Ackerman, D. *HIV and AIDS –Related Stigma Challenging Faith Communities: A Feminist Theological Response* Unpublished paper presented at an International Colloquial in Stellenbosch, 5 July 2006 p. 2

<sup>147</sup> Ibid

the situations that they are powerless to change and depriving them of their full humanity”<sup>148</sup>

Much has been written on the HIV and AIDS as a gendered pandemic by African women feminist theologians, such as Musa Dube and Isabel Phiri. Much of the studies have shown how HIV and AIDS is really a gendered pandemic. According to the South African HIV and AIDS Epidemic Report of 2004:

Inequality and power imbalances between women/girls and men/boys in our society heighten the vulnerability of females to infection. In South Africa, women are often taught from early childhood to be obedient and submissive to males. In sexual relations, women are usually taught not to refuse sex to their husbands, regardless of whether the husband has other partners or is unwilling to use condoms <sup>149</sup>

Added to these gender inequalities is the fact that many women in the country have received higher education and this lack of education makes them more vulnerable to contracting HIV.

Nadja Jacobowski in his publication has examined the link between heterosexual marriage and women’s vulnerability to HIV in the Indonesian context. He states: “In this country, gender relations are currently dominated by traditional beliefs and practices and by religious morality”.<sup>150</sup> Although this context is different from our African context, the two contexts have some similar ways of handling traditional marriage practices, such as early marriages.

Contrary to the text John 8:1-11, the African feminist theologian Musa Dube has made an attempt to re-read the story of Mark 5:21-43. She writes this text “...from the multiple levels of postcolonial, feminist and HIV and AIDS perspectives”.<sup>151</sup> Dube notes that re-reading the story of the bleeding woman in Mark 5:21-43 together with the

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<sup>148</sup> Ackerman, D. *HIV and AIDS –Related Stigma Challenging Faith Communities: A Feminist Theological Response* Unpublished paper presented at an International Colloquial in Stellenbosch, 5 July 2006, p. 2

<sup>149</sup> “Commonwealth Secretariate”, *Gender Mainstreaming in HIV/AIDS: Taking a Multisectoral Approach* London: Marlborough House 2002 p.30

<sup>150</sup> Jacobowski, N. “Marriage is not a Safe Place: Heterosexual Marriage and HIV-related Vulnerability in Indonesia”, in *The Culture, Health & Sexuality: An International Journal for Research, Intervention and Care* Vol. 10 2007 p. 87

<sup>151</sup> Dube, M. “Re-reading the Bible: Biblical Hermeneutics and Social Justice”, in Katongole, E. (ed) *African Theology Today* Scranton: University of Scranton Press 2002 p 57

story of HIV and AIDS<sup>152</sup> "...should be a central part of our learning, living, researching, writing and teaching as the academy and also as communities of faith to bring hope, healing, liberation and life to a world that is often overshadowed by death"<sup>153</sup>

Denise Ackermann, an African feminist theologian offers a preliminary framework for the story of Tamar, 2 Samuel 13:1-22. In her publication, entitled, *Tamar's Cry: Re-Reading and Ancient Text in the Midst of an HIV and AIDS Pandemic*, Ackermann's work focuses on "possible clues on how the Body of Christ can find its way through the present ravages of sickness and death".<sup>154</sup> Ackermann's re-reading of the Tamar story is from her context, which she terms "my place, a place in which the "bleak immensity" of violence against the bodies of women and children, now haunted by the spectra of HIV and AIDS, rages on".<sup>155</sup> She sees gender inequalities resulting in rape, and poverty as the driving forces for HIV and AIDS as she points out that: "Gender inequality and the snail-like pace at which poverty is being tackled are the main problems blocking effective HIV and AIDS prevention".<sup>156</sup>

### **3.4.3.1 Use of Language**

Re-reading the texts Mark 5:21-43; 2 Samuel 13:1-22 and John 8:1-11 from a feminist cultural hermeneutical point of view invites us to open our eyes and realize that what happens in our communities, especially issues concerning violence against women, have a resource in the Bible. For this reason, the language used in the church concerning women's issues needs to be revised. Phiri in her publication, *The Church as a Healing Community...* observes that:

The language for God also reflects how women are imaged. Women have been made to feel that they are excluded from some aspects of the Church because of the Church's interpretation of their bodies, which are

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<sup>152</sup> Dube, M. "Re-reading the Bible: Biblical Hermeneutics and Social Justice", in Katongole, E. (ed) *African Theology Today* Scranton: University of Scranton Press. 2002 p 57

<sup>153</sup> Dube, M. "Rereading the Bible: Biblical Hermeneutics and Social Justice", in Katongole, E. (ed). *African Theology Today* Scranton: University of Scranton Press. 2002 p 59

<sup>154</sup> Ackermann, D. "Tamar's Cry: Re-reading and Ancient Text in the Midst of an HIV and AIDS Pandemic", in Dube, M. and Kanyoro, M. (eds) *Grant me Justice! HIV/AIDS and Gender Readings of the Bible* Pietermaritzburg: Cluster Publications 2004 p.28

<sup>155</sup> Ibid

<sup>156</sup> Ibid.

considered to be impure. The church in Africa needs to proclaim a Gospel that presents both women and men as reflecting the image of God.<sup>157</sup>

This means that when texts like 2 Samuel 13:1-22 and John 8:1-11 are imposed on women who have been raped or living with HIV in our contexts, the church shows no compassion or ability to accommodate these women. Instead, the church authorities are too quick to judge women as they find support from the biblical texts that stigmatize women.

The reason for HIV to be a gendered pandemic is “because of social pressures and cultural norms, as women may also have limited access to information about HIV and AIDS, sexuality and reproductive health”<sup>158</sup> The cultural norms blindfold women from seeing the oppressive structures imposed on them. This reinforces oppression of women by women.<sup>159</sup> For instance, many women in polygamous marriages are threatened by each other; as a result, their lives are surrounded by jealousies, quarrels and fights. Moreover, their education is limited because they are not exposed to the relevant information they may have had through education.

Some cultural norms such as widowhood inheritance are fuelled by women and these contribute to women being the target of being infected by HIV and AIDS.<sup>160</sup> It is stated that “there are also harmful traditional and customary practices that make women and girls more vulnerable, such as early marriage, wife inheritance and wife cleansing”.<sup>161</sup> Both women and girls are exposed to HIV and AIDS because they want to fulfil the cultural duties which make them risk their lives in contracting HIV and AIDS. In conclusion one may deduce that “the reasons for this vulnerability include factors relating to poverty, lack of information, lack of economic and social empowerment, and lack of availability of protective methods”.<sup>162</sup>

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<sup>157</sup> Phiri, I. “The Church as a Healing Community: Voices and Visions from Chilobwe Healing Centre”, in Phiri, I. and Nadar, S. (eds) *On Being Church: African Women's Voices and Visions* Geneva: WCC Publications 2005 p. 29

<sup>158</sup> “Commonwealth Secretariate”, *Gender Mainstreaming in HIV/AIDS: Taking a Multisectoral Approach* London: Marlborough House 2002 p. 34

<sup>159</sup> Ibid

<sup>160</sup> “Commonwealth Secretariate”, *Gender Mainstreaming in HIV/AIDS: Taking a Multisectoral Approach* London: Marlborough House 2002 p. 35

<sup>161</sup> Ibid

<sup>162</sup> Ibid

Traditionally, an African woman has little to say over the sexual practices she engages in.<sup>163</sup> This “little say” creates vulnerability because women are disempowered from participating in making decisions about activities in which they are the main actresses.

In some African traditional societies, marriage is the center of the African community as is the patriarchal center, which puts an African woman into the subordinate position<sup>164</sup> Phiri reports that some Evangelical Christian women say that, “a good Christian woman does not deny her husband’s sexual advances except for prayer”.<sup>165</sup> These kinds of beliefs are common even in South Africa. Indeed, as Phiri puts, such beliefs disempower Christian married women in challenging their husband’s infidelity.<sup>166</sup> This therefore leads to the conclusion that some religious norms should be revised because if they are not presented well, can mislead the public to view religious marriages as a major risk factor in societies especially for religious women. This kind of teaching finds support in some African patriarchy discourse, which has proved to particularly detrimental to women. Landman gives another example of such discourses as follows: “a woman’s body belongs to her husband...God wants women to provide sex to men but not to enjoy it”.<sup>167</sup>

Power issues in our society cause some groups to be devalued and others to feel superior. Gender discrimination supports these inequalities. Gender is not synonymous with sex; it refers to the “wide expectations, and norms within a society about appropriate male and female behaviour.”<sup>168</sup> This has caused men to be seen as responsible for the productive activities outside the home, while women are expected to be responsible for reproductive and productive activities within their homes.

This tends to result in women being disempowered, subservient and excluded from decision-making. This subservient status often means that women are not in a position to negotiate conditions of sex or demand the use of condoms. However, status and their

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<sup>163</sup> Tallis, V. “AIDS in Crisis for Women”, in *Agenda Vol. 39* 1998 p.9

<sup>164</sup> Phiri, I. “The Initiation of Chewa Women of Malawi: A Presbyterian Women’s Perspective”, in Cox, J. (ed) *Rites of Passages in Contemporary Africa* London: Cardiff Academic Press 1998 p.143

<sup>165</sup> Ibid

<sup>166</sup> Ibid

<sup>167</sup> Landman, C. and Viljoen, J. “White, Rich, but I have AIDS”, in Phiri, I. and Nadar, S. (eds) *On Being Church: African Women’s Voices and Visions* Geneva: WCC Publications 2005 p.127

<sup>168</sup> Sanders, F. “Gender is not Synonymous with Sex”, in *AIDS Bulletin Vol. 93* September 2000 p.15

ability to protect themselves from infection, is largely determined by their access to education, employment and political representation.

These factors are compounded by identities such as race, ethnicity, class, religion, sexual identity and social status, which may marginalise women. Women who are economically marginalised are often only able to support themselves and their children by exchanging sex for money. In these situations women may be unable to control the conditions under which to have sex and therefore may take part in unprotected sexual activity.<sup>169</sup> Despite the fact that these women have no other option but to engage in sex work for a living, they are stigmatised by the society. "Men may be HIV positive but because of fear of dismissal from work and of being unable to play their traditional gender role as breadwinners, they refuse to disclose their HIV status."<sup>170</sup>

Culture is very complex in its totality. At the heart of cultural complexity lies the problems HIV positive women suffer. "In some cultures women are not recognised as having any status, and they are blamed easily for things happening in the society."<sup>171</sup> Women's cultural norms are that they are expected to sacrifice a degree of freedom and individuality. It is unfortunate that even religion is not immune to the wrong teaching of culture.

Beyond doubt, major religions of the world have dubious records with regard to women.... For example Buddhist women could not hold any position in a religious community. Hinduism usually hold women ineligible for salvation. Islam sees a woman's witness only worthy half that of a man. Christianity called a woman the weaker vessel, the more blurred image. Jewish men blessed God for not having made them women.<sup>172</sup>

Christian women are influenced by male clergy to believe that the Christian Scripture teaches this gender inequality. This was taught in some churches, such as the African Indigenous Churches (Asics).<sup>173</sup> There was often the old mind-set of interpreting the

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<sup>169</sup> Sanders, F. "Gender is not Synonymous with Sex" *AIDS Bulletin Vol. 93* September 2000 p. 16

<sup>170</sup> "Gender and Women's Health", in *Church and AIDS Reader for Masters and Honours Students* 2005 p. 9

<sup>171</sup> "Situation Analysis: Social Structure Beyond Inequalities of Women in South Africa", Johannesburg: SARDC 1997 p. 32

<sup>172</sup> "Situation Analysis: Social Structure Beyond Inequalities of Women in South Africa", Johannesburg: SARDC 1997 p. 33

<sup>173</sup> "Situation Analysis: Social Structure Beyond Inequalities of Women in South Africa", Johannesburg: SARDC 1997 p. 33

Scriptures to suit old practices in spite of all the new awareness in the area of women and gender-issues.<sup>174</sup> Some Christian women accepted from males that God brought about this form of gender discrimination. Beverly Haddad, commenting on the teaching of the church writes, “there is much evidence to suggest the church leadership is fueling HIV and AIDS stigma and discrimination, particularly in disadvantaged rural areas where access to educational resources is limited.”<sup>175</sup>

As mentioned previously, focusing on women’s stigmatisation and their vulnerability to HIV is not to suggesting that men are not stigmatised as well. It is, rather, to show that women are more vulnerable and stigmatised than men. “Vulnerability refers to a lack of power, opportunity and ability (skills) to make and implement decisions that impact on one’s life”<sup>176</sup> This shows that the society at large is clearly divided on the matter of facing HIV, which is capable of destroying it. This fact promotes the destructive power of the epidemic and unless South African society addresses such issues as gender bias we will not come to grips with HIV and AIDS in our communities. In doing so the society must recognise that women are more vulnerable to the pandemic than men.

The African culture as well as religion should be looked at in a theological anthropological way in order to bring about the humanity of people in solidarity. As we have seen in this study, HIV and AIDS as a gendered pandemic is rooted in the patriarchal centre of religion and African culture which dominates women; their rights of speech and sexual behaviour.

#### **3.4.4 Death and Stigma of HIV and AIDS**

Skhosana pointed out that, “as an illness, HIV and AIDS is loaded with socio-cultural meaning because it is associated with anti-social attributes, the person becomes a living corps and people have no way of relating to him”.<sup>177</sup> Some people believe that the long trajectory of AIDS illness means that HIV positive people are in a progressive state of pollution as they approach their death.

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<sup>174</sup> “Situation Analysis: Social Structure Beyond Inequalities of Women in South Africa”, Johannesburg: SARDC 1997 p. 34

<sup>175</sup> Haddad, B “Reflection on the Church and HIV/AIDS: South Africa”, in *Theology Today* Vol. 62 2005 p. 32

<sup>176</sup> Tallis, V. “AIDS is a Crisis for Women”, in *Agenda* Vol. 39 1998 p. 9

<sup>177</sup> Ashforth, A. *Witchcraft, Violence and Democracy in South Africa* Chicago: Chicago University Press 2002 p.124

Adam Ashforth, drawing on his experience of living in Soweto argued that:

AIDS stigma ...is best understood as a product of fears relating to the dangers of pollution by invisible forces associated with dead bodies fears that deeply rooted feature of indigenous funeral customs ...Dead bodies are widely considered dangerous entities, and where they congregate are dangerous spaces from which emanate mysterious forces that can result in real physical misfortunes. Failure to cleanse oneself of invisible pollutants after attending a funeral or visiting a home of a recently deceased person opens one to the risk of illness and misfortune.<sup>178</sup>

Ashforth also suggests that the common description of AIDS by some people as an incurable disease is "a tantamount to saying that the person is already dead and thus to raise questions about the dangers of pollution that a person may present to others with whom they come into contact".<sup>179</sup> The bodies of those who died of HIV and AIDS are sometimes seen as polluting and dangerous. In a research done by Skhosana in Soweto with some families, in 2001, she highlighted that "the bodies of people who died of AIDS-related causes were not brought home on the night before the funeral. This was because such deaths were due to unnatural causes and was believed to be polluting in the sense that they would cause more deaths of this nature in the family."<sup>180</sup>

In South African townships, it used to be customary to paint widows with ash as a sign of death in the family. This practice is now seldom practiced and news of a death is usually spread by word of mouth.<sup>181</sup> The curiosity that surrounds an AIDS-related death in the township means that the news of such a death will be known far and wide in a short space of time. Despite the physical segregation of people living with HIV and AIDS from mainstream society, AIDS-related illness and deaths continued to attract much public interest.

So intense is community interest in AIDS-related deaths that one of my interviewees told of the following experience: some neighboring women came to her place to mourn her "death", only to meet her as they were coming through the gate. These women quickly retreated in embarrassment. She said:

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<sup>178</sup> Ashforth, A. *Witchcraft, Violence and Democracy in South Africa* Chicago: Chicago University Press 2002 p.124

<sup>179</sup> Ibid

<sup>180</sup> Ibid

<sup>181</sup> Ibid

According to my neighbours, I died on the 12<sup>th</sup> of March [2006] and that was the rumour that was spread. I am still waiting for those women to come to me and say something because now none of them can look at me. I have become a living ghost to them.<sup>182</sup>

This example demonstrates the power of rumour and how people living with HIV and AIDS are anticipated to die sooner than other people. Another HIV positive woman I interviewed said that when she was taken by ambulance to the hospital, the rumour spread that she had died. In her case no one came to mourn her death, but it was believed that she would be soon be buried. People were willing to tell her what the rumour had been, thus confirming her belief that she no longer mattered to the society.<sup>183</sup>

As already mentioned, in some cultures, the long trajectory of an AIDS death means that a “victim” is in a progressive state of pollution, as he or she is approaching his or her death. Their possessions, especially the clothes that they wore in their last few months, would be considered polluted and would have to be burnt. The fear of contagion that characterised relationships while the deceased was still alive continues to concern the living after his or her death.<sup>184</sup> The advent of HIV and AIDS and death from AIDS-related complications have led to old rituals gaining a new meaning as people try to deal with this reality. For example, in some African societies, especially among the Nuns, a murdered person was not open for public viewing. Older members of the family would view the body at the morgue and there the coffin was sealed and never re-opened. This practice is also seen with AIDS-related disease.<sup>185</sup>

This I witnessed when I attended a funeral of a person who died of AIDS, in the Eastern Cape, in 2001. Her body was not brought home on the night before the funeral, and this was unusual. Normally, in the Xhosa culture, when a person dies, his or her body would be brought home a night before the funeral. The funeral service was held in the deceased’s person home, without the body present. Later, the body was transported home while the service was on and was acknowledged while in the hearse.

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<sup>182</sup> An interview with an HIV positive woman from the Esibusisweni Congregation in Durban, on the 14 August 2006

<sup>183</sup> An interview with an HIV positive woman from the Esibusisweni Congregation in Durban, on the 14 August 2006

<sup>184</sup> Skhosana, N. *Women, HIV and AIDS Stigma: An Anthropological Study of Life in Hospice* Unpublished Masters Thesis, Johannesburg: University of Witwatersrand 2001 p. 123

<sup>185</sup> Ibid

This was because her death was due to “unnatural” causes and it was believed to be polluting in a sense that it would cause more death of that nature in the family.

The possibility that the levels of stigma may be partly conditioned by beliefs in pollution raises the question of whether other dimensions of pre-existing understandings of disease, death and misfortune may be implicated in creating high levels of hostility to people living with HIV and AIDS. One dimension might be witchcraft.

### **3.4.5 Witchcraft and Stigma of HIV and AIDS**

Ashforth argued that HIV and AIDS lend itself to explanation within “a witchcraft paradigm”.<sup>186</sup> He wrote, for example, that symptoms of the disease are sometimes interpreted as *idliso* (a form of poison inflicted by witches). Furthermore, silence and stigma surrounding HIV and AIDS makes much more sense if their perceived dimension of witchcraft is taken into account:

With cases of witchcraft, silence and discretion are the norm. No one wants to publicise the fact that they have been cursed. Such publicity would not only be embarrassing, but dangerous, because it would enable the witch to gain intelligence of the efforts being made to counteract his or her assault.<sup>187</sup>

The belief that AIDS-related deaths are brought by witchcraft is not widespread in South Africa, but still present. For example, one of my interviewees said:

My fiancée died of AIDS in 2000. After he died, his parents thought that his aunt bewitched him. They went to a witchdoctor and they were told that that he was bewitched by his aunt. They knew that he died of AIDS, but they couldn't believe that he was really HIV positive. From there, they stopped talking with the aunt, and they do not even visit each other with the aunt because they say she is a witch.<sup>188</sup>

In other countries, like Uganda, there are also people who also believe that HIV and AIDS is the result of witchcraft. Research by UNAIDS on the nature and causes of stigma in Uganda revealed that at first people thought the disease was the result of witchcraft. One Ugandan woman said that she was the first to be known as HIV

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<sup>186</sup> Ashforth, A. *Witchcraft, Violence and Democracy in South Africa*. Chicago: Chicago University Press, 2002 p. 39

<sup>187</sup> Ibid

<sup>188</sup> “Fighting HIV-Related Intolerance: Exposing the Links between Racism, Stigma and Discrimination”, Geneva: UNAIDS 2001 p.5

positive within her family but that, since then several other family members had become sick and died.<sup>189</sup> “It looked like I put a curse on my family” she said.<sup>190</sup>

Witchcraft beliefs may also have contributed to the extent to which women are stigmatized as a source of HIV infection. Witchcraft is believed by many to be a primarily female preserve.<sup>191</sup> However, historical research suggests that the assumption that women dominated the ranks of witches was not evident in pre-colonial African societies and may have been partly conditioned by the corrosive effects of colonialism and capitalism on relations between the genders.<sup>192</sup>

### **3.6 Differences and Similarities of HIV and AIDS-related and Stigma of Deformity**

Between the stigma of deformity and HIV and AIDS, there are similarities and differences. For example, both are sometimes viewed as a punishment from God and are likely to increase people’s isolation in the society. For instance, when I was a child, I used to hear elderly people saying that in the olden days children born disabled were thrown into bushes and removed from the society. It was believed that being born disabled was the result of sin. This information was passed from generation to generation, through oral tradition. People living with HIV are also witnessing this kind of exclusion. Though they are not thrown into bushes, the discrimination and abandonment which they experience daily is worse than being thrown into bushes. For example, Nokhaya Makiwane<sup>193</sup> witnessed a said situation of a young woman in Pietermaritzburg.<sup>194</sup> A social worker for one of Sinomlando’s<sup>195</sup> partner organisations invited Nokhaya to visit a woman called Lahliwe (not her real name), who was dying of

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<sup>189</sup> “Uganda: HIV and AIDS Related Discrimination, Stigmatisation and Denial”, Geneva: UNAIDS 2001 p. 20

<sup>190</sup> Ibid

<sup>191</sup> “Fighting HIV-Related Intolerance: Exposing the Links between Racism, Stigma and Discrimination”, Geneva: UNAIDS 2001 p.6

<sup>192</sup> Delius, P. “Witchcraft and Missionaries in the Nineteenth Century” in *Journal of Southern Africa*. Vol. 27 2001 p.33

<sup>193</sup> Nokhaya Makiwane is a Programme Co-ordinator in the Memory Box Programme for Sinomlando Centre for Oral and Memory Work in Africa

<sup>194</sup> Radikobo Ntsimane is a Researcher at the Sinomlando Centre for Oral History and Memory Work in Africa.

<sup>195</sup> Sinomlando is a Centre for Oral History and Memory Work in Africa.

AIDS.<sup>196</sup> According to the social worker, Lahliwe refused to disclose her AIDS status to her family, because of the fear of being rejected.<sup>197</sup> However, she finally disclosed her status to her family. When Nokhaya and the social worker visited her, “she was dying in a garden tool shed she was sharing with the rats”.<sup>198</sup> Before disclosure, Lahliwe lived in the warmth of her family. After disclosure, she died in the company of rats, alone and disowned. This may be because Lahliwe’s family regarded her as being punished by God and had to suffer the consequences of her sin, since some people regard HIV and AIDS as a punishment from God.

HIV positive people end up being excluded from their families, especially women. Like HIV positive women, the disabled women, experience greater stigma than men, although there are levels of differences. As I have discussed earlier in the chapter, the disabled women experience more discrimination than other women because of their inability to live up to the demanding ideals for womanhood. For example, they can’t do household duties such as cleaning of the house, taking care of their husbands, like “normal” women. In the same way, women are more vulnerable to HIV infection because of economic, biological and cultural factors that will be discussed in the next chapter.

There is also a difference between the stigma of deformity as a punishment from God and HIV and AIDS as a punishment from God. The difference is that with deformity some people believe that it is the results of sin/sins committed by the parents of the disabled individual. With HIV and AIDS, some people believe that it is a punishment from God because of promiscuity, especially among women.

### **3.7 Conclusion**

Though there are many forms of stigma, this chapter has focused on explaining those types of stigmatisation that are relevant to the study. As will be discussed in the following chapters, HIV and AIDS stigma spreads across different societies and cultures. From a historical point of view, stigma was evident and was influenced by

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<sup>196</sup> Ntsimane, R. “To Disclose or not to Disclose: An Appraisal of the Memory Box Project as a Safe Space for Disclosure of HIV Positive Status” in *Journal of Theology for Southern Africa Vol.1* July 2006 p. 8

<sup>197</sup> Ibid

<sup>198</sup> Ibid

what was happening at a certain time and context. In our modern times, stigma is still present as it relates to the new epidemic of HIV and AIDS. In the following chapter, an analysis of the interviews on HIV and AIDS stigmatisation will be discussed. This is critical because the study focuses on reviewing how HIV and AIDS stigmatisation is prevalent in our modern societies.

## Chapter 4

### **A Brief Historical Overview of the Machibisa and Esibusweni Lutheran Congregations**

#### **4.1 Introduction**

Lutherans comprise a small portion of the South African population. However, more than a century ago, Lutherans operated more than a third of the mission stations in South Africa. Seventy percent of those mission stations were in Natal and Transvaal. In these two regions, half of the missionaries were Lutherans.<sup>199</sup> “Among many black communities in Natal and Transvaal, Lutheranism became the majority expression of Christianity by the early twentieth century, though it was later overtaken in some regions by other denominations. Black Lutherans have long outnumbered white Lutherans.”<sup>200</sup> This chapter will give a brief historical background of the Evangelical Lutheran Church in Southern Africa (ELCSA). This will lead to the brief history of the two Lutheran Congregations, namely, Machibisa and Esibusweni. These congregations are in different parishes. The two parishes fall under the South Eastern diocese of ELCSA. The chapter will focus on these two congregations.

The brief historical background Evangelical Lutheran Church in Southern Africa (ELCSA) is based on written sources. A brief historical background of the Machibisa congregation is based on written and oral sources, and a brief historical background of the Esibusweni congregation is based on written sources. The Machibisa congregation recommended two elders as reliable sources of information. However, they did not have sufficient information on the history of the congregation. The Esibusweni congregation recommended both the minister and one old member of the women’s league as reliable sources of information. As compared to the Machibisa congregation, they had sufficient information about the history of the congregation. The history of the two congregations is not available in the church archives. For both congregations, no information is available in the church archives.

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<sup>199</sup> “Condensed Report of the Statistical Committee of the United Missionary Conference”, Alice: Lovedale Mission Press 1889 p. 16

<sup>200</sup> Scriba, G. “Lutheran Missions and Churches in South Africa”, in Elphick, R. and Davenport, R. (eds) *Christianity in South Africa: A Political, Social & Cultural History* Cape Town: David Philip Publishers 1997 p. 173

## **4.2 A Brief History of ELCSA**

The Evangelical Lutheran Church in Southern Africa is a traditionally “black” church which resulted from missionary activity by Lutheran churches from America, Scandinavia and Germany. These were the Berlin, Hermannsburg, Church of Sweden, American Board and Norwegian Lutheran Missions. ELCSA was formed in December 1975, in Rustenburg. It included four black regional churches. These were the South Eastern, Tswana, Cape Orange and Transvaal Regions.<sup>201</sup> The South Eastern Region was the first region to be founded. When ELCSA was founded, all the three regional churches merged into one church, with five dioceses and later seven dioceses. These are the Botswana, Cape Orange, Central, Eastern, South Eastern, Northern and Western Diocese.<sup>202</sup> Each diocese has one diocesan bishop. All the diocesan bishops are under the Presiding Bishop of ELCSA. The General Assembly elects the Presiding Bishop amongst the seven diocesan bishops while the Diocesan Synods elects the bishops of the dioceses for the period of six years. The Diocesan Council, and the diocesan synod meet to run the affairs of the diocese every two years. The dioceses are divided into circuits. Each circuit is led by the Dean. The circuit consists of parishes, and a parish consists of different congregations.

Now I consider the above historical background to be enough to enable me to move to the focus of my thesis, that is, a brief historical background of Machibisa Lutheran Congregation, a congregation situated in the Umngeni Circuit of the South Eastern Diocese of ELCSA. Furthermore, I will discuss a brief historical background of the Esibusweni Lutheran Congregation, a congregation situated in the Durban Circuit of the South Eastern Diocese of ELCSA.

## **4.3 Background of the Machibisa and Esibusweni Lutheran Congregations**

In both congregations, elders and pastors run the church. Activities are performed by leagues and associations such as women, youth, Sunday school, men, and evangelization. Each of these leagues and associations has its own constitution to provide guidance and direction on their activities.

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<sup>201</sup> Winkler, E. *The Divided Roots of Lutheranism in South Africa: A Critical Overview of the Social History of the German Speaking Lutheran Missions and the Churches from their Work in South Africa*. Unpublished Masters Thesis, University of Cape Town 1989 p. 52

<sup>202</sup> Zikode, L. “History of the Emmaus Mission”, (no date) Unpublished paper, p. 10

#### **4.4 The Machibisa Lutheran Congregation**

The congregation of Machibisa is comprised of about five hundred members. Women outnumber men. The congregation of Machibisa is under the Pietermaritzburg-South parish, which falls under the Umngeni Circuit. The Pietermaritzburg-South parish has five congregations, namely, Willofontein, Khumbulani, Mooi River, Imbali and Machibisa. The Machibisa congregation is located in Machibisa, which is part of Edendale Township in Pietermaritzburg. Edendale is a township of roughly 100, 000 people, almost entirely Zulus, on the south-western edge of Pietermaritzburg. It is located in the valley of Msunduzi River. Thirty percent of households live in poverty, 40-50 percent of households live in mud-built dwellings and 60 per cent have no sanitation. Yet there is a small core of high-income families who in most cases are government employees and pensioners. There has been genuine improvement since 1994, notably in the almost universal provision of electricity.<sup>203</sup>

##### **4.4.1 History of the Machibisa Congregation**

The Machibisa congregation was started in 1960, under the leadership of Rev. G. Karalluss. He was from the Berlin Mission Society, in Germany. He was assisted by Rev. Mazibuko and the evangelist Mvelase. The church structure was erected from mud. Later in 1960, a new structure was established with the help of young men from the Vocational Training School. Rev. G. Karalluss dedicated the church in April 1961.<sup>204</sup> As the congregation grew, some members of the church were elected to be elders, helping the missionaries to lead the congregation. They also held services and preached. The need to train evangelists led to the decision to institute the Evangelical Training College at Emmaus in 1905. In 1912 Emmaus became the joint venture of all Lutheran missions in Natal. The first evangelists from Machibisa to be trained at Emmaus were the following: Phakathi, Nxumalo, Malonga, Mbonane, Ngubane, Gumede and Mazibuko.<sup>205</sup>

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<sup>203</sup> Garner, C. *Religion as a Source of Social Change in a South African Township* Cambridge: University of Cambridge Unpublished PHD Thesis 1998 p. 6

<sup>204</sup> Interview conducted with Mr. Michael Sithole on the 31 March 2006 in Pietermaritzburg.

<sup>205</sup> Interview conducted with Mr Michael Sithole on the 31 March 2006 in Pietermaritzburg (Mr Sithole does not remember the names of the first evangelists of the Machibisa Congregation).

#### **4.4.2 Ecumenical Relations**

About the relationship of the Machibisa Congregation with other denominations, I interviewed Mr. Mavundla, an evangelist of the congregation. He said that it has not been easy to have close relationships with other denominations for example, Methodists and Presbyterians. These denominations emphasize the pulpit that is for preaching, but they hardly have an altar.<sup>206</sup> Furthermore, he said that over the recent years there has been closer co-operation between the Lutherans, the Catholics and the Anglicans. The Lutherans use servers as well as the Catholics and the Anglican. He also said that there are times when the Lutheran congregation in Machibisa shares services with the Catholics and Anglicans. For example, there have been cases where the Catholics and Anglicans have conducted the weddings and funerals at the Lutheran Church in Machibisa.<sup>207</sup>

#### **4.5 Esibusisweni Lutheran Congregation**

This Esibusisweni Congregation is situated in Ntuzuma Township. Ntuzuma is a formal township under the North Central Council within the Durban Metro. It has presently three squatter camp areas surrounds it. The other formal townships around are KwaMashu, Inanda and Phoenix. The population is between 120 000 and 300 000, including the new areas that have been incorporated to Ntuzuma due to the new metro demarcations.<sup>208</sup> In the Ntuzuma Township, some people own property and others rent their houses. The unemployment rate is said to be high. Most of the families have single breadwinners ranging from youth to pensioners. Most of the people who are employed work in Durban, which is about 35 kilometres from the Ntuzuma township. The Ntuzuma township has a high rate of illiteracy, and high rate of crime.<sup>209</sup>

##### **4.5.1 History of the Esibusisweni Congregation**

The Esibusisweni congregation is one of the congregations that resulted from the work of Rev. Schreuder who was from the Norwegian Mission Society, in Norway. During the time of the arrival of the first Lutheran Missionary (Rev Schroeder) to Zululand, in 1844, Durban (then Port Natal) was a transit place. It was starting to develop from a small settlement into an attractive town, with a British garrison at the Durban Bay. Durban

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<sup>206</sup> Interview conducted with Mr Meshack Mavundla on the 31 March 2006 in Pietermaritzburg

<sup>207</sup> Mr Meshack Mavundla, 31 March 2006 in Pietermaritzburg.

<sup>208</sup> Interview conducted with Rev. Njabulo Sithole on the 31 July 2006 in Durban.

<sup>209</sup> Interview conducted with Rev. Njabulo Sithole on the 31 July 2006 in Durban.

became a centre of developing industry and a business, thus attracting more and more people from the interior. Young Zulus moved to Durban in search of employment.<sup>210</sup> In migrating to Durban, they were exposed to urban culture and a different lifestyle, which posed a potential danger, in the minds of the missionaries, for the young Zulus. For this reason, the Norwegian Mission Society began its work at Milne Street in Durban in 1890. Rev. Staven was serving the Norwegian Community in the harbour town, and at the same time he began to gather the first Lutheran Zulu congregation in Durban in a small church house on Milne Street, which was later replaced by a large church building. His successor was Rev. Eriksen.<sup>211</sup>

Through the work of Rev. Eriksen, educational work was stressed as an additional aid for young people, who had to find their place in city life and the industrial environment. Evening schools were held on weekdays. They were attended by an average of 90% of young men and an average of 10% of young women. Many people moved into Durban and the government embarked on the establishment of major housing projects to cope with the influx of African people.<sup>212</sup> For this reason, Milne Street Congregation was faced with a new challenge. The work of the church could hardly keep pace with these developments. When the various Mission Societies working in Durban handed over their work to the newly founded South Eastern Region in 1960, the urban work had to be re-organised through a division into Durban South and Durban North Parishes. Out of this division, Esibusisweni Congregation was born.<sup>213</sup>

The Esibusisweni Congregation is under Ntuzuma Parish. The Ntuzuma Parish covers the area, which is called "INK" (The Inanda, Ntuzuma and KwaMashu). The Ntuzuma parish has five developed congregations. The Esibusisweni Congregation is the main Congregation. This congregation is situated in the Ntuzuma Township. The five congregations are situated in different places, namely, KwaMashu (Esangweni Congregation), Inanda (Thandanani Congregation) Lindelani (Vumukholo Congregation), Ohlange (Osizweni Congregation).<sup>214</sup> There are newly developing

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<sup>210</sup> "A Family in the Faith: Lutherans in Greater Durban", Durban: The Lutheran Ministers' Fraternal 1979 p. 12

<sup>211</sup> Ibid

<sup>212</sup> "A Family in the Faith: Lutherans in Greater Durban", Durban: The Lutheran Ministers' Fraternal 1979 p. 13

<sup>213</sup> Ibid

<sup>214</sup> Interview conducted with Rev. Njabulo Sithole on the 31 July 2006 in Durban

congregations under the Ntuzuma Parish. One of them is at Avoca Hills near Corvoca and the other one is situated at Umhlanga. These two congregations are called preaching places and not long they will be given the status of a congregation.

#### **4.5.2 Ecumenical Relations**

The Esibusisweni Congregation, together with other denominations in the northern part of Durban are concerned about many things that bother their community. They are faced with HIV and AIDS, with crime that is escalating in their communities and the high level of poverty and unemployment. All these things have pulled them together as member churches to work together as the body of Christ.<sup>215</sup> The minister of the Esibusisweni congregation said:

I began my ministry as a parish minister in January 8, 1998. In 1998 I joined the Ministers Fraternal where we together as ministers from different denominations combined our strength and became the conscience of the community. We further formed the Forum, which is known as the Ministers' Forum that tries to address the issues of crime prevention. It is in this Minister's Fraternal that we have a slogan that says "What I do in my denomination must benefit the other denomination"<sup>216</sup>

In the past they used to have big rallies as churches together. They used to address ethical issues and they would invite guests to address them. They are affiliated with the Diakonia Council of Churches, an organization that works towards unifying member churches with various Programmes to achieve the mission of the Church in the world. The Diakonia Council of Churches has played a major role in matters of HIV and AIDS since 2001.<sup>217</sup> Diakonia Council of Churches conducted a series of workshops and seminars with the member churches. The minister of the Esibusisweni Congregation invites people to give talks in the congregation on HIV and AIDS-related stigma. This has helped the Esibusisweni Congregation to include HIV and AIDS in their liturgy. They also have "Pulpit Exchanges" where a congregation invites someone from a different denomination to preach and do other things such as conducting a funeral.<sup>218</sup>

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<sup>215</sup> Interview conducted with Rev. Njabulo Sithole on the 31 July 2006 in Durban.

<sup>216</sup> Interview conducted with Rev. Njabulo Sithole on the 31 July 2006 in Durban.

<sup>217</sup> Interview conducted with Rev. Njabulo Sithole on the 31 July 2006 in Durban.

<sup>218</sup> Interview conducted with Rev. Njabulo Sithole on the 31 July 2006 in Durban.

#### **4.7 Conclusion**

This chapter has given a brief history of the Machibisa and Esibusweni Congregations and the Lutheran Church in Southern Africa. The two congregations provide the context in which black South African women experience the issue of stigmatisation.

## **Chapter 5**

### **Stigma as Experienced by the Women of the Machibisa and Esibusisweni Congregations**

#### **5.1 Introduction**

Chapter three offered a theoretical discussion on stigma in general, and HIV and AIDS-related stigma. There is insufficient understanding of the impact of stigma upon HIV positive women. Understanding the manner whereby women living with HIV and AIDS experience stigma and their coping process and strategies is key to structuring any intervention. This research has used the Machibisa and Esibusisweni Lutheran congregations as a case study to explore the stigmatisation of HIV positive women and see what these two congregations should do to address gender-based destigmatisation.

This chapter will give a brief history of the AIDS Programmes in the two congregations in order to inform the discussion on a number of issues. It will also present the data that came from the field research as to give an understanding of how gender-based destigmatisation can be addressed. Furthermore, it will give a brief explanation of the research process, research findings and data analysis.

The interviews with the minister and the co-ordinator of the AIDS Programme of the Machibisa congregation were conducted in Zulu and translated into English as were the interviews conducted with the nine HIV positive women from the Esibusisweni Congregation. The interviews with the minister were conducted in English.

#### **5.2 The Machibisa Congregation**

##### **5.2.1 The Background of the Interviewees**

Both the minister and the chairperson of the AIDS Programme interviewed are Zulu men. The interviews were conducted in both Zulu and English languages. The minister is 48 years old, and he is married with three children. He has a Masters Degree in Theology. The chairperson of the AIDS Programme Committee is a 32 years old single man without children. He has a Diploma in Marketing Management. He is currently working as a junior manager at First National Bank in Pietermaritzburg.

### **5.2.2 The Research Process in the Machibisa Congregation**

In March 2006, before the research began, I met with the minister in order to get permission to do research in the Machibisa Congregation. The minister agreed and referred me to the congregation leader. The congregation leader also agreed. The interview with the minister was conducted on the 2<sup>nd</sup> of June 2006 in his office, at the Machibisa Congregation. The follow-up interview was also conducted with the minister on the 2<sup>nd</sup> and 6<sup>th</sup> of December 2006

The congregation leader assisted me in getting a key person to be interviewed from the AIDS Programme committee members. I made it clear to the congregation leader that the research was for academic purposes, and that the research findings were not for commercial purposes. At first it was difficult to get a key person for the interview from the AIDS Programme committee members because at that time they had no portfolios. I had to wait for about a month, in order to get the key person for the interview. Finally, in July, the chairperson of the AIDS Programme committee agreed to be interviewed. We then agreed on the possible date and place for the interview process.

The interview was conducted on the 12<sup>th</sup> of August 2006, at the Lutheran Theological Institute, in Scottsville. After the interview, I asked the interviewee to help me with identifying HIV positive women from the Machibisa Congregation who would be willing to be interviewed. The interviewee said that there is no one in the congregation who has disclosed her or his HIV positive status, except one woman who only disclosed to him. Furthermore, he said that people who are HIV positive are reluctant to disclose their HIV status because of the fear of being stigmatised.<sup>219</sup> However, he promised to talk with the woman who disclosed her HIV positive status to him, and find out whether she will be willing to be interviewed. On the 27<sup>th</sup> of August 2006, I called the interviewee to find out whether the woman has agreed to be interviewed. The interviewee said that the woman was not willing to be interviewed. According to the interviewee, the woman thought that if she told me about her status I might tell the minister. She did not want the minister and other people to know about her HIV positive status, except her family and the chairperson of the AIDS Programme.

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<sup>219</sup> Interview conducted with the chairperson of the AIDS Programme of the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

Therefore, I did not manage to get any HIV positive women to be interviewed from the Machibisa Congregation.

### **5.2.3 The HIV and AIDS Programme of the Machibisa Congregation**

The chairperson of the AIDS Programme in the Machibisa congregation was interviewed about the history of the Programme. According to the interviewee, the AIDS Programme in the Machibisa congregation started in February 2006. The aim of the Programme is to bring HIV and AIDS awareness in the church. The Programme committee member has not yet applied for external funding. They first want to have people who can disclose their HIV status in the congregation before they can apply.<sup>220</sup> The Programme does internal fundraising in the congregation by selling cakes. On every second Sunday of the month, after the service, some women from the congregation sell cakes baked by themselves to the congregation members. The money that these women collect through “cake sale” is used as a donation for the AIDS Programme.<sup>221</sup>

According to the “internal survey” throughout the congregation, many people who have been buried, especially youth, died of HIV and AIDS. For this reason, the congregation decided to face the reality that HIV and AIDS is there and they decided to start the HIV and AIDS Programme. The congregation realised that it has a prominent role to play on the issue of HIV and AIDS. The congregation council, together with the minister, discussed this in 2005 and it was agreed that the AIDS Programme committee should be formed.<sup>222</sup> Within the congregation, there are different committees from each league. These are the women’s league, men’s league and youth league committees and from each of these committees, there is a representative in the AIDS Programme committee.<sup>223</sup>

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<sup>220</sup> Interview conducted with the chairperson of the AIDS Programme from the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

<sup>221</sup> Interview conducted with the chairperson of the AIDS Programme of the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

<sup>222</sup> Interview conducted with the chairperson of the AIDS Programme of the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

<sup>223</sup> Interview conducted with the chairperson of the AIDS Programme on the 12 August 2006 in Pietermaritzburg.

#### **5.2.4 Disclosure in the Machibisa Congregation**

As mentioned previously, so far there is only one woman who has disclosed her HIV status. However, the woman only disclosed her status to the chairperson of the AIDS Programme Committee (interviewee) and does not want other people to know. I asked the chairperson how they identify people who have died of AIDS, because he previously said that no one in the congregation has ever disclosed his or her HIV status, except one woman who only disclosed to him. The interviewee responded by saying:<sup>224</sup>

The symptoms are obvious, people talk. For example, in the congregation, if a woman has a sick child or partner, we will look at the symptoms of the sick person, on whether they are HIV and AIDS symptoms or not. If the sick person shows the symptoms of HIV and AIDS, like shingles and loss of weight, then we will conclude that the person is HIV positive<sup>225</sup>

However, the interviewee said that sometimes the suspicion might be wrong because the cause of death might be a different disease from HIV and AIDS, for example, Tuberculosis (TB). There are also some symptoms of TB, such as loss of weight, which are similar to HIV and AIDS symptoms.<sup>226</sup>

The fact that the interviewee said symptoms of HIV and AIDS are obvious and people look at those symptoms to identify whether the “carrier” of those symptoms is HIV positive or not, indicates that there is stigma in the congregation. Identifying HIV positive people in the congregation by looking at the symptoms might lead to the fear of disclosure, which is one of the indicators of stigma. These identifications might cause “gossip” in the congregation and this might discourage those who have not disclosed their status. Therefore, one may conclude that those who are HIV positive in the Machibisa Congregation are not disclosing their status because of what some congregation members may say or think of them. It may also be that they have heard the rumours about other people who have those symptoms in the congregation.

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<sup>224</sup> Interview conducted with the chairperson of the AIDS Programme from the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

<sup>225</sup> Interview conducted with the chairperson of the AIDS Programme from the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

<sup>226</sup> Interview conducted with the chairperson of the AIDS Programme from the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

Furthermore, what the interviewee said is very common, especially in the townships. If people notice that a particular person is losing weight, the first thing that will come to their minds is that, he or she might be HIV positive, and the rumour will go around the township. This is what is called a “township gossip”. In most cases, this happens when a person comes from big cities like Johannesburg. This is because of the belief that Johannesburg is full of prostitutes.

Many unemployed women from the rural areas, especially in the Eastern Cape and KwaZulu-Natal, go to Johannesburg in search of jobs. Through the “township gossips” about somebody’s HIV positive status, some people fear to disclose their HIV positive status, both in their congregations and communities. Some would prefer to disclose their status to their families only. However, disclosure of one’s HIV positive status needs right time and space.

#### **5.2.5 Stigma in the Machibisa Congregation between 1995 and 2005 (males and females)**

I asked the chairperson of the AIDS Programme how he compares AIDS-related stigma between males and female in the Machibisa congregation between 1996 and 2005. He said that it is difficult to say because no one has ever disclosed his or her HIV positive status in the congregation. Furthermore, he said that stigma makes it difficult for people to disclose their HIV positive because they sometimes think that their self-esteem will go down.<sup>227</sup> This is self-exclusion, which is one of the indicators of stigma. Self-exclusion is when an infected person rejects external interventions for HIV positive people in the Machibisa Congregation because of the fear of being stigmatised.

The interviewee said that in 2003 there was a drastic increase in the number of people who died of HIV and AIDS, and the majority of those people were women. This they found out through the “internal survey” which I mentioned previously.<sup>228</sup>

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<sup>227</sup> Interview conducted with the chairperson of the AIDS Programme of the Machibisa Congregation on the 12 August 2006 in Pietermaritzburg.

<sup>228</sup> Interview conducted with the chairperson of the AIDS Programme of the Machibisa Congregation on the 12 August 2006 in Pietermaritzburg.

I also asked the minister of the Machibisa congregation how he compares stigma in the Machibisa congregation between males and females, between 1996 and 2005. He said:

Stigma is there in the Machibisa congregation, especially among women. Since I started working in the Machibisa congregation, there are only fifteen people who disclosed their HIV positive status to me. They do not want their status to be known by the congregation. Three of them are men, and the others are women. They are all single. One of those women died in 2004 and the other one died in 2005. I remember in 2002, one of those women came to my office and she looked so disappointed. I asked her, "What is bothering you". She replied by asking a question, saying, "Pastor, did you tell people about my HIV positive status". I told her that I never told anyone. She said, "when we had a youth conference people were not talking to me and some of them did not want to sit next to me, I think they were gossiping about my HIV positive status. I also think that they were afraid that they would be infected if they sit next to me. I was very hurt and I had to wonder if AIDS is only transmitted sexually. One my friends from the youth group gave me a bucket, saying that I should wash in it. She told me that so and so... died because she got the HI Virus through sharing a bucket with an HIV positive person."<sup>229</sup>

This woman experienced prejudice from her friend. It shows that her church friend couldn't sustain a healthy relationship with her as she needed it. This is a indicator stigmatising act driven by suspicion of her HIV positive status and the fear that she might infect her if they share the same washing bucket. The woman suffered direct rejection because her friend told her directly that she couldn't share a same bucket with them.

Furthermore, this illustrates the challenges HIV positive people face from day to day due to other people's unfounded fears that they will infect them. It seems that the HIV positive woman found herself in the dilemma as to what to believe. On the one hand, she was treated as though her illness was highly contagious. On the other hand, the medical experts told her that this was not the case. She wondered why her friend behaved towards her in an extremely discriminate manner. By not allowing her to share the same bathroom facilities with the others her friend demonstrated the pervasive nature of stigma against HIV positive people.

The minister said that he never told anyone about the woman's HIV positive status, but he thinks that people were suspicious that she might be HIV positive, because

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<sup>229</sup> Interview conducted with the Minister of the Machibisa Congregation on the 2 June 2006 in Pietermaritzburg.

she was losing weight. He also said he cannot force people to disclose their HIV status, if they are not ready for it. He always encourages them to take time and when the right time comes for them to disclose their HIV status, they can do so. He further said:

I think it is enough if their families know about their HIV positive status because there is still stigma in our congregation. I hope that one of the outcomes of the AIDS Programme in the congregation would be to combat stigma and I think it would be much easier for the HIV positive people to disclose their status once the whole congregation gets directly involved in the AIDS Programme.<sup>230</sup>

Sometimes people stigmatise others because of their insufficient knowledge about HIV and AIDS, therefore if the whole congregation is involved in combating stigma, there might be a difference in terms of stigma. It is possible that among those who are stigmatising others, there are also some who are HIV positive. Perhaps, they might be doing it so that people would not be suspicious of their HIV positive status.

I asked the minister about his perception as to why some people did not want their HIV positive status to be known in the congregation. The minister said:

Some of them do not want to lose their positions in the congregation. For example, one of the women who disclosed her status to me in 2001 was a secretary of the youth league. She said to me, "please pastor, don't tell anyone about my HIV positive status. If you tell people, they might put somebody else in my position, because of my HIV positive status".<sup>231</sup>

The woman feared to be rejected if the congregation members found out about her HIV positive status. If there was no stigma in the congregation, this woman would not have the fear of being rejected. Her fear of being rejected is an indicator of stigma in the Machibisa Congregation. Therefore, in order to keep herself on the safe side, she decided to keep the information about her the status between her and the minister.

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<sup>230</sup> Interview conducted with the Minister of the Machibisa Congregation on the 2 June 2006 in Pietermaritzburg.

<sup>231</sup> Interview conducted with the Minister of the Machibisa congregation on the 2 June 2006 in Pietermaritzburg.

### **5.2.6 Gender-based de-stigmatisation in the Machibisa congregation**

I asked the minister what the congregation had done to bring gender-based de-stigmatisation. The minister said that it was difficult for the congregation to do anything on gender-based de-stigmatisation because people did not want to talk about HIV and AIDS in the congregation, in view of the fact that it involved issues of sexuality.<sup>232</sup> However, as a congregation they are trying to involve women in many things, such as preaching and leadership roles. The minister wants women to have a voice in the congregation because thinks that this will make it easier to enact gender-based de-stigmatisation. As the congregation, they are hoping to achieve that by the end of 2007.<sup>233</sup> The minister further said:

Women are reluctant to talk about issues pertaining HIV and AIDS. In 2003, I asked one of the committee members of the Women's League if they sometimes discuss about gender-based de-stigmatisation on HIV and AIDS when discussing women's issues. She said, "Pastor, first of all discussing about HIV and AIDS is not easy, it brings lot of controversies because it involves issues of sexuality. It becomes worse when involving the issue of gender because some of us were raised in way of understanding that a man will always be a man in the Zulu culture and you cannot discuss gender issues".<sup>234</sup>

I asked the minister about his perception on what the woman said. The minister said, "if we always say that according to the Zulu culture things should be done this way...then it means we can achieve what we want to achieve".<sup>235</sup> According to the minister, it is the culture that encourages men to sleep around. He said, "in the Zulu culture there is a proverb which says, a man is like an axe that cuts everywhere".<sup>236</sup> This means that a man can have as many girlfriends as he wants.

These cultural beliefs contribute to the spread of HIV and AIDS and gender-based stigma. Gender is a cultural and societal construction of roles for men and women. For example, in a Zulu culture, if a man has many girlfriends, that proves his manhood, whereas for a woman to have many boyfriends is regarded as shameful. It is also

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<sup>232</sup> Interview conducted with the Minister of the Machibisa congregation on the 6 December 2006 in Pietermaritzburg.

<sup>233</sup> Interview conducted with the Minister of the Machibisa congregation on the 2 December 2006 in Pietermaritzburg.

<sup>234</sup> Interview conducted with the Minister of the Machibisa congregation on the 2 December 2006 in Pietermaritzburg.

<sup>235</sup> Interview conducted with the Minister of the Machibisa congregation on the 6 December 2006 in Pietermaritzburg.

<sup>236</sup> Interview conducted with the Minister of the Machibisa congregation on the 6 December 2006 in Pietermaritzburg.

believed that *indoda ayihlabi ngomhlathi owodwa* (“a man cannot be satisfied by one woman”).<sup>237</sup> Proverbs like this suggest that a man has no limits as to how many sexual partners he may have. This gives men the potential to spread HIV to their many sex partners. Nevertheless, because the woman is prohibited from having many sex partners, an HIV positive status labels her as promiscuous, thereby invoking gender-based stigma.

Linked to that notion is a belief that at a particular age (17 years), a girl must have a child, even if she is not married, so that the society does not view her as having a serious problem or else she will be called *inyumba*, which means barren.<sup>238</sup> That is an insult in the Zulu culture. Therefore to avoid these labels and stigmatisation, young Zulu women engage in an unprotected sex. The sex itself is not a taboo but a sign of fertility. Yet for a woman, a sex-related disease is a taboo because it carries the assumption that she has had many sexual partners.

### **5.2.7 HIV and AIDS Awareness in the Machibisa Congregation**

The presence of stigma in the Machibisa congregation delayed the congregation from starting the AIDS Programme. According to the AIDS Programme chairperson, it had been difficult for the previous minister to initiate the Programme because of HIV and AIDS-related stigma in the congregation. The interviewee said that the previous minister had indirectly attempted to raise HIV and AIDS awareness in the church by including gender and HIV and AIDS subjects in some of her sermons. The interviewee said that this was an attempt to combat stigma, but indirectly, through raising AIDS awareness.<sup>239</sup>

According to both the chairperson of the AIDS Programme and the minister, it was difficult for the congregation to respond to gender-based HIV and AIDS-related stigma in the last ten years because some members of the congregation were reluctant to talk about HIV and AIDS. However, in February 2006, the congregation finally managed to start the Programme on HIV and AIDS. The minister said some members of the

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<sup>237</sup> Moyo, H. “Mphophomeni a Community of Hope”, Unpublished paper presented for an HIV and AIDS Conference in Pietermaritzburg, 19-21 October 2005 p. 14.

<sup>238</sup> Moyo, H. “Mphophomeni a Community of Hope”, Unpublished paper presented for an HIV and AIDS Conference in Pietermaritzburg, 19-21 October 2005 p. 15

<sup>239</sup> Interview conducted with the chairperson of the AIDS Programme of the Machibisa congregation on the 12 August in Pietermaritzburg.

congregation had been reluctant to talk about HIV and AIDS was because it implicated the issue of sexuality and, in his view, talking about sex was regarded as a taboo.<sup>240</sup>

### **5.2.8 The Role of the Media on HIV and AIDS-related Stigma in the Machibisa Congregation**

According to the chairperson of the AIDS Programme, “the media played an important role on the issue of HIV and AIDS-related stigma in the congregation. People are aware of the negative effects of stigma on HIV positive people through what they have heard or learnt from the media, such as radio and television”.<sup>241</sup> The congregation is trying to combat the stigma of HIV and AIDS. The congregation has started the HIV and AIDS awareness through including HIV and AIDS in the sermons.<sup>242</sup> The interviewee further said:

We are looking forward for the 1<sup>st</sup> of December, for World AIDS Day, where we will do a campaign in the church, we will invite the media, but we are waiting for the parish council to approve our policy.<sup>243</sup>

Media can play an important role in HIV and AIDS awareness, as the interviewee has pointed out. However, Skhosana observed that the media in South Africa has played a major role in portraying HIV and AIDS only in the black community. Furthermore she said:

A poor township woman, for example, is more likely to agree to be interviewed, hoping that she would get financial and other kinds of assistance by participating. Her situation is more desperate than her white counterpart and so will be the measures she takes to access help. The privacy of [those] women and rights to informed consent becomes secondary to perceived benefits in desperate circumstances.<sup>244</sup>

Patton noted that, “while the media have been instrumental in raising awareness about AIDS, the reportage has consistently misinterpreted the basic concepts of HIV, sensational faulty research and selectivity on conflict data”.<sup>245</sup>

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<sup>240</sup> Interview conducted with the Minister of the Machibisa Congregation on the 6 June 2006 in Pietermaritzburg.

<sup>241</sup> Interview conducted with the chairperson of the AIDS Programme of the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

<sup>242</sup> Interview conducted with chairperson of the AIDS Programme of the Machibisa congregation 12 August 2006 in Pietermaritzburg.

<sup>243</sup> Interview conducted with the chairperson of the AIDS Programme of the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

<sup>244</sup> Skhosana, N. *Women, HIV and AIDS Stigma: An Anthropological Study of Life in Hospice* Unpublished Masters Thesis, Johannesburg: University of Witwatersrand, 2001 p. 24.

<sup>245</sup> Patton, C. *Inventing AIDS* London: Routledge Publishers 1990 p. 26

### **5.2.9 Plans of the Machibisa Congregation HIV and AIDS Programme to Combat Stigma**

The AIDS Programme Committee members of the Machibisa Congregation are planning to start a hospice, which will be a pilot project. Although it is still difficult for people to disclose their HIV status, the interviewee thinks that once they start a hospice for HIV positive people, it will be easier for them to disclose their HIV status and fight stigma.<sup>246</sup> Putting HIV positive people in hospices might have negative consequences. It might not shake off the community rumours that the person is suffering from AIDS, in the case of those who want to keep their HIV positive status secret.

The chairperson of the AIDS Programme also said that the congregation has no resources for HIV positive people. Therefore it becomes difficult for people to disclose their HIV status. Furthermore, he said that he thinks it might take some time for HIV positive people to disclose their status in the congregation. However, if they first get support from their families, it would be easier for them to disclose their HIV positive status in the congregation. The interviewee thinks that some of those who do not want to disclose their HIV positive status in the congregation do not get enough support from their families.<sup>247</sup>

The AIDS Programme of the Machibisa Congregation has started networking with Treatment Action Campaign (TAC), in Pietermaritzburg. TAC will train some members of the congregation as “peer educators”. The AIDS Programme Committee is planning to work with HIV and AIDS Faith Based Organizations because they want their programme to be in line with Christian values.<sup>248</sup>

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<sup>246</sup> Interview conducted with the chairperson of the AIDS Programme of the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

<sup>247</sup> Interview conducted with chairperson of the AIDS Programme of the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

<sup>248</sup> Interview conducted with chairperson of the AIDS Programme of the Machibisa congregation on the 12 August 2006 in Pietermaritzburg.

### **5.3 Esibusisweni Lutheran Congregations**

#### **5.3.1 Profiles of the interviewees**

The interviews were conducted with HIV positive women who are members of the Esibusisweni Lutheran Congregation in Ntuzuma Township, Durban. The women interviewed were between the ages of 25 and 40 years old, according to background information provided the interviews. They are all single mothers. The educational level of the women interviewed is between grade 10 and grade 12. The women interviewed have no tertiary level education, with the exception of one woman who is working as a nurse in Durban. Seven of these women are not working and one is working as an AIDS counsellor at Durban Central Chest Clinic. The minister of the congregation is a forty-five year-old married man. Rev. Sithole has a Bachelor of Theology Honours degree from the former University of Natal in Pietermaritzburg. He is the HIV and AIDS Programme co-ordinator of the South Eastern Diocese of the Evangelical Lutheran Church in Southern ELCSA (ELCSA-SED).

#### **5.3.2 The Research Process in the Esibusisweni Congregation**

In May 2006, before the research was embarked, I phoned the minister of the Esibusisweni Congregation in order to get permission to carry out the research in his congregation. The minister agreed, and suggested that we meet in Durban on the 20<sup>th</sup> of July 2006. The interview was conducted with the minister at his house in Ntuzuma Township, on the 20<sup>th</sup> of July 2006. After interviewing the minister, he suggested a key person, an HIV positive woman, to be interviewed about the HIV and AIDS Support Group of the Esibusisweni Congregation.

On the 1<sup>st</sup> of August I called the woman to make an appointment for the interview that was to take place on the 14<sup>th</sup> of August 2006. The interview was conducted on the 14<sup>th</sup> of August 2006, in Durban, at the Ntuzuma congregation resource centre. Three other women were also interviewed on the same day. On the 20<sup>th</sup> of August, I travelled to Durban to interview two other women. One was interviewed at the resource centre, and the other one was interviewed at her house in town. The one who was interviewed at her house is a nurse and not a member of the support group. On the 12<sup>th</sup> of October, I traveled to Durban for the last interview. The interview took place in the interviewee's office, at Durban Chest Clinic, where the interviewee is working. She is also not a member of the support group due to not having enough time to attend support group

meetings. However, she used to be a member of the support group before she got appointed at Durban Chest Clinic.

On the 30<sup>th</sup> of November, follow-up interviews were conducted in Durban with the three women interviewed previously. They were interviewed at the church resource centre. On the 31<sup>st</sup> November, follow up-interviews were also conducted with the other four women interviewed. They were conducted in their places. On the 3<sup>rd</sup> of December two more women were interviewed at the church resource centre.

### **5.3.3 The HIV and AIDS Programme of the Esibusisweni Congregation**

In the first years of the 21<sup>st</sup> century, Diakonia Council of Churches organized a series of workshops for ministers who are from different denomination and working in the city of Durban.<sup>249</sup> The aim of these workshops was to help the ministers “to change their attitude and mindset about HIV and AIDS, especially those who still regards it as a punishment from God”.<sup>250</sup> In the same year, the Esibusisweni Congregation started the HIV and AIDS awareness campaign. The minister of the Esibusisweni Congregation tried to implement in the congregation what he learnt from Diakonia Council of Churches, such as organising Bibles studies and workshops on HIV and AIDS in the congregation as a way to combat stigma.<sup>251</sup>

Later, the parish council of the Ntuzuma Parish felt that as a parish they must do something constructive about HIV and AIDS. It was discussed during the parish council meeting that this should be done by all the congregations that belong to the Ntuzuma Parish, including the Esibusisweni congregation. The Esibusisweni Congregation invited some people who had disclosed their HIV positive status in public to give talks, have discussions and address the various groups in the congregation about HIV and AIDS.<sup>252</sup>

In 2001, a resource centre was formed at the Esibusisweni Congregation. The aim of the resource centre was to address the problems of the community, such as poverty and HIV and AIDS. The resource centre is funded by the Norwegian Church Aid and the

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<sup>249</sup> Interview conducted with Rev. Njabulo Sithole on the 20 August 2006 in Durban.

<sup>250</sup> Interview conducted with Rev. Njabulo Sithole on the 20 August 2006 in Durban.

<sup>251</sup> Interview conducted with Rev. Njabulo Sithole on the 20 August 2006 in Durban.

<sup>252</sup> Interview conducted with Rev. Njabulo Sithole on the 20 August 2006 in Durban.

partner parishes from Germany.<sup>253</sup> Within the resource centre, there is a “mother” Programme called “Senzokuhle Orphan Centre”, where vulnerable children are taken care of. The congregation members decided that within the resource centre, there should be a soup kitchen, especially for HIV positive people who are taking anti-retrovirals (ARV) and the needy.<sup>254</sup>

The minister offered a garden in his yard to be utilised by the members of the support group to grow their own vegetables. The minister said that they are addressing the issue of HIV and AIDS in all levels of the church, especially the young people.<sup>255</sup> He further said that they have developed a policy of separating the young men from young girls in order to address them separately about HIV and AIDS and to find out from their groupings how to curb the HIV infection. In 2004, a support group for HIV positive people was formed in the Esibusisweni Congregation. It is also part of the resource centre.<sup>256</sup>

#### **5.3.4 The HIV and AIDS Support Group of the Esibusisweni Congregation**

One interviewee claimed to have started the HIV and AIDS Support Group in the congregation in 2004. Herself HIV positive, she included the other four HIV positive women in the congregation and later became the chairperson of the group<sup>257</sup>. When she started the support group, she was employed by the congregation as a person-in-charge of the resource centre. According to the interviewee, it was part of her job description to start a support group, since the resource centre is also dealing with the issues of HIV and AIDS.<sup>258</sup> The other reason that she decided to start the support group was that those with whom she started the support group used to travel a long distance from Ntuzuma to KwaMashu township in order to meet with the members of the Methodist Church HIV and AIDS Support Group.<sup>259</sup>

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<sup>253</sup> Interview conducted with Rev. Njabulo Sithole on the 20 August 2006 in Durban.

<sup>254</sup> Interview conducted with Rev. Njabulo Sithole on the 20 August 2006 in Durban.

<sup>255</sup> Interview conducted with Rev. Njabulo Sithole on the 20 August 2006 in Durban.

<sup>256</sup> Interview conducted with Rev. Njabulo Sithole on the 20 August 2006 in Durban.

<sup>257</sup> Interview conducted with an HIV positive woman from the Esibusisweni Congregation on the 14 August 2006 in Durban.

<sup>258</sup> Interview conducted with an HIV positive woman of the Esibusisweni Congregation on the 14 August 2006 in Durban.

<sup>259</sup> Interview conducted with an HIV positive woman Esibusisweni Congregation on the 14 August 2006 in Durban.

For some of them, it was difficult to get money to travel from Ntuzuma to KwaMashu Township because they were not getting the HIV and AIDS support grants from the government. She also suggested that they should network with other HIV and AIDS support groups.<sup>260</sup> The other HIV positive woman whom I interviewed said that the support group accommodates even those who are not members of the Lutheran church. She also said that they are now a group of eighty-one women and there are only eight Lutheran church members from the support group, and the rest are from different denominations.<sup>261</sup> When the support group first started, there were two men and three women, and later those men pulled out. They were all members of the Lutheran church. Furthermore, the interviewee said, some of the HIV positive members from the congregation do not want their HIV positive status to be known, and that is why they have a smaller number of the Lutheran church members in the support group. The support group members are between the ages of 25 and 42.<sup>262</sup>

### **5.3.5 Disclosing HIV positive status in the Esibusisweni Congregation**

Experiences of diagnosis and disclosure were investigated and explored as they play out in the context of the family, the society and the church. The research highlighted both positive and negative experiences. Eight out of nine women interviewed reported that their families supported them when they disclosed their HIV status, rather being stigmatised. One woman said:

I was diagnosed HIV positive in 1998. At first I was afraid to disclose my HIV positive status to my family. During those years it was not easy to talk about HIV and AIDS. Later in 2000, I decided to tell them. After disclosing my status to them, they developed a negative attitude towards me and my child, especially my sister. They regarded me as an "unclean" person. If I cook, they would not eat the food. Later in 2001, I decided to leave them and look for a house to rent. I also decided to join the support group in our congregation. That is where I fell at home. I am more with being with the members of the support group than being with my own family and the minister is very supportive to us, as members of the support group.<sup>263</sup>

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<sup>260</sup> Interview conducted with an HIV positive woman of the Esibusisweni Congregation on the 20<sup>th</sup> August 2006 in Durban.

<sup>261</sup> Interview conducted with an HIV positive woman of the Esibusisweni Congregation on the 20<sup>th</sup> August 2006 in Durban.

<sup>262</sup> Interview conducted with an HIV positive woman of the Esibusisweni Congregation on the 20<sup>th</sup> August 2006 in Durban.

<sup>263</sup> Interview conducted with an HIV positive woman of the Esibusisweni Congregation on the 20<sup>th</sup> August 2006 in Durban.

According to my observation of the Ntuzuma resource centre, the HIV positive women are always happy when they are together. I witnessed them laughing and singing and praying together as a group. I witnessed an atmosphere in which a woman was allowed to do what she felt like doing.

According to the minister, there are two different kinds of groups for HIV positive people in the congregation. The first one is for those who are not afraid or who are free to disclose their HIV positive status to the congregation. The second one is for those who have disclosed their HIV positive status to their families and the minister only. They do not want their HIV positive status to be known by the rest of the congregation members. This is because of the fear of being stigmatised.<sup>264</sup>

I interviewed one woman who is not a member of the “visible” support group, known in the congregation, on why she is not part of it. She said:

It is not because I am afraid of disclosing my HIV positive status. I am working as a nurse and I work almost every day, until late. Therefore, I do not have enough time to meet with the support group. I do not hide my HIV positive status. Many people from the congregation know my HIV positive status because I always talk about it, especially with those close to me, and the youth members. I was a youth leader, so am very free with the youth members. For me it has not been difficult to tell people about my HIV positive status because as a nurse I work with HIV positive people. Where I work, there are also other nurses who are HIV positive and we support each other. We are in the process of forming our own support group as nurses. I was diagnosed HIV positive in 1995, but even before I was diagnosed, I had much information on HIV and AIDS, through the work that I am doing as a nurse. The minister sometimes refers to me those who do not want to disclose their HIV positive status in public, or to their family members, for encouragement and emotional support. I never experienced any kind of stigma in the congregation. I was even elected as a congregation leader in 2003. Before the elections, there were no problems concerning my HIV status. Many people were in support of me being elected as a congregation leader.<sup>265</sup>

Out of nine women interviewed, the woman mentioned above is the only one who said that she never experienced any kind of stigma in the congregation. The reason might be that she is an educated woman and a nurse, whereas the other HIV positive women, with an exception of one, who also said she never experienced stigma, are not educated. As in these cases, uneducated women often experience more stigma than educated

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<sup>264</sup> Interview conducted with Rev. Njabulo Sithole on the 20 July 2006 in Durban

<sup>265</sup> Interview conducted with an HIV positive woman from the Esibusisweni Congregation on the 12 October 2006 in Durban.

women. Sometimes it happens that people who stigmatise HIV positive people are also HIV positive, and by stigmatising others, they hope to prevent others from becoming suspicious of their HIV positive status, as I have mentioned previously. In this case, because this woman is a nurse, some HIV positive people who might stigmatize her, rather would look to her as a source of knowledge on HIV and AIDS. That might be the reason why there were no problems with her being elected as a congregation leader.

### **5.3.6 Holy Communion and HIV and AIDS- related Stigma in the Esibusweni Congregation**

The minister said that he endeavoured to eliminate the stigma through campaigns, inviting the guest speakers to address the problem, during the last ten years. For the congregation, it has not been easy to deal with HIV and AIDS. It has been an ongoing struggle, and it prompted the implementation of the two groups of HIV positive people, which I have already mentioned.

Eight out of nine women interviewed said that there is no problem with HIV and AIDS and Holy Communion in the Esibusweni congregation. However, one woman said that before they started the support group, if some people in the congregation know your HIV positive status, during the Holy Communion, they would not want to share the same cup with you.

She further said:

I remember one day, it was the 6<sup>th</sup> of November in 2000 and it was a Sunday service. The previous month [October] of that year I disclosed my status to one of my church friends. I was going for Holy Communion, following two women who were in our youth group members. One of them turned back and saw me behind her. She quickly went back and sat down. She did not partake in the Holy Communion. She is also a friend to my friend, whom I disclosed my HIV positive status to. She also knew about my status. I felt like crying loud and asking God why He brought this disease to earth.<sup>266</sup>

Similarly, the minister said:

To me stigma has been with us the longest. I remember one of our female student pastors who was HIV positive, who is now late. One day she came very angrily saying, "Look pastor, when I was in the line to receive Holy Communion and lot of people did not partake, why?" I told her these are the very people who cried when you disclosed your HIV positive status. To me

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<sup>266</sup> Interview conducted with an HIV positive of the Esibusweni Congregation on the 3 December 2006 in Durban.

when they cried, they were pretending. You must face it!" That has decreased the number of people interested in disclosing openly. I also discourage that. It is enough if it's only the members of the family who know about their HIV positive status, and as a minister I can refer the HIV positive person to places of safety.<sup>267</sup>

What the minister and the woman I interviewed said indicates the presence of stigma in the Esibusweni congregation. This is due to the broken relationship between the woman and her congregants. The fact that some congregation members are reluctant to partake in the Holy Communion because of the presence of HIV positive people shows that they do not want to accept or associate with them. One may also conclude that this is an indirect rejection because those who do not partake in the Holy Communion do not state their reason for not partaking, but they show signs of rejecting HIV positive people.

Sharing the same wine and using the same cup during the Holy Communion is still a problem for some Christians. In the *AIDS Report to the Synod of Bishops on Some Theological and Ethical Issues*, the South African Anglican Theological Commission in the Natal Branch mentioned the issue of the common cup during Holy Communion as part of the discussion.<sup>268</sup> It was discussed that those with the fear of contracting HIV because of sharing the same cup should feel free to receive the communion in one kind only, or deep the bread into the wine, thus not touching the cup with their lips.<sup>269</sup> Confronting this problem would help those HIV positive people feel that they are welcomed in the church.

Stigma in terms of the Holy Communion is rooted in the practices of the Dutch Reformed Church during colonial times and the apartheid regime.<sup>270</sup> At an early stage of the Dutch settlement in the Cape Colony, it became customary to make special provisions for ministry among the indigenous Khoikhoi people, as well as the slave population, which came from Indonesia, Madagascar, East and West Africa.<sup>271</sup> This

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<sup>267</sup> Interview conducted with the Minister of the Esibusweni congregation on the 20 July 2006 in Durban.

<sup>268</sup> "AIDS: A Report of the Synod of Bishops on some Theological and Ethical Issues", *Synod for the Bishops of Church of the Province of Southern Africa* March 1991 p. 20

<sup>269</sup> Ibid.

<sup>270</sup> Ibid

<sup>271</sup> Bosch, D. "Nothing but a Heresy", in De Gruchy, J. and Villa-Vicencio, C. (eds) *Apartheid is a Heresy* Cape Town: David Philip Publishers 1983 p. 24

was in line with “the basic principle of preaching the Gospel in the language of the people”.<sup>272</sup> At one stage, “however, there was even a faintest suggestion of a theological justification for the idea of creating separate congregations, let alone separate church structures for converts from the above mentioned groups”.<sup>273</sup> Once they became Christians, they were to enjoy their privilege as members together with the Dutch Christians.<sup>274</sup>

By the beginning of the nineteenth century, suggestions were from time to time that Holy Communion should be administered separately to converts, yet within the “orbit of the same church affiliation. This was, however, rejected. An 1829 resolution of the Cape Town Presbytery in this regard was illuminating”.<sup>275</sup> It resolved that “it was compulsory, according to the teaching of Scripture and the spirit of Christianity, to admit such persons simultaneously with born- Christians to the communion table”.<sup>276</sup> The synod of 1834 endorsed this viewpoint as “an unalterable axiom which is founded on the infallible Word of God...and all Christian congregations and each Christian in particular have to think and act in accordance”.<sup>277</sup>

In comparing the story mentioned above and the stigma of Holy Communion with regards to HIV and AIDS in the Esibusisweni congregation, one may highlight some similarities. The white Dutch Christians did not want to share Holy Communion with the slave converts because they regarded themselves as a chosen nation of God. They regarded the slave converts as “unhygienic”. They also wanted to maintain their superiority and social distance from the slave converts.

Those unwilling to share Holy Communion with HIV positive women in the Esibusisweni congregation might similarly desire to maintain “self purity” and

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<sup>272</sup> Bosch, D. “Nothing but a Heresy”, in De Gruchy, J. and Villa-Vicencio, C. (eds) *Apartheid is a Heresy* Cape Town: David Philip Publishers 1983 p. 24

<sup>273</sup> Ibid

<sup>274</sup> Bosch, D. “Nothing but a Heresy”, in De Gruchy, J. and Villa-Vicencio, C. (eds) *Apartheid is a Heresy* Cape Town: David Philip Publishers 1983 p. 25

<sup>275</sup> Bosch, D. “Nothing but a Heresy”, in De Gruchy, J. and Villa-Vicencio, C. (eds) *Apartheid is a Heresy* Cape Town: David Philip Publishers 1983 p. 25

<sup>276</sup> Bosch, D. “Nothing but a Heresy”, in De Gruchy, J. and Villa-Vicencio, C. (eds) *Apartheid is a Heresy* Cape Town: David Philip Publishers 1983 p. 30

<sup>277</sup> Bosch, D. “Nothing but a Heresy”, in De Gruchy, J. and Villa-Vicencio, C. (eds) *Apartheid is a Heresy* Cape Town: David Philip Publishers 1983 p. 29

hygienic distance from HIV positive people who are sometimes regarded as unclean and sinful.

### **5.3.7 Stigma in the Esibusisweni Congregation between 1995 and 2005 (males and females)**

According to the minister of the Esibusisweni congregation, stigma has been the same between males and females in the last ten years. In the congregation, there is no problem of gender equality as both men and women are treated equally. Therefore, in his estimation, stigma knows no gender.<sup>278</sup> I think what the minister said about gender equality in the congregation is true. For example, the congregation leader is a woman. Many congregations in the black Lutheran churches in South Africa are led by men. This shows gender inequality.

According to the minister, since he became a minister of the Esibusisweni congregation, teaching on HIV and AIDS in the congregation had no positive influence on the congregants with regards to stigma. This is because the congregation has not yet dealt with the root of stigma, views on sexuality.<sup>279</sup> According to Khatide, HIV and AIDS is largely a human issue and “it is urgent to look into our attitude towards sex”.<sup>280</sup> Unless this changes, the fight against HIV and AIDS will become difficult. “The church, as a body that claims to be the conscience of humanity and the custodian of moral values needs to lead in the campaigns to break the conspiracy of silence, but because of the history of the silence on sexual matters, the church finds it difficult to open up”.<sup>281</sup>

Foster notes that:

When people turn to the church for direction in sexual matters, they are usually met with stony silence or a counsel of repression. Silence is no counsel and repression is bad counsel.<sup>282</sup>

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<sup>278</sup> Interview conducted with Rev. Njabulo Sithole on the 20 July 2006 in Durban.

<sup>279</sup> Interview conducted with Rev. Njabulo Sithole on the 20 July 2006 in Durban.

<sup>280</sup> Khatide, A. “Teaching and Talking about Our Sexuality: A Means of Combating HIV and AIDS”, in Dube, M. *HIV/AIDS and the Curriculum: Methods of Integrating HIV/AIDS in Theological Programmes* Geneva: WCC Publications 2003 p. 1-2

<sup>281</sup> Ibid

<sup>282</sup> Foster, R. *Money, Sex and Power* London: Hodder & Stoughton 1985 p.120.

In most African countries, silence is compounded by both our cultural socialization and spiritual or theological perceptions. It is therefore important to focus on these factors and see how they contribute to silence on sexual matters.<sup>283</sup> In addition, people need informed knowledge on HIV and AIDS. This will enable them to know that there are other ways or routes of transmission of the disease. By that, stigma attached to the people living with the virus will be reduced if not eradicated.

Three out of the nine women interviewed said that since they started the support group in the congregation, there is less stigma, although it is not yet completely gone. One woman said:

Women are the most stigmatisers as compared to men. They like gossiping about each other. With men, you would not hear them gossiping about each other, even if they know somebody HIV positive status, unlike women.<sup>284</sup>

This is common among women. In most African societies, it is believed that a woman cannot keep a secret. If you say something to one woman, she will go around telling others.

### **5.3.8 The Experiences of HIV positive Women in living with “Spoiled Identities”**

Two out of the nine HIV positive women interviewed experienced stigma for a long time in the church before they could overcome it. These women drew on negative social discourses around HIV, which were then internalised, to become part of their sense of self. The narrative experiences of these women showed that these women resisted this stigmatised identity by distancing themselves from negative representations, although it was not easy.

One of the nine women interviewed said:

Before I overcame stigma, I used to regard myself as a sinner who needs prayers for repentance. I thought that my being HIV positive is a result of sin. However, one day, I was invited by a friend who is also HIV positive, to attend a Bible study that was organised by her minister, in the Methodist church in KwaMashu Township. The theme of the Bible Study was “The Bible and HIV and AIDS”. That is where I realised that AIDS is not a punishment for sin.<sup>285</sup>

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<sup>283</sup> Foster, R. *Money, Sex and Power* London: Hodder & Stoughton 1985 p.120

<sup>284</sup> Interview conducted with an HIV positive woman of the Esibusweni Congregation on the 12 October 2006 in Durban.

<sup>285</sup> Interview conducted with an HIV positive woman of the Esibusweni Congregation on the 12<sup>th</sup> October 2006 in Durban.

The reason for this woman to see herself as deserving punishment can be understood through Susan Sontag's work. Sontag highlighted that people who are ill from stigmatised diseases feel very unfortunate, not merely because they are ill, but because they are ill from a disease that invokes shame.<sup>286</sup>

### 5.3.8 Stigma and Culture

Three out of the nine women interviewed associated stigma of HIV and AIDS with culture. They also emphasised that culture is brought into the congregation and it contributes a lot to stigma. One of those three women said that in the Zulu culture there is a belief that if you are HIV positive, you are "unclean" and you will bring death to the whole family.<sup>287</sup>

When I conducted the follow-up interviews, I asked Rev. Sithole about his perception of HIV and AIDS as a polluting disease. He said:

I have been called on many occasions to minister in funerals of people who have died of HIV and AIDS-related diseases. Some funeral homes had special quarters where families could perform the ritual cleansing of bodies. These quarters are used where a death is believed to have been caused by witchcraft. In such instances, the body is doctored so that the curse may return from where it came from. The body is similarly doctored if the death resulted from homicide. In this case the "dark cloud" is reversed to the murderer. Although some AIDS deaths are believed to be brought by witchcraft, this belief is not widespread. AIDS-related deaths are associated with the pollution of sin and moral decay and as a result ritual cleansing are emphasised. Depending on the belief of the family, and people from the church or traditional healers would be taken with the older member of the family to the funeral parlour on the day before the funeral. Here prayers of forgiveness are said on behalf of the deceased. The coffin is then sealed and not opened.<sup>288</sup>

As a corpse, the deceased is seen to be polluting, as a soul he or she has been judged to be tainted and as a social being notions of promiscuity are brought to bear on his or character.<sup>289</sup> In some cultures, HIV and AIDS is not only associated with death and pollution, but also with promiscuity. However, not everybody get the HI virus through promiscuity. For example one of the women I interviewed said:

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<sup>286</sup> Sontag, S. *AIDS and Its Metaphors* London: Penguin Publishers 1989 p. 53

<sup>287</sup> Interview conducted with an HIV positive woman of the Esibusisweni Congregation on the 12 October 2006 in Durban.

<sup>288</sup> Interview conducted with the Rev. Njabulo Sithole on the 20 July 2006 in Durban.

<sup>289</sup> Prior, I. *The Social Organisation of Death: Medical Discourse and Social Practices in Belfast* London: Macmillan Press Ltd 1989 p. 17-18

In the Zulu culture, for some ethnic groups, we have the ritual of *ukugcaba* [making of small cuts on the forehead and cheeks, using a blade]. This is done to protect the family members from “bad spirits” and it is also a sign that you belong to a certain ethnic group. I am also from an ethnic group, which performs this ritual. I was diagnosed HIV positive in 1992. The fact that I was diagnosed in 1992 does not mean that I got the virus in 1992. It is possible that I might have gotten it through this tradition of *ukugcaba* because when it is performed, one blade is used for everybody. Through this, one might be easily be infected by the HI virus, if one person is HIV positive. However, people still associate the HIV and AIDS with promiscuity.<sup>290</sup>

Some people who perform the ritual of *ukugcaba* do not think that one can easily be affected by the HI virus, especially those in the rural areas. This is because of insufficient knowledge on HIV and AIDS.

### **5.3.9 Stigma and the Bible**

Prayer and reading of Scripture has become a pillar of support for some of the women interviewed. For example, one woman said that she identified herself with Job who was persecuted by the devil. The woman further said that through her HIV positive status she had a chance to nurture her relationship with God, as she believed that “suffering” brings a person closer to God. A belief in God’s deliverance gave her hope when her family spurned her.<sup>291</sup> The religious belief of this woman went beyond the punitive moral tone that accompanied HIV infection; instead she focused on the salvation and hope offered by religion and the Bible.

HIV infection is accompanied by many losses. The stigma that surrounds infection deprives those who are infected of the support of others and inhibits them from coming to terms with the disease. Instead they are forced to hide their anguish and cope, as best as possible, in isolation.

Seven out of the nine women interviewed thought that the Bible has nothing to do with the stigma of HIV and AIDS. Two women thought that the Bible has an influence on the stigma of HIV and AIDS. They associated stigma and leprosy in the Bible. One of them said:

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<sup>290</sup> Interview conducted with an HIV positive woman of the Esibusweni Congregation on the 12 October 2006 in Durban.

<sup>291</sup> Interview conducted with an HIV positive woman of the Esibusweni Congregation on the 30 November 2006 in Durban.

To me, the way we as HIV positive women are stigmatised is not a surprise. Even the lepers in the Bible were also stigmatised, although they were not only women. People associate HIV and AIDS with leprosy. Well, we can say that leprosy was a result of sin because during the Old Testament time, God was a punishing God. But now, we cannot associate AIDS with leprosy. AIDS is not a result of sin! We are living in a time of a new covenant. Our God is a God of compassion and He is not a punishing God. He gave us his only Son to die for our sins. We are justified by faith alone, nothing else.<sup>292</sup>

Ronald Nicolson asserts that, "leprosy provides something of a New Testament equivalent to HIV and AIDS."<sup>293</sup> As lepers were isolated in the Old Testament, so we isolate those living with HIV and AIDS through stigma and discrimination. In the New Testament, the Pharisees, the Scribes and the Sadducees discriminated against those with leprosy, but Jesus treated all people as equal.<sup>294</sup> He accepted those with leprosy, the deaf, and the blind. He loved them. He never rejected them. Today people who are HIV positive are stigmatised and are usually considered a source of shame in their families, society and even the church, and as a result they suffer discrimination and rejection. Stigma excludes the stigmatised from those that are viewed as living a good moral life. However, if the analogy of leprosy is useful to understand the stigma of HIV and AIDS, it does not explain why women are more stigmatised than men. Women are different from men because of power imbalances, and this has been discussed in chapter one.

There are some biblical texts, for example the book of Hosea, that stigmatise women's sexuality. In this book:

Female sexuality is depicted as depraved. The passages of the Hosea draw a parallel between Hosea's adulterous wife and unfaithful Israel. The woman here is depicted as pursuing lovers and conceiving children in disgrace. This woman seemed to have no reconciliation with the husband, but was rebuked, publicly stripped naked, deprived of drink and enjoyment, walled in, bought like a slave and ordered to be faithful. While this prophetic depiction of depraved female sexuality and the necessity for violent punishment is couched in a metaphor, it could nevertheless be said to have very negative and damaging implications for actual women.<sup>295</sup>

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<sup>292</sup> Interview conducted with an HIV positive woman of the Esibusweni Congregation on the 30 November 2006 in Durban.

<sup>293</sup> Nicolson, R. *AIDS: A Christian Response* Pietermaritzburg: Cluster Publications 1994 p. 35

<sup>294</sup> Nicolson, R. *AIDS: A Christian Response* Pietermaritzburg: Cluster Publications 1994 p. 35

<sup>295</sup> Stiebert, J. "Women Sexuality and Stigma in Genesis and the Prophets," in Dube M. and Kanyoro M. *Grant me Justice! HIV/AIDS & Gender Readings of the Bible* Pietermaritzburg: Cluster Publications 2004 p. 85

For the Bible to compare the life of Israel with adultery, using women without mentioning men poses a great question that requires thought. "While all these prophetic depictions of depraved female sexuality and the necessity for violent punishment are couched in a metaphor, they could nevertheless be said to have very negative and damaging implications for actual women."<sup>296</sup> This text represents a potential danger for the fight against stigmatisation of women living with HIV and AIDS. The feminist biblical scholar, Naomi Graetz, argued that "it is no longer possible to argue that a metaphor is less for being a metaphor. In using female sexuality as a symbol for evil, a woman reader is forced to identify against herself and accept blame, stigma, and punishment".<sup>297</sup>

One of the nine women interviewed said that people in the church equate HIV and AIDS with leprosy in the Bible and see it as a punishment from God. Furthermore, she said that she also regards it as a punishment from God because she was never a "loose" woman. She only had one partner, but now she is HIV positive, whereas some "loose" women do not get infected with the virus.<sup>298</sup>

Another woman said that the Bible has nothing to do with the stigma of HIV and AIDS. She further said that there is a verse in the Bible, which says, "When the world shall come to an end, there will be incurable diseases." She said that this is what is happening today and Christians do not want to accept that those things are happening.<sup>299</sup>

Stigma is the result of how people interpret the Bible. AIDS is often considered to be God's punishment for sexual transgressions. Some people overlook the fact that, although promiscuity is indeed one of factors contributing to the spread of the virus, "hundreds and thousands of children and adults are infected and affected without being guilty of such offence".<sup>300</sup>

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<sup>296</sup> Ibid

<sup>297</sup> Graetz, N. *God is to Israel as Husband to Wife: Metaphoric Battering of Hosea's Wife in a Feminist Comparison Latter Prophets* Sheffield: Sheffield Academy Press 2005 p. 128

<sup>298</sup> Interview conducted with an HIV positive woman of the Esibusweni Congregation on the 3<sup>rd</sup> December 2006 in Durban.

<sup>299</sup> Interview conducted with an HIV positive woman of the Esibusweni Congregation on the 3<sup>rd</sup> December 2006 in Durban.

<sup>300</sup> Nurnberger, K. "Acceptance in Action-A Lutheran Approach to HIV Pandemic", in Nurnberger, K. *Martin Luther's Message for us Today* Pietermaritzburg: Cluster Publication 2005 p. 295.

### **5.3.10 Conclusion**

The stigmatisation of women living with HIV and AIDS calls the Church to ask itself what it means in our time to be the inclusive community that Jesus proclaimed. As a community of disciples of Jesus Christ, the Church should be a sanctuary, a safe place, a refuge, a shelter for the stigmatised and the excluded. The Church is called to work towards both the prevention of stigma and the care of the stigmatised. This challenges our understanding of the Church's identity and calls for deeper reflection on the issue of inclusion and exclusion within our communities. Jesus' ministry was inclusive. HIV and AIDS leave no Christian family or church congregation untouched. Paul's teaching that if one part of the body suffers, all suffer together (1Cor. 12:26) is a call of the church worldwide to acknowledge the epidemic as its own.

## Chapter 6

### 6.1 Recommendations and Conclusion

#### 6.2 Recommendations

HIV and AIDS is a dreadful disease that is prevalent in our society, in particular amongst the youth of South Africa and the churches. It carries stigma because it is associated with sex. Based on the findings of this research, the following recommendations can be made.

Gender dynamics are complex and play a significant role in the shape and prevalence of HIV and AIDS. These need to be understood in their complexity and responded to accordingly. Both men and women should adopt a culture of openness about sexuality. This should be coupled with respect to the rights and dignity of others. Ministers need to be trained through workshops and seminars. That will help to eliminate the ignorant from the pulpit and to change the mindset of the minister to look at HIV and AIDS as a challenge. Ministers should aim at opening the minds of people in the church and the society by organising awareness campaigns. Young people should be trained as peer educators in order to ensure that the youth are well educated on issue of sexuality, gender, and HIV and AIDS prevention.

There is also a need for the church to create a safe space where HIV positive people, especially women, are able to talk about their HIV positive status, encourage and support one another. Ministers should break the silence and stigma of HIV and AIDS.

The church should not tell women who are HIV positive and abused by their husbands, what to do.<sup>301</sup> The abused married women should not be referred for marriage enrichment, as this may be stressful and dangerous for women, for they will not be comfortable to speak in the presence of their husbands. Instead, they should be referred to agencies with expertise in dealing with abuse.<sup>302</sup>

Creating a safe space for HIV positive women can also be done by bringing discussions of HIV and AIDS and sexuality into the church in order that HIV people can be

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<sup>301</sup> Rackozy, S. *Silent No Longer: The Church Responds to Sexual Violence* Pietermaritzburg: Natal Witness Printing Publishing Company 2000 p.42

<sup>302</sup> Rackozy, S. *Silent No Longer: The Church Responds to Sexual Violence* Pietermaritzburg Natal Witness Printing Publishing Company 2000 p.42

reassured that the church is a safe place to disclose their status. This will not only break stigma, it will empower HIV positive people, especially women, to be actively involved in support programmes for church and community members. The fears that abound regarding AIDS have to be addressed so that the stigma that surrounds this disease can be minimised. The fact that HIV is not easily transmittable should be communicated in such a way that will not diminish the reality of its existence.

In 2002, a Church Leader's Conference of the Lutheran Communion in Southern Africa (LUCSA) met in Bonaero Park to draw up a joint *Plan of Action*<sup>303</sup> with a proposed Programme in response to HIV and AIDS pandemic. The document (*Plan of Action*) contains the Lutheran approach to major societal problem both in theological and practical terms.<sup>304</sup> If church leaders can apply it in a co-ordinated determined thrust, it could make a considerable difference to the problem of stigma. The *Plan of Action* was based on the recommendations of the LUCSA workshop held in Bulawayo in 2000 and a conference organised by the Lutheran World Federation held in Nairobi in 2002.<sup>305</sup>

As far I can see through my research, from the Machibisa congregations the *Plan of Action* has no decisive impact on the practical HIV and AIDS policies to combat stigma. In the Esibusisweni congregation there is less stigma because the minister, who is a chairperson of the AIDS Programme in the South Eastern Diocese, is directly involved in combating stigma in the congregation, in terms of helping the HIV and AIDS support group in getting funds for their sustainability and inviting people to give talks on HIV and AIDS and stigma in the congregation.

### **6.3 Conclusion**

This research portrays the lives of black women from the two Lutheran congregations who are living with HIV and AIDS and its challenges. Moreover, this research seeks to show experiences that are pertinent to women, thus giving a voice to a category of people that has been often relegated to the fringes of important issues. Lack of adequate knowledge about HIV and AIDS, fear of infection, the moral tone that accompanies the

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<sup>303</sup> See Appendix

<sup>304</sup> Nurnbeger, K. "Acceptance in Action-A Lutheran Approach to HIV Pandemic", in Nurnberger, K. *Martin Luther's Message for us Today* Pietermaritzburg: Cluster Publication 2005 p. 293

<sup>305</sup> Nurnbeger, K. "Acceptance in Action-A Lutheran Approach to HIV Pandemic", in Nurnberger, K. *Martin Luther's Message for us Today* Pietermaritzburg: Cluster Publication 2005 p. 294

disease and blame were some of the factors that further exacerbated the stigma of HIV and AIDS.

This dissertation has argued that negative attitudes towards HIV positive people discourage disclosure and force the infected to keep their diagnosis secret. As shown in this dissertation, HIV and AIDS is highly stigmatised and any display of associated conditions has the potential to discredit the individual. For some women, life experiences before an HIV diagnosis became different from those after the diagnosis. This was not because of the disease itself, but because of the meaning that had been brought to the disease. As a result, those infected and affected would rather take the secret to the grave than let it be known that they were afflicted by this morally stigmatised disease.

Women's gatherings can help to relieve and heal if they open up questions to their experiences. "The church if informed and sensitive can play a supportive role".<sup>306</sup>

This research has been analysed and used four indicators of stigma namely: broken relationships and the difficulty to sustain healthy relationships, rejection, self-exclusion and fear of disclosure. These have revealed that stigma still exist in the Machibisa and Esibusisweni congregation.

However, there is less stigma in the Esibusisweni Congregation as compared to the Machibisa Congregation because some members of the Esibusisweni congregation have been able to disclose their HIV positive status and they get support from the church. The Esibusisweni congregation has followed the LUCSA plan of action, but not completely. For example, the HIV and AIDS committee only consists of HIV positive people. According to the LUCSA *Plan of Action*, it should consists of a minister, health worker, social worker (where available), a youth members and a person living with the virus. Its' task should be informing the wider community about HIV and AIDS on a regular basis and on the other side to determine actual cases in the community. The Esibusisweni congregation is full of social workers and health workers but they do not

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<sup>306</sup> Buckenham, K. and Dlamini, L. "Violence Against Women: Some Spiritual Psychological and Emotional Dimension and the Process of Healing", in Rackozy, S. *Silent No Longer: The Church Responds to Sexual Violence* Pietermaritzburg Natal Witness Printing Publishing Company 2000 p. 28

involve themselves on issues of HIV and AIDS, with the exception of one HIV positive health worker and the minister. Both the minister and this HIV positive woman are involved in issues of HIV and AIDS, as already mentioned in the previous chapter.

With regards to the Machibisa congregation various people from different categories are committee members of the HIV and AIDS Programme. However, the minister is not part of the Programme and there is no HIV positive person involved. The fact that the minister is not involved in the Programme might not help in reducing stigma. Perhaps, the absence of the minister explains why there are no HIV people involved either. In many Lutheran congregations, people regard the minister as the one who should give direction to people.

In view of this fact, it is recommended that the two congregations should make use of LUCSA *Plan of Action* which spells a way forward for the parishes in dealing with stigma, particularly among women, as a response to the HIV pandemic.

**Appendix**  
**LUCSA's *Plan of Action***  
**The Lutheran HIV/AIDS *Plan of Action***

**1. Introduction**

On the 5 June 2002, the LUCSA Church Leaders' Conference, representing sixteen Lutheran Churches in Southern Africa, met in Bonaero Park (Johannesburg) to design a joint *Plan of Action* to combat HIV and AIDS pandemic. They also took account of the experience gained in projects already operational among the member churches. Though Lutheran Churches are already involved in the struggle against the pandemic and its consequences to various degrees, it is clear that a much more determined and coordinated effort is needed from the side of the Lutheran community as a whole

**2. The *Plan of Action***

The Conference drew up a *Plan of Action* for consideration, adaptation and implementation by the Lutheran Churches in Southern Africa. The *Plan of Action* can also augment and strengthen existing initiatives. The foundation of the *Plan of Action* is the quest for appropriate responses to actual cases at grass roots level. Whatever the Church does should empower the affected communities to cope with the calamity. Regular cost-benefit analyses should be conducted to determine the usefulness of costly formal institutions. Expensive and unwieldy bureaucracies, which work top down and have no commensurate impact on the grass roots should be avoided or abolished.

a) At the lowest level, a Support Group should be formed for each individual case, or strengthened and encouraged where it already exists. It should be recruited from family members, neighbours, congregants, and the wider community according to local circumstances. Its task is to prevent isolation and loneliness both of infected and affected; to comfort, reconcile and counsel; to overcome destitution, to find food, clothing and school fees. It is imperative that, according to good African traditions, the responsibility remains that of the family and the community. However, situation may have deteriorated to such an extent that there are more people living with the virus than potential helpers. In these cases orphanages, day care facilities, foster care programmes, frail care centers and other such institutions may have to be established as the need may be. Co-operation with other agencies is essential in these cases.

b) At parish level a Parish AIDS Committee should be formed, or encouraged and strengthened where it already exists. As far as possible, it should consist of a pastor, a health worker, a social worker (where available), a youth member and a person living with the virus.

Its tasks are, on the one hand, to inform themselves, the congregation, and the wider community about HIV and AIDS on a regular basis and, on the other hand, to determine actual cases in the community and establish Support Groups for each of these cases. It should work towards making the congregation an accepting and caring community, co-ordinate all efforts of the Parish, seek co-operation with other churches, NGO's and state agencies and generate funds to assist the Support Groups.

Parishes that do not seem to be affected yet should become proactive, make their members well informed in good time and discover the problem in their closer environment, for instance, among the employees of their members. To avoid fatigue and bitterness, it is important to ensure that voluntary groups are not overburdened, that the workload is spread evenly and that the whole community backs up the efforts of individuals. A good idea is to rotate the membership of these groups on a regular basis so that more people gain experience and share the burden.

c) At circuit or district levels there are various possibilities. One is to appoint a trained co-coordinator whose task is to initiate, train, guide and empower Parish AIDS Committees, to co-ordinate their actions and represent them at higher levels. Another possibility is to form a Circuit AIDS Committee representing all Parish AIDS Committees. The latter may be less efficient than the former. One could also combine the two approaches, so that the Committee is a consultative and policy-making body, while the co-ordinator is the executive. Care must be taken that costs do not spiral out of hand.

d) At a diocesan or church level, unwieldy and expensive structures should be avoided. However, the Conference became persuaded that the forthright, positive and active stance of the church leader is decisive for changing the mood of the diocese or church. Concrete cases have shown that where a church leader had addressed the issue of sex

and the virus openly, fearlessly and with determination, both clergy and laity find the courage to take initiatives.

Lutheran church leaders should also come out of their reserve and go public as the leaders of the churches do. The Conference was challenged by the suggestion that Bishops should volunteer being tested in full view of the media to remove the stigma and fear connected with such tests. The church leader should ensure that progress reports on the HIV and AIDS programmes are placed on the agenda of all meetings at parish, circuit and diocesan levels. The issue should figure prominently at all visitations. Church leaders should also seek consultation and co-operation with other churches, NGO's and the state where applicable.

e) It is important that the issue of HIV and AIDS becomes an integral part of training at all levels, especially at the theological seminary, but also in lay training, Sunday school, Confirmation class and adult education. Pastors should not hesitate to include it in their sermons and liturgies, to conduct special services and organise workshops on combating the pandemic in co-operation with their Parish AIDS Committees. Ecumenical co-operation should be sought wherever possible.

f) LUCSA's role should be that of co-ordinating the *Plan of Action*, encouraging the churches, monitoring their progress on a regular basis, consulting with other agencies, raising funds, establishing and maintaining links with overseas partners.

### **3. Conclusion**

“Jesus went about all cities and villages, teaching in their synagogues, proclaiming the good news of the kingdom and curing every disease and every ailment. When He saw the crowd, He had compassion for them, because they were harassed and helpless, like sheep without a shepherd...Then Jesus summoned His twelve disciples and gave them authority over unclean spirits, to cast them out and to cure every disease and every ailment” (Mt. 9:35f; 10:1). Christ prayed to His Father: As you have sent me into the world, so I have sent them into the world” (Jn 17:18). These texts show that Christ continues His redeeming work, through His Church. Every Christian is privileged to become Christ to others. It is in the power of His Spirit that we will be able to make a difference.

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### **Appendix of LUCSA's Plan of Action**