

Attitudes and Beliefs Around HIV and AIDS Stigma  
*The Impact of the Film “The Sky in Her Eyes”*

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A mini thesis submitted in partial fulfilment of the requirements for the degree of  
Masters in Development Studies in the Faculty of Arts, Institute for Social  
Development, University of the Western Cape.

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May 2005

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**Key Words:**

Stigma

Social Phenomenon

HIV

AIDS

Culture

Diseases

Attitudes

Beliefs

Film

Social change



## **Abstract**

This research explored cultural perceptions of HIV&AIDS with students at the University of the Western Cape and attempted to understand how these perceptions of the disease reinforce stigma and stigmatising attitudes towards people living with HIV&AIDS. This study investigated HIV&AIDS stigma as a social phenomenon and analysed the socio-cultural and historical roots of HIV&AIDS stigma. The methodology utilised to collect data integrated the components of a short film “The Sky in Her Eyes”, as a triggering agent to move deeper into the discussion on HIV&AIDS stigma. Questionnaires with open-ended questions and focus group discussions were also employed in the research. The data collection phase took approximately one month to complete. The focus group discussions with students revealed that the lack of stigma recognition by those whose behaviour is perceived as stigmatizing by those who have been affected by HIV&AIDS is among the main reasons why stigma persists. The students are not aware, or refuse to acknowledge that their own actions of laughing and the use of derogatory words perpetuate stigmatising behaviour. Moreover, the lack of correct knowledge about non-sexual modes of transmission combined with fears and cultural perceptions of the disease further maintain stigma. Cultural perceptions that encompass the explanation of the origins of HIV&AIDS as witchcraft or as punishment from God further reinforce stigmatizing behaviour. Furthermore, the norms and taboos about sex, such as explanations of HIV&AIDS in terms of purity and pollution or associations of HIV&AIDS with deviant behaviour make it difficult to talk about sex, adding further to stigmatising attitudes and behaviour. The findings also revealed that individual experiences of stigma are intertwined with other contextual stigmas of age, class or gender. The questions that emerged out of this research call for urgent further investigations in the field of HIV&AIDS stigma. The implications of this work are wide ranging for intervention programmes dealing with HIV prevention as well as for creating a more supportive atmosphere which will allow people living with HIV&AIDS to receive the acceptance, support, care and treatment which is their right.

## Declaration

I declare that "Attitudes and Beliefs Around HIV and AIDS Stigma: *The Impact of the Film "The Sky in Her Eyes"*", is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Igor Lesko

May 2005



Signed.....

## **Acknowledgements**

My greatest thanks belong to the following:

1. The Students at the University of the Western Cape who participated in this research. Thank you very much for allowing me to enter your space and for sharing your views and opinions with me.
2. My family, especially my mom, for supporting me throughout my studies.
3. The Sauls family who became my second family here in South Africa. You accepted me as a member of your family since I arrived to the country. Without your support I would not have been able to continue with my studies. Words can hardly explain how thankful I am for everything you have done for me. Amelia, Heidi, Roderick and Rael, thank you very much.
4. My supervisor, James Lees and my co-supervisor, Cheryl Ann Michael for your constructive criticism, support and guidance throughout my studies. Jim and Cheryl, thank you very much for everything. 
5. The staff at the Institute for Social Development for assisting me during the data collection process. I wish to express my warm appreciation to Priscilla Kippie and Benita Sauls for helping me to organise the venue and for fixing the last-minute problems.
6. Fiona, Solomon, Marion, Mandy, Fuzzy and my friends in Slovakia for emotional support.
7. The VLIR Prestige Scholarship Programme for financial support. Without your financial support this research could not have been undertaken.

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# **1.Introduction**

## **1.1 Understanding Stigma**

Stigma has been preoccupying the minds of various researchers for decades. Since Goffman's original work on stigma, an enormously vast body of literature has emerged that either elaborated or extended Goffman's ideas. Stigma is an everyday reality. It is known to everyone who "even temporarily slips beyond the bounds of social acceptability" (Ainly et al. 1986: 1). The purpose of this research is to explore this complex social phenomenon by looking at stigma associated with HIV&AIDS in particular. It is hoped that this can contribute to the broader understanding of stigma and the stigmatisation process. In relation to HIV&AIDS, I want to investigate possible causes of stigmatising attitudes and behaviour towards people who have HIV or AIDS. I want to move beyond mere analyses of manifestations of stigma. There has been a range of studies that explored stigma from an attitudinal perspective, concentrating on negative attitudes and beliefs of the people who are viewed to stigmatise others. Additionally, Goffman's definition of stigma as a "discrediting attribute", "led to a focus on stigma as though it were a kind of thing-a relatively static characteristic or feature" (Parker and Aggleton, 2003:14). Despite the amount of studies and educational interventions that have built upon the above approaches, stigma still persists. In this study, I will proceed with the understanding that stigma is the result of complex interactions on many levels, including but not limited to culture, identity, social psychology, history and political demands. While Goffman failed to take into account these broader contexts within which stigma exists and to understand the socially constructed nature of stigma, in this research, I have therefore studied the causes of HIV&AIDS stigma within a broader socio-cultural and historical context. Through the consideration of stigma as a social phenomenon, this research will consider how the stigmatizing behaviour of UWC students toward their peers who are infected or affected by HIV&AIDS can be challenged.

This thesis investigates stigma with students at the University of the Western Cape (UWC). Students at higher education institutions are particularly important because they are "the future high knowledge and skills base of the economy" (Lickindorf, 2004:9). At the same time, university campuses are "focal points of social and sexual

interactions” (Ibid: 9). While the HIV&AIDS programme at UWC works intensively with students through its Peer Education Programme and other training and intervention mechanisms, stigma remains a serious problem at the university. Since my research involves only university students, it is a biased sample. However, many of the selected students come from different parts of the country, bringing their culturally determined perceptions of the disease. In this sense, this research provides valuable information about stigma in general and HIV&AIDS stigma in particular. The ultimate goal of this thesis is to feed this information back to the people who work on developing new interventions in the field of stigma.

## **1.2 Labelling**

Why do we use labels? What meaning do they have in our lives? What is the connection between labels and stigmas? Greene (2001: xvi) points out that “what we see, hear, and feel around us is known by means of perceptual and conceptual structures, constructs that we (as social beings) build for ourselves.” Not all labels are stigmatising. In fact, some labels are very useful. They provide us with a meaning of a social world around us. For example, even such a thing as going to a shop to buy our favourite loaf of bread wouldn’t be possible if this commodity wasn’t labelled and placed into distinct categories. Our names are labels as well, and it is usually the first thing that we learn about people when we meet them. However, even labels like names may create a platform for stigmatisation. Whether this happens or not, depends on a particular social interaction and a cultural context within which an interaction occurs. For example, the bearers of Muslim names may nowadays feel temporarily stigmatised upon the arrival to the United States because they have been labelled as associated with terrorist threats, irrespective of nationality or ideological beliefs.

Labels can be comforting. They bring an order into chaos. We have created countless categories in which to place ourselves based on ethnicity, nationality, colour of skin, one’s preference of music, sexual orientation, educational background, family background or position in a society. These categories illuminate the ‘unknown’ immediately. They give us satisfaction in that sense. Hudak and Kihn (2001: 3) point out that “given the daily stresses of modern life, it may be the case that we have arrived at a moment in history where the label is in fact what we are seeking: some

quick linguistic cure to help us through the day.” What happens then in the presence of an ‘unknown’ and ‘mysterious’ which is perceived as a threat? What happens when HIV&AIDS is involved?

According to Greene (2001: xvi), “there are many constructs, unreflected upon, that carry the messages of power: they demean; they exclude; they create stereotypes. There are problems having to do with ethnicity, with diversity, with difference that arise from the heartless and immoral manipulation of labels.” These labels are stigmas. Stigmas, Peshkin (1991: 25) writes, “arise from a common sense of rejection, from a sense of being different, and needing to stand together in opposition to the notion of outsiders that what makes them different also makes them inferior.” The question then is what are the meanings behind HIV&AIDS labels? Why do they trigger stigmatising responses? How do labels define people as socially unacceptable? What labels have been created relating to HIV and AIDS, and what is the consequence of this labelling for intervening into the epidemic itself?

### **1.2.1 Medical labels**



In many instances, especially in a medical field, labels are applied with an intention to help. By naming certain medical conditions, specific measures can be put in place. For example, a student at school, who has serious learning difficulties, might face severe stigmatisation for not doing well, unless a ‘learning disability’ is diagnosed. This type of a student can then be referred for special education usually in an institution that will address this learner’s specific needs. There is no doubt that these types of educational and psychological interventions can be helpful; however, they also segregate. By naming a student’s ‘learning disability’, a sense of ‘otherness’ is created. A student might not feel ‘normal’ anymore, but feels different to his or her peers (Dillon, 2001: 27-38).

People living with HIV&AIDS are encouraged to disclose their status to help challenge surrounding silence and stigma around HIV&AIDS, and, by doing so, encourage other people to disclose as well. In recent years, we have witnessed an increased number of celebrities in the west and prominent people disclosing their HIV or AIDS status publicly. However, stigma attached to HIV&AIDS is tied to the

structures of power and differs by socio-economic status in society (as does access to treatment options and the stigma one experiences that hinders or promotes access to treatment itself). As Link and Phelan (2001: 8) explain, “people with more resources of knowledge, money, power, prestige and social connections are better able to avoid risks and adopt protective strategies.” They argue further that, “through mechanisms of discrimination, stigma places a person at a significant disadvantage with respect to knowledge, money, power, prestige, and social connections...”(Ibid:8). It is noteworthy to mention recent responses to stigma from Edwin Cameron. In his poignant work, Cameron highlights class differences in experiences of HIV&AIDS and associated stigma, and also links different forms of stigma such as race and sex. Cameron (2005: 211) argues, “We live in a contorted world, where some - including myself - live in relative affluence and comfort, our health secured by medical attention and access to care and treatment. Others live in grotesquely contrasting poverty, deprived of the essentials of life. Those living in affluence often do not see, still less have any contact with, people suffering from preventable illnesses, avoidable hunger and remediable destitution. Distance, ideology and the inevitable frailties of human understanding and connection help maintain comfort.” The above discussion raises troubling questions about people in poorer communities and campaigns that urge people to “come out” with their HIV status. Is it helpful to encourage people to disclose their status, and in that respect identify with an HIV or AIDS label, if we don’t really know what causes HIV&AIDS stigma? Does it really help when appropriate support structures are not in place for individuals “who might face rejection by their loved ones, in some case are evicted from their communities, are refused employment, or entrance to schools, as a result of their HIV status?” (Link and Phelan 2001; Herek and Capitano 1998, 1993; Save the Children 2001; Policy Project 2003).

### **1.3 Statement of the Problem**

#### **1.3.1 Context**

South Africa has one of the fastest growing HIV&AIDS epidemics in the world with about 5 million South Africans infected with HIV (UNAIDS, 2002: 190).<sup>1</sup> HIV&AIDS presents a threat to democracy and it could seriously jeopardise developmental efforts in the post-apartheid South Africa. Jackson (2002: 22) argues, “Because AIDS affects primarily the productive age range in the population, where the epidemic is most serious, it effects productivity and production, and household, community, sectoral and national economic security.” Although it is difficult to predict long-term impacts of HIV&AIDS on South African society, the micro-level impacts on households are immediate. Lehutso and Naidoo (2002: 14) state that “The more disadvantaged households, which are already trapped in poverty, tend to experience higher unemployment, and if they are employed, their jobs tend to be insecure with low wages, and do not offer medical aid and other benefits. HIV and AIDS affliction could mean a shorter, unproductive and lower quality of life for such individuals. This can be attributed to a poorly managed cycle of disease due to poorer nutrition, lack of medication and education and an inadequate support network. Not only do HIV and AIDS affect the day-to-day quality of life of HIV positive individuals and their families; the disease removes these people from their places of work while they are ill, leading to increasing absenteeism also on the side of spouses.” As a result, household-spending power usually decreases while there are increased spending demands on medications which often leads to the sale of the household’s assets. In addition to the aspects of HIV&AIDS mentioned above, the number of children orphaned by AIDS is increasing at an alarming rate. Dorrington & Johnson (2002) propose that: “The total number of children in South Africa who will have lost their parent/s to HIV and AIDS and any other causes (paternal, maternal and double orphans) could reach a staggering 5 700 000 by 2015.”

Recently, a report issued by the World Bank (2003) warned that HIV&AIDS may cause far greater long-term damage to national economies than previously assumed.

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<sup>1</sup> South Africa has been classified according to the Jaipur Paradigm as a country that will have an accelerated high prevalence of HIV, primarily because of its low levels of social cohesion and, although its levels of income are relatively high, the level of income inequality may be a contributory factor. The Jaipur Paradigm, as a conceptual model, originated in India in 1995 as a result of a workshop that tried to explain why some countries have witnessed HIV spread uncontrollably whereas other regions have lower rates. The article is available online: [www.rnw.nl/humanrights/southafrica/html.jaipur.html](http://www.rnw.nl/humanrights/southafrica/html.jaipur.html)

Summarizing the report, Hay and Rios (2003: 1) point out that “by killing mostly young adults, the disease is robbing the children of AIDS sufferers of one or both parents to love, raise and educate them, and so undermines the basis of economic growth over the long haul.” The World Bank report (2003: 8-9) stresses that “AIDS destroys existing human capital in a selective way. It is primarily a disease of young adults. A few years after they become infected, it reduces their productivity by making them sick and weak, and then it kills them in their prime, thereby destroying the human capital built up in them through child-rearing, formal education, and learning on the job.” Furthermore, “if one or, worse, both parents die while their offspring are still children, the transmission of knowledge and potential productive capacity across the two generations will be weakened.” Lastly, “as the children of AIDS sufferers become adults with little education and limited knowledge received from their parents, they are in turn less able to raise their own children and to invest in their education.” Based on the above-mentioned warnings, the report concludes that, “South Africa could face economic collapse within several generations” (Ibid: 8-9).



The future predictions arising from this report are alarming. HIV&AIDS is not only a serious threat to national economy, but also to the social fabric of South African society. It is, therefore, quite disturbing to read responses to the World Bank report from some of the leading economists and analysts in South Africa: “I am glad that the report picks up on secondary economic effects, but I’m concerned that this kind of thing will affect investor sentiment;” “What I point out is there is a tremendous amount of uncertainty. We do know that the AIDS epidemic could have a devastating impact on the social fabric which in turn will effect the economy, but we don’t know by how much;” “Many infected people are already unemployed and not contributing to the economy” and are therefore irrelevant to South Africa’s economic health (Independent Online, 2003: 1-2). These responses completely ignored the main points of this report, and are reflective of the denial nature around the HIV&AIDS epidemic. The ability of HIV&AIDS to reverse decades of development was well summarised by the UN Secretary General (2001: 6). “It [HIV&AIDS] changes family composition and the way communities operate, affecting food security and destabilising traditional support systems. By eroding the knowledge base of society and weakening production sectors, it destroys social capital. By inhibiting public and private sector development and cutting across all sectors of society, it weakens national institutions. By

eventually impairing economic growth, the epidemic has an impact on investment, trade and national security, leading to still more widespread and extreme poverty.”

### **1.3.2 Stigma**

According to Bond and Nubani (2000), “Stigma attached to HIV and AIDS is one of the most significant challenges to effectively fighting the spread of HIV and AIDS. Stigma increases vulnerability to HIV and worsens the impact of infection. Fear of being identified with HIV keeps people from learning their serostatus, changing behaviour to prevent infecting others, caring for people living with HIV and AIDS, and accessing HIV and AIDS services.” Additionally, “stigma intensifies the emotional pain and suffering of people living with HIV and AIDS, their families and caregivers” (Castro et al. 1998). Peter Piot (2001: paragraphs 4&5), Executive Director of UNAIDS, stated: “HIV stigma comes from the powerful combination of shame and fear. HIV is transmitted through sex and so is surrounded by taboo and moral judgement...giving in to HIV/AIDS by blaming others for transmitting HIV creates the ideal condition for the virus to spread: denying there is a problem, forcing those at risk or already infected underground, and losing any opportunity for effective public education or treatment or care.”

Despite numerous studies on the nature of stigma conducted worldwide, much work needs to be done to understand the underlying causes of HIV&AIDS stigma. While many studies have examined stigma from the position of self-reported attitudes, they have failed to provide deeper socio-cultural, historical and political understandings of HIV&AIDS related stigma and stigmatisation (Crandall 1991, Herek & Capitano 1993, 1998, 2002,). The studies conducted by Herek and Capitano (1993, 2002) concentrated on manifestations of stigma through respondents’ self-reported attitudes. The 1993 study found that “African Americans expressed greater support for policies separating persons with AIDS from others and stronger desire to avoid these persons, whereas whites expressed more negative feelings toward them and a greater willingness to blame them for their illness.” The 2002 study pointed out that “although overt expressions of stigma declined throughout the 1990’s, inaccurate beliefs about the risk posed by casual social contact increased, as did the belief that people with AIDS deserve their illness.” Although these studies inform us about the

manifestations of stigma, they don't explain causes behind the stigmatising attitudes towards people living with HIV&AIDS. "Studying stigma at this level has the effect of treating it as an individual attribute rather than as a social process."(ICRW, 2003: 6)<sup>2</sup> "Stigma and discrimination are social and cultural phenomena linked to the actions of whole groups of people, and are not simply the consequences of individual behaviour" (Parker & Agletton, 2003: 17). "A new transitional approach to studying stigma is thus needed that explores stigma as a social process that can be challenged through social action" (Parker&Agletton, 2002: 9).

### **1.3.3 The Impact of HIV&AIDS on South African Universities**

The decision to conduct research of this nature with students at the University of the Western Cape (UWC) was influenced by several factors. First, and foremost, I am a human being. Being human means, among other factors, treating each other with respect and humility. HIV&AIDS stigma produces the opposite, it dehumanises. In fact, stigma dehumanises both the stigmatised and those who stigmatise. As Freire (1970: 28) writes, "Dehumanisation, which marks not only those whose humanity has been stolen, but also (though in a different way) those who have stolen it, is a distortion of the vocation of becoming more fully human." Second, through my involvement in the VLIR funded Education Faculty project "Addressing the Direct and Indirect Impact of HIV&AIDS on Pre- and School-Going Children in South Africa", I gained an insight into the HIV&AIDS situation at the University. The HIV&AIDS epidemic hasn't left any levels of South African society unaffected, the universities included. The consulting firm ABT Associates estimated that "the rate of HIV infection among the South African undergraduate population in 2000 was 22 per cent and that it would rise to 33% by 2005" (SAUVCA, 2001: 4). According to Volks

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<sup>2</sup> In recent years, a body of literature has emerged that examines HIV&AIDS related stigma as a societal phenomenon. For example, a study conducted by the International Centre for Research on Women (ICRW), in partnership with organizations in Ethiopia, Tanzania, and Zambia (2003), revealed the social, historical, and economic aspects of HIV&AIDS stigma by looking not only at self-reported attitudes, but also at the socio-economic status, age, gender relations etc. Similar efforts in studying stigma as a societal phenomenon in South Africa are being currently undertaken by The Siyam'kela Project. This is a joint project of the Policy Project, the Centre for the Study of AIDS at the University of Pretoria, the United States Agency for International Development (USAID), and the Chief Directorate: HIV&AIDS and TB, National Department of Health. The Human Science Research Council (HSRC) currently also works on a project that attempts to understand HIV& AIDS stigma in social and historical context.

(2004: 162), “HIV&AIDS continues to have a considerable impact on higher education institutions. Since they are the structures that produce our future leaders and educated workforce, as well as producing the research that guides industries and government, the importance of higher education institutions in the fight against HIV and AIDS is incalculable.” He argues that “The possible impact of HIV and AIDS on tertiary institutions is manifold and includes effects on student academic performance and social development, management of student health, management of staff health and benefits, staff education, staff absenteeism due to illness and funeral attendance, and staff replacement costs” (Ibid: 167).

The former Education Minister, Prof. Kader Asmal pointed out in his 1999 speech on the impact of HIV&AIDS on tertiary institutions that:

“...all our planning will come to naught unless we take seriously the impact of HIV&AIDS on the education system and indeed, on a society as a whole. The projections of the extent of this pandemic are mind boggling. If the prevalence of HIV&AIDS is as high as 32% in some parts of the country, what does this, for example, mean for future student enrolments? What impact will the declining life expectancy rate have on the future viability of the National Student Financial Aid Scheme? Concrete and substantive mechanisms must be in place at an institutional level in order to respond to the crisis. Higher education also has the responsibility to mobilise its resources and capacity to support research into every aspect of the scourge.”

The response from South African higher education institutions towards HIV&AIDS in the 1990s has been described as “slow” and “fragmented” (Volks 2004, Lickindorf 2004). However, Lickindorf (2004: 9), explains that “A 1999 Tertiary Institutions Against AIDS conference rallied the commitment of leaders in this sector to respond in a ‘more institutionalised way.’” Since that time most universities have finalised their HIV&AIDS university policies and education and outreach programmes that raise awareness on issues related to HIV&AIDS. The University of Cape Town tackles the issue of HIV&AIDS through its HIV&AIDS Unit. The University of the Western Cape (UWC), which was established in 1959 as a ‘coloured’ university, celebrated its 40<sup>th</sup> anniversary in 2000. It has been internationally recognised for its stand against the apartheid regime. UWC addresses the issue of the epidemic through its HIV&AIDS Programme. The HIV&AIDS Programme, together with the university’s Student’s Health Centre, creates HIV&AIDS awareness among the students and the

staff through workshops, providing free confidential voluntary testing and counselling services (VCCT), a support group to HIV positive students and staff and promoting safer sex practices through distributing free condoms on campus. All the new first year students at UWC are provided with HIV&AIDS workshops during the orientation week and many students also participate in educational workshops throughout the year.<sup>3</sup> What is also particularly important about UWC's efforts in addressing the epidemic is the commitment and leadership shown by the university's Rector. The Rector is well known for his engagement in the fight against HIV&AIDS by encouraging the students to participate in the VCCT. However, the director of the HIV programme, Dr. Vergnani, feels that despite of the amount of educational activities, insufficient numbers of students seem to be taking advantage of the University's VCCT programme, and stigma still remains a significant barrier in the promoting efforts.<sup>4</sup> Typically, most interventions on campus have focused on educating students about HIV&AIDS transmission routes and methods to reduce risk and change behaviour. Subsequently, evaluation studies examined how the students' knowledge changed or reinforced their stigmatising attitudes towards people living with HIV&AIDS.<sup>5</sup> There is no doubt that these types of educational interventions are very important. However, the challenge is to provide a deeper socio-cultural understanding of stigmatisation among university students, which prompts my study on understanding of stigma.

## **1.4 Methodology**

### **1.4.1 The Qualitative Research Methods**

The nature of this study demanded employment of the qualitative research methodology. According to Weiss (2001: 6), "Qualitative methods are better equipped to capture the contextual, psychological and behavioural dimensions of stigma and discrimination." Weiss further states that, "qualitative and narrative accounts that complement survey data and elaborate features of stigma are needed to clarify the

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<sup>3</sup> It is also important to mention the activities of the English Department at UWC that engages its first year students in the HIV&AIDS issues through reading stories and writing essays on this topic.

<sup>4</sup> I obtained this information when I talked to Dr Vergnani in April 2004.

<sup>5</sup> For example, see a report compiled by Dr. Teresa Barnes: *The Impact of HIV/AIDS on the University of the Western Cape. 2000*

nature of the burden and indicate particular ways to deal with it” (Ibid: 6). In this research, focus group discussions were employed to collect data. Focus groups, according to Jewkes (2001: 733-744), “are useful as means of gathering information about group behaviour rather than individual behaviour.” However, the topic of stigma is very sensitive. Throughout informal discussions on HIV&AIDS stigma that I had with several people, I found that respondents, if asked directly, generally avoided the topic or claimed that “stigma doesn’t exist,” it “was not their problem,” or that “they didn’t know anything about it.”<sup>6</sup> Buskens et al. (1997: 83) explain<sup>7</sup>, “research into stigmatising conditions is research of a particularly sensitive nature. Sensitive research is a research which potentially poses a substantial threat to those who participate.” Additionally, as Buskens et al. (1997: 83) write, “respondents are often encouraged by researchers to reflect deeply on personal issues, and in the direct contact with researchers, respondents may feel exposed and vulnerable.”

#### **1.4.2 The Use of the Film: “The Sky in Her Eyes”**

Given the sensitive nature of this research, I decided to use the short film, “The Sky in Her Eyes”<sup>8</sup> as a mechanism to move gently into conversation with students on stigma. This short film, which is only 11 minutes long, tells a story of a little African girl in Kwazulu Natal and her mother who is dying of AIDS. This internationally acclaimed film won the 2003 Djibril Diop Mambety Prize at the Cannes Film Festival and has been screened at a number of international film festivals. After viewing the film, I asked participants to respond to a set of open-ended questions related to the experiences of the little girl after her mother’s death. According to the film directors (2003: 3, Steps for the Future Film Synopsis), this short film was made in response to “HIV/AIDS organizations which are urging production houses to produce informative material that is both emotionally and intellectually stimulating; material that’s aimed at changing attitudes towards people living with HIV/AIDS and towards the epidemic itself.” The ability of this film to challenge negative attitudes was also highlighted by Retha Wigget (2003: 1), “If you’ve ever been to see a great movie or had a visual experience that changed the way you think about things, you’ll appreciate the power

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<sup>6</sup> Informal discussions with several people were conducted throughout February and March 2004

<sup>7</sup> Busken refers to Lee (1993).

<sup>8</sup> The Sky in Her Eyes (2001) was produced by Julie Frederikse of Vuleka Productions and directed by Quida Smit and Madoda Ncayiyana.

of film. And given the growing state of the epidemic, there is an urgent demand in South Africa to raise awareness of HIV/AIDS effectively. In a land where literacy and cultural diversity challenges effective understanding, the power of visual communication is undoubted.”

Originally, I had intended to use this film throughout the duration of this research with students. I had hoped that this film would lead to a questioning of and a breaking down of stigma, as was assumed by the filmmakers. However, during the course of group discussions, unexpected questions appeared about the film, which indicated that the use of the film is more complex. The film was not exactly doing what I expected. At this point I had to make a decision on how to proceed. My focus turned towards students’ lives and how they understand their own behaviours, some of which stigmatise others. However, the film served as a ‘trigger’ and, to a certain extent, provided a platform for focus group discussions on stigma. Based on the students’ responses, I discussed some of the problems associated with this film in the Findings chapter. Sturken and Cartwright (2001: 25) write, “The capacity of images to affect us as viewers and consumers is dependent on the larger cultural meanings they invoke and the social, political, and cultural contexts in which they are viewed. Their meanings lie not within their image elements alone, but are acquired when they are ‘consumed’, viewed, and interpreted.” I explored to what extent the filmmakers’ assumptions about the effects of the film were accurate. I looked at how the filmmakers attempted to achieve feelings of empathy that they assumed would lead to reformulating of negative attitudes, and how students perceived and negotiated the meaning of the events in the film. I explored whether this film succeeded in challenging HIV&AIDS stigma or reinforced the notion of HIV&AIDS as a stigmatised disease.

#### **1.4.3 What have I got to do with it?**

It is important to state that research of this nature has not been unrelated to my life. It became very clear to me that I was driven to this topic because of my particular experiences. I also realised that the process of self-reflection could not be divorced from qualitative methodological practices. I understood how important and, at the same time, difficult it was to engage in self-reflection while participating in a

workshop on qualitative research methodology that was organised by Ineke Buskens. Although people participate in self-reflection, it is extremely hard and even harder to do it well. It thus moved me further into a methodological reality where the importance of the 'personal' in one's research is viewed as the most important component in the journey for quality in one's research. Buskens (2002: 12) states that: "As qualitative researchers we know that our research practise involves us as the total human beings we are. We also know that we experience change and transformation in and through our research. In the striving towards quality therefore, we must pay attention to the dimension of our 'being' next to the dimension of our 'doing'." As she goes on, she writes "we know that we have to be involved in our research with our total human being-ness. We need the freedom to bring our being in. Only out of that freedom can we create and reach out to the other research actors" (Ibid: 13). She concludes that: "Thus one could say that the research situation is the context in which scientific norms find personal justification, while methodological discourse is the context in which personal discovery finds scientific justification. Whichever aspect one examines, be it the personal or the scientific, one immediately finds the other hidden within it" (Buskens, 1997: 112). One's own story therefore, should not go untold in one's write up of research. As Buskens points out "existing methodological criteria are challenged and reinterpreted in such a way that space is created for the personal involvement of the researcher" (Ibid: 112).

I thus make a following crude attempt to understand my own experience of stigma as a personal lens through which I conducted the research. I know what stigma does to people because I lived through stigma as a result of my parents' divorce. My parents divorced primarily because of my father's alcohol problems. Divorce and alcoholism are two heavily stigmatised conditions in Slovakia. The institution of marriage is deeply rooted in Christian traditions. Under the norms of the Roman Catholic Church, divorce is unacceptable and it is sanctioned. People who have problems with alcoholism are, in most cases, viewed as being morally corrupted. I know that my mother had to work through many things as a result of her divorce; however, it seems that the implications for children under the umbrella of divorce and alcoholism are much stronger. There is a saying that goes around in our country that 'the apple doesn't fall far from the tree'. This label meant that I was most likely going to be like my father, possibly having problems with marriage and drinking in the future, a good-

for- nothing individual. Within the range of cultural expectations, I was automatically predisposed to failure in life. A part of me believed that. I struggled with it for as long as I can remember.

According to Goffman (1963: 12), stigma reduces the bearer “from a whole and usual person to a tainted, discounted one.” Stigma makes people less than human. In this sense, stigma dehumanises because the stigmatised individuals are not able to exercise their full potential as human beings. Stigma makes people feel ashamed, not believing in their own abilities to accomplish things and succeed in life, not being good enough. Stigma is therefore oppressive. Freire (1970: 28) writes about this phenomenon as “the voice of the oppressor.” The voice of the oppressor in the oppressed can be described as the voice that tells people that they are no-good, the voice that makes them less than human. It is the voice that the oppressed have internalised throughout the years of injustice and discrimination. Throughout my childhood and teenage years, I internalised the “voice of the oppressor”. I felt ashamed and not ‘good enough’. This was mainly reinforced during my primary and high school years when I had to negotiate the absence of a dominant male figure in my life. Additionally, for the teachers at school, my situation provided them with a quick ‘packaging’ cure in case I was not doing well. They were all too quick to compare me with my father in the presence of any mistakes or failures on my side.

According to Oyserman et al. (2001: 6), “the targets of prejudice and discrimination should concentrate on preventive efforts, by minimising negative outcomes, as well as orientate on attaining important life goals such as achieving in schools, being happy, valued and respected.” One of stigma’s effects on me was that I attempted to counterwork against it by overachieving at school. I felt that I constantly had to prove that I was ‘good enough’, so I worked extra hard. My hard work was against the label. I was not doing it for who I was, but for who I did not want to become. I was constantly looking over my shoulder instead of looking ahead. Stigma thus significantly circumscribed my life and behaviour. It made me define myself in a certain way.

Given a brief history of my family and personal background, it might not seem surprising that I chose the topic of stigma as a main focus of this mini-thesis.

Although this research had a specific focus around HIV&AIDS stigma, it also created a platform, on a personal level, for self-reflection. Furthermore ‘working through’ stigma is a long process, but it is not impossible. As I delved deeper into the literature on stigma I was able to frame my own experiences within this particular theoretical context. Even though it was a difficult experience it was liberating as well because I realised the impact of stigma on my life. Through keeping a personal journal during this research recording my own emotions, memories and thoughts about stigma, I was able to be more cautious about projecting my own journey of self-discovery onto the short journey some research subjects took in our discussions on stigma. For me, it was a journey into my heart and of reconnecting with my “true self”<sup>9</sup>. It was a journey of healing and becoming fully human<sup>10</sup> again. It was and is a journey I wish more people could experience, one I believe will lessen the stigmatizing behaviour all of us as human beings are capable of exhibiting.

### **1.5 Aims of the Thesis**

This research investigates stigma as a social phenomenon, and analyses the socio-cultural and historical roots of stigma in general and HIV&AIDS stigma in particular. The study explores cultural perceptions of HIV&AIDS with students at the University of the Western Cape, and attempts to understand how these perceptions of disease can reinforce stigma and stigmatising attitudes towards people living with HIV&AIDS. Within this framework, the research also tries to determine to what extent stigma is a reflection of cultural norms and perceptions, and to what degree it is a manifestation of individually held attitudes. Additionally, the research also investigates how stigma is perceived and recognised among university students, and how stigmatising attitudes can be challenged; what enables the recognition and questioning of stigma; if knowledge about HIV&AIDS automatically leads to reformulating of negative attitudes; and why stigma remains even in the context where information on the disease is available. The ultimate goal of this research is to inform the people who

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<sup>9</sup> Hudak (2001:19) explains, “The True Self is the source of our feeling alive, of feeling real, of feeling accepted and a part of the surroundings within which we live.”

<sup>10</sup> According to Hudak (2001:13), “being human entails, among other aspects of living, a spiritual dimension... We attend to the spiritual each time we treat one another with humility and mutual respect in day-to-day living. The spiritual, which is grounded in faith and realised through love, provides us with a source of hope in the world by expanding our vision of self and society. This expanded awareness of life is a kind of nourishment for the soul; it feeds us when we are ‘down’.”

work on developing interventions in the field of stigma about new ways of understanding of stigma in general and HIV&AIDS stigma in particular.

## **1.6 Structure of the Thesis**

The thesis is divided into five chapters. Chapter One states the motivation for this research and defines as well as contextualises the study. It begins by explaining what role labels have in our everyday lives and under what circumstances they change into stigmas. Furthermore, this chapter articulates the statement of the problem, gives an indication of the methodology used during the research procedure, and formulates the aims of the thesis. Within the methodology context, the chapter also provides a rationale behind the personal choice of this topic by the researcher.

Chapter Two involves a discussion on stigma. It provides a theoretical and conceptual framework for the research, and clarifies the key concepts such as stigma, culture, attitudes, beliefs, and stereotyping. The literature review also reveals the assumptions underlying the topic of my research. The review, therefore, creates a logical framework for the research, but it also helps to explore the various dimensions of the concept of stigma and related theories. This chapter begins with Goffman's definition of stigma. It evolves a discussion around stigma as a 'static attribute' and stigma as 'a dynamic element within social interactions'. Scott & Miller show that stigma is not static and that it manifests itself during social interactions. The chapter continues with explanations of stigma as a social and cultural construct, clarifies the relationship between stigma and deviance, and brings perspectives on causes of stigma from social psychologists. Furthermore, it also explores dynamics of stigma by looking at the history of diseases such as TB, Leprosy, Bubonic Plague, Cancer and Cholera. In comparison with HIV&AIDS stigma, the representation of disease, of sufferers of disease, and social attitudes are discussed. Additionally, this chapter also addresses the cultural, historical and political aspects of HIV&AIDS and stigma in South Africa, and shows that blame and denial have formed a standard way of response towards various epidemics not only in South Africa, but also around the world. The chapter concludes by summarising the key approaches in the studies of stigma.

Chapter Three discusses the research design and methodology. It explains the research instruments that were used as well as motivation for choosing these. This chapter also explains in detail the data collection process and the challenges that were encountered. It concludes by describing the data analysis procedures.

Chapter Four presents the results of this research. It first explains how the filmmakers attempt to achieve the feelings of empathy that they assume will lead to reformulating of negative attitudes, and situates these assumptions against students' responses to the film. Furthermore, this chapter proceeds by showing how stigma is reinforced by the lack of stigma recognition. Moreover, it shows that tackling stigma is very complex because people quite often don't realise that their own actions are perpetuating stigmatising behaviour. Lack of knowledge, fear of death, and cultural perceptions of the disease are discussed as reasons why stigma persists.

Chapter Five summarises the findings that emerged out of the group discussions with students. It clarifies which factors underlie UWC students' stigmatising beliefs, attitudes and behaviour to HIV&AIDS. Furthermore, this chapter frames the most important findings in dialogue with the existing literature. It concludes by raising questions that emerged out of the research and provides suggestions for further explorations in the field of HIV&AIDS stigma.

## 2. Literature Review

### 2.1 Introduction

This chapter discusses literature on stigma. It first gives attention to Goffman's definition of stigma. Although Goffman has been recognized as a leading social scientist in the field of stigma, his focus on stigma as a "discrediting attribute", evoked criticism from other theorists in the field. Scott and Miller question Goffman's approach because they argue that such an emphasis leads to the understanding of stigma as a static attribute. They view stigma as a part of constantly changing social processes. The next part of this chapter evolves discussion on stigma from a socio-cultural perspective. Stigma is examined as a social construct. Becker and Arnold discuss what is considered stigma in various cultural contexts; how cultural meanings reinforce stigmatising responses, and how stigma changes over time. Furthermore, Stafford and Scott, in their approach to stigma as an act of deviance and social control, show how different societies define difference as deviance, and Link, Phelan and Parker discuss how societies use stigma either to secure existing power structures or create new ones based on ethnicity, race, class, or gender, and how societies control these structures through various ways. Martin introduces the concept of stigma from a social learning perspective. He examines how we learn to stigmatise socially and argues that learning to stigmatise is part of our early upbringing. Crocker and Lutsky examine the development of stereotypes and generalisations and their impact on the perceptions of stigma. While discussing the "attitudinal" and "schematic" approaches to the analyses of the stigmatisation processes, they offer insights into what prompts or inhibits changes in stigmatising attitudes. Since HIV&AIDS is as much about biological and medical concerns as it is about social ones through stigma, the following part of this chapter discusses why health practitioners are concerned with HIV&AIDS stigma. Weiss and Freidson discuss the impact of HIV&AIDS stigma on treatment seeking. Furthermore, Nzokia, Parker and Aggleton focus on HIV&AIDS stigma in particular and show how it is tied to pre-existing stigmas and 'deviant behaviours' of class, gender, race, women, sex workers or drug users. This is followed by literature on various diseases such as TB, Bubonic Plague, HIV&AIDS, leprosy or cancer and the responses that these diseases evoked throughout the history. Doka,

McNeill, Hourani or Quam present overviews of various diseases, and point out the ways in which attitudes about diseases have affected the nature of the societies they afflicted. The literature on diseases shows that blaming ‘others’ and denying the magnitude of the epidemics have accompanied various diseases throughout the history around the world but also in South Africa. Phillips and Jones examine more closely South Africa’s reactions towards diseases such as the Bubonic Plague, cholera or HIV&AIDS. Moreover, the next section discusses how fears of various diseases prompted metaphoric thinking and how the construction of meanings behind diseases reinforced stigmatising responses and ultimately influenced control measures. Sontag and Doka teach us that illnesses have always been used as metaphors. Sontag provides a valuable insight into how metaphoric thinking about diseases such as TB or cancer changed with time, and, more importantly, how the concept of one’s responsibility for one’s disease developed. This chapter concludes by summarising the key approaches in the studies of stigma, identifying gaps in the existing literature and establishing the viewing platform for the researcher.

## 2.2 The Concept of Stigma



In the vast body of existing literature on stigma, Erwin Goffman’s (1963) work, Stigma: Notes on the Management of Spoiled Identity, is widely recognised as a standard point of departure for researches pursuing an investigation into this topic. According to Goffman (1963:11), “in the original Greek meaning of the term, stigma referred to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor – a blemished person, ritually polluted, to be avoided, especially in public places.” Today, Goffman continues, stigma “is applied more to the disgrace itself than to the bodily evidence of it.” In short, Goffman’s definition suggests that stigma is an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one” (Ibid: 11-12).

Since Goffman, elaborated definitions have varied. For example, Crocker et al. (1998:505) indicate that, “stigmatised individuals possess or are believed to possess some attribute, or characteristic, that conveys a social identity that is devalued in a

particular social context.” Scott & Miller (1986: ix), support Crocker’s view and extend the definition of stigma as a “product of definitional processes arising from social interactions between those who acquire potentially discrediting conditions and the individuals with whom they interact.”<sup>11</sup> These authors thus critique Goffman’s notion of stigma as an “attribute that is deeply discrediting” (Goffman, 1963:13). They argue that attributes themselves don’t automatically qualify persons for stigmatisation, but rather view stigma as a dynamic element within the processes of social interactions (Ibid: ix). People, they write, “qualify as stigmatised only within the context of a particular culture, historical events, or economic, political, or social situation” (Ibid: ix).

Scott, Miller and Crocker raise three important points. First, stigma is not static. Second, it exists within a particular socio-historical and cultural context. Third, stigma is manifested during social interactions between those who acquire a potentially stigmatising attribute and the people with whom they interact. As culture is in a constant flux, stigma evolves as culture changes. However, a question arises as to whether stigma can operate in the absence of social interactions. In other words, are social interactions a prerequisite for stigma to manifest itself? This is a question with which I will engage in considering the importance of group dynamics in my focus group’s responses to the film.

Stigma can be either “internal” or “external” (UNAIDS, 2002a). External stigma refers to “actual experiences of discrimination. This may include the experiencing of domination, oppression, the exercise of power or control, harassment, categorising, accusation, punishment, blame, devaluing, prejudice, silence, denial, ignorance, anger, a sense of inferiority, social inequality, exclusion, ridicule, resentment or confusion” (Policy Project, 2003:4). Additionally, external stigma has a “powerful capacity to produce internalisation and acceptance of inferiority by the oppressed group and justification of discrimination by the dominant group” (Ibid: 5). Here we can speak of the internalised stigma, which is an indirect result of the stigmatisation process. Internal stigma, on the other hand, is the “shame associated with HIV&AIDS

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<sup>11</sup> Notice the transitional difference between Goffman’s and Scott & Miller’s definition of stigma. In the case of the former, stigma is treated a static attribute. The word stigma refers to a noun. In the later, stigma is a ‘product’. It refers to a verb. Stigma, in this case, is a dynamic element within social processes.

and fear of being discriminated against. Internal stigma is a powerful survival mechanism to protect oneself from external stigma and often results in the refusal or reluctance to disclose HIV status or the denial of HIV&AIDS and unwillingness to seek help” (Ibid: 4).

Individuals, who possess a potentially stigmatising attribute, or might acquire one at a later stage in life, are usually aware of the negative cultural perceptions and representations surrounding them. Based on the preconceived ideas about their particular condition that reflect dominant cultural beliefs and attitudes, these individuals might choose to withdraw, or isolate themselves, or to hide the ‘marks’ of their condition unless it is a socially salient one such as physical deformity (Oyserman and Swim, 2001: 1-14). Oyserman and Swim (2001: 1-14), continue that “the stigmatised individuals can concentrate on a prevention focus, which involves efforts to minimise prejudicial encounters and their negative effects, by, for example, avoiding certain situations.” Thus social interaction in the case of internal stigma doesn’t have to occur at all. Certain individuals might live their whole life without anybody knowing about their situation. Homosexuals, who have been frequently associated with HIV&AIDS and subsequently blamed for it, often choose not to disclose their sexuality to their family, friends, or community because of the negative perceptions and stigmatising responses surrounding them.

In the case of HIV&AIDS this phenomenon is also apparent. Individuals have often delayed testing before finding out that they were HIV positive, and often refused to disclose their status once this was known to them, for fear of being stigmatised. Although it is possible for people with HIV to hide their status in the initial stages of the disease, they are likely to experience external stigma as the disease progresses. Alonzo and Reynolds (1995: 303-315), describe this as “the illness trajectory of HIV.” “The experience of stigma and the strategies used to avoid, minimise, or cope with it changes over the course of a single illness trajectory” (Ibid: 303-315). Individuals will probably experience both internal as well as external stigma as HIV progresses into AIDS, and the disease becomes ‘physically visible’ as a result of many opportunistic infections that accompany HIV&AIDS.

There are similarities as well as differences that ‘internal’ and ‘external’ stigma share together. They reflect culturally held attitudes. An individual becomes either “discreditable” or “discredited” (Goffman, 1963: 14). In the first case, an individual assumes that “his different-ness is not immediately apparent, and is not known beforehand.” The issue then is how to “manage information about his failing.” “To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where” (Ibid: 57). In the second case, “the stigmatised individual’s different-ness is known about already or evident on the spot.” The main problem of the individual is how to “manage tension generated during social contacts” (Ibid: 57). In both cases, stigma significantly modifies life chances of individuals, and has a great impact on one’s perception of self worth. This research will consider this particular concept while exploring whether students would feel comfortable going for an HIV test or disclosing their status if they were HIV positive.

### **2.3 Social and Cultural Construction of Stigma**

Mazrui (1986: 239), defines culture as “a system of interrelated values active enough to influence and condition perception, judgement, communication, and behaviour in a given society.” Furthermore, Airhihenbuwa and Webster (2004: 5) refer to Hahn (1995) and emphasise “the role of culture and society in relation to sickness and healing, and highlight the use of language in the understanding of illness concept.” Additionally, they highlight Brody’s (1987) view that “one’s cultural belief system influences one’s social roles and relationships when one is ill” (Ibid: 5). The approach that emphasises the notion of stigma as a cultural and social construct critiques the view of stigma as an expression of individually held attitudes. This notion stresses the importance of historical, social and cultural contexts of stigma that influence the individual. Stigmatising attitudes are, therefore, not a property of individuals, but they are shaped within a cultural context. The reason it is difficult to establish a definition of stigma within this particular framework is that what is perceived to be stigmatisation varies in different cultures. For example, in discussing behaviours that can lead to stigmatisation, Becker and Arnold (1986: 41), express Marshall’s (1979) view that “among the Trukese, drinking and aggressive behaviour are considered culturally appropriate, even expected, conduct for men and are not stigmatised.” In a

different cultural context, however, drinking might be considered as reaching beyond the cultural norm and may be stigmatised (Ibid: 41). Additionally, they point out that, “the cultural meaning attached to certain attributes, determine how they will be viewed in their cultural context” (Ibid: 41). In relation to these theories, this research will investigate cultural meanings attached to HIV&AIDS and how these reinforce stigmatising responses.

## **2.4 Stigma and Deviance**

Another way of examining stigma is through the notion of deviance and social control. In this sense, we can talk about the universality of stigma. Each society establishes its norms and values that define acceptable attributes and behaviours for its majority. Each society also defines instruments of social control in a form of laws to ensure adherence to such norms (Becker and Arnold, 1986: 39-40). If someone breaks a norm, punishment is imposed. Following the approach of deviance and social control, Stafford and Scott (1986: 81), propose that stigma is “a characteristic of persons that is contrary to a norm of a social unit” where a “norm” is defined as a “shared belief that a person ought to behave in a certain way at a certain time.” The basic premise behind the notion of deviance and social control is that established norms reflect the views of the majority. However, it is disputable who composes the majority as well as whose interests the majority represent. According to Link and Phelan (2001: 2), “stigmatisation is entirely contingent on access to social, economic and political power that allows the identification of different-ness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination.” Parker and Aggleton (2003:15-24), in turn suggest that, “stigma can become firmly entrenched in a community by producing and reproducing relations of power and control. Stigma is used by dominant groups to legitimise and perpetuate inequalities, such as those based on gender, age, sexual orientation, class, race or ethnicity.” They argue further that the ability of the stigmatised individuals to resist is quite limited because of their marginal status (Ibid: 15-24). Finally, Link and Phelan (2001:2) emphasise that stigmatisation occurs when the following interrelated components emerge:

- 1- People distinguish and label human differences

- 2- Dominant cultural beliefs link persons to undesirable characteristics-to negative stereotypes
- 3- Labelled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them”
- 4- Labelled persons experience status loss and discrimination.

The question of deviance as a basis of stigma is another aspect that this research will explore in group responses.

### **2.5 Stigma from a Social Learning Perspective**

This particular perspective deals with questions about “how people come to know stigma because stigmas are discrediting marks that are understood by others in social encounters and involve affective responses, such as avoidance, disgust, disgrace, shame, or fear” (Martin, 1986: 144). Stigma, according to this approach, is tied to social learning and socialisation that already starts from an early age. Goldstein (1981:237) asserts that, “socialisation may be considered as social learning insofar as it is aimed at the acquisition of behaviours and attitudes that conform to existing social norms and expectations. But social learning can also have rather contrary purposes when the experience is largely individualistic and the person’s pursuits may have little to do with or conflict with established standards.” Martin (1986:149), further points out that, “social learning tends to contribute substantially to the individual’s personal view of social reality, shapes his or her values and determines the extent to which he or she will successfully manage encounters with others in the social environment. Social learning is a powerful mechanism for both the acquisition and maintenance of behaviours that stigmatise others.” He also suggests that, “much social learning of stigma occurs during the period a child’s elementary and secondary school years, when children observe who is treated best by teachers in the classroom, who is not liked in their small reference groups, and against whom the rules of social conduct seem to work” (Ibid: 151). Goffman (1963:46), also points out that “public school entrance is often reported as an occasion of stigma learning, the experience sometimes coming very precipitously on the first day of school, with taunts, teasing, ostracism and fights.” Ultimately, emerging attitudes and beliefs that prompt generalisations and stereotypical thinking influence what we will learn and how new

information will be perceived. Generalisations, Martin writes, are identified as beliefs that are established upon one experience. Stereotypes emerge when generalisations are treated to be universally true (Martin, 1986: 155-156).

## **2.6 Stigma and Social Cognition**

Social psychologists investigate “how and what we think about groups and persons that are stigmatised” (Crocker and Lutsky, 1986: 95). The argument behind this approach is that “although stigma exists in a larger historical, social and cultural context, this context requires the participation of the individual members of a society” (Ibid: 95). The notion of social cognition encompasses “attitudinal” and “schematic” approaches (Ibid: 95-100). Crocker & Lutsky (1986: 98) explain that an attitudinal approach has “much in common with sociological definitions. According to this approach, individuals hold strong pre-existing beliefs (in a form of stereotypes) about the stigmatised, which influences the social interaction. Stigma is sustained through individually held attitudes that reflect larger social and cultural contexts.” Thus stigma, according to this approach, is static and doesn’t allow for attitude change. On the other hand, Crocker and Lutsky continue, the schematic approach emphasises “cognitive approaches that may be responsible for the construction, application, and revision of social perceptions and evaluations. Individuals may hold pre-existing beliefs that they don’t endorse personally. The process of categorisation, attitude construction and information application operates on various past and present sources of information” (Ibid: 99). This study will trace what prompts these changes in stigmatising attitudes. Does knowledge about the disease change stigmatising attitudes? This research will also explore how participants reflect on pre-existing beliefs and social norms.

## **2.7 Why Stigma Matters in Health Research?**

Stigma plays an important role in health research because stigma contributes to the suffering from illnesses in various ways, and it may delay appropriate help seeking as well as terminate treatment for treatable health problems (Weiss, 2001: 3). Weiss points out further that, “for diseases and disorders that are highly stigmatised, the impact of the meaning of the disease may be as great or a greater source of suffering

than symptoms of disease” (Ibid: 3). Furthermore, “Stigmatising cultural meanings have a serious impact on the illness experience, help seeking, and treatment” (Ibid: 5). For example, in Southeast Asia, stigma of TB is enhanced by association of TB with AIDS, and this has been shown to contribute to treatment delay for tuberculosis in an HIV high endemic era of Thailand (Ngamvithayapong et al., 2000: 1413-1419).

Feidson (1970:235-40) explored the phenomenon of stigma as a dynamic element in the way we respond to certain illnesses. “For ‘normal’ illness, many normal obligations are suspended; only the obligation to seek help is incurred. But in the case of the stigmatised, a complex variety of new obligations are incurred. Whereas in the former instance the burden of adjustment (through permissiveness and support) lies on the ‘normals’ around the sick person, the burden in the latter lies on the stigmatised person when he is around ‘normals’.”

Stigma can be a response to fear, risk, or a threat of disease that is incurable and can be deadly (Gilmore and Somerville 1994). Epidemics that present an overt threat to the values of a community are especially likely to evoke a stigmatising response, as stigma is used to “enhance or secure social structuring, safety and solidarity...or reinforce societal or community values by excluding divergent or deviant ones [or individuals]” (Gilmore and Somerville 1994). Stigma related to medical conditions is greatest when the condition is associated with deviant behaviour or when the cause of the condition is viewed as the responsibility of the individual. This becomes particularly strong when the illness is associated with religious beliefs and thought to be contracted through morally sanctionable behaviour (Alonzo and Reynolds 1995). Stigma is also more evident when the condition is unalterable, incurable, severe, degenerative, and leads to readily apparent physical disfigurement or to an undesirable and unaesthetic death (Cogan and Herek 1998; Alonzo and Reynolds 1995).

## **2.8 HIV and AIDS Stigma**

HIV&AIDS have all the characteristics associated with heavily- stigmatised medical conditions. They are associated with socially “improper” forms of sex and injecting drug use, socially censured behaviours that are viewed as a responsibility of the

individual (Nzioka, 2000: 1-14). Goffman (1963:14), describes three different types of stigma:

- 1- Abominations of the body-the various physical deformities
- 2- Blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behaviour
- 3- Tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all members of the family

People living with HIV&AIDS almost always are associated with the first two because of the physical manifestations of AIDS and the association of HIV with “deviant” and “immoral” behaviours (particularly sexual “promiscuity” and intravenous drug use). In addition, many people living with HIV&AIDS are members of groups that are already marginalized such as sex workers, women, homosexuals, the young and the poor. This particular subset of individuals with HIV&AIDS experiences multiple stigmas, with HIV stigma compounding pre-existing stigmas (known as double or compound stigma) (Parker and Aggleton 2003). HIV&AIDS stigma is then used to justify further marginalization of such people, further entrenching deeply rooted prejudices (Ibid).

## **2.9 Stigma as a ‘Standard’ Response to Diseases**

According to Brandt (1998:148), “the way a society responds to problems of disease reveals its deepest cultural, social and moral values”. As Brandt continues, “the epidemic has been shaped not only by powerful biological forces, but by behavioural, social and cultural factors as well” (Ibid: 148). Quam (1990:35), points out that “the ascription of stigma to any condition arises out of the symbol system within a culture, and, like other symbolic acts, follows a logic within which relationships are more emotional than rational.” The South African chair of the AIDS 2000 Conference said he “could find no parallel in history for AIDS” (Coovadia, 2001). He further stated that HIV&AIDS was an epidemic “the likes of which we have never seen” (Ibid). This view suggests that HIV&AIDS indeed is a very new disease, and that its

magnitude cannot be compared to any other diseases throughout our history. However, if we look closely at the history of representations of various ‘deadly’ diseases and compare them against the reactions towards HIV&AIDS, we will see that there is nothing inherently new about it.

The dynamics of stigma are reflected in the history of diseases such as TB, Leprosy or Bubonic Plague. Blame, denial, and fear that accompany various diseases have formed a standard way of response towards the epidemics that were perceived as ‘deadly’ or ‘dreadful’, thus reinforcing stigmatising responses.

It is estimated that the Bubonic Plague decimated more than “100 million people throughout the 6<sup>th</sup> century” (Marks and Beatty, 1976). The disease wiped out families and communities and, in many cases, whole villages and towns disappeared. The disease reoccurred again in Europe in the 14<sup>th</sup> century, however this time known as “The Black Death.” From 1346 to 1361, it is estimated that more than 27 million people died. Most estimates are that 25-40% of the population was killed, although some estimates are even higher” (McNeill, 1976). Some believe that the Bubonic Plague even changed the course of a history. Hourani (1991) viewed the plague as a “significant factor in Islamic society, depopulating cities and reducing its agricultural base so that it was less prepared for Christian counter-attackers that allowed the reconquest of Spain and Ottoman capture of the Islamic world. Some have seen the Black Death as contributing to an emergent individualism and a decline of feudalism.” Similarly, cholera led to death and terror on a vast scale when it came to Europe from India in the third decade of the nineteenth century (Doka, 1997:8). The influenza epidemic of 1918-1919 caused around 700,000 deaths (Ibid: 3). It might, therefore, not seem surprising that diseases of such proportions generated fear amongst the wide population. At times when medical science could offer only a very limited knowledge on how and why these epidemics originated, blame and denial emerged as a standard response towards the epidemics.

### **2.9.1 Blaming Others in the Light of Diseases**

As discussed earlier, blaming others, especially ‘outsiders’, in the face of threatening diseases has been a standard response throughout history. Mary Crew (1992:14),

writes, “to blame others is psychologically reassuring. The fact that it is their fault divides “us” from them. We are innocent, at the mercy of fate; they are guilty and have behaved in such a way as to put us all at risk. We have been invaded from without, polluted by some external agent.” Doka (1997:18), writes “the influenza epidemic was popularly blamed on the Axis powers, especially Germany. The assumption was (despite the fact that Germans were dying from the disease) that the Germans directly caused this plague, releasing infection from U-boats and spoiled medicines and indirectly as a result of poison gas.” Similarly, Doka explains, “Catholic Spanish Christians had accused the Moslem King of Grenada of spreading the Black Death” (Ibid: 5). In their attempt to explain the cause of the Black Death, Hecker (1846: 15) writes, “some learned men of the time emphasized astrological explanations, blaming the plague on the triple concoction of Mars, Jupiter, and Saturn. Other scholars thought the atmosphere was to blame. They believed the air was fouled by noxious fumes released from earthquakes and volcanoes, or mounds of Eastern unburied dead, or by an evil mist drawn up of poisoned waters from the Indian Sea, which had been corrupted by massive fish kills.” Additionally, Phillips (2004:34)<sup>12</sup> explains that in 429 BC Peloponnesians were blamed by Athenians for the plague which decimated the city, and in 1830 Russians identified Polish agents as the bringers of cholera to their country. Syphilis also generated blame and accusations. “The French blamed Naples; Naples blamed the French. Almost everyone in Europe blamed the Moors and the Turks. Some blamed prostitutes; during the siege of Naples they were eventually expelled for spreading syphilis” (Doka, 1997: 29). Leprosy in the United States was blamed on “the filthy, vicious, debased, leprous Chinese” (Gussow, 1989: 56). What all of these have in common as responses to diseases is the creation of the “Other”, a scapegoat. The “other” becomes a projection of fears. In their attempts to explore causes of stigmatisation, various theorists explored the self/other binary opposition. The self-enhancement theory explains that people have a need to believe that the self is good and worthwhile (Crocker & Lutsky, 1986). Since the evaluations of the self are derived by comparing the self to other people (Festinger, 1954), it is important to identify those who can be regarded unfavourably to ensure positive evaluation of the self (Taylor, 1983). Additionally, a just-world theory explains that the world is a safe and orderly place in which people get what

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<sup>12</sup> Phillips makes a reference to the following authors: Thucydides (1974), and McGrew (1965:161).

they deserve (Lerner and Miller, 1978). People are “motivated to believe that others deserve or bring upon themselves the unpleasant events that befall them because the belief that ‘bad things happen to good people’ would lead to uncomfortable feelings of vulnerability” (Crocker & Lutsky, 1986: 103). The self/other binary opposition as a cause of stigmatisation is another aspect that I will explore in my group responses.

### **2.9.2 The Politics of Denial**

History shows that there is nothing unusual about denying the magnitude of the epidemics in their early stages. Denial creates ‘comfort’ zones where commitment and responsibility to address the epidemics are neglected, and, by doing so, creates ideal conditions for the disease to spread. Denial, Doka (1997:16) writes, took on specific forms: “The disease will not reach here, or if it does it will not touch my strata or group.” Doka continues, “As Americans heard of the migration of cholera into Europe, they still assumed that the disease would stop at the Atlantic. Even when the disease appeared in Canada in June 1832, Americans believing they were free of the poverty and degradation associated with Europe, felt that the disease would not have a great effect on them. Once it did strike, first infecting a few Irish migrants in New York City, many still hoped and assumed that the disease would stay within the city, the slums, the Irish, and the poor” (Ibid: 16). The mainstream medical views and explanations have often been ignored in favour of larger political and economic interests. Phillips (2004:36)<sup>13</sup> informs us that “South Africa’s Department of Health and Welfare was equally keen to deny that fearsome cholera was rampant in its bantustans lest doing so meant that it had to accept responsibility for counter-measures. At first it attributed the rising tide of deaths to gastroenteritis, and when this fiction could not be sustained, it tried to suppress the mortality figures.” This research will explore how denial as comfort zones is evident in the students’ responses.

### **2.9.3 South Africa’s Epidemiological History**

The South African responses to various epidemics, and HIV&AIDS in particular, illustrate steps that are no different to the rest of the world. Blaming others in the light

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<sup>13</sup> Phillips refers to Marks and Anderson(1988: 257-8).

of a life-threatening disease, as well as denying the extent of the epidemics, has had a long tradition. Phillips (2004:33), explains “The spread of smallpox in Cape Town in 1840, 1858 and 1882 was blamed on ‘dirty Malays’ by the white establishment – even to the point of rumours that Muslims were deliberately infecting whites’ clothing so as to wipe them out.” Similarly, “the Bubonic Plague in 1901 was attributed by many whites to ‘unhygienic’ Africans. The Spanish flu in 1918 was ascribed to, inter alia, devilish German gas warfare, irresponsible members of the Native Labour Corps or malevolent whites wanting to exterminate Africans by, respectively, super-patriotic English-speaking South Africans, Afrikaners hostile to the very idea of Africans in uniform and rural Africans leery of white behaviour towards them in general” (Ibid: 33). This shows how a long history of racism in South Africa, which remains politically sensitive today, shapes official responses in ways significantly different to other African countries.

In the light of HIV&AIDS, it seems that history didn’t teach much. However, it is generally believed that one of the main reasons why countries like Senegal or Uganda managed to significantly decrease prevalence of HIV cases was because they addressed the issue of the epidemic from the outset. Since the first HIV cases appeared in Senegal in the mid-1980, infection rates have remained consistently low at under 2% (WHO). In Uganda, HIV infection rates among pregnant women attending antenatal clinics in the capital city fell from 31% in 1993 to 14% by 1998. Among men attending STI clinics, HIV infection rates fell from 46% in 1992 to 30% in 1998 (WHO). This was possible due to these countries’ political commitment, including the personal involvement of the president Yoweri Museveni in Uganda, as well as nationwide campaigns. Both countries recorded a massive mobilisation of churches, NGO’s and other sectors of society that all harmonised their agendas on how to address the epidemic effectively. Among many other activities, sex education programmes were introduced at schools; churches and religious leaders frequently discussed the issues around HIV&AIDS, providing counselling and care as well as promoting tolerance towards infected individuals. In South Africa, on the other hand, the issue of HIV&AIDS became a ‘hot political potato’ evoking blame, denial, and finger pointing as its main responses.

In the initial stages of the HIV&AIDS epidemic in South Africa, gay white men were blamed for spreading the HIV through what was labelled as their “devious form of sexuality” or “the perverted practices of promiscuous homosexuality” (Grundlingh, 1999: 61-66). On a global scale, AIDS has been described as “Wrath of God Syndrome” or “Gay-Related Immunodeficiency” (Treichler, 1989). Phillips (2004: 34)<sup>14</sup>, writes that “as the disease became more common among heterosexuals, especially Africans, racist accusations turned their directions too. An anonymous right-wing pamphlet circulating in 1989 urged whites to have their black domestic workers regularly tested for HIV ‘to safeguard your family’.” The suspicions among Africans were equally strong. Phillips (2004: 34)<sup>15</sup> continues: “AIDS was frequently explained as a “conspiracy against Blacks.” Additionally, some believing that AIDS was “a plot devised by the government...to convince black people to have less sex, and therefore fewer babies, lampooned the acronym AIDS as really meaning ‘Afrikaner Invention to Deprive us of Sex’” (Ibid: 34).

The South African government managed to generate even more confusion in the issue of HIV&AIDS. At the time when the international community was encouraging countries in Africa and all around the world to effectively address the issue of HIV&AIDS, and more importantly, to translate their commitments into practise, President Thabo Mbeki turned his efforts elsewhere. He thought that it was necessary to discuss the causal link between HIV&AIDS. He went so far as to convening an international congress of experts to “reassess...various aspects of AIDS science” (Jones, 2001: 26). The congress met in May 2000. Jones (2001) continues, “when the President reopened the question of the causal link approximately one year later, leading virologists and epidemiologists thought that it was an act of ‘irresponsibility that borders on criminality’” (Ibid: 28). When the international and domestic communities warned about the possible impact of HIV&AIDS on the fabric of the South African society, Mbeki responded, in the context of AIDS, that “we lack proper mortality figures to tell us ‘what are the things that kill South African’” (Cullinan, 2004). Although the Medical Research Council’s (MRC) study in 2000 estimated that about 40% of premature deaths of South Africans aged 15 to 49 were the result of AIDS, their results were subsequently critiqued. This was demonstrated by the health minister’s

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<sup>14</sup> Here Phillips refers to Jochelson (1999:235)

<sup>15</sup> Phillips makes reference to van der Vliet (2001:155)

audit in the MRC to establish who had “leaked” the results (Ibid). Whereas NGO’s and governments in Senegal and Uganda coordinated their efforts in fighting the epidemic, the South African government declared “war” against organisations promoting free roll-out of antiretroviral drugs to pregnant women to prevent mother-to-child transmission of HIV. The critics of the government policies were labelled as delinquents, racists or unpatriotic<sup>16</sup> (Jones, 2001: 30). When public health campaigns were encouraging people to disclose their HIV positive status, Mbeki, once again, got involved by stating that he “doesn’t know anyone who died of AIDS”. Similar rhetoric resonated throughout his cabinet. Ashforth (2001:3), writes that “One of the most notorious examples of hypocrisy surrounding HIV&AIDS was the official prevarication over the death, in his late thirties, of ANC Presidential spokesperson Parks Mkahlana in November of 2000. The official pronouncements that the young man had died ‘after a long illness’ provoked a nation-wide wave of speculation about AIDS as the cause of death, prompting bitter denials from his family and former colleagues.” It is important to note that these types of responses towards the HIV&AIDS epidemic from the ‘official circles’ were not unusual in other parts of the world. For example, Quam (1990: 36), points out that “during the first five years of the epidemic while thousands of cases were appearing, the president of the United States did not publicly mention the name of this dreaded disease.” This “strategy” in official responses to HIV&AIDS could be possibly reflecting a crisis in the definition of nationhood. Anderson (1991: 4) writes, “Nationality or nation-ness and nationalism are cultural artefacts of a particular kind.” He argues further that “nation-ness is the most universally legitimate value in the political life of our time” (Ibid: 4). HIV&AIDS presents a serious threat to democracy (Jackson, 2002:22). South Africa has re-emerged and redefined itself as a new nation in the post apartheid era. HIV&AIDS could be threatening the definition of this new nationhood by showing that South Africa is thus vulnerable. In his writings about President Mbeki’s HIV&AIDS denialism and his emphasis on environmental causes of HIV&AIDS,

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<sup>16</sup> Labelling people, especially medical practitioners, as unpatriotic during various epidemics has been also portrayed in Henrik Ibsen’s play: *An Enemy Of the People*. Ibsen’s 19<sup>th</sup> century play was adapted by Satyajit Ray who, almost a century later, produced a film called: *An Enemy of the People*. Satyajit Ray asked the same question of religion and stigma in 20<sup>th</sup> century India, as Henrik Ibsen in 19<sup>th</sup> century Norway. Ray depicts the struggle of a medical practitioner who tries to prove to the local authorities that the river Ganga, one of the central places for Hindus, is polluted and causes cholera. Thus the doctor became an “enemy of the people” not only for the Hindus but also for the local authorities.

Cameron (2005: 119) argues, “President Mbeki’s emphasis on the broader context of Africa’s ailments is part of a heroic campaign against a grossly unjust economic world order, which holds Africa captive to its history of colonialist exploitation. His historic legacy might yet lie in his leadership of this broader campaign, with its insistence that the world should acknowledge the burdens of racism and colonialism that African economies and African people are still forced unjustly to bear.” The HIV&AIDS situation in South Africa can be described as a crisis of its leadership. One of the unfortunate outcomes of the government’s ‘strategy’ was that it echoed with the general public’s attitudes of denial and blame, thus reinforcing fear and stigma and prompting the constructions of various meanings behind HIV&AIDS.

#### **2.9.4 The Meanings Behind Diseases**

Berger and Luckmann (1966:68), state: “Language objectivates the shared experiences and makes them available to all within the linguistic community... Language provides the means for objectifying new experiences.” Entwisle (2003:1), further explains that: “Literal meanings are accompanied by and inextricably linked to social, historical, political, and experiential factors pertaining to the speaker, the listener, and the environments of both.” Sontag (1978:62-63) notes, “Nothing is more punitive than to give disease a meaning – that meaning invariably a moral one. Any important disease whose causality is murky and for which treatment is ineffectual tends to be awash in significance. First, the subjects of deepest dread (corruption, decay, pollution, anomie, weakness) are identified with the disease. The disease itself becomes a metaphor. Then, in the name of that disease (that is, using as a metaphor), the horror is imposed on other things. The disease itself becomes adjectival, meaning that it is disgusting or ugly.”

Throughout history, great epidemics such as the Bubonic Plague, cholera, or influenza evoked fear among people especially for the large amount of deaths they had caused. However, there was another category of diseases such as tuberculosis, syphilis, cancer or leprosy that generally had not been feared for their death tolls. Although the bubonic Plague, Cholera or Influenza were highly contagious, cancer is actually very difficult to get. In fact, cancer is not contagious at all. However, all of these diseases left signs of stigma and shame on their victims. Thus the ‘failure’ of medical science

to explain the aetiology and causes of the diseases, either from its own limitations or for being distrusted, led people onto the path of fear and construction of meanings behind diseases (Doka, 1997: 25).

Sontag (1978: 10) writes, “Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious.” Sontag further states that: “Contact with someone afflicted with a disease regarded as a mysterious malevolency inevitably feels like a trespass; worse, like the violation of a taboo” (Ibid: 10). HIV&AIDS has also been regarded as an act of malevolency although Ashforth (2001: 8-11) writes, “the chain of reasoning that distinguishes it from other hypotheses about invisible powers (such as divine retribution, or punishment by ancestors for infringing taboos, or sin...), is that the origin of misfortune is social. It is another person, ordinarily conceived, who is hypothesized to have caused the harm.” This is another aspect that will be explored in this study. How does the reading of HIV&AIDS in terms of a mystery or witchcraft affect stigmatisation? Additionally, what evokes a change in stigmatising attitudes? Is it more information about the disease or how the information is put across? The Bubonic Plague and cholera were viewed as a “divine retribution perhaps for sexual indiscretions or tolerating heresy” (Doka, 1997: 7). In addition, cholera was equated with poverty and poor hygiene and sanitation. As Doka (1997: 10) writes “to some cholera was a judgement on a society that tolerated slums and poverty.” The name leprosy, Doka (1997: 26) explains, has become a metaphor for “loathsomeness.” The term “leper was a synonym for an isolated, diseased outcast” (Ibid: 26). Furthermore, Doka (1997: 40) points out, lepers were viewed as “angry, suspicious, scheming, and full of bad habits.” Some people even believed that leprosy was transmitted sexually. Doka (1997: 40) writes “lepers were seen as lecherous, seeking to infect others through the close contact of sexual intercourse.” Syphilis also fell into the category of stigmatising diseases, and was frequently blamed on a variety of things – “heresy, blasphemy, and licentiousness” (Ibid: 29).

TB and cancer are most frequently associated with HIV&AIDS because they accompany the disease as it progresses through various stages as a result of a weakened immune system. Although both diseases used to be highly stigmatised in the past, the intensity of stigmatisation and metaphoric thinking about them seemed to

have decreased with time. Perhaps the aetiology of these diseases became clearer, with the diseases losing their meaning as 'mysterious'. Alternatively, with the advancements in the medical field, they became curable or at least manageable so they lost their meaning as being 'dreadful' (Doka, 1997: 49-58). Sontag (1978: 25) reminds us that TB and cancer were regarded as diseases of "passion." "TB was thought to come from too much passion, afflicting the reckless and sensual. Today many people believe that cancer is a disease of insufficient passion, afflicting those who are sexually repressed, inhibited, unspontaneous, incapable of expressing anger" (Ibid: 26). It seems that there was something shameful about having cancer as a result of having suppressed emotions. In the past, TB used to be romanticised. The afflicted individuals were viewed as artistic, and to die from TB was regarded as an "aesthetic death". More importantly, the disease was regarded as matching one's character (Sontag 1978: 36-37). However, this has changed with the concept of modern diseases. Sontag (1978: 50) continues, "With the modern diseases (once TB, now cancer), the romantic idea that the disease expresses the character is invariably extended to assert that the character causes the disease – because it has not expressed itself. Passion moves inward, striking and blighting the deepest cellular responses. Illness is in part what the world has done to a victim, but in larger part it is what the victim has done with his world, and with himself." This seems to be a crucial distinction in how individuals with diseases are viewed. Diseases are no longer viewed as matching one's character, rather the individuals are assumed to be responsible for their fate.

People suffering from HIV&AIDS are, in most cases, blamed for their status because they are believed to have behaved in a way that caused their disease. Since the main transmission route of the HIV virus is through sexual intercourse, individuals are very often viewed as being promiscuous, thus deserving of their fate. And although people contracting HIV through blood transfusions are usually viewed as 'innocent victims'<sup>17</sup>, the fear of HIV&AIDS tends to evoke equal stigmatising responses towards all the HIV positive individuals regardless of the way of contracting the disease. Sontag (1979: 51) warns, "Such preposterous and dangerous views manage to

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<sup>17</sup> Entwisle (2003: 5) informs that associations of PLWHA have repeatedly requested that the 'AIDS victim' be dropped from a common usage. The term People Living With HIV and AIDS (PLWHA) focuses on empowered 'living' with the disease as opposed to passive 'victimization' by the disease.

put the onus of the disease on the patient's ability to understand the range of plausible medical treatment but also, implicitly, direct the patient away from such treatment." Many HIV positive individuals thus avoid medical treatment because they fear stigmatising responses.

By the close of the 19th century, Doka (1997: 32) explains, "TB was considered a mark of shame, a reminder of dark tenements and unsanitary conditions." Sontag (1978: 19) expresses similar view, "TB was often imagined as a disease of poverty and deprivation – of thin garments, thin bodies, unheated rooms, poor hygiene, inadequate rooms." TB was therefore blamed on the poor. Cancer, on the other hand, was thought of as a disease of a middle-class. It was connected with a specific, affluent life style. Cancer, according to Sontag, assumed the role of "an illness experienced as a ruthless, secret invasion" (Ibid: 5,8,13). Other interpretations of the cause of cancer included the notions of "imbalance of humours," or it was believed to be "hereditary; a notion that also contributed to a sense of shame and silence because it made family members less desirable as potential marriage partners" (Doka, 1997: 33). History shows that the fear of various diseases influenced not only medical treatment or reactions towards the afflicted individuals, but also impacted public health policies. For example, syphilis, which is also associated with HIV&AIDS because it is transmitted sexually, was frequently blamed on the prostitutes. Thus prostitutes, who are perceived to occupy lower social status in society specifically for their "immoral" behaviour, were subjected to segregation and discrimination. During the Bubonic Plague sufferers were often quarantined. In the name of 'treatment', TB patients were often isolated in sanatoriums that were situated in remote settings because patients were ordered a 'rest cure' (Ibid: 32). However, this was not happening because of a concern for the well-being of patients, but because the general public opposed the presence of such institutions near them. Doka (1997: 32) writes, "Hospitals and physicians often refused to treat TB patients. In many areas it ended any marriage possibilities. Suspected TB victims were often sorely discriminated against – removed from public transportation and markets." In South Africa, discriminatory policies against 'socially weak groups' in the presence of various diseases have had a long history. Phillips (2004: 35) points out, "In 1982 the Cape government enforced quarantines of cases of smallpox, especially those found in Muslim communities. In 1918, only Africans with symptoms of 'Spanish' flu were

prevented from travelling by train. Furthermore, during the typhus epidemics of 1917-24 and 1933-5, compulsory de-verminization of all third-class African passengers on trains from the Transkei was introduced.”

Doka (1997: 26) explains that the stigma of leprosy “reaches back to Biblical times when lepers were expelled from their communities, doomed to wander as the walking dead. Having leprosy meant that one became socially dead.” Additionally, during the Middle Ages, Sontag (1979: 62) writes, “the leper was a social text in which corruption was made visible; an exemplum, an emblem of decay.” What is particularly ‘interesting’ about leprosy is that, as with HIV&AIDS nowadays, it was defined in terms of ritual purity. As Douglas (1966: 35) points out, “pollution is the result of our contact with ‘dirt’.” Douglas continues that dirt is “matter out of place. Dirt is the by-product of a systematic ordering and classification of matter, in so far as ordering involves rejecting inappropriate elements” (Ibid: 39). Thus persons classified to be “out of place” are then labelled as socially dangerous and treated as such. For example, Doka (1997: 26) refers to Brody (1974) and writes, “one medieval monarch felt the ritual was unnecessary symbolic and thus burnt or buried lepers alive.” How has HIV&AIDS come to be identified in terms of ritual purity? Douglas (1966: 35) writes: “Our idea of dirt is dominated by the knowledge of pathogenic organisms.” Quam (1990: 38) elaborates Douglas’ ideas, and in relation to HIV&AIDS states “the orifices of the body where the virus enters, at least when it is sexually transmitted, are symbolically considered “dirty”: the anus because of faeces, the vagina where menstrual blood flows, and the penis because of urination, ejaculation, and penetration of the “dirty” vagina or anus. The fact that two primary vital elements, semen and blood, should be the carriers of pollution and death increases the sense of the polluting power of AIDS and the fear of the disease.”

## **2.10 Conclusion**

Conclusions drawn from the literature are that stigma is a major challenge to South Africa as it confronts its HIV&AIDS epidemic. Stigma is a very complex societal phenomenon that has deep roots in the spheres of class, race, gender, ethnicity or culture. The dominant approaches in the studies of stigma encompass Goffmans’ work, particularly his focus on the concept of the ‘discredited’ and the ‘discreditable’.

The socio-cultural approach explains that people's stigmatising attitudes and behaviour are framed within a particular context (see Scott, Miller, Crocker, in this chapter). Furthermore, theorists approaching the topic of stigma from the position of deviance and social control offer insights into how difference, in various societies, is treated as deviance and controlled through structural means to maintain or create social order (see Becker & Arnold, Stafford & Scott, Link and Phelan, in this chapter). Social psychologists have utilised cognitive approaches to show how people construct categories and include them in generalisations and stereotypes. Additionally, most diseases throughout history prompted metaphoric thinking and construction of various meanings because they were feared either for their death tolls or the aetiology of the diseases was unknown (see Sontag, Doka). However, the notion of construction ultimately allows a possibility for 'de-construction', rethinking, and reformulating of stigmatising attitudes. Social psychologists bring useful insights into how various past and present sources of information determine our interactions with the stigmatised individuals (see Crocker and Lutsky, in this chapter). The schematic approach raises an important question as to how HIV&AIDS educational programmes influence one's stigmatising attitudes, beliefs, and behaviour towards the afflicted individuals in the presence of pervasive cultural beliefs. Moreover, the world of literature or the arts also shows us how meaning is imagined or invented. Henrik Ibsen, Satyajit Ray, *La Boheme* and *La Traviata*, explore consumption or TB in the way Sontag suggests. This also allows for possibilities of re-imagining or redefinition. The producers of the "Sky in Her Eyes" work with the same concept. They believe that the film will allow for redefinition of stigmatising attitudes. That disease is explored through the medium of the arts reflects preoccupation with meaning making.

Perhaps one of the biggest gaps in the literature is that various disciplines tend to treat stigma as their 'property', either overlooking or disregarding other approaches. Most disciplines usually establish working definitions of stigma that fit their particular research requirements instead of looking at how perspectives from other disciplines can complement and clarify some of the complexities around stigma. Social scientists who emphasise interdisciplinary approach in the explorations of stigma and the stigmatisation processes generally share this view (Coleman, 1986). What is needed is an interdisciplinary approach. Each discipline has got something to offer. I went to this research 'armed' with approaches from various disciplines because I didn't want

to restrict myself to only one particular perspective. For example, if I worked only with Goffman's definition of stigma my understanding of the possible causes of the students' attitudes and behaviour would have been significantly limited. For the purpose of this research, I utilised all the above-discussed approaches and situated them against the students' responses from the focus group discussions. I examined whether students' answers supported, contradicted or advanced these particular theoretical concepts.



### 3. Methodology

#### 3.1 Introduction

*To be a good [participatory researcher] means above all to have faith in people; to believe in the possibility that they can create and change things. It is also necessary to love..., to be convinced that the fundamental effort of community...education, is toward the liberation of people, never their "domestication." This liberation begins to the extent that men[and women] reflect on themselves and their condition in the world-the world in which and with which they find themselves. To the extent that they are more conscientised, they will insert themselves as subjects into their own history. [Freire, 1971: 62]*

This chapter introduces the methodological practices that were used to collect data. The research methods that were utilized encompass the use of a short film as a triggering agent, open-ended questionnaires, and focus group discussions. Furthermore, the chapter clarifies time and setting of the meetings and describes in detail how each session was conducted. The concluding part describes the data analyses process.



#### 3.2 Qualitative Research Methods

Throughout this research with the students, qualitative research methods were employed because they were appropriate to explore the issue of stigma, which was a topic of a particularly sensitive nature. Although it is difficult to describe what qualitative research methodology is, traditionally, it has been used to refer to a range of methodological approaches such as observation studies, interviews, or focus group discussions. Sherman and Webb (1988: 7), point out "...qualitative implies a direct concern with experience as it is 'lived' or 'felt' or 'undergone'...Qualitative research, then, has the aim of understanding experience as nearly as possible as its participants feel it or live it." Qualitative methodology creates a space where we-the researchers, and the research participants meet to have a discussion about our lives. Although our research is purpose-driven in the sense that we need to answer our research questions, the research "involves us as the total human beings we are" (Buskens, 2002: 12). Our knowledge, life experiences, worries, insecurities or fears are discussed, challenged

and re-examined in a complex web of interactions between the research participants and us. In this process we learn, we reflect on our lives, and we transform. At the end of the research, we are changed human beings (Buskens, 2002).

### **3.3 Data Collection Instruments**

Wallerstein (1992: 197-205), argues that to Freire (1970), “the purpose of education is human liberation which means that people are the subjects of their own learning, not empty vessels filled by that knowledge of experts. To promote the learner as subject, Friere proposes a listening-dialogue-action approach.” The first step is “listening to the generative themes or issues of community members in order to create a structural dialogue in which everyone participates as co-learners to jointly construct a shared reality of themselves as individuals in their social context. Individuals must not only be involved in efforts to identify their problems but also engage in conscientisation (critical engagement with knowledge), to analyse the societal context for these problems. The goal of dialogue and conscientisation is praxis, the ongoing interaction between reflection and the actions people take to promote individual and social change” (Ibid: 1992). Within the Freirian “listening-dialogue-action” framework, I combined several techniques to gather my data. I used a short film “The Sky in Her Eyes,” questionnaires with open-ended questions, and focus group discussions to explore emerging themes in relation to stigma in depth.

#### **3.3.1 The Significance of Visual Triggers**

Wallerstein and Duran (2003: 42), point out that, “Much of the creativity of the Freirian approach, also called popular or empowerment education, has been in the development of codes (sometimes called triggers or discussion catalysts) that codify the generative themes into a physical form (using pictures, videos, role-playing, and so on) so that participants can ‘see’ their reality with new eyes and consequently develop alternative ways of thinking and acting.” The short film, “The Sky in Her Eyes,” served two main purposes. First, it allowed the students to reflect on their own reality through examining the experiences of a little girl after her mother died of AIDS. During the focus group discussions I engaged with a question whether students

could relate the film to their own experiences or experiences in their communities. Second, one of the disadvantages of the focus group discussions in the initial stages is that some students did not feel comfortable to share their views and experiences in the group. They felt ‘exposed’ and vulnerable, especially when the discussion evolved around sensitive issues. I began our discussions by asking questions about the film, so I partially overcame this problem. We were then able to approach the issue of relevance of events in the film to their communities. In short, the film served as a tool that allowed students to reflect on their own experiences, thus allowing them to reflect deeply on the issues around stigma.

### **3.3.2 Questionnaires**

The questionnaires, which I distributed to the students immediately after the screening of the film, consisted of open-ended questions about the main events in the film. I decided on the open-ended character because these types of questions often provide useful indications of the kinds of issues that might be worthwhile following up in focus group discussions. They also allow respondents to draw attention to anything they feel strongly about. Hardon et al. (2001: 249), highlight that open-ended questions are particularly beneficial because “issues not previously thought of when planning the study may be explored, thus providing valuable insights into the problem.” They argue further that “information provided spontaneously is likely to be more valid than answers suggested in options from which the informant must choose” (Ibid: 249). The disadvantage of the open-ended questions is that their analysis is time consuming.

Chavez et al. (2003: 89), point out that the key principle in research is that “it must be produced, interpreted, and disseminated to community members in clear, useful, and respectful language.” They continue, “nonetheless, academia has its own language and assumptions that often clash with those of the majority of the people in the communities where research is conducted. Thus the commitment to disseminate research...requires that researchers go outside the usual boundaries of academic convention” (Ibid: 89). I purposefully decided not to complicate the questions. My goal was to ease the atmosphere and to create a safe space for the participants to comment freely on some of the aspects in the film before we moved into discussions.

The questions were structured in a simple everyday language without containing any acronyms or academic concepts that could have confused the participants. I proceeded this way throughout our discussions as well. After the research was done, many participants specifically highlighted the fact that I didn't overwhelm them by any complicated concepts. They told me that they had often felt intimidated throughout various educational workshops because the facilitators used 'high' academic language that they couldn't understand; saying their ability to learn and to respond at that time was thus quite limited.

### **3.3.3 Focus Groups**

Hardon et al. (2001: 209), point out that focus group research “involves organised discussions with a selected group of individuals to gain insight on their views, feelings, beliefs and experiences regarding a certain topic.” In comparison with an individual interview they claim that, “the advantage is that some ideas, experiences, and feelings are more likely to be revealed in the interaction within a group” (Ibid: 209). This method was very useful because it allowed me to gather data that reflected different and often complex perceptions and views of people on issues being discussed. I decided on focus groups primarily because they generate group norms rather than individual ideas and behaviour, which was crucial in my research of studying stigma as a societal phenomenon rather than individual attitudes.

Although I acquired some facilitation skills while co-facilitating a few focus group discussions in the past, facilitating the discussions was a challenging process. I constantly had to re-examine my approaches during the research with the students to avoid or minimise possible biases. Throughout the process I had to be aware of my own tone of voice, facial expressions, and body language. I worked on this aspect by reflecting on the process throughout the focus groups, but also after the sessions. It became a question of constant self-reflection, self-control and self-management.

I also had to systematise the discussion from time to time and reorient the discussion if it went off the track. Buskens (2003b: 1), provides a very useful analogy between the two main types of facilitators: “There is a stern taskmaster, the directive, authoritarian traffic -cop who, while focusing single-mindedly on the destination,

dismisses the journey as well as the people who are travelling. Then there is the non-directive, non-judging, all-embracing tour guide who indulges the travellers' whims and fancies and who may end up anywhere but at the original destination." I didn't want to become either of these two types. Although I came into the research with the agenda of obtaining answers to my research questions, the very nature of my research meant that I entered the realm of the unknown. I was armed with various theories and concepts about stigma, but I wasn't sure what was going to emerge as a result of our discussions. I sometimes had to allow the participants to guide me through the process. I didn't want to rush through the discussion following strictly my agenda because I could have overlooked some important aspects. On the other hand, I also didn't want to be a 'tour guide' who ended up everywhere but nowhere. For this reason I decided to pursue with what Buskens (2003a: 1) calls "non-directive controlled" technique. Buskens (2003a: 1) explains that interviews (in my case focus groups) are "non-directive in the sense that the respondent and not the interviewer defines the direction of the exchange. They are controlled in the sense that the interviewer contains the process and keeps the process aligned with the purpose."

In this way, I was no longer the centre of the activity as the participants proceeded in the discussions with each other. I assumed the role of a 'manager' of the process and asked only clarifying or exploring questions although, at certain times, I had to intervene when the dominant participants overtook the course of the discussion. I solved this problem by explaining that I also needed to hear from other participants. It was also difficult to manage the discussions because my groups were inclusive. In the process of selecting the students I realised that they were eager to participate and share their views on stigma, so I didn't put any restrictions on the number of new participants coming into the focus group discussions. I had to work with around 15 to 16 participants each time instead of the optimum size of 6 to 12 participants per group. I also made this decision based on the fact that the students wanted to bring additional participants as well. Anyone who wanted to share his/her views was thus welcome to participate in the group discussions.

### **3.4 Data Collection Process**

#### **3.4.1 Sampling**

I selected the participants at the University of the Western Cape. The limitation of my research was that I didn't use any particular statistical sampling method, thus the results couldn't be generalised to the broader population. I approached the students directly, but I also applied snowball sampling. I asked the students to refer me to other potential informants. In many cases, the students offered to help me to get more participants, or asked whether they could bring their friends. I approached the students while I was walking through the University's campus or in the computer laboratories. I also approached students sitting in front of the library or in the students' campus centre. I introduced myself and briefly informed the students about the purpose of my research as well as the duration of each session. When they agreed to participate, I asked them to provide their names, phone numbers, the course and the year of study, and consequently arranged the time and place for the first session. The advantage of the focus groups is that the sample doesn't have to consist of large numbers of participants because this method is used to gather information about group behaviour. I decided to target a sample of 30 students. Over the period of two weeks, 35 students participated in the research. One week later, I repeated the research with additional 18 students.



### **3.4.2 Time and Setting**

I began the process of data collection during the second week of September, and it took approximately two weeks to complete this phase. My choice to intervene during this particular period wasn't coincidental. At that time, the students had a one-week university break. They just finished their exams and assignments, and were about to start the 4<sup>th</sup> quarter. This was the ideal time to gather students for my research since they weren't preoccupied with any schoolwork. To gather the students wasn't difficult at all. In fact, they were eager to participate. I began to search for the students in the morning, and, after a couple of hours, I had enough participants to conduct the first session, which followed the same day in the early afternoon hours. I repeated the same process on the following day. Altogether, a group of 25 students participated in the introductory sessions over the period of two days. Their numbers were higher during the focus group discussions because some participants brought additional students. After the first session was completed, I arranged a time with students for our focus group discussion, which happened two days after the introductory sessions. I

agreed to meet the students at a time most suitable for them. I also agreed to reimburse some students' travelling expenses because they weren't staying on campus, so it would have been difficult for them to come to our discussions. The return rate to our second meetings was much higher. The original size of the groups usually increased by 7-8 new participants throughout the second meetings.

My choice of the venue for our meetings was determined by the fact that I wanted to conduct the sessions in a neutral setting. Students would not have felt comfortable discussing the issues around HIV&AIDS stigma in their dormitories, and I also wanted to avoid places where they usually studied or took classes. I thus had to conduct the sessions in a 'safe' place, and I decided to book the venue at the School of Government, which was located by the campus's nature reserve. It was a quiet location. The room that I used was ideal for about 20 participants and it was free from any disturbances. One participant said during the discussion, "Ja like, when you involve yourself in the AIDS, HIV&AIDS activity, you are seen as being infected. If you take this table outside (*everybody in the group started to laugh*), and somebody passes by and hear talking about AIDS. I am telling you. If we were to walk somewhere, they will whisper: That One! They assume that by your virtue of being there, you know, you are infected" (Focus Group, Thursday 4<sup>th</sup> September, 2004).

### **3.4.3 Ethics**

I had to adhere to strong ethical rules all the time because I was working with human subjects. First, I had to obtain ethical clearance from the ethics committee. I prepared a consent letter that had to be signed by all the participants. Before I began the introductory sessions formally, I informed all the students about the purpose of my research in detail, and explained to them their rights. I went through all the points of the consent letter together with the students, ensured them of the confidentiality, anonymity, and highlighted the aspect of voluntary participation. I also explained to them whom they could contact in case they would have any complaints or worries. After I made sure that everyone understood the consent letter, I asked the students to sign it.

### **3.5 Conducting the Sessions**

#### **3.5.1 Introductory Sessions**

As I have already mentioned, the introductory sessions preceded the focus group discussions. I asked the students to watch the short film “The Sky in Her Eyes”, which was only 11 minutes long. After the film, I distributed the questionnaires. I gave the participants approximately 40 minutes to respond in writing to the questions. The first sessions took approximately one hour. After that, we set the time for our focus group discussions. I provided refreshments throughout the duration of each session.

#### **3.5.2 Focus Groups**

I arranged the focus group discussions two days after the introductory sessions, which gave the participants some time to reflect on their responses in the questionnaires. It also gave me the opportunity to analyse their answers, and to prepare additional questions for the focus groups. I usually used some of the questions from the questionnaires to start the discussion. It wasn't necessary to prepare a list with too many questions because 4 to 5 questions were more than enough for about two to three hours of discussion. Additionally, participants usually built on what other persons said, and new questions emerged throughout the discussions. I began each focus group session by introducing myself, and I asked other participants to introduce themselves as well. I asked them for permission to tape-record our discussions. This process would involve questions about the students' activities and their hobbies. The next phase evolved around group rules. I didn't want to restrict the groups by imposing rules on them, but rather asked the groups if they thought it was necessary to have certain rules of discussion. Together with the groups, we created the following rules: There were no “right” or “wrong” answers. Our group was a safe place for everybody to discuss his or her views and opinions. The aspect of respecting each other was especially highlighted. Furthermore, nobody was allowed to discuss other student's views and ideas outside the group unless the particular individual granted his/her permission to do so. In this sense, we agreed to strict confidentiality. Additionally, we stressed the importance of listening to each other, not a mere

'hearing'. We all agreed that we met to learn from each other and to engage in a discussion. We also stressed that everybody had to get a chance to talk and to express his or her views because a focus group discussion wasn't meant to be a dialogue between few individuals. Lastly, the only rule I imposed was to ask the participants to switch off their cell-phones to avoid any unnecessary disturbances. After we established the rules, we proceeded with the discussions. One of the groups requested an additional meeting. Thus we met again one week later. After that, they required more meetings. They wanted to discuss issues around stigma further. It was only due to the time constraints that I couldn't continue having more and more meetings. However, we agreed to follow up at a later stage, and, in the meantime, think of ways to establish a forum where students could discuss their views around HIV&AIDS stigma. Each focus group session took about three hours, so I prepared food for the participants. The food that we shared after the sessions concluded played a very important role. As I mentioned earlier, I ensured students of safety by my choice of the venue because our discussion evolved around sensitive issues. Throughout the discussions, the students often shared personal experiences in relation to stigma. The food then served as a closure to this process. It was a safe transition of emotions before everybody left the venue.



### **3.6 Data Analyses**

Ely et al. (1991: 140) explain that, “to analyse is to find some way or ways to tease out what we consider to be essential meaning in the raw data; to reduce and reorganise and combine so that the readers share the researcher’s findings in the most economical, interesting fashion. The product of the analysis is a creation that speaks to the heart of what was learnt.” The phase of data analyses was an ongoing process throughout the research procedure. In order to prepare for the focus group discussions I had to review the responses to the questionnaires. Additionally, I had to analyse the group dynamics throughout the focus group sessions to know how to continue with the discussions. I proceeded with the analyses of the final data by applying what Ely et al. (1991: 143)<sup>18</sup> specify as “thinking units”, which could be categorised as some sort of sorting files. Thus I re-read the transcripts several times and established certain

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<sup>18</sup> Ely et al. refer to Lofland and Lofland (1984).

emerging units. These units later formed a set of categories and sub-categories which I developed into themes. I then organised and contrasted the themes in relation to the existing research literature.

### **3.7 Conclusion**

Qualitative research methods are very helpful to explore sensitive issues. However, they put great demands on the researcher. There are a number of issues that the researcher encounters during the process that may impact on data collection and interpretation. Focus group discussions provide information about group norms and behaviour. They enable an exploration of stigma in a larger socio-cultural and historical context. However, whether the researcher succeeds in obtaining the information depends on how he/she presents him/herself and how the focus group sessions are conducted. Visual triggers can be very useful tools to start the discussions. They allow for reflection on the issues discussed. Lastly, the analysis of qualitative materials is a complex and time-consuming process.

In relation to these methodologies, I begin the next chapter by considering how stigma is perceived and recognised. I discuss what enables the recognition and questioning of stigma. Based on the filmmaker's assumptions, I examine whether the film has the capacity to challenge negative attitudes. Furthermore, I look at how stigma can be recognised and challenged through carefully mediated group work. Moreover, I consider how other discourses of science seek to confront stigma, and if information about the disease is enough to challenge or change negative attitudes.

## **4. Results Presentation**

### **4.1 Introduction**

This chapter presents the findings that emerged out of the focus group discussions with students. It first proceeds by developing a discussion around the STEPS initiative and the short film, “The Sky in Her Eyes”, which was used, for the purposes of this research, as a triggering agent to move deeper into the issues around stigma. This internationally acclaimed film has been praised for its ability to challenge negative attitudes towards people living with HIV&AIDS. But does it really? Does this assumption work as simply as it is made? During the course of the discussions unexpected questions emerged about the film. This chapter thus explores the assumptions of the filmmakers about the intended effect of the film and its actual impact on the participants. It examines how the filmmakers intend to achieve the effect of empathy that, they assume, will automatically lead to re-formulation of negative attitudes. Furthermore, this chapter explores whether the film provokes thinking about stigma and evokes self-reflection. The next part includes findings about causes of stigma. It discusses the role of knowledge about HIV&AIDS, fear of the disease and a lack of stigma recognition in relation to HIV&AIDS stigma. Furthermore, various intervention programmes in the area of HIV&AIDS and stigma explore whether acquiring knowledge about the disease is sufficient to challenge negative attitudes. The following part thus complicates this notion further by exploring the role of cultural perceptions of the disease and norms about sex in maintaining stigma. This section also investigates how a particular social context influences stigma experiences and helps to maintain stigma.

### **4.2 Challenges in Challenging Stigma**

#### **4.2.1 Film as a Tool of Attitude Change**

“The Sky in Her Eyes” is part of the Steps for the Future<sup>19</sup> initiative. Steps for the Future was set up by Likka Vehkalathi, documentary commissioning editor at YLE

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<sup>19</sup> Steps for the Future is part of a non-profit organization in South Africa called STEPS-Social Transformation and Empowerment Projects.

Finnish Broadcasting company, and South African filmmaker, Don Edkins. This project brought together international filmmakers to work together with the participants of the Steps project. Their aim was to provide professional advice to the directors without altering the goal of the filmmakers. The Steps collection contains 36 films that vary in length from 4 to 74 minutes. These films have been produced in 6 African countries and they have been broadcast in 15 countries around the world. In addition, they have been screened in various international film festivals and have received numerous awards.

The Steps for the Future project has been created as an intervention by the filmmakers into the HIV&AIDS epidemic, using film as a powerful medium to address attitudes such as denial, discrimination and stigmatisation. Additional issues covered in the films include orphans and child headed households, prevention and treatment and migrant labour. The films portray how people deal with HIV&AIDS, focusing on positive life stories with a purpose of leaving the audience members inspired and informed once they view the films (Steps for the Future, 2001: 1-3). One of the main goals of the Steps films is to provoke emotional responses from viewers. As Stadler (2003:3), points out “Film engages us physically as well as intellectually in acts of perception, attention, imagining, perspective taking. In the experience of empathy and imagination, in resistance or responses to others that are felt bodily.” It is important to define the difference between sympathy and empathy. The World Book Dictionary (1987: 2125) defines sympathy as “a sharing of another’s sorrow or trouble.” Empathy is described as “the quality or process of entering fully, through imagination, into another’s feelings or motives” (Ibid: 691). Sympathy allows feelings from ‘distance’. However, empathy requires much deeper involvement. It requires imaginative transformation. The filmmakers assume that the film will evoke empathetic responses from the viewers, which means that audiences are required to imagine themselves experiencing the life of the little girl. It is hoped that these films will reach people, provoke debates and make a real difference where established ways of health education have failed to stop the spread of HIV. The Steps films “form part of a media advocacy campaign which is intended to promote debate and discussion around HIV&AIDS-related topics such as disclosure, discrimination, treatment, and living positively” (Steps for the Future 2001). At the same time, these films aim to

“redress the dominant media’s shortcomings” in the HIV&AIDS advocacy campaigns (Levine, 2003: 8).

Jane Standler (2003:2) highlights that “the positive impact of the Steps series results largely from facilitated discussions following screenings, and the provision of access to further HV&AIDS related resources, information and support.” The Steps Impact Study (Levine and Englehart 2003) indicates that under such conditions the films will initiate discussion and debate. Levine and Englehart argue further that, “the viewers throughout the region empathize with the characters in the Steps film collection. The films give people the chance to look inside themselves and then look at one another in a new light” (2003:4). In her writing about the capacity of signs to produce feelings, mental stimulation, reflection and change, the anthropologist Leslie Devereaux (1995B: 68) theoretically supports the Steps’ Impact Study findings. She argues: “Here we have a view of cultural meaning in which significance passes through persons, embodied consciousness, changing in the process and also altering the person, who then may effect change in the world through action.”

In relation to the Steps’ Impact findings, two points emerge that were relevant for my research. First, for these films to have the intended effect of producing change in stigmatising attitudes and creating effective awareness around HIV&AIDS issues, they must be followed by facilitated discussions after the screenings. It is these discussions that maximize the exchange of information among participants (Stadler, 2003: 2-3). The facilitated discussions after the films have been a common practise of outreach organizations working with the films throughout the Southern African region<sup>20</sup>. Additionally, The Steps for the Future has developed a facilitator’s guide to assist in initiating discussions. The guide breaks down each film into its key points it addresses<sup>21</sup>, offers questions for discussions and gives suggestions on how to facilitate debates in a variety of settings as well as tips for setting up the screenings.

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<sup>20</sup> The films from the Steps collection have been made available to a variety of NGO’s, HIV&AIDS support groups, local and provincial health authorities, youth centres, churches etc. Some of the films have been made in 15 different local languages. The films are taken to communities and screened in community halls, churches, etc. Similar projects are currently underway in Zambia, Malawi and Zimbabwe. Distribution of the films is also being developed in Namibia and Mozambique. To obtain more information on these projects visit the Steps website: [www.steps.co.za](http://www.steps.co.za)

<sup>21</sup> According to the Guide, “The Sky in Her Eyes” addresses the issues of orphans and HIV, stigmatisation and discrimination.

Second, Jane Standler (2003:3) argues that: "...a form of experiential and empathic understanding is required to spark behavioural change, to make the personal and social relevance of HIV transmission be felt and needed." Empathetic responses from audiences throughout the Southern African region have been mainly achieved through the main protagonists in the films who, in many instances, facilitated the discussions after the screenings. In one of the Steps' films, "Mother to Child"<sup>22</sup>, Pinkie and Patience who are the main characters in the film step out after the screening and talk to pregnant women in antenatal clinics. Both women are HIV positive. They aim to persuade the pregnant women at the clinic about their obligation to confront HIV&AIDS for the sake of their babies. The first step is to know their status. If the result is positive they can learn how to come to terms with it and how to live as healthy as possible. Summarising the Steps Impact Study, Englehart (2003: 10-12) highlights one of the effects of this film after the discussion guided by the main characters in this film was that more women participated in HIV testing at the clinics. Standler (2003: 8) points out that: "In this way Steps films offer a sense of interconnectedness with people throughout Southern Africa whose lives have been touched by the virus, and enable us to learn from their experiences. This deep-seated, experiential knowledge is key to messages about HIV related issues hitting home and translating into behavioural change." The ultimate goal of the Steps for the Future is to initiate "social change through individual transformation" (Levine and Englehart, 2001: 1).

Having placed "The Sky in Her Eyes" within the context of the Steps initiative, I now proceed with the findings and discuss its effect on the students who participated in this research.

#### **4.2.1.1 The Impact of "The Sky in Her Eyes"**

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<sup>22</sup> "Mother to Child" was produced by Lipman and Jane Thandi in 2001. It is 44 minutes long. The copy of the film can be ordered through the Steps for the Future initiative: [www.steps.co.za](http://www.steps.co.za)

The short film, “The Sky in Her Eyes”<sup>23</sup>, aligned with the purpose of the Steps initiative, was designed to achieve several goals. First, it is supposed to create awareness around HIV&AIDS and AIDS orphans. Second, the film addresses the issues of stigmatisation and discrimination. Third, the filmmakers assume that the film will evoke feelings of sympathy and empathy. These aspects, according to the directors, will lead to challenging or re-considering of negative attitudes towards people living with HIV&AIDS. As the film directors proclaim (2003: 3, Steps for the Future, Film Synopsis), the film “challenges negative attitudes and the damaging stigma that can further wound children who are dealing with the death of loved ones.” They expect to achieve this effect through carefully depicted life situations of the little girl when she is taking care of her sick mother and the ‘treatment’ that she receives from the community after her mother’s death. Additionally, the filmmakers emphasize the scene where the girl attaches the picture of her mother onto a kite. In the reading of the film, this is a moment of a child’s symbolic funeral for her deceased mother, but it also shows how stigma can be challenged or overcome through a compassionate act of a little boy who helps the girl with the kite. Stated simply, the assumption of the filmmakers is that this film will succeed in challenging of negative attitudes. This film is currently being developed into a feature-length film. It was also highly praised at the United Nations Special Session on Children and the World Summit on Sustainable Development. According to the Steps Facilitator’s Guide, the film targets a range of audiences including children, youth and adults.<sup>24</sup>

A short contextualizing passage, written in English, precedes the film’s opening credits. Presenting itself as information on the impact of HIV&AIDS on the orphans’ situation in Africa, the passage establishes the filmmaker’s desire to inform the audience about the increasing rate of AIDS orphans. The text states that: “By the year

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<sup>23</sup> “The Sky in Her Eyes” is part of a larger outpouring of creative works engaging with the issue of stigma. Besides the Steps initiative, I would like to mention the “Memory Box Project” which is an outreach programme within the AIDS and Society Research Unit, Centre for Social Science Research, University of Cape Town. The HIV positive participants make a memory box as a form of telling empowering narratives about their lives. “The Memory Box Project” also cooperates with Medicins Sans Frontiers in the “Body Maps” art project. Participants in this project paint representations of HIV virus and symbols of personal power onto life size sheets of their bodies. Most recently, it is worth mentioning the film “Yesterday” directed by Darrel Roodt that depicts the life of an HIV positive woman who is compassionately taking care of her dying husband while encountering stigmatisation by the rural community. What all these texts have in common is an assumption that representations of stigma and of positive approaches to HIV sufferers will lead to rethinking and challenging of stigma.

<sup>24</sup> This information was obtained from the Facilitator’s Guide. The guide can be downloaded free of charge from the Steps website or purchased in a hard copy. For information refer to the Steps’ website.

2010 an estimated 26 million children, most in Africa, will lose their mother or both parents to AIDS.” Following an opening sequence of shots of a blue sky with clouds, and the setting of rural KwaZulu-Natal, the film portrays a woman in a white skirt with bright red flowers approaching the hut. She has a yellow bucket filled with water and a little baby on her back. Her daughter sings along happily and pulls the red sash of her mother’s skirt. In the following part, the audience’s attention is directed towards the scene where the girl, fingering the red sash, is taking care of her sick mother, who is dying. The next scene depicts the girl at her mother’s funeral. She is fingering the same red sash. After the funeral, back in the hut, the girl draws a picture of her mother with her flower skirt and the red sash across her skirt. She then puts the drawing in a small tin and stores it in a safe place. The part when the little girl goes to fetch water from a nearby river becomes the filmmaker’s bridge into the next segment of the film, the portrayal of stigmatisation from the community. As she walks down the hill, the children avoid her and they seem to be laughing at her. She stops and looks at the children while they are passing by her. There is a close-up shot of her sad face. At the river, she sees the image of her mother in the water. A boy in a red T-shirt throws a stone, which spoils the image. As she walks to the hut, she sees the same boy flying a kite. On her way back, she also faces stigmatising attitudes from the elders who tell her to get out of the way. At the hut, she takes the drawing of her mother with the red sash and asks the boy to attach it to the kite. This is the concluding section of the film where the filmmakers depict how stigma can be challenged or overcome through a compassionate act of the little boy. The girl jumps up and down happily as the kite flies in the sky. There is a close-up shot of her smiling face. She looks sad when the kite falls down. The boy and the girl are then sitting together on the edge of a cliff overlooking a valley and exchanging glances. The boy teaches her how to do it and she flies the kite herself. The shot freezes on her happy face as she watches the kite flying in the sky<sup>25</sup>. The voice-over of the mother reminds the child that her love will endure, thereby assuring the girl of a future: “When I am no more here, look up to the sky, the sky that gave birth to the sun, the moon, and the stars.”

This film is expected to reach a wide range of audiences because there is purposefully very little dialogue. Rutha Wigget (2003:1) argues that this film is a very important

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<sup>25</sup> The film’s soundtrack is a composition by Sazi Dlamini, sung by local vocalist Nina Mkhize.

medium because it “focuses on a uniform language” in a country where “the diversity of our national languages and cultures has challenged non-profit organizations to reach their objectives effectively.” The Zulu language that was used on very few occasions thus wasn’t expected to create any problems for the viewers in the reading of the film.

#### **4.2.1.2 Research Findings and Focus Group Responses**

For some students, the Zulu language proved to be an obstacle in an effective understanding of the events in the film. One student explains that it is not clear whether the film depicts the issues of HIV&AIDS:

“Because actually there is nothing like a commentary or anything. And you know I asked you after the movie what language was spoken in the movie. I don’t understand what they are saying. So for me, it was not clear at all.” (*Focus Group Discussions, September 4, 2004*)

Another student says that:

“For me, I think because the movie didn’t have any words really that I could understand and there was no commentary, so I think after the movie I was trying to figure out, I was trying to kind of put everything together. And understand like if it was AIDS because it was nothing explicit that it was AIDS.” (*Focus Group Discussions, September 4, 2004*)

From the students’ responses, the following can be concluded. The lack of commentary and the use of Zulu language, even though it was used very briefly in three different occasions in the film, created a sense of ‘alienation’ for some participants from the events in the film. This also raises another important question. How did the students perceive the information about AIDS orphans with which the film begins? I purposefully paused the video in this part before the participants came into the room. Before we began watching the film, when everybody was already seated, I still kept this information paused for another 30 seconds. However, the information on AIDS orphans seemed to have escaped students’ attention. Did the participants simply miss out this information or is this perhaps a form of willed resistance to HIV&AIDS? Furthermore, how do these responses contradict Wigget’s

argument on the power of films to reach wide range of audiences because it “focuses on a uniform language?” (2003:1).

Thus before I even begin to talk about whether and how stigma is recognised in the film, I need to clarify how the filmmakers try to create awareness on HIV&AIDS issues and how students attempt to understand the events in the film as being HIV&AIDS related. The red colour is used as a universal metaphor for HIV&AIDS. The filmmakers applied this symbol on several occasions throughout the film such as the red sash and red flowers of the girl mother’s skirt, a boy in a red T-shirt, or the little girl wearing a red skirt after the funeral<sup>26</sup>. The students were aware that I was doing research on HIV&AIDS, which gave them an indication that the film did portray these issues. For some, it then became a question of looking for clues in the film that would indicate that. It also became clearer after I explained this to the students after watching of the film.

“...If we didn’t know what we were gonna discuss about we wouldn’t have that idea. If we just walked in here not knowing that what we were gonna talk about AIDS like I got the idea that the mother died of AIDS. But if I got here not knowing that we were gonna discuss about AIDS I wouldn’t have gotten the like that idea.” (FGD, September 5)

“It is hard for me to say because I walked here thinking this is about AIDS. So at that point before I even started watching the film I already knew it. I already made up my mind. But when I started watching it I took it as an ok if this is about AIDS it has to show to me that it is about right? The movie wasn’t making any indication on its own.” (FGD, September 5)

On the other hand, there were participants who point out that the film clearly depicts HIV&AIDS issues. The students recognise this according to a variety of factors. Among many, I will mention visual symbols like the red ribbon, the symptoms of the disease, the atmosphere at the funeral, or the ‘eroded’ traditional care and support systems.

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<sup>26</sup> This also raises another important question. Was it the filmmakers’ intention to portray the girl in red skirt after her mother’s funeral? At the beginning of the film, the girl wore a blue skirt. Does this signify that the girl is now marked with red skirt, as an AIDS orphan? Do the filmmakers indicate that she is an outcast? This brings us to novels like the one written by Nataniel Hawthorne: The Scarlet Letter where the main character of the novel was convicted of adultery and as a result of that she had to wear a big red “A” sign on her chest, indicating that she was an adulterer.

“For me it was the red ribbon that the girl attached to the kite. It was clear for me that her mother died of aids.” (FGD, September 4)

“I think I started realising that that the woman suffered of AIDS and when she started sweating, coming weak, and couldn’t handle it anymore. So, because I think the symptoms of someone with HIV like you sweat every time, can’t work hard.” (FGD, September 4)

“I realised at the time when that woman is buried. I see that the people the way they were reacting at the funeral, because there was no priest and there was no formal attendance because there was always rush. So I realized it is this issue.” (FGD, September 4)

“Ok, I think what made it more for me to realise in our communities, especially when you are an orphan, the community will always like be there for you feel pity for you, now that one is like now like keep a distance so that doesn’t happen usually when is usually any other disease can only happen when is HIV AIDS. So it became clearer like that.” (FGD, September 4)

Having said that, I looked at how the group responded to the two main events in the film. The first is the scene where the girl went to fetch water from the river. This is the part where the filmmakers attempt to create stigma recognition. In the second scene, I explore her interaction with a little boy when she attaches a picture of her mother onto his kite. This is where stigma is supposed to be challenged through an act of compassion. The filmmakers applied certain techniques to indicate the presence and effects of stigma as well as transcendence and overcoming of stigma through friendship and compassionate act of the little boy. A series of close-ups of the little girl were utilised throughout the film when she was dancing happily with her mother, then taking care of her. The filmmakers used close-ups as a technique for creating intimacy. A close-up shot of the girl’s sad face followed when the children and the community avoided her. In the concluding part, a close-up shot of her happy face was used when she was flying the kite with her mother’s picture. In the case of the first scene, the group discussion revealed that stigma recognition was far more complex when compared to the intentions of the filmmakers. Most of the students recognised the presence of stigma in a form of avoidance and discrimination of the little girl from the community. They say that the community either rejects or discriminates against

the little girl. Additionally, she becomes a “social outcast”, or she is “no longer a human being”:

“The community rejected her and some children even threw stones at her.”

“She became a social outcast like many other children with AIDS or with parents dying of AIDS.”

“They saw her as “nothing”.”

“They reacted as if she was no longer a human being and that she should also follow her mother.” (*Responses to Questionnaires about the Film*)

However, a number of participants were not clear about why this was happening. In addition, they do not recognise the presence of stigma in the film at all. The behaviour from the community towards the child is viewed as normal or culturally appropriate. Does this imply that there is a lack of stigma recognition or refusal to acknowledge recognition of stigma among the students?

“There is nothing bad with the children. In our culture, you have to move away when you are in a way.”

“I can’t judge these parents against the reaction. There is nothing wrong with it.” (*Focus group responses, 17 September 2004*)

Furthermore, the scene with the kite is equally complex. Some participants viewed the act of attaching a picture of the girl’s mother onto a kite as a symbolic funeral, when she sends her mother’s spirit to rest. There are some who did not see any particular meaning of this act. More importantly, the act of compassion from the little boy completely escaped students’ attention.

“The girl lets her mother’s spirit to rest.”

“ I can’t explain what this means.”

“I believe it might have to do something with religion, that when somebody dies he/she goes to heaven. It is a belief that her mother is watching over her.”

“Her mother is at a better place.”

“It means that the little girl can still feel the presence of her mother.”

“It was a way of remembering her mother.”

*(Responses to Questionnaires about the Film)*

The filmmakers utilised visual metaphors of freedom and transcendence in a number of ways in the concluding part of the film. They highlight the part when the two children sit next to each other and exchange glances, thereby acknowledging the importance of eye contact in recognizing another's humanity. What's more, the metaphor of freedom and companionship was portrayed through the use of landscape, panoramic views of hills and sky and the children running together through it. Other techniques included the use of close-up shots of the girl's smiling face or the voice-over of the mother reassuring the girl of a future. Despite these visual cues in the film, the participants concentrated, in relation to stigma, on the aspects of loss and death in these particular 'kite' scenes. Does this perhaps suggest the overwhelming influence of stigma, so that the visual metaphor of freedom and transcendence are not recognized? How does this reading of the film from the viewers affect the intended impact of the film to challenge stigmatising attitudes through the acts of compassion and friendship?

Having raised these questions, it becomes apparent that the filmmakers' assumptions do not work as straightforwardly as they assume that they will. I managed to clarify some of the misconceptions arising from the film and explained the filmmakers' intention with particular scenes during the group discussions. However, many of the Steps' films have been screened on national television. The South African Broadcasting Corporation (SABC) has broadcast the Steps films in a weekly documentary spot over the period of 4 months in 2003. In the presence of misconceptions arising from the films, when the private home viewing is not followed by a discussion, it remains a problem as to how the 'home' audience will be able to understand the often very complex issues portrayed in the films (Stadler, 2003:1-2), as well as what impact these films will have on the viewers. In the following section I demonstrate how stigma is recognised and how it can be challenged through participatory group work.

#### 4.2.2 The Lack of Stigma Recognition

“Sorry. That word is kind of like confusing me. Stigmatised What really is it?”  
(FGD, 12 September)

From this research it is evident that there is a contradiction between what the respondents say they wouldn't do and their actual behaviour. They have intentions not to stigmatise. In most cases, they explain how important it is not to discriminate and stigmatise, however, they often do not recognise or refuse to recognise that their own actions, such as laughter, gossip or the use of derogatory words, are perpetuating stigmatising behaviour. In relation to the film, when the girl is subjected to stigmatisation after her mother dies of AIDS, respondents express that discrimination and isolation are not right and that people should be taken care of instead because they are still human beings.

“I think when someone lost parents, he/she needs support from others. Discrimination and isolation is not what he/she needs.”

“They are human beings and need love and care.”

“A person is still a person whether that person is HIV positive or not.”

“The movie is kinnda agitating like to everybody. We mustn't isolate people that are HIV and AIDS and like we must still take care of people that are HIV positive because they are still people they still exist.”  
(Responses to the questionnaires)

The Students also recognise the use of language as a stigmatising tool. They highlight that people living with HIV&AIDS often experience discrimination in a form of derogatory words and gossiping. Additionally, stigmatising language is used to avoid possible association with a particular person. This also shows to be one of the main reasons why students wouldn't go for HIV testing or disclose their HIV status if positive. However, even though they recognise stigma in this form, they often do not acknowledge that their own actions such as laughter and the use of derogatory words are perpetuating discriminatory behaviour, attitudes or language. In other words, they do not label their behaviour as stigmatising. The group discussion revealed some of these complexities. I thus present the following data in a form of discussion between the participants and me, in connection to going for a voluntary counselling and testing on campus:

**Student:** “I won’t feel comfortable to go and test in on campus because I hear there is a student counselling the ones who go for the test. So I won’t feel comfortable.”

**Researcher:** “So what if there is a student who is counselling?”

**Student:** “What if you are HIV positive, then the rumours will spread, then the whole campus will know about your status. And I don’t think it is confidentiality there. That is my opinion.”

**Researcher:** “So what do you think would happen if the campus knew about your status?” (*Everybody laughed*).

**Student:** “Spread it and just like everybody in the campus knows. They treat you in such a way....”

**Researcher:** “In what way?”

**Student:** “Like for instance, some other people they can talk about it about you even if you are next to them. You know.” (*Everybody laughed*). “Because if you are HIV and AIDS you can’t feel like heavy all the time when you go around the campus if you are HIV and AIDS. But it is better if you don’t know yourself.” (*FGD, September 12, 2004*)

The most common words and phrases identified by students that are used to describe people living with HIV or AIDS encompass the following:

- Beaten By Thieves
- You Have Got Three Words (HIV)
- You Won a Lotto (You got what you deserved)
- You Got That Thing
- Unalento Ikhoyo (The thing that everyone talks about)
- HIF/HIV
- Umatsaya Abhuqe (It is a destroying thing. Destroys and Kills the family)  
(*FGD, September 12, 2004*)

**Participant:** “The thing is that people give you names when you are HIV positive. And you also don’t like that kind of thing. For example, what is she suffering from? Oh, she has been beaten by thieves.” (*Everybody in the group began to laugh again*). “But it is not nice. That’s why you trying to isolate yourself.”

**Researcher:** “Why do people use these names?”

**Respondent:** “When scared they don’t wanna refer directly. At the same time, they can talk about you because you don’t understand the language.”

**Researcher:** “Don’t you think that these words are hurtful to individuals?”

**Respondent:** “For me, I don’t think it is the way of discriminating people. I think it is a way of actually laughing at those people. It is not hurtful when you say that you have been beaten by thieves. To me, I think, it is a way of laughing at you.”

**Researcher:** “So how do you think that person feels?”

**Respondent:** “Bad.”

**Researcher:** “So don’t you think it is a form of discrimination?”

**Respondent:** “Ja.” (*Silence*)

**Researcher:** “Have you guys used these terms?”

**Group:** “Yes, always.” (*Everybody laughed again*)

**Researcher:** “Do you think that you respect a person when you use these terms?”

**Group:** “No. Not at all. You just got three words.” (*Silence*)

**Researcher:** “So you basically reduce this person to three words.”

**Group:** “Yes, that’s what we do.” (*Silence*)

**Participant:** “What I wanted to say like when AIDS like really hit at you at your home you will not use these words, never. You will say my brother has AIDS. You won’t say he has been Beaten By Thieves. So they are not nice words to use. People use them; they don’t know the impact they have if the person could hear what they are calling them. We won’t say it if your brother or sister has HIV&AIDS.”

**Researcher:** “So how does it make you feel now guys? Finding out how hurtful these words are?”

**Group:** “Bad” (*Silence*)  
(*FGD, September 12, 2004*)

This discussion revealed several important aspects of stigma and attitude change. First, the students recognise the use of words and phrases as a form of stigmatisation and discrimination. Second, they are equally aware of the damaging impact these words have on individuals. However, when it comes to their own behaviour, they do not acknowledge it as stigmatising. Through a carefully mediated participatory group

discussion it was possible to create not only stigma awareness but also to provoke self-reflection. For example, throughout the course of discussion, the act of laughing became a form of resistance or avoidance of acknowledging stigma. While laughter is often a form of tension release, it is also a shared activity that makes one a part of the group and not a potentially stigmatized outsider. Students responded with silence and frozen downward stares when their laughter was discussed as hurtful and stigmatizing behaviour. While they were critical of their own laughter after realizing its power to hurt, one wonders how many people with stigmatized diseases like HIV& AIDS join in such group laughter in order to hide their own situation that carries the weight of stigma with it. One wonders how many people who have HIV or AIDS or have been affected by it participate in externally stigmatizing behaviour like laughter and in so doing contribute to their own internal experience of stigma.

#### **4.2.3 The Lack of Knowledge**

The focus group discussions reveal that incomplete knowledge about how HIV is transmitted strengthens fears about non-sexual modes of transmissions. Most of the respondents know HIV is transmitted through unprotected sex. However, there is lack of knowledge about how HIV is not transmitted. Additionally, HIV&AIDS is viewed as some kind of 'transferable' disease that can be 'caught' by a casual contact with an infected individual. This belief results in an immediate avoidance and isolation from people living with HIV&AIDS.

“I heard that you can get pregnant while swimming in the water and if there is a sperm. So, can AIDS be transmitted like that? Because it is sexual. So if you can get pregnant you can get also AIDS.”

*(FGD, September 12, 2004)*

“I believe that her mother died of a transferable sickness- HIV&AIDS.”

“They thought that if they interacted with her they would catch AIDS.”

*(Responses to the film)*

Furthermore, this research also indicates that students do not know that there is a difference between HIV&AIDS. For example, they refer to an HIV test as an AIDS test. Furthermore, they are also not aware of how HIV progresses into AIDS and how

long a person with HIV or AIDS lives. Most respondents generally believe that individuals will die shortly after getting infected.

“I am going to think when I am going to die. If you get HIV you can die anytime.”

“I am not quite sure which things can make people get AIDS.”

“What happens is that sometimes someone is diagnosed this year and then dies the next year. Why is that?”

*(FGD, September 5, 2004)*

These fears are related to the phenomenon of delayed testing in South Africa. Because people fear stigma and discrimination, they postpone testing until the symptoms of the disease can no longer be hidden. There is then little that can be done to help particular individuals in the advanced stages of the disease. When the individuals are diagnosed with HIV, at this stage, they often-times die in short time, reinforcing the equation of AIDS equals death. This is also the reason why people, in many instances, perceive HIV positive results as a death sentence and rather avoid the testing. The participants further highlight, and in some cases justify, that a lack of knowledge leads to stigmatisation, and that acquiring information about HIV&AIDS is a key to overcoming it.

“They didn’t have enough knowledge about HIV&AIDS.”

“They thought she was HIV positive and she was going to infect them with the disease. For them, it was wise not to have contact with her.”

“Considering the fact that it was in a rural area where people probably didn’t know how HIV was spread. I can’t blame them because they fear that they could also catch the disease and die.”

*(Reponses to the film. Why was the girl discriminated against?)*

“I think like some of us don’t feel like very confident to go and test. So we need knowledge about this HIV&AIDS thing. So if we can like get knowledge that stigma can be minimised. Because then people will not say this and this about people who are HIV. They are not gonna spread rumours.” *(FGD, September 4, 2004)*

#### **4.2.4 The Role of Fear**

“It scared everybody. It came as a shock to everybody how the disease could kill so many people. So it is only human to be scared it is only human to wonder a lot. You know. To even have that whole ignorance thing in not wanting to know more because you are thinking that the more I get involved the closer I am to infection. So everybody was scared about it.” (FGD, September 5, 2004)

HIV&AIDS is highly feared because it is believed to lead into certain and painful death. HIV&AIDS is known as a ‘killer’ disease. As some students point out:

“I think the main factor is that the disease cannot be cured. It is something that is deadly. I mean once you get, at the end of the day you will die and it is not only that you die but you die after having suffered. So, I think, to me it is like inevitable that you die and you die after suffering. So, I don’t know.”

“It is because, I think, if you discover that you have got AIDS you are like I am going to die. And if you studying or doing something it is a waste of time. I am gonna die at the end. That’s why people get scared and you are kind of killing yourself, kind of isolating yourself from other people. (FGD, September 4, 2004)

Furthermore, the discussion indicates that HIV&AIDS evokes stigmatising responses because students view it as a new disease for which there is no cure. Stigmatising behaviour and attitudes then emerge as means of dealing with the fear of the disease. It is believed that once a cure is found, the fear and stigma of the disease will be minimised.

“Like nowadays if you have got cancer, if you are, if you got cancer nowadays and you go to doctor they will treat you and then you will be fine. And now like, I think it is this thing of a cure because HIV doesn’t have a cure in the meantime. So like, now people think oh this HIV& AIDS is a huge disease and then cancer is just a minor because if I got cancer I can still go to the doctor and maybe the doctor will treat that cancer and then I will probably be fine again.”

(FGD, September 5, 2004)

“Maybe in years to come when the disease is something that we all know about then it will be like you take anti-retrovirals, you do this, and then it is gone. Everybody will get used to it. But up till now it has been only 20 years so it is gonna take a while for everybody to get used to it. People will change with time but now they are reacting that way.”

(FGD, September 4, 2004)

Additionally, this research in many instances also reveals that the notion of HIV&AIDS as a 'killer' disease has been reinforced by representations of the disease from media. As some respondents highlight:

“It is the way that AIDS is presented to us. It is just too scary. They are putting that kind of fear into us that I want nothing to do with it. That is the presentation. I wish that they did present it as other diseases like fever. I don't think many people would be reacting that way. It is the way you get to know about it as a deadly disease from media, community, and friends.” *(FGD, September 5, 2004)*

“To me it's like, it is not only AIDS that is a deadly disease. We have other diseases. But the way they (media) presented it. To scare. It is a dreadful disease. It kills. *(FGD, September 5, 2004)*

### **4.3 Cultural Beliefs of HIV&AIDS**

#### **4.3.1 HIV&AIDS as Witchcraft**

Throughout the course of focus group discussion, students increasingly directed my attention toward the issue of witchcraft. They thought it was important to discuss witchcraft as one of the reasons why people stigmatise those with HIV&AIDS.

“And very often people who have HIV they don't want to talk about it. They go to sangomas and you know ja traditional healers and go like the someone who bewitched the one who has HIV& AIDS you know.”  
*(FGD, September 5, 2004)*

Incomplete knowledge and the fear of the disease are intertwined with cultural perceptions of disease. One of the cultural beliefs includes the explanation of the origins of HIV&AIDS as witchcraft. Witchcraft, within the South African context, means “the manipulation by malicious individuals of powers inherent in persons, spiritual entities, and substances to cause harm to others. The origin of one's misfortune is social” (Ashforth, 2001). If someone becomes infected, somebody else is responsible for it. It is then up to sangoma (a spiritual healer) to solve the “problem”(HIV&AIDS) and ‘send it back’ to a person who used witchcraft.

**Student:** “The sangoma will give maybe like medicine. And then like ok, or even if it is not a medicine sangomas will tell you like I must slaughter a sheep. I must go and find some money, borrow some money so that the person can be sick also. You will believe that, no, it is gonna work out. It is gonna work out. Maybe like maybe say that the person maybe died after what and then you will think oh the sangoma got that person. You see? He really got him.”

**Researcher:** “Which person?”

**Student:** “Like the person that maybe bewitched you. Or maybe if it is not even the person that bewitched you just but because the sangoma will throw the bones and say Unati is bewitching you and you will believe that when you see Unati you will just hate Unati because Unati is bewitching you.” (FGD, September 5, 2004)

Sangomas have traditionally been a very important part of African culture. They are viewed as doctors with natural healing powers. In the case of HIV&AIDS, since there is no cure, it is believed that sangomas will provide a cure for this disease.

**Student 1:** “It is better for an African man like me to go to a sangoma when I am ill to look for cure. By sangoma at least I have an opportunity now to deal with this HIV&AIDS issue.”

**Student 2:** “But there is no cure for AIDS”

**Student 1:** “Yes I know that. There is no cure for AIDS but I am using alternative. Like if I have a headache now you see. I go to the western doctor; he doesn’t know how to cure this headache. If I go to sangoma, he will find a way to cure this headache.” (FGD, September 4, 2004)

Sangomas then, to a certain degree, provide reassurance that any condition, HIV& AIDS included, is curable. Recently, supporters of the Traditional Healers Organisation showed their support for the Health Minister’s suggestions that diet and indigenous cures are the key factors in combating HIV&AIDS (Weekend Argus, 2005: 1).

“You know the thing with sangomas, for instance, is that there is always a medicine that can cure everything. Like this African potato. They always think that African potato is gonna cure everything is gonna cure HIV&AIDS is gonna cure whatever.” (FGD, September 4, 2004)

However, sangomas also reinforce stigmatising attitudes and behaviour because explaining that HIV&AIDS is a form of witchcraft creates additional fears of the

disease. What's more, people don't want to be associated with the so-called 'cursed' people.

**Researcher:** "So are you and people in your community scared of witchcraft?"

**Group:** "Yees. Everybody is scared."

**Student 1:** "Ja, I think also, with that thing of cursing. I think, in the rural areas is where more the belief is very strong into witchcraft. So if a migrant worker maybe comes from an urban area comes to rural community. When he comes there, he comes to die. Around the communities, especially in rural communities like oh, he has been cursed. The ancestors are angry at him for doing this and this. Instead of saying hey how did you get this stuff? He did forget to slaughter the cow at such and such time."

**Student 2:** "In the set-up of rural areas they think maybe, it is like, not associating yourself with so called cursed people. And you are not cursed no no no no no. I think it is like I am not one of them. It is like trying to isolate yourself from what's happening its like oh this family this and that." (FGD, September 4, 2004)

On the other hand, the participants also believe that going to a sangoma is a form of denial of HIV&AIDS and is an interplay of blame and denial. The sangoma concludes that someone has committed witchcraft thus blaming someone else for the individual's 'misfortune'. This is 'psychologically reassuring', and it also serves to avoid one's feelings of shame of the disease. The infected individuals are then 'innocent victims', and the responsibility for one's condition is shifted elsewhere.

"Since they say that there is no solution, there is no cure for HIV&AIDS so that is why everybody is afraid to talk about HIV. The problem with witchcraft is that people just want to run away. They want to run away from what is the truth. Since sangoma will conclude that somebody has bewitched you it is ok, I feel that is the real thing. If you go to the traditional healers you will be fine, there is no such a thing of AIDS."

"It is in a way running from the point running from that thing that I am HIV positive. You are running away from that. (FGD, September 4, 2004)

#### 4.3.2 Purity and Pollution

The research findings show that stigmatisation against people living with HIV&AIDS also arises as a result of not wanting to be associated with the so-called “polluted<sup>27</sup>” people. In this case, HIV&AIDS is understood in terms of ‘purity’ and ‘dirt’. In other words, perceptions of the hygiene and disgust associated with bodily fluids, such as blood or semen play a role in how individuals with HIV&AIDS are viewed in a particular social context. Avoiding infected individuals then means to make a statement that we are ‘pure’ while they (people with HIV&AIDS) are ‘dirty’.

“And in like, how to put it. We cannot compare it to any other disease because it is like the one disease shocked everybody. Nobody could get a cure. That’s why it wasn’t easy. It was more like oh my goodness you get it through having sex, blood, and stuff like that. So, that’s why it made everybody scared.” (FGD, September 5, 2004)

“You are like trying to make a barrier that you are pure. As long as you are not associated with, people not view you also as being one of them. It is like certain focus of being clean, of not having the disease. Maybe like the particular family not being associated with the disease. It is only that particular family. They view it as the family thing or personal thing.” (FGD, September 5, 2004)



#### **4.3.3 The Norms and Taboos about Sex**

The reality that HIV is transmitted through sex contributes to a particularly severe stigmatisation. When I asked why people with HIV&AIDS cannot be accepted and are discriminated against, one student responded, “It is the way HIV is transmitted. Through sex.” The norms about sexual behaviour make it even more difficult. People believe that individuals suffering from HIV&AIDS behaved in a way that caused their illness. Thus HIV&AIDS is viewed as a result of ‘deviant behaviour’ and infected individuals are looked at as being promiscuous.

“People will assume that it is maybe because the individual was promiscuous. Everyone still assumes that the only way you can get HIV is through being promiscuous. People assume that you were promiscuous. That is also part of the stigma because people won’t think about where you got it from. People assume that you were promiscuous.” (FGD, September 4, 2004)

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<sup>27</sup> This concept was used by Mary Douglas.

The discussion also indicates that media may have reinforced the notion of HIV&AIDS as being a promiscuous disease. Although media have played a major role in providing information about HIV&AIDS, the central premise behind educational messages from the media is to have only one partner and to stay faithful in order to stem the spread of HIV. These messages echo in the general public and translate into antagonistic meanings. An infected individual has been either promiscuous or unfaithful. Additionally, students believe that the representation of the disease concentrates only on one aspect; that HIV is transmitted sexually thus neglecting other possible forms of transmission.

“It is being promiscuous. The media warn you about the disease. They tell you not to sleep around. So when they say to be safe, to not to sleep around so then when you get sick people say oh you were sleeping around.” (FGD, September 5, 2004)

“The presentation of HIV&AIDS is always on one side. That it is sexually transmitted. They forget about other means of contracting this disease. You see? You can get it this thing through unsterilised needles, stuff like that. They forget about that aspect totally. The only aspect the media is talking about condom, this that that. You were sleeping around. So the idea of everybody that is HIV positive is that he/she has been sleeping around. So it is how we pass on this message that matters. Not just only our individual assumptions that just HIV is a dreadful disease. Fine it is dreadful disease but what are other ways of contracting it. It shouldn't just be sex sex sex” (FGD, September 5, 2004)

Moreover, people living with HIV&AIDS are held responsible for their behaviour. In other words they 'got' what they 'deserved'. Ultimately, this leads to the feelings of shame among HIV positive people. In response to the events in the film one student highlights, “HIV&AIDS is associated with promiscuity so they probably thought the woman (the girl's mother) was promiscuous, so she deserved to die.” Another student expresses similar view:

“Ja, I also think the same thing. Because with any other disease they don't push you away. We don't know about the mother actually sleeping around for whatever but maybe they thought that she was sleeping around. I don't know about that woman. I don't know how she got AIDS. But maybe they just thought she deserved it. That's what happens in the communities. People see that you get AIDS; they think you deserved it.” (FGD, September 4, 2004)

In relation to the film, “The Sky in Her Eyes”, what impact does this statement have on the intended effect of the film? The filmmakers’ aims to evoke feelings of empathy and sympathy don’t take into account the stereotypical gender context within which stigmatisation occurs. The film portrays the mother in positive terms by using the background song or the time when she is dancing with her daughter. However, the positive portrayal of the mother does not seem to have shifted these stereotypical perceptions.

The research also shows that feelings of shame and self-hatred associated with breaking of sexual norms and the fear of stigmatisation prevent people from HIV testing and disclosing their status. Cameron (2005: 45) states that: “ Perhaps worse than many of its other features, more puzzling, less tractable, and besides everything else, AIDS is also shame. Shame-the humiliation or distress that arises from self-knowledge of dishonour or offence or impropriety or indecency.”

“It is difficult for me. Because if I find out that I am HIV positive, I will feel hate about myself because there is something on me. It is better to know nothing.” (FGD, September 12, 2004)

**Student:** “Even like myself, even if I knew it like today that I slept with someone whom I suspect is HIV positive, I still wouldn’t be encouraged to go to doctor to get tested. Because I wouldn’t want to know if I am HIV positive or not.”

**Researcher:** “Why?”

**Student:** “If I knew I am HIV positive and these are my friends. I won’t tell them. I will just go away from them. Because they will pass judgement on me. They will not treat me the same way as they treated me before.” (FGD, September 12, 2004)

Religion, in many instances, may also reinforce stigmatising attitudes and behaviour towards people living with HIV&AIDS. HIV&AIDS is regarded as a punishment from God.

“Like I think some of the religion they believe that in the bible there is a verse in some chapter that says that there will be diseases that will not be cured. And now like according to God it is that time of resurrection I think. So now like, this is the time because we have got firstly it was cancer and then now like it’s HIV&AIDS and all those TB’s and all the. So now like some of the religions believe that it is that time of God’s resurrection. You know like all the people are gonna die and there is

gonna be another disease coming up and all those things. So they believe now this is the time God is punishing everyone.” (FGD, September 5, 2004)

Furthermore, people who have faith in GOD believe that they are protected from getting infected, and that a cure for HIV&AIDS is in one’s faith. As one student said, “You know like, you know according to religion they believe that like for GOD nothing is impossible. You know. He created everything. And there is a cure. Somebody who got HIV&AIDS he can be helped.” (FGD, September 5, 2004)

**Student 1:** “It is the way they (church) used to talk to people. It is like that those who don’t believe in God they are those people who can be affected by HIV easily. Those people who are at church like they can’t get affected by HIV&AIDS.”

**Student 2:** “How can you say that?”

**Student 1:** “Because I mean people who are really I mean we are talking about really Christian you know they are faithful to their partners you know.”

**Student 2:** “How can you say that?”

**Student 1:** “They are committed. The church will tell you need to be faithful to your husband or wife.” (FGD, September 5, 2004)

On the other hand, it is evident from the student’s responses that religion provides psychological support for infected individuals, and it also encourages non-stigmatising attitudes. In response to why people with HIV&AIDS shouldn’t be stigmatised one student says, “I am a Christian and it is in the Bible that we should love our neighbours like ourselves.” (FGD, September 4, 2004)

“It is like you want to get a support. Some people they like don’t believe in a support groups some other people don’t believe like in God. You know. It is up to them. The church to them is like a support group is something that is strengthening them.” (FGD, September 4, 2004)

#### 4.4 Experiences of Stigma in the Context

The focus group discussions reveal that the individuals’ experiences of stigma depend on a range of factors. Race, class, gender, age or education level, all have an impact on how people experience stigma and how they deal with it. The poor and the rich have different experiences with stigma. HIV&AIDS has been presented as the disease of the poor. This is due to the fact that the rich have more resources to find treatment

and to hide their status. The poor, on the other hand, experience greater stigma because they can't hide their status.

“Poverty plays role. It is easier to detect somebody that he or she is HIV positive when somebody is poor as compared to somebody who is like I would say well off. So if you are poor it is more like to say HIV that you have died of HIV rather than somebody who rich. It is more presented as a disease of the poor rather than the rich. That's how it has been presented. Like the rich person dies of cancer, the poor dies of AIDS.” (FGD, September 12, 2004)

This statement is supported by the findings of the Policy Project that conducted research on “Stigma in Selected South African Media.” The results from the research inform that, in the print media, in the period between January-March 2003, “HIV&AIDS was most often depicted as affecting people who were poor (31%)” (2003:7). Could the film, “The Sky in Her Eyes”, also have reinforced such representations through its rural setting?

Women are at a higher risk of HIV infection because of the gender based power relations. The research shows that women in Africa are 4 to 6 times more at risk for HIV infection than men (O'Sullivan, 2000: 25-31). In many cases, they do not have negotiating power when it comes to safer sexual practises because males refuse to use condoms. At the same time, the female participants feel that if they insist on using the condoms, it will make them less attractive for the males, and they fear that they will lose their partners.

“The girls are more vulnerable to get infected because sometimes the guys don't want to use condoms. They get carried away. That's how you can get infected.”

“I think that guys put so much pressure on girls. And the lady ends up having sex with that guy.”

“If I use condom, I will be less attractive, it will make sexual activities less attractive for guys.”

“The other thing, I think is that men are culturally perceived as having power over girls. It is about power. Men feel they have power over us and it works.” (FGD, September 12, 2004)

These findings support Tallis's view (2000), that “the inequality of power in gender-relations affects health behaviour. Women are often unable to insist on the use of condoms in sexual intercourse or to influence men's sexual behaviour.” Furthermore,

females with HIV&AIDS are subjected to stronger stigmatisation because they are viewed as unfaithful. As one male participant declared, “The problem is that girls are not faithful” (*FGD, September 12*). This belief can have another negative effect on the reading of the film. The filmmakers assume that the emotional bond between mother and child will evoke sympathy. The perception of female promiscuity from male participants in the focus group discussions could become an obstacle to accepting this sentimental trope. Do the filmmakers assume that using the mother and child will automatically enable sympathetic reading? Although this trope, mother and child, has a strong cross-cultural meanings of compassion and care<sup>28</sup>, this research suggests that in fact women, even mothers, are more easily stigmatised, and that the perceptions of children and youth are often discounted. This also raises the issue of ‘transferred stigmatisation’ from mother to child, which affects the reading of a child as a metaphor of innocence.

The youth are particularly severely stigmatised because they are blamed for getting

HIV through ‘promiscuous’ behaviour:

“And to most of our parents it came as a surprise. WOW. There is such a disease. Not in our time there was nothing like that. You guys are behaving very badly. You can’t behave yourself. So the disease is more attached to promiscuity. Behaving like not taking care of yourself.” (*FGD, September 4, 2004*)

Additionally, the youth experience several stigmas. They are treated with less respect because of their perceived inexperience in the world.

“And the other thing about like this issue is that if you are trying to explain something to them if you are trying to convince them they will take you as if you are maybe trying to be better or what, they will watch your steps.” (*FGD, September 4, 2004*)

“And it is like if you are promoting people to have sex. If you are maybe telling them to use condom. They say like if you are a virgin, you are supposed to abstain. No condom. You are not supposed to have sex.” (*FGD, September 4, 2004*)

“Sometimes you mustn’t talk about this issue, because they think that you are gonna affect some other children as well. Like in our cultures.

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<sup>28</sup> The universal trope of mother and child signifying compassion, care, and innocence is also often portrayed in the presentations of the Madonna with baby Jesus in the Christian religion.

You have got different cultures. So like now if I come to my culture people will think oh this one is old she knows a lot more than is her age so like now I am gonna influence the ones that doesn't know anything. I am gonna influence them to know like what boyfriends are and all those stuff. So they think I know a lot and according to my age I am not supposed to know already that knowledge. So in Xhosa culture there is this thing like you stay a teenager they think you are innocent and even like when you are still at university under 21 your parents will treat you as if your are innocent you don't know anything. And like now it makes it difficult to talk about AIDS. Because then like in a way they are gonna ask you how do you know (everybody said yeah) and now like we are not gonna be open to say no the university they teach us these things." (FGD, September 4, 2004)

#### **4.5 Conclusion**

This chapter began by discussing the STEPS initiative and the use of the short film as a tool for re-considering of negative attitudes. It showed that the assumptions and techniques of the filmmakers did not work as simply as they intended. Furthermore, It demonstrated how stigma was 'recognised' and challenged within a participatory group process. The findings also showed that the lack of stigma recognition, the lack of knowledge, and the fears of disease are among the main reasons why stigma persists. Moreover, this research suggests that stigma is maintained by culturally held perceptions of disease. These include the notion of witchcraft, the explanation of HIV&AIDS in terms of "pollution", or punishment from God. Stigma is further maintained by norms and taboos about sex, and the association of HIV with 'deviant' and 'promiscuous' behaviour. Gender, age, one's socio-economic status or educational background influence individual experiences of stigma. Finally, the research also shows that students feel that their own recognitions and transformations would not necessarily lead to a wider cultural transformation. They show anxiety and ambivalence about how they will be received. This also opens up questions about the filmmakers' assumptions about the personal transformation that will take place after the viewing of the film. The students, therefore, may choose silence or conformity. What is the role of silence? Does silence serve as a form of self-protection or safety? The following chapter discusses these findings in dialogue with the existing theoretical concepts on stigma, (see chapter 2), to identify where students' responses confirm or contradict thinking in the field of stigma. In addition, the next part provides conclusions and suggestions for further research.

## **5. Conclusions and Suggestions for Further Research**

### **5.1 Introduction**

I start this chapter by summarising the findings that emerged out of the focus group discussions. First, I show which factors underlie UWC students' stigmatising beliefs, attitudes and behaviours to HIV&AIDS stigma. Second, I frame some of the most important findings in dialogue with existing theoretical concepts in the field of stigma. Furthermore, I proceed by summarising the impact of the film "The Sky in Her Eyes" and discuss the film in relation to the theories of film use. I conclude this chapter by raising questions that emerged out of this investigation and provide suggestions for further research.

### **5.2 Summary of the Findings**

This research shows that stigmatising attitudes, beliefs and behaviour of the students at UWC are influenced by several factors. Lack of stigma recognition or refusal to acknowledge stigma plays a major role in perpetuating stigmatising behaviour among the students. Students frequently reported how important it is not to stigmatise people with HIV&AIDS. They consider stigmatising behaviour to be "wrong". However, the findings reveal that when it comes to their own behaviour, they do not acknowledge it as stigmatising. Although laughter and the use of derogatory words are recognised as stigmatising tools among the students, they are either not aware or refuse to accept that their own behaviour such as laughing or gossiping about people with HIV&AIDS is perpetuating stigmatising behaviour. Furthermore, Lack of correct knowledge about the modes of transmission of the disease was frequently reported as a cause of HIV&AIDS stigma. Most of the respondents know that HIV is transmitted through unprotected sex. However, they lack knowledge about non-sexual modes of transmission and are not sure how the disease progresses and how long a person with HIV or AIDS lives. The students report that acquiring correct knowledge is a key to fighting HIV&AIDS stigma effectively, but also express ambivalence as to whether knowledge will lead to a wider cultural transformation because of the overwhelming influence of cultural perceptions of the disease. Lack of knowledge reinforces fear of the disease. Fear, stigma's affective component, influences how individuals with HIV&AIDS will be viewed during social interactions. Fear of HIV&AIDS was

reinforced by the perceptions that the disease will lead to a “certain” and “painful” death; HIV&AIDS is viewed as a new disease for which there is no cure; the representations of the disease from the media as a “killer” disease and students expressing fears of being stigmatised themselves. Furthermore, cultural perceptions of HIV&AIDS further maintain stigmatising attitudes and behaviour. Cultural perceptions include the explanations of the origins of the disease as witchcraft or a punishment from God. Additionally, the norms and taboos about sex and association of HIV&AIDS with “deviant” behaviour reinforce stigma and make it difficult to discuss issues around HIV&AIDS. This research also reveals that HIV&AIDS stigma is intertwined with other contexts within which people are defined and live which themselves are often labelled and stigmatized. The poor, the rich, women, males or the young all experience stigma differently. Some students might experience multiple stigmas because they are young, females, and poor. Thus HIV&AIDS is layered upon pre-existing stigmas of class, gender, age, race, colour, education level and more.

### **5.3 Theoretical Considerations**



#### **5.3.1 Knowledge**

As I mentioned earlier, lack of knowledge about how HIV is transmitted combined with incorrect knowledge about non-sexual modes of transmission are among the main reasons behind stigmatising attitudes among the students. Participants repeatedly expressed the view that lack of knowledge is a cause of stigmatisation and that acquiring knowledge about the disease is necessary to change stigmatising attitudes and behaviour: “It shows like that they (people who stigmatise) don’t have knowledge of HIV&AIDS”; “If there can be like more education or information to people. People will at least understand”; “I strongly believe that you know, attitude will change when, you know, when you understand” (Focus group discussions). Empirical research strongly supports that people with better knowledge about HIV&AIDS exhibit less discriminatory attitudes towards people living with HIV&AIDS (Lau&Tsui, 2003; Chliaoutakis&Trakas, 1996).

However, it is also generally perceived among the students that there is more than enough information on HIV&AIDS. They often express their “boredom” with “too

much information”. One student pointed out, “I think like, most of them, they are sick and tired of AIDS. They are sick and tired of hearing a thing of AIDS. I think they don’t want anything to do with AIDS. Like they take it for granted that they know but they don’t” (Focus group discussion). Another student replied, “I don’t think it is because of a lack of knowledge. Because if you go everywhere people are talking about AIDS. You are reading it on all the billboards. You know, about these signs of AIDS. It is all about ignorance. People, they don’t want to respond.” Another student confirmed that, “The community do know about these things even if they don’t want to talk about it. Because every issue is about AIDS. To them it is boring. So what about other things? Because it is all about AIDS&HIV” (Focus group discussions). These findings correspond with the results of a study conducted by Levine & Ross on the attitudes to HIV&AIDS among young adults in Cape Town. Respondents reported that they are “bored with AIDS education”; and “sick and tired” of hearing about AIDS (2002: 89). Moreover, the students pointed out that they “wouldn’t even come to the venue if the announced topic for discussion was HIV&AIDS” (Ibid).



The students who highlight that there is enough information on HIV&AIDS thus provide explanations of stigmatising behaviour as a form of “willed ignorance” that is caused by the fear of HIV&AIDS. “Willed ignorance” towards HIV&AIDS could be described as a conscious effort of not wanting to know more or ignoring what one has learned about the disease. This research shows that resistance to knowledge can serve as a preference for the comfort of blame. “Ja ok, to me, the movie depicted the ignorance among us in the community and the fear that prevent us from knowing more about the disease. Instead of knowing more, you just like ignore”; “It is just heading to one sort of thing. They don’t know like they don’t have interest in knowing or what killed them or how do you get affected by AIDS. It is like they are just ignorant” (Focus group discussions). In relation to the intervention programs that focus on educating people about HIV&AIDS and safer sex practices, the findings that emerged in connection with knowledge pose a challenge. It seems that educational efforts could be seriously hampered through what Goffman (1963: 29) described as a ‘courtesy’ stigma. In relation to the family members or friends of the stigmatised, Goffman applied this concept to emphasize that “the individual who is related through the social structure to a stigmatised individual - a relationship that leads the wider society to treat both individuals in some respect as one. Thus, the loyal spouse of the

mental patient, the daughter of the ex-con, the parent of the cripple, friend of the blind, the family of the hangman are all obliged to share some of the discredit of the stigmatised person to whom they are related” (Ibid: 30). From this definition it becomes evident that individuals who are associated with the stigmatised might experience similar stigmatising behaviour as the stigmatised themselves (Castro et al., 1998; ICRW, 2003). The findings from the focus group discussions indicate that incorrect knowledge about modes of transmission combined with the fear of being discriminated against cause that some students do not want to know more about the disease. They either fear that by knowing more they will be “closer to infection”, or that they will be associated with HIV&AIDS just by “virtue of being involved in HIV&AIDS discussions.” Some students pointed out: “It is only human to even have that whole ignorance thing in not wanting to know more because you are thinking that the more I get involved the closer I am to infection”; “When you involve yourself in the AIDS, HIV and AIDS activity. You are seen as being infected. They will whisper: That One!” (Focus group discussions). Since the students are aware how people with HIV&AIDS are treated in a society, some of them want to avoid the possible consequences of the “courtesy” stigma by ignoring information about HIV&AIDS or activities around HIV&AIDS in general. Theoretical support for this argument is offered from Coleman (1986: 228) who, referring to Barbarin (1986), emphasises that “people irrationally feel that, by separating themselves from the stigmatised individuals, they may reduce their own risk of acquiring the stigma. By isolating individuals, people feel they can isolate the problem.” The conclusion that can be made from the students’ responses is that by distancing themselves from information about HIV&AIDS, they feel that they can also ignore the existence of the problem and thus construct an ‘illusional’ space of safety for themselves. Knowledge itself begins to be seen as a carrier of stigma.

The lack of correct knowledge about HIV transmission raises another important point. Many students believe that HIV is a ‘transferable’ disease that can be ‘caught’ by casual contact. This belief supports Sontag’s (1978:10) argument that diseases will be felt “morally, if not literally” contagious, if they are treated as a “mystery”. Beliefs that HIV&AIDS could be transmitted through social interactions result in an immediate avoidance of people living with HIV&AIDS. Considerable empirical support exists for this theory (Connors & Heaven, 1995) as well as for misconceptions

about HIV&AIDS transmission among the youth and the university students (Dias, 2005; Bhattacharya et al., 2000; Davis et al., 1998, Barnes, 2000).

### **5.3.2 Fear**

Coleman (1986: 225) argues that “what gives stigma its intensity and reality is fear.” So far, the consequences of the students’ fears have been discussed through fear of death, fear of infection and fear of being discriminated against through “courtesy” stigma. The findings suggest that HIV&AIDS is also highly feared because it is considered a new disease for which there is no cure. Empirical research and various theorists support this argument. Certain diseases elicit fear because the aetiology of the disease is unclear, unpredictable or unexpected (Sontag, 1978; Doka, 1997; Coleman, 1986). Additionally, the findings are also consistent with Doka’s view that, in relation to various diseases, “rather than death, it was the quality of life that provoked fear” (1997: 25). One student said, “I mean sometimes you can think what if I can be HIV positive how am I going to live? I mean I am not going to live a life like the way I am living now.” Another student replied, “I think, if you discover that you have got AIDS you are like I am going to die. And if you studying or doing something it is a waste of time” (Focus group responses). Furthermore, it is generally perceived among the students that once a cure is found, HIV&AIDS will be considered a “normal’ disease for which there is a treatment, and the level of stigmatisation will decrease or disappear. The literature on various diseases informs us that the level of metaphoric thinking and stigmatising attitudes towards certain diseases changed or decreased because the aetiology of the disease became known or the treatment was developed thus the diseases lost their meaning as “dreadful” (Sontag, 1978; Doka; 1997). Becker and Arnold (1986: 43) highlight that in relation to various diseases, “cultural perceptions shift over time, fed by social and historical changes. They determine how we organise and categorise experience.”

### **5.3.3 Cultural Perceptions**

Perhaps the most important aspect that emerged out of the group discussions in relation to cultural perceptions of HIV&AIDS is the creation of “Other” that becomes a projection of fears. The findings indicate that although students’ perceptions of

HIV&AIDS reflect larger cultural context, stigmatising reactions from each individual towards people with HIV or AIDS are ultimately underlined by many complex factors. For the purpose of my research I will discuss the self/other binary opposition and the purpose of such a construction. In the social science discourse, this aspect reflects the discussion between pro-attitudinal and pro-socio-cultural theorists that explore the causes behind holding stigmatising attitudes. At the beginning of this enquiry into HIV&AIDS stigma I aimed to explore to what extent stigma is a reflection of cultural norms and perceptions, and to what degree it is a manifestation of individually held attitudes. This research strongly suggests that it is a combination of both. Becker and Arnold (1986: 40) emphasize that “broad views about what constitutes stigma are generally shared by members of a society. They will hold common beliefs about both the cultural meaning of an attribute and the stigma attached to it.” Students’ responses suggest that viewing HIV&AIDS in terms of “witchcraft” or “purity” and “pollution” are shared beliefs in their communities. They are equally aware of the negative consequences of these attributes. If I examine students’ responses within the socio-cultural perspective, then the notions of witchcraft and “purity” and “pollution” are established stereotypical and labelling categories to classify people with HIV&AIDS. Avoidance emerges as a typical behavioural consequence of viewing HIV&AIDS as witchcraft or pollution. In this respect one has to ask what is the meaning of avoidance. Here, the attitudinal theories to the studies of stigma offer some insights. This research shows that the aim of avoiding people with HIV&AIDS, if viewed in the context of witchcraft or purity and pollution, is to make a certain statement on the part of those who stigmatise. In relation to witchcraft it is to state that: “They (people with HIV or AIDS) are “cursed” *and* “I am not and, therefore, I am not one of them.” The findings reveal this quite clearly. As one student points out, “It is like, not associating yourself with so called cursed people. And you are not cursed no no no...It is like, I am not one of them” (Focus group discussions). Similarly, avoiding people, if examined within the context of “purity” and “pollution”, is to state that: “I am pure and clean, while a person with HIV or AIDS is dirty.” This aspect was also depicted in the students’ responses: “...As long as you are not associated with (people with HIV or AIDS), people not view you as being one of them. It is like certain focus of being clean, of not having the disease” (Focus group discussions). These findings support the attitudinal “self enhancement theory” where the self is evaluated by comparing the self to other

people. Within this framework, it is therefore necessary to identify those who can be regarded unfavourably to ensure positive evaluation of the self (Festinger, 1954; Taylor, 1983). At the same time, these findings reflect larger socio-cultural aspects of witchcraft as an act of malevolency by malicious individuals (Ashorth, 2001), disgust with bodily fluids through how HIV is transmitted and preoccupation with “dirt” that is associated with the parts of the body where the virus enters (Douglas, 1966; Quam, 1990).

### **5.3.4 HIV& AIDS and Deviance**

Before I begin to discuss HIV&AIDS from the position of deviance, one important question needs to be addressed. How did HIV&AIDS become associated with the concept of deviance? According to the classical sociological classifications, deviance occurs when the individual’s behaviour violates established norms of how an individual should behave (Stafford and Scott, 1986). Students’ responses indicate that HIV is associated with deviant behaviour because when someone is HIV positive, he/she is considered promiscuous. Promiscuity could be, therefore, defined as a deviation from a norm of being faithful to one partner. This raises another important question. How was ‘being faithful to one partner’ established as a “norm”? The answer seems to be behind governmental media advocacy campaigns and various intervention programs aiming to reduce the spread of HIV by educating people about HIV&AIDS or safer sex practices. One of the main messages from the governmental ABC campaigns is to encourage people to stay faithful to one partner. However, the respondents frequently complained that messages from the media ‘concentrate only on one aspect of HIV transmission, through sex.’ Paradoxically, although these campaigns aim to help they could be responsible for reinforcing stigmatising attitudes and behaviour towards people living with HIV or AIDS. With the notion of deviance also comes the issue of one’s responsibility for one’s behaviour. Cohen (1966: 36) indicates that: “whereas deviant roles are socially disvalued roles..., not all disvalued roles are deviant....What [deviant roles] have in common is the notion of a person who knows what he is doing...and chooses to violate some normative rule.” Feidson (1965: 76), supports Cohen’s argument and states that: “When the individual is believed to be responsible..., some form of punishment is likely to be involved....When he is believed not to be responsible..., permissive treatment...is

used.” In relation to HIV&AIDS, Cohen’s definition suggests that stigmatising attitudes towards infected individuals will vary based on their perceived responsibility for their ‘misfortune’. There is a strong empirical evidence to support this argument (Alonzo and Reynolds, 1995; Nzokia, 2000). It has also been found that people living with HIV or AIDS who contract HIV through means that are beyond their control (for instance, blood transfusion) are treated more favourably by the public, as compared to those contracting the virus through needle sharing (Leone & Wingate, 1991). However, students’ responses in this research suggests that HIV&AIDS evokes equal stigmatising responses towards all the HIV infected individuals regardless of the way of contracting the disease. These findings confirm links to cognitive theories of stigma. “Perceiver’s goals in a particular situation and the kinds of information available to the perceiver have been shown to influence the effects of stereotypes on judgments about the individuals” (Crocker and Lutsky, 1986: 118-119). The absence of any information on how a particular individual contracted the HIV virus, within the context of fear of the disease, can thus lead to immediate stigmatisation from the perceiver. This is partly explained by our need to “immediately organise information in the social world” (Crocker and Lutsky, 1986; Hudak, 2001). This research shows that during social interactions between the stigmatised and those who stigmatise, information on how an individual contracted the disease is not always available. In the absence of this information, how do people decide which stereotypical category to apply as well as the behavioural intensity of such as a decision? In other words, when someone has HIV, how do people decide whether it is the result of witchcraft, promiscuity or other cognitive categories?

#### **5.4 Summarising the Impact of “The Sky in Her Eyes”**

Although it is difficult to identify the strengths and weaknesses of “The Sky in Her Eyes”, the following points can be raised from the discussions with students. If the film is to achieve its intended effects of sympathy and empathy, and trigger a change in stigmatising attitudes, there needs to be a process of discussion and negotiation of meaning. In the context where discussion does not follow the screenings, such as home viewing of this film (Stadler, 2003: 1-2), there is a possibility that this film might not necessarily achieve its intended effects because it allows for a variety of interpretations of the portrayed events. Levine and Eglehart (2003:8) point out that the

films (in the STEPS collection) are “intentionally designed to be non-didactic in order that they may transport people beyond the unimaginative spectacle of condom demonstrations and other HIV&AIDS material that respondents say “bore” them”. However, Stadler (2003: 15) argues against the non-didactic nature of these films, “Lack of an explicit narrator directing our attention and shaping our response to and interpretations of the stories leads us to rely more heavily on positioning devices embedded in the texts themselves. These include point of view shots, framing camera people, camera angle and proximity, the use of hand-held footage, music, sound effects, editing, and the quality of performances.” In relation to this argument as demonstrated in the Results chapter, the filmmakers of “The Sky in Her Eyes” applied various techniques to achieve their intended effects of sympathy and empathy on the viewers, but, in the absence of a “narrator”, the research shows that particular scenes evoke a variety of interpretations from the viewers.

Despite the raised concerns about the effects of this film on the viewers, the research does reveal that “The Sky in Her Eyes” triggers discussion. Many respondents expressed the view of liking the film because it “showed how other people are treating people with HIV like around South Africa or over the world”, or because it illustrated that “we mustn’t isolate people that are HIV&AIDS and like we must still take care of people that are HIV positive because they are still people they still exist” (Responses to the film). However, the students accept the stigmatising behaviour towards the little girl even though they feel it is wrong. Their language around ideal behaviour is prescriptive, “we must not discriminate”, “we should not”, but it also reveals a sense that stigmatising behaviour will continue.

There need to be trained facilitators who work with the film in a group environment in order to clarify certain misinterpretations arising from individual scenes. Stadler (2003:2) points out that: “Films that are perceived as being highly credible and relevant by the communities they represent and address, and that lack the anchorage of post-screening facilitated discussions, are particularly open to multiple interpretations.” Although most respondents disagreed with the way the community reacted to the child, they accepted that this was the case and even provided explanations and justifications. One student said, “That’s how it happens in the world. Kids in the communities without any parents and people start looking at you funny.

They don't know how to react to you once they know you have AIDS or anybody in your family have it." However another student says that: "It is only human to be scared, it is only human to wonder a lot. To even have that whole ignorance thing in not wanting to know more" (Responses from focus group discussion). These responses reveal the students' ambivalence and, therefore, a need for a careful mediation of the discussions. In a group discussion meaning can be negotiated through sharing of opinion.

### **5.5 Suggestions for Further Research**

At the beginning of this enquiry into the complexities of stigma and stigmatisation process, I asked several questions. What is stigma, how is it reinforced and maintained? What is the socio-cultural context within which stigmatisation occurs? How can stigmatisation be challenged? With regard to the last question, I also asked whether visual arts, like the film "The Sky in Her Eyes", provide more successful means of challenging stigma than various educational interventions or whether such works reinforce the notion of HIV&AIDS as a stigmatising disease. Furthermore, I questioned whether more information on the disease leads to reformulating of negative attitudes. In the concluding part of this analysis, based on the findings, I ask more questions. Is stigmatisation a 'complex web' of human emotions reflecting the fear of disease? What is the connection between "willed ignorance", "resistance" and stigmatisation? How do we work with these concepts? How do these aspects affect the notion that more information on the disease leads to change in stigmatising attitudes and behaviour? If it is not "willed resistance" and "ignorance", does it mean that we are unaware of our own stigmatising behaviour? How can we then create awareness on this aspect of stigmatisation?

The findings revealed several important questions about how stigma is revealed and recognised or resisted. Although the students recognize the use of derogatory words as stigmatising, they are not 'aware' that their own actions perpetuate stigmatising behaviour. The language thus can be used to limit or block understanding. Is this perhaps resistance to acknowledging stigma that is "unconsciously" achieved through ignorance? Although laughter is recognised as a form of discrimination among the students, only through the process of mediated discussion was it possible to create

awareness on this aspect, which then allowed the participants to reflect critically on their own behaviour. Additionally, the notion of “willed ignorance”, resulting from fear of the disease, needs to be adequately researched because it does not affect only the stigmatisation process but also the reception of educational materials that aim to stem the spread of HIV.

There is a need for empirical research, combining a range of qualitative and quantitative methods that will explore how people’s stigmatising attitudes change over a period of time after participating in educational interventions. The challenge with studies measuring the change in stigmatising attitudes on scales after the interventions are that the results reflect the changes in respondents’ attitudes only on a piece of paper. How do these individual changes actually translate into a wider social transformation? What are the experiences of individuals returning to their communities after they participate in educational workshops? Do they affect change in their communities, or do they choose silence or ignorance against the enduring cultural perceptions of the disease and through fear of being stigmatised themselves? This also raises a question of trauma for people who choose silence after they acquire knowledge about the disease and stigma because they are then aware that they are engaging in discriminatory behaviour.

Furthermore, there is an urgency of further research to indicate what the correlation is between statements of “boredom” with “too much information” and actual HIV&AIDS knowledge levels. This will serve to either confirm or disprove whether there, in fact, is too much information which should also reflect in high scores on knowledge based questionnaires, or whether the information levels are low which would indicate that ‘ignorance’ and ‘resistance’ serve as ‘protective’ mechanisms because of the fear of disease. If the later is true, how is awareness created?

Moreover, the aspects of silence and empathy need to be urgently addressed. What is the purpose of silence? Does it serve as a protection from stigmatisation or for the purposes of safety? How does silence affect the reception of educational materials? Additionally, the issue of empathy emerged very strongly in this research. Empathy is required to spark behavioural change. The filmmakers of the “Sky in Her Eyes” work with the assumption that empathetic responses from the viewers will evoke changes in

stigmatising attitudes and behaviour. In that sense, they assume that the notion of empathy is straightforward. However, this research shows that empathy does not work as straightforwardly as they assume it will. I utilised the notion of empathy during the focus group discussions as well when I asked the participants to imagine how people with HIV&AIDS, who are stigmatised through laughter or the use of derogatory words, feel. Working with the notion of empathy in this case proved to be a highly effective methodological practise to create awareness and to provoke self-reflection among the students about the consequences of their own behaviour. The questions that emerge in relation to these findings encompass a dilemma as to what is the goal of facilitators during the group discussions? Do they aim to spark behavioural change through empathy? This also highlights a difference between participatory discussion, where participants are encouraged to critically engage with knowledge, and ‘taught’ workshops that aim to educate but not necessarily to critically engage. This research also suggests that challenging stigmatising attitudes does not only depend on knowledge levels but also on the forms in which knowledge is distributed and the kinds of language in which it is discussed.



Recent areas of focus in the field of HIV&AIDS stigma, that I observed while participating at the AIDS IMPACT conference in April 2005, encompass the research on people’s knowledge levels and how these reinforce stigmatising attitudes and behaviour<sup>29</sup>; the impact of highly effective antiretroviral therapy (HAART) on people’s stigmatising attitudes<sup>30</sup>; the development of AIDS related stigma scales to measure people’s stigmatising attitudes and behaviour<sup>31</sup>; or the gendered stigmatisation of HIV&AIDS<sup>32</sup>. Furthermore, a recent attempt to engage questions of stigma comes from Edwin Cameron. In his book Witness to AIDS Cameron (2005), who is a judge at the Supreme Court of Appeal Justice, offers a powerful personal story about his experiences with HIV&AIDS and stigma. In connection with HIV&AIDS and access to treatment, Cameron highlights differences between those who have and those who have not. He speaks from his position as being white, privileged, having access to good AIDS care and treatment, but he also addresses

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<sup>29</sup> AIDS Related Stigma and Attitudes Toward Infected People Among Adolescents: Dias, S.

<sup>30</sup> Management of HIV Related Stigma and Adherence to HAART: Mutombo, T. B.

<sup>31</sup> Reliability and Validity of the AIDS Related Stigma Scale for Use in Southern Africa: Kalichman, S.

<sup>32</sup> The Gendered Stigmatisation of HIV/AIDS: Shefer, T.

More information on the above-mentioned research projects can be obtained through the conference’s official website: [www.aidsimpact.net](http://www.aidsimpact.net)

those who do not have any access to medical treatment. In relation to HIV&AIDS stigma Cameron links together different forms of stigma such as race, class, gender or sexual orientation. For example, if poverty has now been reconsidered or is largely seen as problematic, and if poverty now usually generates sympathy, then by linking AIDS stigma to this kind of stigma, Cameron is hoping that this kind of reconsideration or move towards sympathy will also follow for AIDS.

Reducing the destructive stigma that surrounds HIV & AIDS calls for interdisciplinary research and for a better understanding of how the very existence of stigmatizing behaviour affects us all. We need to better understand when and how we stigmatize and when we choose to suspend stigma and for whom. As one student said, “What I wanted to say...when AIDS like really hit(s) at you at your home...you will not use these words, never. You will say my brother has AIDS. They are not nice words to use.” My brother has AIDS. These are not simply words nor are they simple words. They carry with them the weight of history and all that keeps all human beings from being who and what we can be. HIV&AIDS labelling and stigmatisation affects us all. It “dehumanises” those towards whom the labels and stigmas are applied as well as those who engage in stigmatising behaviour because “it interferes with the individual’s ontological and historical vocation to be more fully human” (Freire, 1970: 37). Stigmas and labelling affect individuals, communities and societies at large and are the source of great suffering on the part of ‘the recipients’ stigmatising behaviour and those who produce it. I hope this research will in some way, no matter how small, be calling for all of us to step out of our comfort zones and to address, discuss, and critically reflect on the issues around HIV&AIDS and stigmatisation. HIV&AIDS and the stigma that surrounds it has “hit” our home, our home as human beings joined together in cultures and society. As human beings, we can no longer afford to allow either to continue.

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8. How would you describe the reactions towards the girl from the community and from the children after her mother's death? Think of the scene when the girl went to fetch water from the river.

Please, describe:

9. Why do you think the community and the children reacted that way?

10. Do you agree with the way the community and the children reacted towards the girl?

Yes

No

Please, explain:



11. At the end of the film, the girl brings the picture of her mother to the boy who attaches the picture inside the kite. She smiles as she watches the kite flying in the air. What do you think is the meaning of the picture and the kite?

Please, explain:

12. Do you personally know anyone with HIV/ AIDS?

Yes

No

## **Appendix II**

### **Student Information And Consent Letter**

Dear Student

#### **About The Study**

This project is conducted in connection with completion of M. A. degree in Development Studies. The project aims to gain a deeper insight into the issues surrounding HIV and AIDS.

#### **What Will Happen?**

I am asking you to complete a simple questionnaire after you watch a short film. The film and the questionnaires will take approximately an hour of your time. The film will also form the base for our focus groups discussions, which will take approximately hour and a half. I will be conducting the questionnaire and the focus group, and I will be available to answer any questions you may have.

#### **Will Anyone Know That I Participated In The Study?**

NO. Your name will not appear anywhere on the questionnaire. Your participation and answers on the questionnaire are strictly confidential. No one other than the researcher will see the answers that you give on the questionnaire. The findings of the research will be compiled into a report with all the student's data combined; therefore your information will not be identifiable. The audiotapes from focus group discussions will be kept in a locked cupboard in the researcher's office. They will be destroyed at the end of the project.

#### **Are There Any Risks?**

NO. There are no risks to you for taking part in the study.

#### **Do I Have To Participate In The Study?**

NO. Taking part in this study is completely voluntary. You may stop participating in the questionnaire or the interviews, or choose not to answer some questions on the questionnaire at any time.

#### **What About The Results Of The Study?**

No information will be given to anyone about any individual student's involvement. The results of the study will form a part of M.A. mini-thesis. The mini-thesis along with the research findings will be submitted for examination.

### **Who Can I Ask If I Have Questions About The Study?**

If you have any questions at a later time you can call:

Igor Lesko  
Researcher  
University of the Western Cape  
Private Bag X 17  
Bellville, 7535  
Tel. 959-3859

Should you have any complaints or worries about this research, please contact:

James Lees  
Supervisor  
University of the Western Cape  
Private Bag X 17  
Bellville, 7535  
Tel. 959-2858

By signing this document, you agree to participate in this study. Your participation is highly appreciated.



-----  
Student's signature

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Date