

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

**'Let me be quiet':
HIV Disclosure, Stigma and Denial in Imizamo Yethu,
Cape Town**

Hanne Jensen Haricharan JNSHAN002

A minor dissertation submitted in partial fulfillment of the requirements for the award
of the degree of Master of Arts in Social Anthropology

Faculty of the Humanities
University of Cape Town
2008

This work has not been previously submitted in whole, or in part for the award of any
degree. It is my own work. Each significant contribution to, and quotation in, this
dissertation from the work, or works, of other people has been attributed, and has
been cited and referenced. Referencing is done according to Harvard.

Signature: _____

Signed by candidate

Date: _____

15.02.08

ACKNOWLEDGEMENTS

This thesis could not have been written without the people of Imizamo Yethu who allowed me into their lives transiently and had the courage to share difficult aspects of their life with me. They made me feel not only accepted, but welcomed. My heartfelt gratitude goes to them.

I am most grateful to my supervisor Dr Susan Levine for her valuable insight, suggestions, encouragement and unwavering support.

Thanks to all the staff at the Department for Social Anthropology for making anthropology such an interesting and challenging study.

Thanks also to friends and family for support, valuable discussions and welcome distractions.

A special thank you to Shanil, my spouse, for his unwavering support and love; and to my children, Milan and Anna-Malika, for constantly reminding me of what is important in life.

ABSTRACT

This thesis argues that disclosure of HIV status has the potential of playing an important role in promoting health and wellbeing of people living with HIV/AIDS and in prevention. However, this potential is limited by low disclosure levels. It identifies HIV stigma as a key factor in low disclosure levels in a disadvantaged South African township. When it does happen disclosure is delayed, mostly partial and carefully managed. Analysing how HIV/AIDS is conceptualised, it suggests that HIV stigma in a community with high HIV-prevalence, and amongst people that are marginalized, should primarily be understood as a defence against a threat viewed in apocalyptic terms, rendering both individuals and the body politic defenceless. It furthermore argues that social marginalisation and the lack of 'liberation' in post-apartheid South Africa have contributed to this sense of vulnerability. This contributes to creating conditions under which stigmatisation becomes a defensive denial of risk. It posits that an ambivalent political response, characterised by 'silence', denial and questioning of illness causation and treatment, has exacerbated the tendency to stigmatise as a way of denying risk. In addition, it suggests that high levels of HIV stigma go unchallenged partly because of a lack of HIV-activism. It suggests that HIV stigma should be addressed through addressing symbolic and instrumental HIV stigma and in particular through replacing the association between HIV/AIDS and death with a discourse of hope.

TABLE OF CONTENTS

1	INTRODUCTION	6
1.1	TO DISCLOSE OR NOT TO DISCLOSE	6
1.2	THE IMPORTANCE OF STUDYING DISCLOSURE	7
1.3	IMIZAMO YETHU	9
1.4	METHODOLOGY	10
1.5	LIMITATIONS	11
1.6	ETHICAL CONSIDERATIONS	12
1.7	THEORETICAL FRAMEWORK FOR UNDERSTANDING HIV STIGMA	13
1.7.1	<i>Stigma as a discrediting attribute, leading to a spoiled identity</i>	13
1.7.2	<i>Instrumental and symbolic stigma</i>	14
1.7.3	<i>Stigma models</i>	14
1.7.4	<i>Stigma as a changing social process</i>	17
1.8	OUTLINE	18
2	DISCLOSURE AS DILEMMA	20
2.1	GLADYS' STORY: 'PEOPLE WILL LOOK AT YOU AS IF YOU ARE A BAD PERSON'	20
2.2	ANDILE'S STORY: 'IT IS LIKE YOU ARE NOT A PERSON.'	23
2.3	RELUCTANCE TO DISCLOSE	26
2.4	DELAYED AND PARTIAL DISCLOSURE	26
2.5	REASONS FOR DISCLOSURE: 'COUGHING IT UP', BEING FREE, STAYING HEALTHY	27
2.6	REASONS FOR NOT DISCLOSING: FEAR OF STIGMA, REJECTION, AND EXCLUSION	29
2.7	RESPONDING TO STIGMA: INSISTENCE ON INNOCENCE	31
2.8	DISCLOSURE AS A CAREFULLY MANAGED PROCESS	35
3	DEATH, DEVIANCE AND DESPAIR: AIDS AS AN EXTRAORDINARY DISEASE FOR STIGMA	38
3.1	INTRODUCTION	38
3.2	AIDS AS AN 'IMMORAL' DISEASE	39
3.3	INDIVIDUALISATION OF BLAME	40
3.4	AIDS AS A 'KILLER DISEASE'	40
3.5	A DISEASE WITH NO CURE	42
3.6	AIDS AS A POORLY UNDERSTOOD DISEASE: CONFUSION AND CONFLICTING CAUSATION	43
3.7	WITCHCRAFT – A SUPPRESSED DISCOURSE	44
3.8	'COMING AS A POWDER AT NIGHT': AIDS AS A HIGHLY CONTAGIOUS DISEASE	46
3.9	APOCALYPTIC BELIEFS – A DISCOURSE OF DESPAIR	47
3.10	SOCIO-ECONOMIC POSITION AND LIMITED POSSIBILITY	49
3.11	UNDERSTANDING HIV STIGMA IN A MARGINALISED COMMUNITY AS DEFENCE	51
3.12	DISCLOSURE, STIGMA AND DEFENSIVE DENIAL	54
4	POLITICAL AMBIVALENCE AND LIMITED ACTIVISM	57
4.1	AMBIVALENT POLITICAL RESPONSE	57
4.2	SILENCE AS A DOMINANT DISCOURSE	60
4.3	SILENCE AS POWERLESS RESISTANCE	63
4.4	POLITICAL AMBIVALENCE, POPULAR UNCERTAINTY AND STIGMA	64
4.5	LATE AND RELUCTANT ROLL OUT OF ARVs	65
4.6	RATH, RESISTANCE AND A DISCOURSE OF FREEDOM	67
4.7	LIMITED ACTIVISM AND COLLECTIVE CHALLENGE TO STIGMA	68
4.8	CLANDESTINE SUPPORT GROUPS	70
4.9	CHALLENGING STIGMA THROUGH CREATING A DISCOURSE OF HOPE	71
5	CONCLUSION	75
	BIBLIOGRAPHY	81

ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANC	African National Congress
ARVs	Antiretrovirals
ASA	Anthropologists Southern Africa
DAG	Development Action Group
HAART	Highly active antiretroviral therapy
HIV	Human Immunodeficiency Virus
IFP	Inkatha Freedom Party
MSF	Medicine Sans Frontiers (Doctors Without Borders)
NGOs	Non-governmental organisations
PLHA	People living with HIV/AIDS
SANCO	South African National Civic Organisation
STD	Sexually transmitted disease
TAC	Treatment Action Campaign
TB	Tuberculosis
VCT	Voluntary Counselling and Testing

University of Cape Town

1 INTRODUCTION

1.1 To disclose or not to disclose

It is a cloudy afternoon in Imizamo Yethu, a black township in Hout Bay near Cape Town. Sitting on the steps leading to the community centre, Iziko Lobomi, I spot Gladys crossing the busy main street. Gladys is on her way to Uncedo Lolunto, a support group for people with HIV. No one is aware of Gladys' destination on Wednesday afternoons, though today is different - Gladys is wearing the group's T-shirt. On the front, the white T-shirt has a big red AIDS ribbon around a cross, and on the back it says, '*Uncedo Lolunto. People's Help, Hout Bay, Support Group for HIV positive.*' While many activists, such as those belonging to the Treatment Action Campaign (TAC), use T-shirts as part of their activism without indicating status, Uncedo Lolunto's T-shirt is only for members of the support group. In this particular context, therefore, wearing the T-shirt is an indication that the user is HIV-positive.

The T-shirt is not the only item that makes Gladys appear different today. Despite it being a cloudy day, Gladys has hidden her eyes behind a pair of big sunglasses and covered her hair with a scarf. Yet it seems as if she is protecting herself, not so much from the sun's glare, but rather from glaring eyes. When I later enquire, she states that she did not want people to recognise her.

Her decision to wear the T-shirt, despite her fear of being recognized, follows an intense discussion at the previous support group meeting at which the group's leader Phelo argued that all the group members should wear the T-shirt for meetings. Phelo is one of the few people living with HIV/AIDS (PLHAs) in Imizamo Yethu who has fully disclosed his status, symbolically showing this by wearing T-shirts that clearly identify him as HIV-positive. Except for Gladys, only a few heeded his call; at subsequent meetings, only Phelo continued to display his HIV-positive identity.

Whether to wear an HIV T-shirt or not, or to disclose ones HIV status or not - that is the vexing question for many PLHAs, including members of this support group.

1.2 The importance of studying disclosure

For few illnesses is disclosure as relevant, yet as problematic, as it is for HIV. Disclosure has become a requirement for accessing treatment in public health care facilities in South Africa (Deacon 2005:77). Clinics, including the one servicing Imizamo Yethu, require that people who start on antiretroviral (ARV) treatment disclose their status to at least one person and solicit the support of a 'treatment buddy' - a person who assists the patient in adhering to the ARV treatment. Disclosure may also enable access to other forms of support – material, social and emotional – which can be crucial in maintaining good health.

Non-disclosure, on the other hand, poses challenges to ARV-adherence. According to Norman, Chopra and Kadiyala (2007), PLHAs have reportedly skipped ARV dosages because they could not take their medication without being observed. Susan Levine (personal communication) notes that many men who have not disclosed their status, and therefore cannot seek ARV treatment, often take their partners' ARVs when sick, thus jeopardizing their own and their partner's health.

Research by Paxton (2002) suggests that disclosure has a positive impact on the health and well-being of PLHAs. Paxton notes that by 'speaking out' and facing HIV stigma, PLHAs experience a sense of psychological release or 'liberation' from the burden of secrecy and shame, leading to alleviation of stress and improved health. It is, however, important to note that her study involved activists from a number of countries who had disclosed publicly. It may not necessarily reflect experiences of those who have only disclosed partially and who have not found support in an activist setting and an activist identity.

Furthermore, Comer et al. (2000) conclude that disclosure does not necessarily lead to better mental health, because of stigma. Comer et al. (2000) and Simoni et al. (1995) also suggest that benefits of disclosure vary amongst different (social) groups. These studies point to the importance of contextualising disclosure. It is important to note that these studies were conducted in Western societies, and are not necessarily indicative of the situation in Southern Africa in 2008.

Disclosure may also be important in terms of prevention. Initiating safe sex practices is obviously easier when partners disclose to each other. A recent survey conducted in Cape Town found that 42 percent of HIV-positive respondents did not disclose their status to their recent sexual partners, and non-disclosure was linked to unprotective sex (Simbayi et al. 2007).

Higher public disclosure rates may lead to a change in perception of risk. Studies show that despite high HIV-prevalence rates and high awareness, many South Africans perceive themselves not to be at risk of contracting the virus (Levine and Ross 2002, Shisana et al.)ⁱ or do not practise safe sex (Leclerc-Madlala 2002, Ipsos Markinor 2005).ⁱⁱ

Some studies indicate that personal knowledge of someone with HIV can impact on behaviour. If so, higher disclosure rates may play a significant role in prevention. Ijumba et al. (2004) found, in a study in Khayelitsha, a township in Cape Town, that those who knew someone with HIV were more likely to have used a condom in their last sexual encounter and also slightly less likely to have multiple sexual partners and casual partners. However, as the study is relatively small, any conclusions must be drawn with care.

Other studies suggest that personal knowledge impact on attitudes to the illness. Norman, Chopra and Kadiyala (2007) refer to a study in Thailand, which shows that those participants who knew people with HIV/AIDS were more tolerant of the disease. Similarly, Derlega et al. (2004) suggest that if people in a community are aware that they personally know someone with HIV, they may talk more about the disease and perhaps discard misconceptions about HIV (Derlega et al. 2004: 750). These studies do not directly address the extent to which discarding misconceptions and being more tolerant lead to changing risk perceptions. But they point to the potential impact that disclosure may have on risk perceptions. Yet, again, the findings of these studies are not necessarily indicative of how disclosure impacts risk perceptions in a South African township.

Thus, disclosure has the *potential* of impacting positively on the health and wellbeing of PLHAs and on prevention. But there is a dearth of research on disclosure in a South African context. This study seeks to contribute to understanding

disclosure in a specific context, namely amongst poor black South Africans, a context where stigma and denial persists.

It aims to understand how disclosure is experienced and managed, and which factors influence the decision to disclose or not to disclose. It seeks to understand the impact of disclosure on PLHAs and people at risk. Finally, it aims to understand how historical and political context impacts on disclosure and stigma.

1.3 Imizamo Yethu

The research for this thesis took place in Imizamo Yethu, an informal settlement in the suburb of Hout Bay in the Cape Peninsula. Imizamo Yethu is a typical emerging South African township, home to about 10,000 mainly Xhosa-speaking South Africans.ⁱⁱⁱ

In stark contrast to the surrounding affluent Hout Bay, Imizamo Yethu is a world of shacks, overcrowding and poverty, in which poor living conditions contribute to a number of social and health problems. HIV infection is one of these problems, with 32 percent of pregnant women testing positive, a figure slightly higher than the national prevalence rate of 29.1 percent for women attending ante natal clinics (South African HIV and AIDS Statistics 2006^{iv}). According to a survey conducted by the NGO Development Action Group (DAG) in 2003, the majority of the inhabitants continue to be positioned at the lower end of the socio-economic order. Notwithstanding, the voluntary assistance from the Trust of Irish businessman and philanthropist Neil Mellon that built 500 formal houses, DAG's survey suggested that only a third of the population live in formal houses. More than half of the residents live in the un-serviced area closest to the mountain, which is also the area where most newcomers settle.

The name Imizamo Yethu, meaning, 'Through united struggle we succeed' in Xhosa, reflects the settlement's struggle to remain on the land. The first residents squatted here to be closer to their places of employment. The land issue continues to be contentious in Imizamo Yethu. Attempts to solve this resulted in serious conflicts – also during the fieldwork period - starting when Cosatu's (a confederation of trade

unions) Western Cape General Secretary Tony Ehrenreich called on people from Imizamo Yethu to initiate land invasions. Marga Haywood from the Democratic Party, elected to the Cape Town City Council in the by-election (early 2007) for Hout Bay and surrounds, suggested that overcrowding should be solved through forced removal of people from Imizamo Yethu.^v Community organisations responded with intense resistance to this suggestion.

The community is serviced by two public health clinics: one that treats young children, STDs, HIV and TB (situated by the main road leading into Imizamo Yethu), and another, a few kilometres away, that treats other diseases. There are between 30-40 *sangomas* and *inyangas* (traditional healers). The Mathias Rath Foundation is active in this area and distributes free multivitamins through a co-operation with the local branch of South African National Civic Organisation (SANCO). There are two support groups for PLHAs, viz. Uncedo Lolunto, and one run by an NGO called Yabonga, which also provides peer education at the clinic and home care visits.

In the heart of Imizamo Yethu is Iziko Lobomi (Centre of Life), a community centre, which was my 'base' during fieldwork. Many meetings and activities take place here. Iziko Lobomi is also the venue for the support group Uncedo Lolunto, with which I worked.

1.4 Methodology

Studying disclosure is inherently complex. A key challenge is identifying people who have not disclosed their HIV status. They are known by healthcare workers who are bound by medical ethics, rightly so, of confidentiality. The people available as informants for a study of this nature are therefore mostly people who have disclosed their status to at least some people. However, as shall become clear later, many only disclose their status after years of keeping silent. Asking them to reflect on their feelings, reasons and experiences in retrospect is therefore one avenue to understanding both decisions of non-disclosure and disclosure, even though they may have 'airbrushed' these experiences somewhat.

Another challenge was finding male informants. Generally, men in Imizamo Yehtu were reluctant to disclose. Of Uncedo Lolunto's 20 members, only one was male. Attempts to find male informants through assistance from the clinic staff and through the support groups were to no avail. Therefore, by default, this study only includes one male living with HIV/AIDS.

As in all ethnographic research, ethnographers are limited by who are available to us as informants. Most of the PLHAs in this study belong to a support group. They have chosen to seek support and to disclose their status, even though it is in the presence of other PLHAs. In addition, I have identified some informants through snowballing, with the assistance of healthcare workers from the local clinic. All informants were people who frequent a (biomedical) clinic. My claims are therefore not to be confused with claims of representivity, but partiality.

As a qualitative study, it uses participant observations, open-ended and semi-structured interviews, and focus groups as means of data collection. I participated in support group meetings, worked in a soup kitchen, 'hung out' in the community centre, and took part in activities and events in the community.

As it was my intention to understand both the lived experience of disclosure and the context in which this took place, my informants include PLHAs, people in the community whose status was unknown to me, community and political leaders, health care workers, traditional healers and religious leaders. I met key informants several times, starting with very open-ended conversations, and returning with more specific questions based on our previous conversations.

1.5 Limitations

The nature of my topic posed certain limitations on my research. In my interactions with PLHAs, I had to take the sensitive nature of the topic into consideration. Most participants had limited their disclosure to a few people, and actively tried to protect their status from others. Notably, many had not disclosed their status to their boyfriends; afraid of the repercussions of such disclosure. This made me aware of the importance to protect their status. To be seen with me posed a

potential risk of exposure, even though I made a point out of stressing that my interactions were with both PLHAs and non-PLHAs. While most agreed to meet with me, they were reluctant to be seen with me, and many did not invite me to their homes. Creating conditions under which my informants could keep their status to themselves was imperative. At times, I used a room in the community centre. But often it was clear that people were uncomfortable meeting me in the township and I had to suggest that we met outside Imizamo Yethu.

Another limitation is that I am not a Xhosa-speaker. During support group meetings, Thandeka, one of the founders of the support group, translated for me. Most people I interviewed were happy to be interviewed in English, though some preferred Xhosa, in which cases Thandeka functioned as a translator. In other settings, I would simply ask people I knew to explain things to me. However, I might have engaged with the group and the community differently had I been a Xhosa speaker. In the same vein, I might have missed certain nuances by interviewing and talking to people in English.

The sensitive nature of my topic, language barriers, and the fact that I did not live in the community (I am a mother of two young children so I chose to commute on a daily basis rather than live in Imizamo Yethu) may have limited the extent to which participant observations could be used. I attempted to do as much participant observations as I could, even when some actions/discussions had to be 'translated' or explained to me. However, people's verbal articulations and self-reported data form a substantive part of the data collected. This was unavoidable because of the nature of my topic and the retrospective way in which it had to be addressed.

1.6 Ethical Considerations

Ethical approval for this study was granted by the Department of Social Anthropology at University of Cape Town. All informants signed a written consent form, as required by the Department. This form states their rights to anonymity and right to withdraw from the study.

I share the views expressed in Anthropology Southern Africa's ethical guidelines. In particular, attention needs to be given to anthropologists' duty to anticipate potential harm. In order to protect their confidentiality, I have given all PLHAs pseudonyms and limited identifying information where necessary.

1.7 Theoretical framework for understanding HIV stigma

1.7.1 Stigma as a discrediting attribute, leading to a spoiled identity

In order to frame my analysis, I will highlight key debates and discussions relating to HIV stigma, a concept that has been used extensively in HIV/AIDS research, but a concept not clearly defined.

As my starting point, I use Edwin Goffman's (1963:3) definition of stigma as 'an attribute that is deeply discrediting'; and the stigmatised person as being viewed as 'not quite human' and 'disqualified from full social acceptance' (ibid:5). Goffman argued that stigma is based on what society constitutes as deviant/different. He identified three types of stigma - the one relevant to this context is the stigma known as 'blemishes of individual character', which refers to an individual's behaviour or character that is seen as deviant (ibid:14). Goffman argued that the individual who possesses these deviant characteristics becomes labelled and, through this stigmatisation, a spoiled social identity is created. To avoid this label, many individuals try to pass as 'normal' and conceal those features which may identify a stigmatizing condition.

Stigma is often seen to be synonymous with discrimination, but it is important to distinguish between these two phenomena. Defining stigma as an ideology and discrimination as overt action, Deacon (2005) pointed out that stigma may be used to legitimize discrimination, but only when enabling circumstances such as power differences between the stigmatisers and the stigmatised are present. On the other hand, a number of other factors – such as concern about risk and resources - might lead to discrimination against PLHAs. Moreover, both Deacon (2005) and Herek (2002) emphasised that stigma does not have to lead to discrimination in order to be detrimental to PLHAs. Expected stigma and internalised stigma impact negatively on

their well-being. As Herek (2002) stressed, internalised stigma, which relate to a stigmatised person's internal sense of shame and fear of persecution, will often restrict their behaviour, motivate them to attempt to pass as 'normal', or limit their opportunities. Thus, sometimes stigma leads to discrimination. But stigma does not have to lead to discrimination to have a negative impact on PLHAs.

1.7.2 Instrumental and symbolic stigma

A distinction between instrumental and symbolic stigma is applied in much of the research on stigma, where instrumental stigma is understood to derive from a fear of AIDS as a communicable and lethal illness. Stigma, in this regard, functions as a defence to preserve 'the self'. Symbolic stigma, on the other hand, functions as a "vehicle for expressing hostility toward other groups already stigmatised before the epidemic began" (Herek 2002:598).

Herek and Capitanio (1998) argued that HIV stigma typically has both instrumental and symbolic components. They suggested that a clear distinction between instrumental and symbolic stigma is not always possible or desirable. Rather, instrumental concerns about illness transmission may not be completely distinct from symbolic concerns about social contamination. With HIV/AIDS, stigma has become a vehicle for expressing attitudes of moral concern. While I agree that symbolic and instrumental stigma may sometimes be intertwined, it is nevertheless a distinction that is useful in understanding the source of HIV stigma, how it functions, and how it may be challenged.

1.7.3 Stigma models

In the following section, I will outline three stigma-models. The first model is the 'blame-model' developed by Helene Joffe (1999) as a theory on how humans respond to risks such as illnesses. It is therefore useful in understanding HIV stigma.

Joffe identified a tendency to respond to threats such as illness with a 'not me - others are to blame' reaction. Drawing on different disciplines within the social sciences, she argued that people control anxiety stemming from danger by forming

social representations which alleviate the worry by portraying 'others' rather than the self and the in-group as the more deserving targets of danger (Joffe 1999:2). She argued that this blaming discourse occurs when a perceived danger threatens physically or symbolically (e.g. threatens the moral order). Through 'othering', people gain an illusion of control. People articulate their own group identities as different in key risk-reducing ways from groups that are stigmatised as deviant.

Furthermore, she argued that social representations are used to make the unfamiliar familiar; and make sense of a new threat, such as a new illness. These social representations of new threats are created through a process of anchoring and objectification, which transform the unfamiliar to something more familiar through imposing past ideas onto new ideas that needs to be understood. One example of this is the way AIDS has been understood or represented in terms of past epidemics, such as tuberculosis, "The anchoring process is a social form of the more cognitive categorisation process. This act of classification - of naming - makes the alien and threatening event imaginable and representable" (Joffe, 1999:94-95). In addition, Joffe stated that the social representations of threats are socially created (as opposed to being created in the mind of the individual). They are created in the 'unceasing babble', the constant dialogue that people have with each other and with the mass media.

While Joffe claimed that all groups have 'others' whom they blame in crisis, she also argued that othering and stigmatisation is linked to power, because dominant groups exert their control over the processes of representation. Some representations gain greater currency than others, and some stigmatizing discourses become widely accepted because they are supported by powerful groups (Joffe 1999: 29). Stigma, therefore, often preserves the status quo.

The fact that social representations of 'the other' serve to defend the self and the in-group, and create a sense of safety and order, could easily lead to an understanding that social representations (and consequent stigma) are resistant to change. However, Joffe argues to the contrary, pointing to the fact that many marginalised groups have been able to challenge them.

Deacon (2005) draws heavily on Joffe's blame model, but uses it specifically to understand HIV stigma. Thus, she defined HIV stigma as a social process by which people use shared social representations to distance themselves and their in-group from the risk of contracting a disease. In this process of 'othering', disease stigma often draws on a variety of other forms of prejudice and follows existing patterns of inequality and prejudice, such as racism, sexism and homophobia. Disease thus becomes a marker for both biological and social difference and disease stigma becomes "negative social baggage associated with a disease" (Deacon 2005:19).

Arguing that humans protect themselves from collapse and chaos through projecting their worst fears onto identifiable out-groups, Campbell et al. (2005) applied a similar understanding of stigma. But they added another dimension: stigma as system justifying. In this understanding, stigma is used by powerful groups to reaffirm and reassert the status quo. They argued that traditional power structures, such as the Church and traditional leaders, view HIV/AIDS in terms of a transgression of sexual norms. These transgressions reflect these institutions' loss of power. They attempt to use the epidemic to reassert that power through HIV stigma. Stigmatisation has served these traditional social institutions in reasserting control over women and young people's sexuality and in reasserting conservative power relations along generational and gender lines. It becomes a form of psychological policing, in Foucault's sense, in which those "who breach power relations of gender, generation, or ethnicity are disciplined and punished" (Campbell et al. 2005: 813).

Parker and Aggleton (2003) advocated a different understanding of HIV stigma: the social exclusion model, which argued that stigma is linked to the (re)production of social difference and social and economic exclusion. Drawing on Foucault's notion of power and knowledge, the authors argued that stigmatisation is central to the establishment and maintenance of social order. They argued that, within this framework, stigma involves the marking of significant differences between categories of people. Through this categorization, people are inserted into a system or structure of power (Parker and Aggleton 2003: 18). They used Bourdieu's ideas of how cultural meaning and practices embody interests and function to enhance social distinction among individuals, groups and institutions. Stigmatisation and

discrimination serve this creation of distinction better than anything else. Stigma must therefore not only be understood in relation to difference, but also in relation to social and structural inequalities.

Using this framework, Parker and Aggleton proposed to understand HIV stigma in relation to broader social processes, namely globalisation and the processes linked to this new economic system. They pointed specifically to two socio-economic trends that occurred simultaneously along with the HIV-epidemic: the feminisation of poverty and an increasing polarisation between the rich and poor, both in the 'developed' and the 'developing' world.

1.7.4 Stigma as a changing social process

All three stigma models view stigma as a social process that can change. Aggleton and Parker's explanation for understanding how stigma changes is particularly useful in this context. They suggested that, while stigma is often internalized and accepted, leading to spoiled identity, it can also be resisted and challenged. They theorized how identities change in relation to experiences of - and resistance to - stigma. The article suggested that three types of identities are possible in response to stigma: Legitimizing identities, which are introduced by the dominant institutions of a society, and lead to an acceptance/internalization of stigma; resistance identities, which are constructed by actors that are devalued and/or stigmatised by the logic of domination; and finally, project identities, which are formed by actors who use 'cultural material' available to them to build new identities that redefine their position in society and, in return, also challenge the overall structure of that society.

Herek (2002) also stressed that stigma is not static. But instead of focusing on PLHAs as the agencies of change, he suggested that change is linked to changing conditions and context. Arguing that one of the factors that make a disease likely to become stigmatised is an aetiology that is not well understood, he suggested that disease stigma may change as new information becomes available, and the disease aetiology clearly understood. Arguing also that a lethal disease is likely to be stigmatised, he posited that a stigma trajectory changes when cures or effective

treatment become available. Exemplifying this is the stigma trajectory for cholera, which changed once disease aetiology was understood, and which made the prevalent moralistic approach irrelevant. Herek argued that this has not happened in the case of HIV for three reasons: Firstly, the public (i.e. the US public) remain ill-informed; secondly, some sectors of the population mistrust scientific data; and, thirdly, a considerable portion of AIDS-related stigma is symbolic.

1.8 Outline

In Chapter Two, I argue that disclosure levels are very low in Imizamo Yethu and that there are few public disclosures. I propose to understand disclosure as an ambiguous dilemma, which has the potential to be both risky and rewarding. I put forward that HIV stigma, and consequent fear of discrimination, is a key factor in the dilemma. The dilemma is managed through two processes: Through a partial disclosure informants seek out a few confidantes, who are carefully chosen to minimise stigma and ensure support. Simultaneously, they deal with internalized stigma by repositioning themselves in relation to an innocent/guilty dichotomy, thus refuting self-stigmatisation without challenging the ideological framework. I propose that, while disclosure has a positive impact on health and well-being, HIV stigma presents a serious limitation to the potential positive impact on PLHAs.

Chapter Three examines the content and context of HIV stigma and suggests that a number of factors make HIV/AIDS a highly stigmatised disease. HIV/AIDS is described as a disease that is conceptualised as deadly and untreatable, associated with immorality, and for which the individual bearers are responsible. I argue that confusion and uncertainty about illness causation contribute to stigma. HIV/AIDS is conceptualised as a highly contagious disease, able to penetrate a permeable and defenceless body. I suggest that apocalyptic beliefs are drawn on to make sense of this 'new' disease. These beliefs reflect a deeper sense of despair over social ills and the informants' position as a marginalised community 'deprived' of 'liberation' in post-apartheid South Africa. Based on this conceptualisation of HIV/AIDS, it is suggested that HIV stigma amongst marginalised South Africans should primarily be understood as a defence against a threat, along a blame model advocated by Joffe (1999),

though it also has a system-justifying function. Through stigmatizing and 'othering' HIV, people are able to protect themselves from feeling at risk.

The fourth chapter examines how the political response to South Africa's AIDS crisis has impacted on stigma and disclosure. It argues that a political 'silencing' of HIV/AIDS has impacted on the conceptualization of HIV/AIDS as a disease against which communities are defenceless. A disjuncture between experiencing HIV as a threat of apocalyptic proportions and experiencing political silence, denial, and lack of action has reinforced the tendency to defensively deny risk through stigmatisation. Secondly, it has contributed to HIV stigma, through reinforcing the confusion about transmission mode and treatment choice. Late and reluctant roll out of ARVs has reinforced the conceptualization of AIDS as a 'killer' disease. In addition, this chapter relates low disclosure level and high levels of HIV stigma to limited HIV-activism, something that makes it difficult for PLHAs to resist and challenge stigma. It suggests that HIV stigma should be addressed through addressing both the symbolic and instrumental dimensions. But it emphasises the importance of reconceptualising HIV/AIDS as a treatable disease through efficient provision of health care and removal of structural barriers.

In the following chapter I analyse the dilemma of disclosure, first through two narratives, followed by a thematic analysis.

2 DISCLOSURE AS DILEMMA

2.1 Gladys' story: 'People will look at you as if you are a bad person'

Like many people living in Imizamo Yethu, 44-year-old Gladys grew up in the Eastern Cape, which she still regards as her home. She has lived most of her adult life in Cape Town; and, since 1992 in Imizamo Yethu. In 2004, Gladys was diagnosed with HIV after she sought treatment for tuberculosis. She explained that the diagnosis came as a shock because she was unaware of an illness called HIV/AIDS and of anyone that had contracted the disease. Neither had she heard about the disease on TV nor on radio. She reiterated these claims on numerous occasions:

I had never heard about anybody who had AIDS. Even at home (in the Eastern Cape), nobody has had AIDS. I have never met anybody. Most people don't talk about it. They talk about TB, but not about HIV. It is different with TB, because there are tablets. With AIDS, they say that you won't last long.

On another occasion, she initially repeated her previous claim of not having heard about HIV/AIDS. But later, she conceded that she had heard about the disease:

I did not like to hear about HIV. When I heard about it, I switched the TV off. I did not want to hear about it. I switched the TV off because I was scared of getting it. Hearing about AIDS made me very nervous. People said that with AIDS you cannot stay a long time. That is why I did not want to hear about it. Tuberculosis is better, because if you have AIDS you can die any time. You also cannot have a child.

Gladys never talked to anyone about her fears, but explained that by switching off the TV she did not have to think about the disease. HIV was frightening both because of its seriousness, and because of the prospect of people finding out about her status and devaluing her because of it. Her main fear was that people would talk ill of her, something she had witnessed happening to others:

People will look at you as if you are a bad person, as if you have done something wrong. When somebody dies of AIDS, we say it is double pneumonia or tuberculosis.

It is a funny disease. If you get it, they say it is because you like to sleep with (many) boyfriends. People don't want to talk about the disease. But sometimes, if they are fighting, they talk about it. Then they will say things like, 'Oh your sister passed away from AIDS. Me, I am much better than you because I cannot get AIDS.'

Linked to her fear of being labelled as a 'bad' person, was also a fear of being discriminated against. Gladys was aware of PLHAs who were forced to leave their homes by their boyfriends or families; and she feared the same fate. She was convinced that, once people became aware of her status, they would not share the same utensils with her, neither would they 'help' her nor provide her with support. Yet, she felt that she should disclose her status. Though she found it very challenging, eventually, two years after her diagnosis, she told her boyfriend.

Contrary to her fears, he did not leave her, at least not immediately. Instead, his reaction was a refusal to get tested. He told Gladys that 'they would just die together'. Six months after her disclosure, the couple separated, after 18 years together. Gladys does not link her disclosure to subsequent events, such as the break up of her long term relationship and the expulsion from her home. However, her boyfriend's reaction in conjunction with these events raises the question of a possible causality between her disclosure and these incidents.

An unemployed Gladys confided her HIV status to her sister, who has been assisting her thus far. She also shared her status with her son, 20, while her daughter, 16, found out when she discovered Gladys' medication. Both her sister and her children have been supportive.

Gladys' disclosure has been limited to these four people and the support group members. Other people close to her are unaware of her status. Since her expulsion from her house, she has slept at a friend's house, but she spends most of time at her uncle's house. Both her uncle and the friend remain unaware of her status.

Prior to her diagnosis, Gladys had conceptualised HIV/AIDS as a deadly, incurable and immoral disease. This not only led her to an initial denial of own risk, but also made disclosure problematic as she feared both stigmatisation and discrimination, themes that came out in many stories.

Gladys is not on ARV treatment, but will consider it if her condition deteriorates. She is indecisive due to negative publicity about ARVs. "They say that

when you get ARV, you get sick. You see snakes at night, your skin becomes wrong and you have bad dreams,” she said. Yet, Gladys has also noticed that some support group members on ARVs regain their health. This observation and knowledge has given Gladys new hope. She rejects her Church’s view of AIDS as a sign of the end of the world - a view pervasive in the community - because of her knowledge that AIDS can be treated with ARVs. Knowledge of the difference between HIV and AIDS has made her realise that an HIV-diagnosis is not a death sentence, a view that she previously held.

Gladys’ disclosure has been followed by a social ‘downgrading’. She had to move from a formal house to being homeless while she builds her shack, a 16m² wooden structure, hidden behind other rows of shacks and situated in the unserviced area of Imizamo Yethu. It is a ‘downgrading’ that clearly affects her wellbeing and upsets her. Tearfully, she lamented how difficult her social situation is, and what a struggle it is to raise money for building material for her shack.

In many ways, Gladys was in a vulnerable, liminal state, something that was perhaps best exemplified by her belief that she had become a victim of witchcraft. One morning, I found her on the street with a baby on her back. Her hair was uncombed, she was wearing only one sock and was not as neatly dressed as she usually is. She was visibly upset, with tears in her tired-looking eyes. She had not slept all night. Her voice trembled and she started to cry, explaining that she had found worms in some of her belongings. Gladys was convinced that the appearance of these worms was due to ex-boyfriend’s new ‘wife’ attempting to bewitch her, and she feared for her life. She also explained that her housemates accused her of being bewitched. Gladys was on her way to the community centre to seek advice.

Later we sat outside together with a woman called Luyiso. She advised Gladys to go to a witchdoctor to find out whether the worms were due to witchcraft as the appearance of worms can be a sign of witchcraft, sent as a message from an ancestor or appearing when something is old. Gladys refused to go to a witchdoctor, saying that she did not believe in them.

2.2 Andile's story: 'It is like you are not a person.'

Andile, 36, wore her Yabonga 'AIDS T-shirt' as a 'badge of pride' (Robins 2006:320). She talked openly about being HIV-positive, her life, and her job as an AIDS counsellor for Yabonga. Talking about her status was something she found easy and important. With a big smile, holding one hand in a colourful glove over her chest, as if to emphasize her words, she said, "I am proud of my status." It is hard to believe that she kept her HIV status a secret for six years. Yet, as she explained the conditions around her diagnosis, the picture became clearer:

When I tested positive in 1995, I did not want to hear about it. I was in denial. When people know that you are HIV-positive, they get scared; they don't want to share their food and other things. When I got sick, I did not know how the illness was transmitted. I just thought that I was going to die. The diagnosis was like a death sentence.

Andile did not receive any counselling. The diagnosis terrified her, both because of the severity of the disease, and because of the implications of having HIV. Disclosure was never even considered. Instead of telling her boyfriend, she packed her bags and 'fled' Johannesburg to Cape Town where she had family. Andile explained that her reaction was also caused by the fact that she was convinced that she could not contract HIV, something that is clearly linked to the social-cultural construction of AIDS as a stigmatised and 'immoral disease', a theme that is carried out in many stories:

Before I was diagnosed, I did not think much about HIV. I thought I could not get it. I thought it was only people who fuck around who get HIV/AIDS. In Johannesburg, I only had one boyfriend. I was telling myself, "I am not that kind of woman." In my mind, only prostitutes got the disease.

Andile feared being labelled and talked about. She feared for her safety and for being discriminated against:

It is like you are not a person. All the time I was thinking, I am going to die anytime. People talked a lot about you if you had HIV/AIDS. They would make jokes about you and call you names. That name 'HIV', it meant death. It meant you are going to die, die, die. And people will hate you. I think that was why I was scared when I tested

positive. Because there was no treatment then. People used to say that if you have AIDS you won't last long. People would talk to you as if you are not a person.

While disclosure seemed impossible, Andile also experienced that keeping her diagnosis a secret was a burden that was 'eating her up'; sentiments many other informants shared with her. Andile felt lonely and lost during that time and resorted to drinking alcohol to cope with the stress. The desire to disclose and the fear of doing so presented a cruel dilemma. But she felt that there was no choice, "I kept telling myself that if I talk, people will run away and they will not drink from the same cup or they will hurt me. So I said to myself, 'Let me be quiet.'"

When she met her new boyfriend, she did not disclose her status because of these fears. Neither did she practise safe sex:

You know African guys, if you tell them to use a condom they will ask why. They will ask, 'Are you sick?' I was scared that he would chase me away or that he would say, 'Fuck off. You come from Jo'burg with this thing, with this HIV'.

Things changed when Andile fell pregnant. At an antenatal check-up, the clinic sister suggested an HIV-test. Contrary to her first test, this test was accompanied by a counselling session, during which the counsellors strongly advised the women to tell their partners about their status in order to make it easier for them to take Nevirapine, an ARV, which reduces the risk of transmitting the virus to their babies.

Andile finally decided to tell her boyfriend, and her fears turned out to be unfounded:

He supported me. He just said, 'Let's go to Church and pray.' He said that he loved me and that we did not know where the disease came from. He also said that the Bible says that in the end there will be these diseases which cannot be cured.

Her boyfriend refused to get tested, citing that he believed in God and would just pray. Andile put her faith in Nevirapine and her daughter Siyanda, now six, was born HIV-negative.

Despite her boyfriend's affirmation, Andile decided not to disclose her status to her family. A change occurred when Andile met a volunteer from the Treatment Action Campaign (TAC) at her work as a security guard. He encouraged her to join

the TAC. Reluctantly, Andile went to a TAC meeting. "When I went there I saw these fat ladies and they were healthy and they told me that they were HIV-positive and I felt for the first time that I am not the only one. And I thought: 'They are fat and they *live with HIV*'" (my italics). Being fat is seen as a sign of being healthy, in contrast to being thin, which is seen as a sign of having HIV.

Still, disclosing to her family felt too risky. Only after she started training to become a counsellor for Yabonga, did she decide to disclose to her mother, almost nine years after her diagnosis. Her mother was supportive. A few months later, Andile decided to tell her sister, and her fear of rejection came true this time:

Since I told her, she has not been the same. Before, she would come to my house. She would ask me if I had cooked *papa* (maize meal porridge) and say that she would like some. Since I told her I am HIV-positive, she does not come to my house anymore. She used to visit, to phone, and we used to go for walks together. Now...I don't know what happened, whether she is scared or what, but it is not the same. My sister, she used to love me...

Despite her elder sister's rejection, Andile decided to tell her two other siblings who were supportive. Since she became involved with Yabonga, Andile has disclosed publicly and has regained her pride:

Now I am not scared anymore, I am not even shy. I talk to everybody about it. There are people who talk bad about you, but I don't care. Because the TAC has taught me that there is a difference between HIV and AIDS. And there are ARVs. There is hope. It is not just that you must die. Now, I feel much better about myself. I feel proud of my status.

Andile is convinced that disclosing has many benefits. She said she felt free and unburdened of the stress of keeping her diagnosis a secret, "I am not the same anymore – because before I was not free – after (disclosing) you feel much better. There is nothing eating your heart up. You just feel okay."

2.3 Reluctance to disclose

The strong reluctance to disclose, as described in these narratives, mirror a general reluctance to do so in Imizamo Yethu. Statistics on disclosure rates in South Africa are not available, but two recent studies give an indication. Norman, Chopra and Kadiyala (2007) provides figures for disclosure, at 40 and 70 percent respectively in the two communities they studied, but there is no indication of whether these are partial or public disclosures. Simbayi et al. (2007) found, as mentioned, that 42 percent did not disclose to recent sexual partners.

While the local clinic could not provide statistics on disclosure rates, they indicated that disclosure was a big problem. The local clinic urges people on ARV treatment to disclose to at least one person, as PLHAs with a 'treatment buddy' show higher adherence. However, Smangele Khumalo, coordinator for the Patients' Advocates at the clinic - who assists and counsel people on ARVs - said that many refuse to bring a 'treatment buddy', indicating that disclosure levels are very low. This reluctance is also exemplified in that many women in the support group spoke about partners who refused to disclose their status. Yabonga has also observed that many PLHAs are reluctant to disclose. Consequently, many reject visits by the home carers as they fear that association with these carers (wearing HIV T-shirts) would expose their status. This resulted in the NGO having to downscale its activities in the township during my fieldwork period.

2.4 Delayed and partial disclosure

Disclosure is, for most PLHAs, a process that is delayed, such as described in Gladys' and Andile's narratives. The sentence 'I was not ready' was used repeatedly, indicating the processual nature of disclosure. The insistence on 'readiness' also indicates that they expected to disclose at some stage. Disclosure was seen either as an ideal or something that was bound to happen.

Public disclosure was limited to few people. Many informants pointed to five people being fully open about their status. Disclosure was, in most cases, partial or selective, such as described in Gladys' narrative. To avoid stigmatisation, PLHAs

have, in some instances, limited their disclosure to a support group. In addition, there is a form of disclosure which I call an ambivalent public disclosure. This form of disclosure is characterized as not active public disclosure, but also not hiding certain behaviours or signs that may be interpreted as indicative of HIV status. For some, the dilemma between wanting to disclose and fearing disclosure is overcome by this form of ambivalent disclosure. A case in point is Neliswa. Only after the birth of her third child did she confide her status to the friend she was living with and her boyfriend. Yet, she decided not to hide the ten kilogram of formula feed that the clinic provides to HIV-positive women; notwithstanding that formula feeding your baby is perceived as an indication that one is HIV-positive.

2.5 Reasons for disclosure: 'Coughing it up', being free, staying healthy

Disclosure is experienced as a dilemma: there are strong motivators for wanting to disclose, but equally strong fears preventing disclosure. An incident at a support group meeting, where a new potential member arrived, illustrated this. The woman, carrying a baby on her back, sat visibly anxious and uneasy on the edge of her chair. After a short while she disappeared. Despite volunteer social worker Marion Frank's^{vi} attempt to get her to return, the woman did not have the courage. Her sudden flight was due to her having spotted a relative at the Centre; and she was afraid of exposing her status.

Daniswa's story is illustrative of the extent of this cruel dilemma. She is a 27-year-old mother with a 4-year-old daughter. She was given Nevirapine, an ARV, to take during labour to reduce the risk of passing on the virus to her baby. When in labour, surrounded by her relatives, she was in a quandary as she had to take her medication. Should she risk exposing her status or her baby's health? After much vexing, she took the medicine under the pretence that they were painkillers.

Many informants described partial disclosure as the 'right thing to do'. They also feared that they could not keep their status hidden as the community knew the signs of the disease. For instance, Daniswa's attempt to hide her status from her

family was unsuccessful as they became suspicious when she did not breastfeed her baby. While in hospital, they perused her medical file which revealed her status.

Hiding their condition felt like a burden, and there was a strong urge 'to let it out'. Informants described their feelings after disclosure as cathartic. Like Andile, they felt free and relieved. Daniswa explained that telling someone was like 'coughing it up'. Others mentioned that, once you disclose, you feel free and can start dealing with your status.

Even when informants did experience rejection, such as in the case of Andile, there was a sense of being freed from a burden. These sentiments are similar to a study by Derlega et al. (2004) in the US and Norman, Chopra and Kadiyala's (2007) study in South Africa..

Many informants were convinced that hiding their HIV status was detrimental to their health and increased their stress level. On the contrary, disclosure made them feel 'healthy'. "You are less stressed and feel better afterwards," said Thandeka. Nosiphomesu explained that, "all her sickness was healed."

Partial disclosure also enables health-seeking behaviour. It becomes possible, or easier, to get support to take ARVs, keep clinic appointments, use condoms, and otherwise lead 'healthy' lives. Two examples illustrate this. Joyce, a 36-year-old mother of two, found through disclosure a supportive partner who encourages her to take her ARV correctly and to keep her clinic appointments. Gladys and her boyfriend also started using condoms after her disclosure.

These narratives support Paxton's (2002) argument that disclosure is beneficial to the health and well-being of PLHAs, and suggest that disclosure does not have to be public – as in Paxton's study – to have a positive impact.

The need for support is another big motivator for partial disclosure. For all members of Uncedo Loluntu, disclosure within the support group enabled them to receive both emotional and material support. Yet support and acceptance by family members seem to matter the most, and most chose to disclose to family members first. Disclosing to family members was regarded as a necessary and unavoidable step by many of the informants. Frances, who has no parents, told her aunt and uncle

first, as she considers it important that families are aware of one's status as they can provide support during periods of illness.

The crucial role of social support correlates with findings of Derlega et al. (2004). Norman, Chopra and Kadiyala (2007) argued that social support, especially from family, both in terms of services and emotional support was crucial in the decision to disclose. The study compared two communities in South Africa with very different disclosure rates. It concluded that the main factor that set the community with high disclosure rates apart from that with low disclosure rates was the availability of social support, such as support groups, and the possibilities for activism. That family is seen as the most important group of people to disclose to correlates with a study in South India (Chandra, Deepthiwarna and Majula 2003).^{vii}

While most confided in family first, many refrained from telling partners. Where disclosure was to partners, it was motivated by a wish to prevent infecting others and protecting themselves from possible re-infection, which obviously has adverse implications for the immune system. Thandeka is one of the few who claimed to have told her partner on their first meeting, motivated by her willingness to practice safe sex.

For those who have disclosed publicly, raising awareness was a strong motivator. Phelo, for instance, cited this as his only reason for disclosure. Similarly, 25-year-old Nolufefe, a fruit seller outside the clinic, openly wears a HIV T-shirt, and is firm about her decision to disclose, "Nobody talks about HIV. If you talk about it in the community, they do not want to hear about it. But you must talk, because it kills people. You must stand up." Derlega et al. (2004) found, similarly, that a willingness or duty to educate was a motivating factor for disclosure.

2.6 Reasons for not disclosing: Fear of stigma, rejection, and exclusion

Despite the many rewards of disclosure, there are also risks. Stigmatisation is the main risk, impacting negatively on disclosure. Many stories reflect a fear of being stigmatised in the sense that Goffmann described it, as the attribution of undesirable

difference which creates a spoiled identity, as being not quite human, having a blemished character, being barred from full social acceptance, and being reduced from a normal person to a tainted one.

Andile's comment that people will 'talk to you as if you are not a person', and Gladys' assertion that 'people will look at you as if you are a bad person', resonates in many other stories. Gladys' retelling of the way in which people claim superiority because they cannot get AIDS is another example of how PLHAs are devalued.

It is also demonstrated in Nolufefe's description of the way in which "people look at you if you are not right." Consistently, informants feared being spoken ill of, being labelled, being called names, having fingers pointed at them, being gossiped about and sworn at – and this prevented them from disclosing. Daniswa, for instance, explained that people often point fingers at HIV-positive people, telling others to avoid them.

In addition, stigma was considered to lead to discrimination, exclusion, violence, rejection and loss of support - as was evident in both Andile and Gladys' narrative. They were concerned that people would not want to share things such as food with them, or would refuse to use the same utensils. Andile's sister's refusal to eat at her house is indicative of this. Daniswa had a similar experience when her cousins refused to share food with her because they feared that, "maybe one day you [Daniswa] will put HIV in our food or maybe you will sleep with our boyfriends and give them HIV."

The fear of stigma and repercussions made many refrain from disclosing to their boyfriends. Many feared being beaten, chased away, losing support, and being rejected because of the negative attributes with which HIV stigma 'stained' them.

Sometimes, linked to the fear of rejection, was a concern for losing material support, such as in the case of Phumlani, who – like many other women - was financially dependent on her boyfriend. Her story exemplifies the almost impossible dilemma of disclosure and the role of HIV stigma. Phumlani, 26, came to Hout Bay in 2004 and tested positive shortly thereafter. When we met, she had not disclosed her status to her boyfriend, whom she was to marry in six months time. She was afraid that he would leave her because he openly criticized and spoke ill about people with

HIV. He also refused to drink from a glass, which he thought an HIV-positive had used. Phumlani felt she had no choice but to pretend. In her daily life she had to hide anything that might be indicative of her status. When she attended the support group, she told him that she was going to a gardening project.

Thandeka and Neliswa, who also participated in the discussion, insisted that it would be difficult for Phumlani to continue 'passing as normal', i.e. HIV-negative, and especially to continue using condoms once her marital status changed. They tried to convince Phumlani that it was better to disclose, however she was still hesitant. Her only experience of disclosure had been negative - when she told her ex-boyfriend he blamed her for 'bringing HIV into their relationship'.

2.7 Responding to stigma: Insistence on innocence

While fear of enacted stigma was a strong factor in deciding not to disclose, self-stigmatisation also played a role. It was evident that all the female PLHAs in this study held stigmatizing beliefs about HIV prior to their own diagnosis and had denied being at risk prior to their diagnosis.

The blemish of individual character, which they experienced, was linked to individual behaviour seen as deviant. Because HIV is transmitted sexually, it is, at least for women, understood as a sign of sexual transgression. An HIV-diagnosis is therefore linked to immorality and deviant behaviour, and something that only happens to 'bad women'. The salience of this discursive construction can be seen in the fact that all women used exactly the same stigmatizing labels to describe women who were likely to contract HIV: 'prostitutes', 'loose women', 'bitches', 'sluts', 'women who like boyfriends too much', 'women who sleep around', and 'women who sell their bodies'.

Furthermore, the endemic explanation for how HIV is contracted is loaded with moralising language such as, 'You get it through sleeping around.' This link between AIDS, immorality, and female sexuality is in line with many studies of the socio-cultural construction of AIDS as an 'immoral' disease (Levine and Ross 2003,

Grundlingh 1999, Delius and Glaser 2005, Sontag 2002 [1991]) and women as AIDS vectors (LeClerc-Madlala 2001, Jewkes et al. 2003, Lawless et al. 1996)

Many explained that they were shocked, and felt ashamed and wrong after being diagnosed HIV-positive. Daniswa phrased it in the following way, “I had always thought that only ‘bad’ women could get HIV. All of a sudden I was one of those women.” Andile’s rejection that she could be at risk because she was not ‘one of those women’ (referring to prostitutes), serves as another example. Joyce rejected the idea that she could get HIV because she ‘was not a bad person’. Her response to her mother’s inquiry about her health during her illness was that she was not HIV-positive, “I refused to think that I could have HIV. I told myself, ‘I am Joyce – I cannot get AIDS.’” Joyce’s rejection of risk was clearly a resistance to having a ‘spoiled identity’.

With the HIV diagnosis, these women were ‘transformed’ into deviant and dangerous women. Before disclosure was possible, a reconfiguration of these spoiled identities had to take place and self-stigmatisation challenged.

The majority of PLHAs responded by ‘insisting on innocence’. The first way of doing this was by professing a lack of knowledge about the disease before diagnosis. Particularly illustrative of this is Gladys’ insistence on ignorance, because that would mean admitting her own potential risk, which evoked not only the fear of HIV/AIDS as a lethal condition, but also the risk of being stigmatised. Illustrative in this regard is also Nolufefe’s story. She lives in the informal part of Imizamo Yethu with her nine-year-old daughter. Nolufefe was diagnosed with HIV in 2004, during her pregnancy, when her CD4 count was 64, indicating that her immune system was seriously compromised. She lost her baby daughter when she was six months old, but said that this was not due to HIV. Nolufefe claimed that she had never heard of HIV, neither in the Eastern Cape where she grew up, nor when she moved to Imizamo Yethu in 2003. Later it became obvious that she – like Gladys - *had* heard about HIV, but she then claimed that she did not really know what the disease was. Admitting to being at risk would be equivalent to admitting a ‘blemished’ character, as the following quote illustrates:

In the community, if you are HIV-positive people look at you like... (She stops talking as if even speaking about it is impossible, but her body language indicates that she 'shrinks' as a person.) ... In the community, they look at you as if you sell your body.

Even Phelo - the support group leader who claimed to have been a 'king' that could, and did, chose many women - claimed 'innocence' by insisting that he did not know enough about HIV. Despite having been trained as an HIV-counsellor prior to his own diagnosis, he insisted that there was a lack of information about HIV in 2002 when he was being diagnosed.

The most prevalent way of insisting on innocence was linked to refuting a blemished character; by reiterating that they were not responsible for their condition through their 'deviant' or 'immoral' behaviour. Gladys and Andile's stories clearly show that they presented themselves as unlikely victims as they were 'not that kind of woman'. To come to terms with her condition, Gladys changed her belief that only 'loose' women could contract HIV to a belief that it can happen to 'respectable monogamous' women, a change that also occurred in others.

In contrast they all described themselves as morally acceptable women, often insisting on their claim to respectability through the sentence, 'I only had one boyfriend.' This became part of an explanation for why they had not seen themselves at risk of contracting HIV and why they were innocent victims. (Though the term 'one boyfriend' often meant one boyfriend at a time, and talk amongst support group members indicated that in some instances it was more an ideal than a reality).

A third way of insisting on innocence was through blaming men and suggesting that their (sexual) behaviour was 'immoral', because men 'slept around' and refused to use condoms. This blaming of men is also reflected in explanatory models of transmission mode. Some women explained how the HI virus is transmitted from men to women because women are 'on their back' (in a passive, vulnerable position) while men are 'on top' during sexual intercourse and the ones 'giving something' (i.e. semen) to women. This biological explanation was used to explain how men pass 'their dirt' to women, and that women are therefore innocent, while men are responsible for passing on HIV.

It is important to stress that by calling this an 'insistence on ignorance,' I am not claiming that insufficient knowledge is not an obstacle. Accessibility of HIV-information, especially in the rural Eastern Cape where most of the informants grew up, may be limited. Nevertheless, the inconsistency, in both Gladys' and Nolufefe's explanations, indicate that this 'insistence on ignorance' was part of the defensive denial to being at risk of a stigmatised condition.

I am also not suggesting that these women's stories of HIV exposure through a single relationship are untrue. It is unquestionable that many women contract HIV through what they consider a monogamous relationship, and that their ability to negotiate safe sex is often limited (see Jewkes et al. 2003). Rather, I am suggesting that their strong emphasis on a sexual history with one or few partners, whether true or not, is a reflection of societal norms around female sexuality and individualisation of risk.

It is equally important to contextualise this construction of ignorance and innocence in relation to women's subordinate role and financial dependency. Almost all the women who participated in this study were unemployed, and the few that were employed worked as low paid domestic workers. Many relied on their boyfriends for help. Many women claimed that, often, they could not insist on safe sex through condom use, something Andile's narrative illustrates. Frances, a single mother of two children and one of the few employed women in the support group, attempted to convince her partner to be monogamous, but was unsuccessful. Thus, women's subordinate role, and the inability to protect themselves, contribute to their denial of risk in the first place and, once they become HIV-positive, they position themselves as 'innocent' victims in response.

In my theoretical framework, I have argued that stigma can be both accommodated and resisted. The decision to disclose or not; and to disclosure partially or fully, is related to this. While many were able to create a 'resistance identity' - resisting a 'spoiled' identity - they rarely created 'project identities', where the stigmatizing beliefs are challenged publicly. Rather, their response remained channelled through this 'insistence on innocence' within a binary framework consisting of 'innocent' and 'responsible' victims, repositioning themselves within this

framework as 'innocent victims' and constructing 'virtuous' selves. Through this they rejected responsibility for their condition, stigma and self-stigmatisation.^{viii} Only when the ideological framework of passing blame on the ill is challenged - or absent, such as in the case of Phelo, who did not fear stigma because of his gender - is full disclosure possible.

Yet, importantly, there are some that have begun to challenge stigma. Frances said, "I don't worry about what people think, because I did not get it from a shop", thus rejecting that her illness was due to her personal flaws.

2.8 Disclosure as a carefully managed process

While some are beginning to challenge stigma, there is much evidence that high levels of HIV stigma continue to pervade Imizamo Yethu.

One indication is the negative response TAC members experienced when they conducted door-to-door awareness campaigns during my fieldwork period. Many people refused to hear about HIV, and closed their doors demonstratively. Another indication is the resistance shown to visits by Yabonga's home carers, as mentioned previously. Thirdly, the narratives of people contemplating disclosure reflect both high levels of stigma that they harboured prior to diagnosis and, as such, reflect stigma in the community; as well as their own experiences of being stigmatised.

However, many PLHAs find support through disclosure. These stories serve as a reminder that the social response to the AIDS-pandemic is complex. Stigma exists alongside support and compassion. In many cases the expected stigma was far worse than the stigma they reported to have experienced after disclosure.

I posit that this discrepancy is linked to disclosure being a carefully managed process. People contemplating disclosure seek out people who are less likely to stigmatise. They disclose to people they trust, often after testing reactions or monitoring their attitudes. Furthermore, they disclose to one person first, observe their reaction, then disclose to another and so on – such as described by Andile and Gladys – and they choose not to disclose to people who will not support them.

Daniswa is another example of this. She chose not to tell her mother because she did not expect support from her, but told her supportive sister. Daniswa also deliberately tested people's attitude. When her neighbours asked her why she was fat, she answered that it was due to the 'tablets I take for HIV', so she could test their attitudes.

Phumlani serves as yet another example. She has contemplated telling her mother, but monitoring her mother's attitudes has made her fearful of her mother's reaction. Phumlani knows that her mother would not accept that her daughter has HIV because, according to Phumlani, she thinks you get HIV either from witchcraft or 'sleeping around'. Phumlani's attempts to talk with her mother about HIV, in order to prepare her, have come to an end because of her mother's negative reaction to HIV.

The dilemma of disclosure is, to some extent, solved through partial and managed disclosure, which enable PLHAs to minimise stigma while achieving the benefits of disclosure: soliciting support, feeling liberated and improving wellbeing. This resembles Norman, Chopra and Kadiyala's (2007:1777) argument that a 'sounding out' preceded disclosure. While most PLHAs participating in this study saw disclosure to people close to them as an ideal, few contemplated full disclosure. I posit that this is because it cannot be managed. When advocacy is not a motivating factor, the risk is too high.

In this chapter I have argued that intense HIV stigma is a key factor in the decision to disclose HIV status. I have argued that disclosure levels are low, and that disclosure is often both delayed and partial. It is a managed process, through which PLHAs minimise stigma while achieving the benefit of disclosure. Finally, the analysis suggests that the partial nature of disclosure means that it often does not entail disclosing to partners – and this naturally has serious implications for the spread of the virus. I have also argued that, before disclosure, a negotiation of identity and construction of an alternative image of the self as 'innocent' takes place. The process leading to full public disclosure seems to differ in a more 'radical' challenge/rejection of stigmatizing beliefs.

Having identified HIV stigma as a key factor in understanding disclosure, in the following chapter I will look at the content and context of HIV stigma.

University of Cape Town

3 DEATH, DEVIANCE AND DESPAIR: AIDS AS AN EXTRAORDINARY DISEASE FOR STIGMA

3.1 Introduction

As Alonzo and Reynolds pointed out, HIV/AIDS is an 'extraordinary illness' in terms of its potential for multidimensional stigma. (1995:305). Many factors point to its stigmatisation. Drawing on Alonzo and Reynolds (1995), Sontag (2002 [1991]), Herek (2002) and Deacon (2005), I will examine the factors that contribute to HIV stigma in Imizamo Yethu. These include the notion of HIV/AIDS as an immoral disease, associated with deviant behaviour, and with the responsibility for contracting it placed on its bearers. It is also viewed as a lethal, incurable disease. It is a disease that is poorly understood. Lastly, it is conceptualised as a highly contagious disease, posing a serious threat.

In addition, I draw on work by Farmer (1992) to suggest that socio-economic context impacts on stigmatisation. I use this analysis of how HIV/AIDS is conceptualised to suggest that HIV stigma in this disadvantaged community should primarily be understood in terms of a blame model.

My interest thus shifts from a focus on the way PLHAs experience the disclosure dilemma to understanding HIV stigma in the broader community. I base my analysis of HIV stigma in Imizamo Yethu (in this chapter and the following) on data from PLHAs, from informants whose status is unknown to me, from community health workers, traditional healers, community leaders, and religious leaders.

A few points need to be made regarding sampling. First, regarding the use of PLHAs: I use PLHAs as informants because I view them as part of the general population, or more accurately, as a sub-system in the community. It is clear that until their HIV diagnosis, these people shared beliefs, views and experiences with the rest of the community. But it is also evident that some PLHAs go through a process in which their knowledge and conceptualisation of HIV change, something clearly pointed out by Gladys. It is important to bear this in mind when using PLHAs as informants and analysing their representations.

I mainly utilise PLHAs by asking them to draw on their *retrospective* reflections on how they perceived HIV/AIDS prior to their own diagnoses, as ('ordinary') members of that community, as an indication of how HIV/AIDS is conceptualised in the general population. The use of other people from the community as informants was also necessary to ensure a broader sampling, as the PLHAs may represent only a sub-system in the community - one that uses the biomedical system.

3.2 AIDS as an 'immoral' disease

One of the central factors in HIV stigma is that, for women, it is conceptualised as an immoral disease because it is sexually transmitted – a notion that I have dealt with in Chapter Two. It is a conceptualisation that is strong in the community at large, with many informants using it to distinguish between 'innocent' and 'responsible' victims.

Zelpha, a woman in her fifties who sold fruit outside the community hall, pointed out that HIV/AIDS is a disease for "bad people because you get it if you sleep around." Pastor Ndongeni of the Four Square Church, one of many Pentecostal Churches in Imizamo Yethu, also said that "most people get it from sleeping around."

The link between HIV and immorality also points to it being understood as moral indictment, as a sin. Hence, HIV stigma is used as a vehicle to express moral condemnation of that behaviour. Most clearly, this was expressed by Pastor Ndongeni's assertion that "AIDS is about loose morals, not poverty." He added that the silence around HIV/AIDS is a consequence of the disease being viewed as a sin in the 'black community':

Most people believe that if you have AIDS it is because you have sinned. But we (the Church) say that it is just a consequence of what has been done in the past. It is because of a sin in the past, but this does not mean that the person is living in sin.

Kenny Tokwe, local ANC and community leader, and business entrepreneur, supported this view, arguing that most 'Church people' also see it as God's punishment, while Daniswa suggested that it was a lesson from God.

3.3 Individualisation of blame

It is also evident that HIV stigma stems partly from the fact that the disease is seen as the bearers' responsibility. Tokwe, amongst others, expressed a view that 'carelessness' is known to cause people to get HIV/AIDS.

In contrast, few blamed HIV/AIDS on poverty and social conditions. Phelo was an exception, arguing that poverty and high unemployment rates caused many young girls to engage in sex to provide for their family, while a traditional healer linked it to 'hunger'. However, most concurred with Pastor Ndongeni's view that AIDS is about loose morals; and not about poverty.

In *AIDS and Accusation* (1992), Farmer shows how the blame for HIV in Haiti was first directed towards sorcery, but later became directed towards poverty and inequality. This removed the locus of blame away from the individual towards structural issues. A similar shift in blame has not occurred in Imizamo Yethu. Instead, HIV is still largely understood as the bearers' responsibility; though research points to the link between illness risk and poverty and inequality (see, for instance, Farmer 1999).

3.4 AIDS as a 'killer disease'

While it is the immoral aspect and the individualisation of blame that is used in the devaluing of PLHAs, the source of HIV stigma is far more complex. One of the main factors that cause HIV stigma is that it is conceptualised as a deadly disease.

These expressions were used repeatedly: 'it is a killer disease', 'with AIDS you won't last long' and 'AIDS is a death sentence'. For most informants the diagnosis was immediately followed by thoughts of death, evident in both narratives. Deacon (2005) refers to similar definitions of AIDS as a killer disease, a conceptualisation that seems to have changed little with the provision of ARVs in the public health sector.

The association between death and HIV/AIDS is strengthened by the fact that the HIV/AIDS epidemic in South Africa has reached a stage where many die from the disease. In Imizamo Yethu, many informants spoke about how every family has experienced an AIDS death, even though this is often not acknowledged, and rarely spoken about. Smangele Khumalo said, “Each and everyone know somebody who has died of AIDS. They don’t talk about it or say that it is AIDS, but they know because they know the signs.”

The importance of the association between HIV/AIDS and death is most strongly expressed by Thandeka, who argued that HIV/AIDS is stigmatised more because it results in death than because it is a sign of immorality. This point was supported by the fact that most of the women in the support group had at least one child out of wedlock, and all of them argued that this transgression had not caused any stigma. Thandeka argued, “It is because HIV is a disease. Having children is not.”

Yet, the narratives clearly point out that the association between AIDS and immorality is a strong factor in HIV stigma. Thandeka’s argument must therefore not be seen as evidence that the issue of immorality is unimportant. Rather, I suggest it should be seen as pointing to the synergistic, multidimensional nature of HIV stigma. It is the fact that HIV/AIDS is a lethal disease, *and* signifying immorality, that contributes to the intensity of HIV stigma.

Furthermore, the importance of viewing sexual transgressions as ‘immoral’ is stronger in other sectors in the community. While PLHAs did not see having children outside wedlock as ‘wrong’, others disagreed with this view. Pastor Ndongeni argued to the contrary. The discrepancy between the pastor’s and Thandeka’s assertions, highlights the conflicting views on women’s sexuality, a conflict that run along gender lines as it is clearly women’s sexual transgressions that are stigmatised, not men’s. Phelo, for instance, explained that he did not fear or experience stigma because of his gender – because men’s ‘sleeping around’ was not associated with immorality, but rather part of a ‘natural order of things’. In addition, it is a conflict which points to the importance of power and challenges one to consider how stigma, and especially the moralising aspect of it, may be used by powerful groups in an attempt to reaffirm

the social order, reassert lost power and confirm status quo. This understanding reflects the view of Campbell et al. (2005), who suggest that HIV stigma is system-justifying with regard to demonising women as AIDS vectors.

This view that HIV stigma is linked not only to 'immorality', but also to death, is also put forward by Delius and Glaser (2005). Using an historic approach, they argued that pre-colonial African societies were relatively open about sexuality and legitimate sexual activity was not confined to marriage. They argued that, while Christianity did bring shame to sex, it never became a hegemonic position, leading them to suggest that the association between AIDS and death should be seen as equally important as the link between HIV/AIDS and sex, a point my analysis supports. I suggest that it is the double association between HIV/AIDS and death, and HIV/AIDS and morality, which causes stigma.

3.5 A disease with no cure

The association between HIV/AIDS and death is strengthened by an understanding that it is a disease with no cure and no effective treatment. Comparing HIV/AIDS to tuberculosis, many informants argued that tuberculosis is different from HIV because the former is a disease that is not stigmatised or silenced, and because tuberculosis is curable. Like Gladys, many commented that for HIV there are no tablets, for TB there is.

The availability of ARVs has had a limited impact on the association between AIDS as a lethal and incurable (and untreatable) disease in this context, something I will analyse in more detail in the following chapter. Here I want to briefly point to other reasons why HIV/AIDS is seen as a disease for which there is no treatment.

Firstly, a clear distinction was being made between cure and treatment, with many people correctly pointing out that ARV treatment is not a cure. In addition, there was a limited understanding of the difference between HIV and AIDS. The fact that people can live with HIV for many years was lost because no distinction is drawn between HIV and AIDS. The importance of this was clear in both Andile's and Gladys' narratives, in which they reflect on how their perception changed when they

understood the difference between HIV and AIDS, and were able to break the association between HIV and imminent death.

3.6 AIDS as a poorly understood disease: Confusion and conflicting causation

HIV/AIDS is in several ways a not well understood disease, something that contributes to its stigmatisation.

Firstly, there was a lack of biomedical knowledge on HIV/AIDS within the community. Though I have argued that claiming insufficient knowledge is, in some cases, used as part of an 'insistence on innocence', there is a real lack of knowledge in the community on the disease.^{ix}

Uncertainty about illness causation also contributed to it being poorly understood. While PLHAs were all convinced that HIV/AIDS is a sexually transmitted disease, at a community level, confusion about illness causation pervades. The difference in their understanding could be due to two things. One explanation could be that PLHAs, who are part of this study, belonged to a group of people who primarily believed in and used the biomedical health system. It could also be attributed to the exposure of PLHAs - through their visits to the clinic - to a better sense of biomedical understanding of illness causation. It is evident that, for some, a 'conversion' to a biomedical understanding - to borrow a term from Robins (2004) - took place. An example of this is Gladys' changed view of HIV after acquiring new knowledge.

Many PLHAs explained that, prior to their own diagnosis, they believed that HIV/AIDS could be caused by things other than a virus, such as a powder, which is something I will return to later. Here, I illustrate the confusion about illness causation through a conversation I had with an *inyanga*, Wiseman Nkaphuza. In the following quote, he explains how HIV is contracted:

If you have a drop and it is not clean, you can catch the disease. It is easy to catch if you are not clean inside. Also when people drink, they need a girlfriend too much and they are forced to go around and find a girlfriend. Fishermen can also catch it because they can easily catch a cold, and then they get a girlfriend. Also hunger can

cause it because if you are hungry and you go and sleep around with an empty stomach, you can easily catch the disease. HIV can also be caused by other diseases such as STDs.

It is evident that illness causation is complex - incorporating the biomedical understanding of HIV with ideas of pollution and impurity and, in addition, linking susceptibility to poverty and hunger. Nkaphuza mediates between different medical systems. Another traditional healer was at a complete loss when asked what causes HIV/AIDS, indicating that nobody knows. While he did treat patients with medicine in the form of a liquid stored in empty cool drink bottles, he doubted that it could treat HIV/AIDS, but felt he had to try.

3.7 Witchcraft – a suppressed discourse

Part of the confusion about causation is that the community at large often drew on a witchcraft paradigm to understand HIV. But it is important to point out, as Ashforth (2001) does, that framing HIV within a witchcraft paradigm does not necessarily mean that it is not understood as a sexually transmitted disease. Rather, the two health models are intertwined. Accepting HIV is a virus transmitted through sex, within this paradigm, does not necessarily mean that the origin of the misfortune lies in the person who passes on the virus. Witchcraft could still lie behind this 'transmission'. Ashforth coined the construct 'sexually transmitted witchcraft' (Ashforth 2001:10). Using Green's (1999) distinction between immediate and ultimate causes, it is possible to understand a virus to be the immediate cause of HIV/AIDS and witchcraft as the ultimate.

The extent of the belief in witchcraft within the community is difficult to estimate for a number of reasons.^x Firstly, many people will not admit to believing in witchcraft. Rather, witchcraft belief seems to be a suppressed discourse, which exists alongside biomedical understandings of HIV/AIDS. Imizamo Yethu resident Sister Matete, for instance, argued that most people believe that AIDS is caused by witchcraft, but do not reveal these beliefs when they visit the clinic, indicating that believing in witchcraft is silenced when interfacing with a biomedical establishment. That notwithstanding,

many people in the community argued for understanding AIDS within a witchcraft paradigm

Another difficulty in assessing the prevalence of the witchcraft paradigm is that many people deny believing in witchcraft but, after further probing, it was evident that this attitude was in fact a rejection of the use of witchdoctors personally, while still an acceptance of the existence of witchcraft in general. Pastor Ndongeni explained:

Witchcraft exists, but God is bigger. I am not spending time worrying about witchcraft because God is my protector. All Africans believe that when something happens against his or her expectations, he will think someone is bewitching him, even when it is AIDS. If someone dies, and that person has all the signs of AIDS, they will not mention AIDS. They will say that the person was bewitched.

Secondly, witchcraft allegations are often kept secret. Nkaphuza explained that witchcraft must be kept secret, and that he advises people not to reveal that they are bewitched, because talking would give the witch information that he can use against the victim. This secretiveness surrounding witchcraft belief is also noted by Ashforth, who argued that it would be both embarrassing and dangerous to publish that one has been a victim of witchcraft (2001:12). Furthermore, he argued that the 'denial' and silence around HIV/AIDS, or what he calls 'wilful ignorance', does not only arise from the fact that HIV is a sexually transmitted disease, but also from it being understood in terms of witchcraft, "With cases of witchcraft, silence and discretion are the norm." (2001:12).

Luyiso, an unemployed mother of five children, who resides in a tiny shack near the community centre, was convinced that people had tried to bewitch both her and her baby, who had been ill with a stomach-ache soon before. Her explanation of the way in which HIV is contracted was complex, with reference to transmission through blood and sex, but ultimately caused by witchcraft:

What happens is that, when you sleep at home, you have a dream that you are having sex. Witches take blood and put it on people at night. I once dreamt that I was having sex with my boyfriend; I woke up and was very furious. Witches put it (unclear whether she talks about the virus or blood) in at night. Then comes the dream. You are not going to know it. You just wake up after that dream, and you have HIV.

Luyiso's explanatory model expresses great uncertainty about transmission mode, an uncertainty also reflected in Nkaphuza's explanation. Attempts at getting them to clarify their understanding were to no avail. Luyiso replied that she cannot explain exactly how the witches get and use the blood of HIV-positive people. Despite this uncertainty, it is important to note that her explanations alludes to the witchcraft paradigm and does not exclude a biomedical explanation.

Luyiso provided an interesting explanation for why witches use AIDS. She argued that, while witches can afflict suffering in many ways, such as by causing car accidents, AIDS is one of the preferred ways because of the immense suffering it causes. As the following quote shows, this is not only linked to physical suffering, but also to social suffering through the fact that it is clearly linked to the sexual nature of the disease, "Witches like HIV a lot because it is a good way for them to hurt people. Because when you have HIV/AIDS people call you names – it is very bad and you don't like that. People will say that you are sleeping around."

This understanding of HIV, as a particularly effective way for witches to cause suffering, is comparable with the findings of anthropologist Tobias Hecht (Robins 2004).

Hence, witchcraft belief contributes to the disclosure dilemma because it 'requires' silence and secrecy. If beliefs about being bewitched must be kept secret, having a disease that others may believe to be caused by witchcraft must obviously also be hidden. Furthermore, this conceptualisation adds to the plethora of explanatory models and thus contributes to it being a poorly understood disease - one of the factors that causes stigma.

3.8 'Coming as a powder at night': AIDS as a highly contagious disease

HIV/AIDS is also understood to be a highly contagious disease, a conceptualisation that clearly plays a role in its stigmatisation. This conceptualisation is understandable, given the high HIV-prevalence.

Many statements refer to fears of it being transmitted through casual contact, Andile's sister's fear may be indicative of this. Many PLHAs reflected on others being fearful of sharing crockery, cutlery and food with them for fear of contamination. In similar ways a man in his thirties talked about fearing drinking from a glass that had been used by a person with AIDS. Two young women also spoke about their fear of contracting HIV/AIDS through eating the same food as someone with HIV. This fear resulted in them stigmatising PLHAs as being 'bad' and labelling them.

The understanding of HIV/AIDS as being highly contagious is also reflected in a conceptualisation of HIV/AIDS as 'coming as a powder at night'; something both Gladys and Luyiso spoke about. Gladys no longer believed in this transmission mode. But Luyiso explained, "it can also happen that way and you would not know if it had come to you". Both argued that it was an understanding that many talked about. Gladys explained, "Sometimes people say that you get HIV when you are sleeping and a powder comes on you. I hear that often when I am sitting with people. Most people say that." This way of viewing HIV is echoed in Luyiso's explanation of the way in which witches use HIV. Again it happens at night, without your knowledge. And because witches – according to Luyiso – are people that are not normally assumed to practice witchcraft, their targets are defenceless.

I offer that both Luyiso's explanation of the way in which HIV is transmitted through witchcraft, and the belief that it comes as a powder at night, is an expression of perceived extreme vulnerability to HIV. Coming at night, when people are asleep, signifies that people are defenceless against the disease. The form of a powder signifies its ability to penetrate a defenceless, permeable body. HIV is thus not only conceptualised as a highly contagious disease - as a lurking danger - but also as a disease against which people are defenceless.

3.9 Apocalyptic beliefs – a discourse of despair

Another expression of a community being defenceless against HIV/AIDS comes across in apocalyptic beliefs, which were frequently used to make sense of the epidemic. These popped up in most conversations and are evident in both narratives.

Two additional examples should suffice: During a Church service at The Gospel Outreach Church, the pastor talked about the world coming to an end as an indisputable fact. He linked this to 'chaos, disorder and incurable diseases'. In a conversation with Phelo, apocalyptic beliefs also featured as the ultimate explanation, "It says in the Bible that in the end there will be incurable diseases and it says that sons will stab their fathers and that is exactly what is happening."

The prevalence of apocalyptic beliefs underlines the importance of conceptualising HIV/AIDS as an incurable disease. Struggling to understand the devastating epidemic, people find the ultimate cause in a religious interpretation of HIV/AIDS as a sign of the end of the world.

Importantly, apocalyptic beliefs are, as the gospel pastor's linkage between HIV and disorder and chaos suggests, embedded in deeper despair over social ills. When people spoke about HIV as a sign of the world coming to an end, they continuously referred to other misfortunes or social ills such as murders, especially between family members, and the rape of small girls. But while apocalyptic beliefs were prominent, they were often talked about with ambiguity, indicating that the community grappled with finding a 'meaning'. Ndongeni's statement epitomises both, the link between HIV and other social problems, as well as the uncertainty:

We don't know whether HIV/AIDS is one of those incurable diseases. But we are concerned that it might be. But there are also other diseases, such as ebola. Another thing we see is brother killing brother, sister killing sister, grandchildren raping their grandmothers. Those things were not around before, but the Bible mentions them.

In their study on stigma in a South African community, Campbell et al. (2005) came across a woman who understood AIDS as a sign of the end of the world. They argued that apocalyptic beliefs, along with linking AIDS with sin and immorality, are the Church's attempt at reasserting its moral authority. Many of my informants also pointed to the Church as the source of apocalyptic beliefs. However, I find that it cannot alone explain why apocalyptic beliefs take such strong hold in a community such as Imizamo Yethu.

My suggestion is that apocalyptic beliefs must be understood as an attempt to make sense of a 'catastrophic' disease/disaster and, as such, represent a profound

despair. In their attempt to make sense of this disaster, people draw on biblical explanations as 'cultural' material which help them understand the devastation and despair that the HIV pandemic causes. This conceptualisation of HIV/AIDS as a threat of apocalyptic proportions causes stigmatisation because it highlights that there are no other 'defence' available against this threat.

Joffe (1999) suggested that a new illness comes to be understood through a process of anchoring and objectification, which transforms the unfamiliar to something familiar. Contrary to Joffe, I found that tuberculosis was not used to 'anchor' HIV. While my informants attempted to 'make sense of AIDS' by comparing it to tuberculosis, they significantly focused on the *difference* between the two conditions. They repeatedly pointed to the fact that tuberculosis was a treatable illness, while HIV was both incurable and a sign of deviance. Thandeka, for instance, explained the silence and denial surrounding HIV/AIDS in the following way, "Tuberculosis, asthma and lung infection have always been here. HIV is a new disease. That is why it is so scary." This indicates that it causes more anxiety.

In addition, traditional healers stressed that HIV is a new and different illness, one for which they have no cure. This leads me to suggest that the 'despair' around HIV/AIDS stems partly from, to a large extent, a failed anchoring and objectification process. Because HIV/AIDS *cannot* be understood by drawing on an understanding of tuberculosis or other diseases, apocalyptic terms are used. In addition, those institutions that usually assist in the meaning-making processes and in understanding new phenomena – healers and religious leaders – express uncertainty and despair. This obviously leads to heightened uncertainty and fear.

3.10 Socio-economic position and limited possibility

In *AIDS and Accusation* (1992), Farmer argued that one of the factors that determines how a new illness acquires meaning is how people see their 'possibility in the world'. Drawing on this, I want to suggest that socio-economic marginalisation contributes to conceptualising HIV as a threat of apocalyptic proportions.

A township like Imizamo Yethu represents a marginalised community in post-apartheid South Africa. Many inhabitants have been forced to migrate to Cape Town from the Eastern Cape in search of a better life, but very few find employment. They continue to be part of a circular migratory system. Many were forced to give up their schooling due to poverty. Robins described a similarly marginalised group as “a generation left behind by the liberation struggle, caught in a liminal space between structural marginalisation and the dreams of post-apartheid liberation” (2006:319). This description is fitting for Imizamo Yethu.

It was evident that most informants viewed their possibility in the world as very limited. Their main concern was survival. As Thandeka explained, “We are very, very suffering, but we survive, we survive.” An expression both of resilience and resignation. The majority expressed no hope or belief that the socio-economic conditions would change. Drawing on Farmer’s ideas of how an illness is conceptualised, as well as my analysis of apocalyptic beliefs, my contention is that their experience of marginalisation and liminality impact on the way AIDS is understood. HIV/AIDS becomes not just another ‘misfortune’, but an apocalyptic disaster, associated with unavoidable social and biological death, and no hope of liberation.

Patricia Henderson (2005:25) interpreted apocalyptic visions amongst rural dwellers in Okhahlamba as a result of alienation from the centres of power. I suggest that apocalyptic beliefs in Imizamo Yethu are a result of powerlessness against AIDS and other social ills, partly resulting from alienation in post-apartheid South Africa and the ‘missed’ liberation.

The experience of limited opportunity and social marginalisation is also relevant in another way, namely in an experience of ‘not being able to cope with HIV’. Many PLHAs argued that, prior to their diagnosis, they rejected being at risk of contracting HIV because they knew that they could not cope with the disease - Gladys being an example of this.

Thandi, a mother of three young children, two of them HIV-positive, is another example. Living in abject poverty with an abusive aunt, she explained that HIV/AIDS was a distant threat with which she was not preoccupied, because she felt she could

not handle that on top of her other problems. Many informants linked this sense of not coping to a wish to remain 'unaware'. Tokwe explained that as there is no cure for HIV/AIDS, people prefer not to know their HIV status because they feel they cannot cope with it.

Clinic staff spoke of a similar tendency amongst many patients who preferred not to know their status because they felt unable to cope with the diagnosis, something evident in both Gladys's and Andile's narratives. Liz Huckle, chairperson of the Health Committee in Hout Bay and a nurse providing care for HIV/AIDS patients, argued that fatalism is prevalent amongst young high school students in Imizamo Yethu with whom she worked. It is something she linked to their lack of hope for a better future, arguing that it also impacted on their risk-taking behaviour.

A young member of the community I met at the community centre spoke in a similar way when he said, "It is better not to know. It would just frustrate your life and upset you. So what's the point?" This 'preference for not knowing' was linked to the fact that AIDS was seen as an incurable disease.

3.11 Understanding HIV stigma in a marginalised community as defence

The ethnographic data has shown that HIV/AIDS is conceptualised as a highly contagious, incurable, deadly disease which is not well-understood and against which both the individual 'body' and the body politic is defenceless. Conceptualised in this way, HIV/AIDS is seen as a threat that this community grapples with understanding and responding to. It is understood as a disease that signals moral decay and the end of the world. This is exacerbated by a general sense and experience of having limited control over 'misfortunes', and limited hope due to a marginalised position in post-apartheid South Africa. Thus conceptualised, many respond with denial and a preference for remaining 'unaware'. This in turn leads to stigmatisation as a defensive response.

Drawing on this analysis of HIV/AIDS as a very tangible threat leads me to suggest employing the 'blame-model', the 'others - not me' model identified by Joffe

(1999). Seen as such, HIV stigma can be viewed as an defence against a perceived threat that protects the stigmatisers from feeling vulnerable, by placing risk onto others through used and shared social representations. The fact that HIV is conceptualised as a lethal threat against which individuals and the body politic is defenseless is key to understanding HIV stigma in this specific context - a marginalised community with high HIV prevalence.

In doing so, I am not arguing that Imizamo Yethu is a homogeneous community void of power differentials, or that power is not important in understanding HIV stigma. The ethnographic data also shows that HIV/AIDS is conceptualised as an immoral 'sinful' disease, a sign of decay and deviance and a threat to the moral order. This supports an understanding of HIV stigma as having a symbolic component, being a vehicle for expressing concerns about moral decay. While this conceptualisation is evident in the community at large, it is a position strongly advocated by institutions such as the Church. This form of HIV stigma must therefore be understood in terms of power. HIV stigma becomes a vehicle, not only for expressing moral concerns, but for (re)asserting power and control. In line with Campbell et al. (2005) I therefore argue that HIV stigma also 'functions' as protecting the status quo and the social order.

These two different ways of viewing HIV stigma, one based on instrumental concerns, the other on symbolic, obviously do not exist in complete isolation from one another. Rather, some of the discourses used by powerful groups have an impact on which social representations acquire dominant positions. Some representations are simply more likely to gain salience when supported by powerful groups, leading stigma to become pervasive. HIV stigma amongst people sharing a marginalised position may primarily be a defensive reaction to a threat, but they draw on these dominant symbolic discourses, which is evident, for instance, in the stigmatisation of female sexuality.

In addition, the social-exclusion model, advocated by Aggleton and Parker (2003), needs to be considered. The social exclusion model is useful in explaining stigmatisation between powerful groups and marginalised groups. It may, for instance, be useful in explaining how AIDS has been stigmatised as a 'black' disease

and how HIV stigma is used to entrench gender inequalities by stigmatising women as AIDS carriers. The fact that HIV infections have largely followed the fault lines of society has led to a stigmatisation of already marginalised groups. Its limitation is that it fails to explain stigma in a context where stigmatisation happens within a shared marginalised community, because it assumes that there is always a power differential between the stigmatiser and the stigmatised. My ethnographic data has shown that stigma *also* occurs between categories of people where there is no significant power differential between the stigmatiser and the stigmatised, something evident in the fact that people who used to stigmatise sometimes end up being stigmatised.

Furthermore, in this *local* context, people who become stigmatised do not belong to an already marginalised group prior to their diagnosis, such as assumed by Parker and Aggleton (beyond the gender aspect). Stigmatisation, therefore, does not reproduce social difference in the local context (again beyond the gender aspect).

Yet, a process of social exclusion is undoubtedly taking place. PLHAs are often discriminated against and excluded from sharing - something which clearly impacted on their decision relating to disclosure. But this process does not occur exclusively along lines of an already established order (beyond the gender dimension). Rather than just reproducing social difference, HIV stigma creates new forms of social difference and exclusion.^{xi} Furthermore, it is important to bear in mind that this process of social exclusion was closely related to instrumental concerns about contagion, rather than a mere process of competition for power and privilege.

In addition, the social exclusion model is based on an assumption that stigma always leads to discrimination. But, as Deacon (2005) argued, stigma does not have to lead to discrimination to be detrimental to PLHAs. Rather, when stigma is internalised or expected, it makes PLHAs place limits on themselves and influences their sense of self. In certain contexts – where power differentials exist - stigma can lead to discrimination and, as such, contribute to social exclusion and entrenched inequality. Yet by viewing stigma as synonymous with discrimination, this model fails to fully understand the impact of stigma. Clearly, the fear of being labeled and stigmatized impacted negatively on PLHAs regardless of whether it led to discrimination or not.

I posit, therefore, that HIV stigma amongst marginalised people is primarily a defence mechanism, which is strengthened by being infused in a moral matrix where it signifies much more than a physical threat to the body and where powerful groups use it to justify the status quo.

The strength of HIV stigma relates to the fact that it is multilayered and multifaceted, and expresses both instrumental and symbolic concerns. Sometimes these concerns are intertwined, making it difficult to determine where the fear of physical contagion ends and the fear of moral contagion begins. The intensity is also related to the fact that many factors contribute to HIV stigma and reinforce it. I have argued, for instance, it is not that HIV is an 'immoral' disease, but rather that it is a deadly disease signifying immorality, which makes it a stigmatised condition.

3.12 Disclosure, stigma and defensive denial

Viewing stigma in this way has implications for understanding disclosure. It is evident that in a context where HIV/AIDS is conceptualised as a lethal threat of apocalyptic proportions, against which individuals and the community are defenceless, disclosure is likely to be met with stigmatisation. In this way, stigmatisers protect themselves against feeling vulnerable.

It is equally clear that this way of understanding stigma raises questions about whether higher disclosure rates - whether personal knowledge of someone with HIV/AIDS - can change risk perceptions.

A thread running through most illness stories was a denial of being at risk, carried out through a defensive stigmatisation of HIV/AIDS – evident in both Gladys' and Andile's narratives. Some informants indicated that they had not perceived themselves at risk because they did not know someone with HIV. Phumlani commented that she was unsure whether HIV really existed because she had never met anybody with the disease, "I was not sure that HIV really existed. Because I used to hear about it, but I never saw someone in front of me with the disease. So I thought maybe it is people from overseas that would get it, but not people from Cape Town." Nolufefe also argued that she would have taken HIV more seriously if she had known

somebody with HIV. Though one should be careful to read too much in these hypothetical deliberations, they indicate that, without personal knowledge of someone with HIV, it might be difficult to realise HIV/AIDS as a personal risk.

Other informants point to the question being more complex. Their knowledge of people who were HIV-positive did not lead them to change risk perception, but instead led them to a denial of their own risk through stigmatisation. Joyce, for instance, knew people with HIV, but rejected being at risk because she viewed herself as different from the women likely to contract HIV. Many created similar distinctions between themselves and people at risk because of their (immoral) behaviour. This denial was influenced by the fact that, by admitting being at risk, they faced not only the fear of a deadly disease, but also of HIV stigma. Furthermore, this denial was influenced by their limited capacity to protect themselves against HIV. Stigmatisation and othering seem, in this particular context, to be the only 'protection' available.

Herek's (2002) reflections around the 'contact hypothesis' are worth pondering upon in an attempt to understand the impact of disclosure on risk perception. The contact hypothesis suggests that people will change their attitudes to HIV/AIDS and stigma when they have personal contact with PLHAs. But Herek questioned whether this is also the case in a context where both HIV prevalence and stigma is high. He suggested that it becomes difficult to take refuge in a belief that 'it cannot happen to me' if those infected are similar to oneself. Stigmatisation often results as a way of creating a sense of being 'invulnerable'. This argument suggests that in a context such as Imizamo Yethu, it is questionable whether disclosure will facilitate higher risk awareness because PLHAs do not represent an already distinct marginalised group. Thus, upholding a sense of 'this cannot happen to me/us' is difficult. Indeed, the message in public disclosure may be understood as, 'it can happen to anybody.'

While personal knowledge of someone with HIV may lead to people challenging their perceptions and discarding their misconceptions, such as suggested in my introduction, it is questionable how it facilitates a change of risk perception in this specific context. Knowing someone with HIV may be a prerequisite for realising

one's own risk, but it is insufficient as a prevention tool in the conditions described here.

Challenging HIV stigma is thus central, both to making disclosure easier for PLHAs and enabling them to achieve the benefits on improved health and well-being; *and* to making it part of a preventative strategy that changes risk perceptions. It is therefore imperative to address the conceptualisation of HIV/AIDS which leads to this form of stigma.

Having outlined my understanding of HIV stigma in a marginalised community, in the next chapter I will focus on how the political context has contributed to making disclosure problematic; and HIV stigma pervasive as a defensive denial. The chapter will also suggest that high levels of HIV stigma persist because of limited HIV-activism and because Imizamo Yethu is a community divided in its response to HIV.

Based on this, I will suggest that higher disclosure rates can only be achieved through challenging stigma, especially its association with death and despair, and replacing it with an alternative discourse of hope.

4 Political ambivalence and limited activism

4.1 Ambivalent political response

South Africa's response to the AIDS epidemic is deeply influenced by the political and historical context in which the AIDS epidemic came into full force. According to Louis Grundlingh (1999), stigmatisation and othering of HIV/AIDS goes back to the very start of the epidemic when the Nationalist Party was still in power. Grundlingh argued that stigmatisation of marginalised groups, racism, homophobia, and conservative morality caused an inadequate response to HIV/AIDS. He suggested that the National Party was reluctant or uninterested in dealing with HIV/AIDS because it was 'a black disease'.^{xii} White South Africans found reassurance in similar beliefs. Conservative politicians, he argued, used AIDS to instil a fear of integration with black South Africans by suggesting that HIV/AIDS could be passed on through casual contact. Clive Derby-Lewis, Conservative Party Member of Parliament, is quoted as having said that, "If AIDS stops the black population growth it would be like Father Christmas." (Grundlingh 1999:73).

Grundlingh argued that the early reaction to the AIDS epidemic led to a wave of blaming and a distinction between innocent and guilty victims. By the time the African National Congress (ANC) came to power, AIDS was already stigmatised as a black disease, leading black South Africans to defensively reject this stigmatisation, often by denying the risk of HIV/AIDS.

With Thabo Mbeki's presidency, denial became a defining characteristic of South Africa's AIDS policies^{xiii}. Shortly after Mbeki became President in 1999, he associated himself with so-called AIDS-dissident thinking, based on the claim that HIV does not cause AIDS, sometimes even refuting the existence of the virus. Part of Mbeki's denialism took the form of rejecting ARVs, which he argued 'Big Pharma' used to exploit poor people and nations.

Mark Gevisser (2007) speculated that it was simply too much for the liberation movement to see the AIDS epidemic threaten the realisation of their dream. Gevisser, along with anthropologists Steven Robins (2004) and Virginia van der Vliet

(2004), also pointed to the role that perceived racism and cultural identity politics played. According to Gevisser, Mbeki saw the way AIDS was represented as “a grievously dehumanising projection of ourselves as Africans” (Gevisser 2007:746). Similarly, Robins argued that race and cultural identity politics shaped both the citizen and political response to the epidemic. Viewing AIDS through a racial lens, Mbeki responded within a defensive African nationalist discourse.

An illustrative example of how the political leadership’s response was a reaction to perceived racism and stereotypes of Africans, and ARVs perceived to be an attempt at exploiting Africans, is found in a document *Castro Hlongwane, Caravans, Cats, Geese, Foot & Mouth And Statistics: HIV/AIDS and the Struggle for the Humanisation of the African, March 2002*. This document was distributed at an ANC National Executive Committee meeting in 2002 and is widely attributed to Mbeki. Though Mbeki told Gevisser that a collective in the ANC had written the document, he conceded that it reflected his views. In August 2006, Gevisser received an updated version of the document from Mbeki, something Gevisser interprets as a sign that Mbeki remains a denialist. The following quote must thus be seen to represent Mbeki’s defensive reaction to AIDS and ARVs:

Yes, we are sex crazy! Yes, we are diseased! Yes, we spread the deadly HI virus through our uncontrolled heterosexual sex! In this regard, yes, we are different from the US and Western Europe! Yes, we, the men, abuse women and the girl-child with gay abandon! Yes, among us rape is endemic because of our culture! Yes, we do believe that sleeping with young virgins will cure us of AIDS! Yes, as a result of all this, we are threatened with destruction by the HIV/AIDS pandemic! Yes, what we need, and cannot afford because we are poor, are condoms and anti-retroviral drugs! Help! (cited in Van der Vliet, 2004:83)

President Mbeki’s response to the epidemic must also be seen in the light of one of his important ‘projects’, namely that of the African Renaissance. Gevisser pointed out that Mbeki was highly sensitive to Afro-pessimism and saw AIDS as the latest racist weapon in the hands of Afro-pessimists. Mbeki’s rejection of biomedical ‘Western’ treatment (ARVs) and reifying of ‘indigenous’ cures can be interpreted in light of an African Renaissance that aims at finding African solutions to African problems. As such, Mbeki’s AIDS denialism can, as Gevisser pointed out, be framed as a quest for self-identification and self-determination through rejecting Western

stereotypes of Africans and Western treatment. His rejection of ARVs was also influenced by a view of globalisation as a new form of global apartheid, which exploits developing countries. Pharmaceutical companies' promotion of ARVs was seen as a prime example of how the West exploited developing countries.

Rejecting conventional AIDS science, Mbeki insisted instead on linking AIDS to poverty and underdevelopment. With its focus on structural constraints as the 'real' cause of the 'AIDS syndrome', it is compelling as a discourse that removes the locus of blame away from the individual to focus on the relationship between inequality, poverty and infectious diseases - a dynamic strongly evidenced in work such as that of Farmer (1999, 2003). It simultaneously removes the charge that Africans are to be blamed because of their 'unruly sexualities'^{xiv} and indirectly posits that those who are responsible for Africa's underdevelopment, namely the West, are also responsible for the HIV epidemic.

This led the political leadership on a defensive path: conventional AIDS science was rejected because Mbeki assumed that Western science is founded on the view that the HIV epidemic stems from 'the reprehensible conduct' of those infected with HIV (Cameron 2005:118). AIDS statistics were contested because they were seen as evidence of a legacy of a scientific racism, used both in justifying colonialism and apartheid (Robins 2004:654). The efficacy and safety of ARVs were rejected and a reification of 'indigenous'/alternative cures were promoted. Political denial also led to a rejection of the severity of the crisis.^{xv}

However, Mbeki and Health Minister Manto Tshabalala-Msimang's position has been challenged both internally within the ANC, and by academics and social movements such as the TAC. Through the TAC's activism, in 2002, the South African government was compelled to uphold a constitutional right to health care; forcing the health sector to provide HIV-positive pregnant women with ARVs and, a year later, to provide ARVs in public health clinics.

Government policy changed. Yet AIDS-activists such as Nattrass (2006, 2007), Cameron (2005) and Hassan (2006) convincingly argued that, while AIDS denialism has strategically been abandoned, it continued to have an impact on implementation and political discourse^{xvi}, often leading to confused messages and

reluctance to prioritise AIDS. Illustrative of this is Tshabalala-Msimang's comment, after the decision to initiate ARV treatment, that she had been forced to give her people poison. Nattrass also argued that Tsabalala-Msimang's support for alternative treatment of AIDS, mainly nutritional, is part and parcel of denialism. The most recent display of South Africa's alternative solution to AIDS treatment manifested itself at the international AIDS Conference in Canada in 2006, when the Health Ministry displayed various vegetables said to be useful in combating HIV/AIDS.

Hope of a significant change in government policy surfaced in 2007 when a new partnership between civil society and government was forged under the leadership of Deputy President Phumzile Mlambo-Ngucka and then Deputy Health Minister Nozizwe Madlala-Routledge. This shift occurred during the Health Minister's illness. The result was a comprehensive national AIDS strategy and plan. But optimism amongst AIDS activists and researchers were dashed with the dismissal of Madlala-Routledge in August 2007.

However, resistance to Mbeki's AIDS policies has continued to gain momentum. The election of Jacob Zuma as ANC president in December 2007, and the hostile reception Mbeki and his allies received at the ANC's National Conference, is viewed by analysts as a vote against Mbeki's politics and leadership. Along with his views on Zimbabwe and economic policies, AIDS policies have been an issue that have mobilised his political opponents.^{xvii} Suggestions about removing Mbeki from office, through a vote of no confidence, are also partly informed by unhappiness with these policies.

It is premature to attempt to analyse how this new momentum will influence AIDS politics and sentiments on the ground. As my fieldwork had ended before these recent events, they are also not reflected in my informants' views.

4.2 Silence as a dominant discourse

One of the results of the political leadership's ambivalence and denial has been a silencing of the epidemic. By political silence I refer not only to a vocal silence, but also to lack of political leadership, and absence of action, that would

indicate that HIV/AIDS is an issue taken seriously by the political establishment. For instance, Mbeki's State of the Nation address, delivered on 8 February 2008, ephemerally referred to HIV/AIDS only once in his speech (Mbeki 2008, para. 81).^{xviii}

Until Madlala-Routledge's public HIV test in 2006 and Jacob Zuma's in 2007, no prominent South African politician had had a public HIV-test. Neither the country's President nor its Health Minister has taken a public test. This silence can also be viewed as a reluctance to disclose HIV/AIDS status amongst politicians. No politician has publically admitted to a positive status, and no deaths have been attributed to AIDS. Prominent ANC politicians such as Peter Makoba and Steve Tshwete died of pneumonia, leading to speculations that AIDS was the underlying cause.^{xix} IFP leader Mangosuthu Buthelezi's admittance that his son died of AIDS and, most importantly, former President Nelson Mandela's public disclosure of how AIDS has affected his own family, has opened up a public space. Yet, by and large, HIV has been politically silenced during Mbeki's presidency.

On the local level, HIV has had a similar low priority in the dominant political party, the ANC. This became evident during a City Council by-election in May 2007, when HIV/AIDS was completely absent from the agenda. On an election pamphlet, distributed by the local ANC branch, HIV/AIDS did not feature among a number of problems the party promised to address. Neither did it come up during a meeting prior to the by-election. The big political issue was housing, an issue that, for years, has been pivotal in Imizamo Yethu. Similarly, the ANC's Human Rights Day Rally focused on housing, not health.

During a conversation with Tokwe, I asked about the biggest challenge facing his community. He concurred with the view that land and housing are the most important issues. Subsequently, he listed a number of problems that needed to be addressed, mainly, poverty and poor service delivery. Asked about health problems, he talked about diarrhoea in children and tuberculosis as big problems. Only when I raised the question of HIV/AIDS directly did he address it, "Yes, AIDS is also a challenge. ... We are sitting on a time bomb."

At a later stage, Tokwe explained that resource constraints is the reason why health has not been prioritised in the local ANC branch, but that he would like to see it

become a priority. He explained that HIV/AIDS was not on the election pamphlet because the branch decided to focus on 'basic services'. For a community like Imizamo Yethu, issues like housing, lack of sanitation and poverty are obviously of tremendous importance. Yet the 'omission' of HIV/AIDS as an issue on the political agenda mirrors the ambivalent national political response to HIV/AIDS. However, there is a disjuncture between Mbeki's reluctance to admit to the severity of the AIDS crisis and the local experience. Tokwe, a self-professed Mbeki supporter, talked readily about HIV/AIDS as a huge problem, once probed.

A popular form of silence was also evident locally. HIV was a topic not often spoken about. For instance, when I brought up the subject amongst the women producing craft at the community centre, nobody seemed to have an interest in talking about it except for Luyiso. Despite the fact that some of them were selling beaded AIDS-ribbons, AIDS was not a topic for conversation. The beaded ribbons were aimed at tourists passing by, not at creating awareness. Neither did I hear the women working in the soup kitchen, their regular customers, the people who frequented the community centre, the people who attended the daily prayer service or socialised next to the vegetable garden, talk about HIV. HIV was visible through many posters adorning the walls of the community centre, but it was rarely spoken about. The following comment from Thandi is illustrative of this, "People don't talk about it. I realise now that people are dying because of AIDS, but I never heard anybody talk about it." Nonkululeku even mentioned that if some politicians had stood up and admitted to being HIV positive, she would have understood that it was a real threat. During my fieldwork period I heard of two deaths, both were said to be caused by TB. Even when the support group members prepared for a funeral, they talked about the diseased as dying of TB without any reference to HIV/AIDS.

A popular silence exists alongside a stigmatisation of HIV/AIDS. Both function as a form of denial. Silencing HIV/AIDS is a form of defensive denial – a sort of first defence - while stigmatisation functions as a form of denying one's own risk of HIV/AIDS, while admitting its existence. Gladys' comment that people don't usually talk about HIV, but start doing so when fighting, is indicative of the relationship between silence and stigma.

While the popular silencing of HIV was clearly linked to HIV stigma, I want to argue that it was also influenced by the political discourse. If discourse, as Foucault suggested, is created both by speech and silence, then this silence around HIV/AIDS, is part of a discourse around HIV/AIDS. It sets out rules for what can and cannot be said and confirms the popular silencing of HIV/AIDS. With very few public disclosures, non-disclosure and silence became confirmed as the norm. Both PLHAs, and people whose status was unknown to me, interpreted this as a sign that HIV was something that should not be talked about. The political silence thus strengthened a popular tendency to silence HIV/AIDS.

In addition, many PLHAs interpreted the political silence as a confirmation that HIV is a stigmatised disease that should not be talked about. They saw the political silence as a reaction to HIV being a 'bad disease' with Nolufefe arguing, "They don't want to hear about it because it is a disease only 'bad' people get."

4.3 Silence as powerless resistance

Rosendal Østergaard and Samuelsen (2004) argued that silence amongst youth in Burkino Faso and Senegal can be understood as a form of powerless resistance because they feel they cannot protect themselves against HIV without compromising other needs. Drawing on their insights, I suggest that popular silence and stigmatisation in Imizamo Yethu is a form of powerless defence against a disease that the community feels defenceless against, and that this is exacerbated by the political 'silence' and their interpretation of this political silence.

Amongst most informants in Imizamo Yethu, political discourse around HIV/AIDS was mainly interpreted as silence. Informants continuously shrugged their shoulders or responded with silence when I asked about what politicians said and did about HIV/AIDS. Hardly any of my informants, PLHAs and people whose status was unknown to me, could recall what President Mbeki or Health Minister Tshabalala-Msimang had said about AIDS. Instead, they interpreted their silence as denial and indifference, "They don't want to hear about people with HIV. They don't talk about it, and they don't do anything about it. They don't want to know," explained Nonkululeko.

I have previously argued that HIV/AIDS is conceptualised and experienced as a highly contagious disease, which the community feels defenceless against; and that this is linked to a social marginalisation and a more general sense of despair. Even though AIDS is rarely mentioned as the cause of death, most people have experienced relatives or friends who have succumbed to the disease.

Simultaneously, they experience a political silencing of the epidemic as a lack of political will and denial. Thus, there is a disjuncture between local experience of HIV and political denial and silencing. My contention is that this disjuncture increases their sense of defencelessness, powerlessness and alienation. This political silence thus contributes to conditions under which a defenceless silence and stigmatisation is the only available response to the HIV epidemic, in a similar way as silence was the only available response to the youth in Rosendal Østergaard and Samuelsen's study.

Joffe (1999) argued that stigma is a social process that can be managed, depending on how a threat is presented. The political 'silencing' of HIV/AIDS presents HIV as a disease that can or should not be addressed. Political silence and inaction leads to anxiety and exacerbates a sense of vulnerability. This anxiety and vulnerability is dealt with through a defensive 'othering' and stigmatisation. Sometimes, it also leads to a defensive questioning of the existence of HIV, denial of own risk and a 'preference for not knowing'.

The disjuncture between local experience and political denial also impacts on the local political leadership's willingness and ability to tackle HIV/AIDS as it exacerbates their sense of powerlessness, and tests their political loyalties. Tokwe's ambivalence about talking about HIV/AIDS results from a discrepancy between his experience of HIV as a 'time bomb' and the political silence by his party and his leader, Mbeki.

4.4 Political ambivalence, popular uncertainty and stigma

The political questioning of traditional HIV-science, and confused or inconsistent messages about causation and treatment, contribute to HIV being poorly-understood - a factor that contributes to HIV stigma. The political discourse, the political debate

'trickles down' and influences popular discourse through casting doubts about causation and confusion about aetiology. Political silence and contestation has contributed to already existing tendencies to deny and doubt the existence of HIV/AIDS. Phumlani's denial of being at risk of HIV was not only linked to a lack of knowledge of people with HIV, but also to questioning whether the disease really existed. Similarly, Nolufefe argued that her lack of knowledge and belief in the existence of HIV prior to her diagnosis was related to the fact that "community leaders and politicians don't say anything so how can you know whether it is for real?"

4.5 Late and reluctant roll out of ARVs

One of the most significant ways in which the political context has contributed to stigma is by strengthening the conceptualisation of AIDS as an incurable, lethal disease. This has happened through a late and reluctant roll out of ARVs,^{xx} a roll out clouded in a 'fog' of concerns about its efficacy and toxicity, and a continued reification of alternative treatment.

Many informants had clearly picked up on issues around alleged toxicity, side effects and questionable efficacy, which made some fear ARVs, though they did not always link this directly to Tshabalala-Msimang's questioning of ARVs. Gladys for instance was very reluctant to start ARVs. Sometimes, the fear was mediated by personal knowledge of people taking ARVs. Joyce, fearing alleged side-effects and toxicity, was not convinced by her doctors' explanation that she could live longer if she took ARVs. But witnessing a friend's health improve convinced her. "My friend said, 'I take these tablets and look at me, I am healthy.' Then I said, 'Okay, I will take ARVs,'" explained Joyce.

In Uncedo Lolunto, there were very mixed views on ARVs. Many members of the support group took 'immune boosters' provided by the volunteer social worker, who always stressed that these tablets were only for people who did not take ARVs. While the choice was left to the group members, it is clear that the social worker was a firm believer in avoiding - or at least delaying - ARVs. She provided immune boosters and promoted healthy living, together with distributing food parcels, which

contained vegetables, fruit and garlic - Tshabalala-Msimang's nutritional cocktail - in addition to tinned food. But other members, notably Phelo, were strong advocates for ARVs.

As both Sontag (2002 [1991]) and Herek (2002) pointed out, a stigma trajectory can be changed when a cure or treatment becomes available. ARVs have the potential to change the association between AIDS and death. But the notion of AIDS as an incurable (and untreatable) killer disease seems not to have changed significantly with the availability of ARVs. The clinic located in Imizamo Yethu was one of the first clinics in South Africa to begin the roll out of ARVs in 2003. According to the coordinator for the Patients' Advocates, Smangele Khumalo, the clinic currently treats 477 people with ARVs.

The argument that ARVs would change HIV stigma is founded on an assumption that people would accept ARV as an efficient treatment, thus delinking the association with imminent death. This would be likely to happen through knowledge of someone living healthily on ARVs, such as was the case with Joyce. It is impossible to put a figure on the number of people who know someone taking ARVs. But given the fact that very few have disclosed publicly, and that there is a strong reluctance to disclose partially, it is questionable what impact the so-called Lazarus-effect (where people return from a visibly sick state to a healthy state) has had.

The perceived inefficacy of ARVs is also influenced by the fact that many people in Imizamo Yethu seek treatment very late, when ARV treatment should have already begun. Indicative of this is that most of my informants only tested when the HIV-test was suggested to them (during antenatal check-ups) or when they were already sick. About half of the PLHAs who participated in this study had CD4 counts below 200 when they tested positive, a level where they should have started ARV treatment. While some observe that people who start on ARVs do better, others concluded the opposite. Tokwe explained his rejection of ARVs, "I have seen people take ARVs and people take (Rath's) vitamins. I have seen vitamins work. ARVs save people to get fat, but then they get thin again, and I have never seen anybody come back after that."

Sister Larisha Esterhuisen, from the local clinic, argued that sentiments like these are common and make people fearful of ARVs. She explained that the apparent deterioration in the health of people on ARVs with the fact that many start ARV treatment very late and improvement is limited.

Low adherence also contributes to a questioning of their efficacy. With an adherence rate of 65 percent, the clinic has problems with getting people to stay on ARVs, a treatment regime that requires a 95 percent adherence and is life-long. Many reasons are given for this: Circular migration complicates the issue for some patients, while other 'defaulters' indicated that they are tired of being on treatment. But uncertainty about what treatment to choose also led some to seek religious 'healing', or to substitute ARVs with vitamins or with treatment from traditional healers. Thus late and reluctant roll out of ARVs combined with late and reluctant commencement of treatment strengthens the conceptualisation of HIV/AIDS as an untreatable, lethal disease, contributing to its continued stigmatisation.^{xxi}

4.6 Rath, resistance and a discourse of freedom

ARVs are highly contested in the local political environment. Tokwe not only rejected ARVs, but promoted an alternative treatment in the form of controversial German vitamin producer Mathias Rath's vitamins. From a 'shipping container' placed opposite Tokwe's house, the local branch of the South African National Civic Organisation (SANCO), in conjunction with the Rath Foundation, provided free vitamins to residents of Imizamo Yethu. Tokwe was involved in SANCO and, when the woman responsible for distribution left, he took over distribution, assuming a central position in promoting this alternative treatment.

According to the woman responsible for the distribution, about 200 people took Rath's vitamins. The woman argued that many took both Rath's vitamins, ARVs and consult traditional healers, again pointing to confusion about treatment choice.

Tokwe's rejection of ARVs is influenced both by his view that they are ineffective, a belief that they are toxic, and a conviction that pharmaceutical companies exploit poor people - a conviction that he shares with Mbeki and AIDS-

denialists. It is a discourse that the Rath Foundation exploits by tapping into an Africanist discourse. The bottles with vitamins are adorned with a picture of Africa, and leaflets show a continent caught in heavy chains. It encourages people to 'break the pharmaceutical colonialism'.

It is hardly surprising if a political discourse rejecting exploitation of Africans by Western (pharmaceutical) superpowers takes hold amongst people who grew up during apartheid and especially amongst those who, like Tokwe, fought against the racialised political system. Neither is it surprising if it gains currency in a developing country in a time when globalisation exacerbates global inequities.

For Tokwe, treatment choice was also an expression of a newly-won freedom. The insistence on people's right to choose became part of a discourse of freedom and rights. Taking a bottle of Rath's vitamins out of his cupboard, Tokwe explained that people must be free to choose their treatment, "We (the local political leadership) say let it be a choice. We encourage free choice." This discourse was reiterated many times by Tokwe and also by another member of the local ANC branch. It also echoes many statements by Tshabalala-Msimang, (see Natrass 2007:143). Exemplifying how this 'right to choice' is linked to identity politics, is a clash between Tokwe and Liz Huckle, retold by Huckle, in which Tokwe accused Huckle of implying that black people are not smart enough to choose their own treatment. Thus, Tokwe's insistence on freedom of choice can be interpreted as a form of self-determination and self-expression similar to the way Mbeki's AIDS politics, according to Gevisser, is a way of expressing self-determination.

4.7 Limited activism and collective challenge to stigma

In Chapter One, I described HIV stigma as a social process that can be challenged and changed. While the political leadership has not challenged HIV stigma, there has been a strong challenge from parts of civil society such as the TAC. The TAC's struggle is often portrayed as a struggle for access to drugs, but as Robins (2004) rightly points out, the movement's scope and quest goes beyond this

struggle, for instance, in creating a new sense of identity and belonging for its members.

Insisting on health as a human and a constitutional right, the TAC challenges the prevailing discourse around health as a question of personal responsibility and choice. Instead, it insists on the link between structural issues, disease risk and limited access to health care. The TAC also challenges HIV stigma and discrimination.

Firstly, it challenges the notion of HIV as an 'immoral' disease, which can be blamed on the individual sufferers. Secondly, its literacy campaigns attempt to make HIV a well-understood disease. Thirdly, it challenges the discourse of death and despair directly through its fight for access to ARVs, and indirectly through promoting a discourse of hope, an insistence that it is possible to *live* with HIV, a realisation that Andile, for instance, came to through her encounter with the TAC. In its messages, the TAC insists that HIV/AIDS is not a death sentence, neither is it an untreatable disease. The very branding of the 'HIV-positive' identity, visible through the wearing of 'HIV-positive' T-shirts, challenges the notion that HIV is a shameful disease. Fourthly, it provides an alternative to the 'spoiled' identity which is often the result of internalising HIV stigma. It does this through turning the 'HIV-stain/label' into a 'badge of pride' (Robins 2006:320). Through this transformation, AIDS activism promotes alternative identities, what Robins called 'health citizenships and subjectivities'.

Robins argued for the importance of movements such as the TAC and Medicine Sans Frontiers (MSF) in creating 'new identities' and resisting stigma. Comparing his experiences in Khayalitsha where the TAC and MSF have facilitated this process, to Mpumalanga where activism was lacking, Robins questions whether socio-cultural obstacles to implementing a mother-to-child prevention programme were due to the absence of the forms of AIDS activism and health citizenship and subjectivities promoted by the TAC and MSF (Robins 2004:667).

Campbell et al. (2005) argued along similar lines for the importance of collective participation from stigmatised groups in combating stigma. They suggested that the most appropriate tool is a didactic approach, which promotes debate and dialogue, including anti-stigma interventions that facilitate the participation of local

community groups in what they call 'critical thinking programs'. Such programmes would aim to "expose, confront, and resist the webs of significations and practices that sustain stigma and undermine the confidence of communities and individuals who might otherwise challenge it" (Campbell et.al. 2005: 814). Moreover, they argued that health promotional projects have greatest chance of success in a united community where there is a strong local solidarity and robust local networks.

4.8 Clandestine support groups

Robins' and Campbell et al.'s analyses are useful in answering the question: why do high levels of HIV stigma persist in Imizamo Yethu?

While Imizamo Yethu, according to DAG's survey, has strong local networks, the community is not united in its fight against HIV/AIDS. SANCO is involved in distributing Rath's vitamins, which contributes not only to HIV stigma, but also adds to a division within the community. Several clashes between supporters and detractors of Rath are reported to have occurred in the past.

Importantly, HIV-activism is very limited. The TAC has a branch in the township, but according to its leader, Buyiswa, it only has 10 members. Furthermore, they do not disclose publicly, as encouraged by the TAC, but limit their disclosure to other TAC members. Imizamo Yethu has two support groups, but the reach of these groups is limited. Although about 800 people, according to the local clinic, are diagnosed with HIV, the two support groups have a total membership of 40, something that may, partly, be attributed to the fact that they remained semi clandestine. Thus, very few PLHAs seek the support of these structures. Furthermore, they do not challenge HIV stigma significantly. It was clear that Uncedo Lolunto was very important for many members in that it provided them with information, advice, and material, social and emotional support. But its collective challenge to stigma was limited, as was the 'critical thinking' and the support for alternative identities. Rather, I have suggested that a struggle was taking place around disclosure; and the group as a whole shied away from public disclosure and confronting HIV stigma. The majority dealt - as described in Chapter Two - with HIV

stigma through an 'insistence on innocence', that challenged their own position in relation to stigma, but not the framework for or content of HIV stigma. While I did not deal with the other support group, there were no visible sign that it publicly challenged HIV stigma or assisted in creating alternative subjectivities. Thus the impact on anti-stigma efforts and improving public disclosure rates through these support groups seems limited.

Deacon (2005) suggested that if alternative frameworks are supported by society, people are less likely to turn to stigmatisation. In Imizamo Yethu these alternative frameworks are absent. The political silence on HIV/AIDS – and indeed on the occurrence of the disease in their midst – has not provided these frameworks, neither has the Church, nor the support groups. Traditional leaders struggle to understand the disease. This leaves a vacuum with no available alternative frameworks for people facing stigma. Thus, high levels of stigma persist along with denial and silence.

4.9 Challenging stigma through creating a discourse of hope

As HIV stigma is multifaceted, consisting of both instrumental and symbolic concerns, so should interventions. Other authors have pointed to developing a rights-based approach (Deacon 2005); or a focus on community projects and challenging stigmatising beliefs through collective action and 'critical thinking' (Campbell et al. 2004, Robins 2004). The importance of all these are obvious.

This thesis has reflected some of these interventions, specifically the importance of challenging symbolic stigma, the association of HIV/AIDS with 'immorality' and the individualisation of risk. The importance of supporting PLHAs to resist and challenge stigma has been highlighted above. But I have argued that, while the discourse of immorality and individual responsibility are used to devalue PLHAs and to stigmatise them, the source of HIV stigma lies as much in the instrumental concerns about contagion and in the association between HIV and death and despair. Therefore, changing the perception of HIV/AIDS as a 'killer disease', is central in challenging HIV stigma.

Needless to say, effective treatment with ARVs would be one way of doing this. I have outlined how treatment choice is influenced by a number of cultural and social factors and sometimes embroiled in national identity politics, influenced by mistrust of 'Western' scientific data, and presented as a question of self-determination and asserting rights.

Yet, it is also clear, that for many people the 'experiential' level has the potential to set these considerations aside. People notice which treatment is working, as Joyce's story illustrates. It is because of this power of the 'experiential' level that disclosure is central to increasing uptake of ARV and challenging stigma. Several of those PLHAs who were on ARVs were prompted to start treatment after observing someone regain health on ARVs. For both Gladys and Andile, ARVs meant hope, and broke their association of HIV/AIDS with death. For Andile, 'knowing someone living positively with HIV' enabled her to come to terms with her situation because it replaced the death discourse with a discourse of hope.^{xxii}

But the relationship between disclosure and HIV stigma is complex and can be described as a catch 22 situation: Low disclosure levels and late commencement of treatment limits the potential positive impact of ARV on HIV stigma because it does not facilitate the association between ARVs and living positively with HIV. HIV stigma, in return, is a key obstacle in increasing disclosure rates and leading people to seek treatment early; and is based on an interpretation of AIDS as a disease for which there is no cure/effective treatment.

A first step in ensuring that HIV/AIDS become viewed as a treatable condition would be to improve the uptake of voluntary testing as people would commence treatment earlier and more people would become living proof of the efficacy of ARVs. I have previously argued that many people test only when it is suggested to them or when they are already very ill. Some informants suggested that they did not want to test because they perceived that confidentiality was not guaranteed by staff members at the clinic. Despite being unemployed, Thandeka chose to go to a private doctor to test in order to protect her privacy, while Luyiso refused to get tested during her antenatal check-up.

Confidentiality was also viewed as 'compromised' by the very fact that health services are divided into an 'AIDS clinic', as the clinic treating HIV/AIDS, TB and STDs is known in the community, and a clinic for other conditions. This is particularly important in a relatively small community like Imizamo Yethu. Several informants confirmed that visits to the 'AIDS clinic' is viewed as having HIV/AIDS, especially if other 'signs', such as emaciation or not breastfeeding your baby, are also present. On two occasions, I heard people stress that they were going to the clinic 'by the harbour', signalling that they were not going to the 'AIDS-clinic'. Many of the staff members are local residents, a situation that many informants were uncomfortable with. The issue of confidentiality resonates with the findings by Deacon (2005) and Levine (2007), indicating that the issue of confidentiality is a general problem in South Africa's public healthcare system. According to Dr Maslate (personal communication January 2008) from the HIV directorate in the Western Cape Provincial Government, VCT facilities are generally integrated in the general health facilities, while ARV provision is mostly handled either in separate clinics or facilities.

Another point relates to information about HIV and awareness campaigns. Herek (2002) points out that, once disease aetiology is understood, stigma will change. This study has argued that there is still much uncertainty about transmission mode, treatability of HIV, outlook of disease and even sometimes doubts about its existence. While I have argued that remaining ill-informed is sometimes a defence against being stigmatised, it is also important to consider that there is a lack of *accessible* information available. As pointed out, it is important to understand the difference between HIV and AIDS; as well as understanding that, despite not being a cure, ARVs mean that it is possible to live with HIV. While information campaigns alone cannot influence stigma, knowledge is obviously a prerequisite both in risk assessment and in determining whether a disease becomes stigmatised.

Finally, I have argued that, faced with HIV/AIDS, my informants' sense of powerlessness, which leads to stigma as defensive denial, is linked to a more general sense of powerlessness and social marginalisation in post-apartheid South Africa. In addition, I have argued that this is closely linked to the political context and, as such,

would also be addressed through policy change that not only addresses HIV, but also poverty and inequality.

When HIV was a relatively new, deadly, untreatable disease, its stigmatisation may have been unavoidable. But HIV does not need to be stigmatised any more. This chapter has shown, not only how the political context impacts negatively on stigma and disclosure levels, but how it could chart the way in which a committed political effort could change the stigma trajectory, disclosure levels, and ultimately the cause of the epidemic. HIV/AIDS, a disease most fraught with meaning, can – as Susan Sontag predicted in 1989 - become just an illness (Sontag 2002:179).

University of Cape Town

5 CONCLUSION

This thesis has posited that disclosure of HIV status in Imizamo Yethu, a disadvantaged South African township, is experienced as an ambiguous dilemma that is both risky and rewarding.

On the one hand, it has described disclosure as a means to the 'cathartic' release from the burden of hiding, receiving support, and promoting both health and well-being; and on the other, disclosure comes with the fear of being stigmatised and being discriminated against.

This thesis has also described disclosure levels as low, and argued that disclosure is mostly delayed and partial. Disclosure to partners is often avoided. It has suggested that HIV stigma and, related to this, discrimination, are the key factors preventing disclosure.

I have suggested that PLHAs 'resolved' or managed the dilemma of disclosure through two simultaneous processes. The first consisted of the seeking out of people that were likely to be supportive and would not stigmatise the PLHAs, monitoring their attitudes and sometimes testing them. Through this process, they were able to minimize the risk of stigma, while achieving some of the benefits of disclosure. Through the second process, they addressed self-stigmatisation. This took the form of rejecting responsibility for their condition. This rejection occurred through three different avenues: Through the 'insistence on ignorance' about HIV/AIDS; (for women) through 'insistence on innocence'; and passing blame on men's 'immoral' sexual behaviour. These processes enabled PLHAs to reposition themselves in relation to the dichotomy of guilty or innocent victim, without challenging the ideological framework for stigma and the individualisation of blame. Through these processes, a carefully managed partial disclosure became possible. Only when a wish to raise awareness was present, was public disclosure seen as preferable.

I have proposed that HIV stigma is caused by a number of factors. Firstly, HIV/AIDS is seen as an 'immoral' disease, for which the bearers are responsible. It is conceptualised as a highly contagious, lethal, and incurable disease - a conceptualisation that remains despite the availability of ARVs. There is great

uncertainty about illness causation, and confusion and despair surrounding this 'new' illness, not the least amongst institutions such as the Church and traditional healers - those who would normally give guidance. Rather, religious leaders and ordinary community members interpret HIV/AIDS as a sign of the apocalypse. I have linked this framing of HIV/AIDS to its conceptualisation as a highly contagious lethal disease, against which the body politic, as well as individuals, are defenceless - suggesting that HIV/AIDS is viewed with despair. Furthermore, this despair is embedded in a more general despair over social ills, this community's marginalisation in post-apartheid South Africa, and their own position and 'possibility' in the world.

Based on this analysis, HIV stigma amongst people who share a marginalised position and live in a community with high HIV-prevalence should be understood within Joffe's blame model - as a defence mechanism against this threat. While I use this model as my foundation for understanding HIV stigma, I have also shown that it has a 'system justifying' function, reasserting traditional authorities' power by stigmatising HIV/AIDS as 'immoral'. I have contended that HIV stigma does create exclusion, an exclusion closely linked to a fear of contagion. Beyond the gender aspect, it does not seem to run along already established fault lines in the local context.

I have described President Mbeki's response to the HIV/AIDS epidemic as denial and ambivalence, influenced by denialism. The political leadership's defensive rejection of both conventional HIV/AIDS science and treatment (ARVs), in addition to 'silencing' HIV/AIDS, has had serious consequences for stigma and disclosure. Firstly, the political silence has influenced popular silencing of HIV/AIDS and thus contributed to reluctance to disclose. Secondly, a disjuncture between the political silence and inaction, and the experience of HIV/AIDS as a threat of apocalyptic proportions, has contributed to a popular silencing and stigmatisation of HIV/AIDS as a defenceless or powerless resistance. Furthermore, I have suggested that the discrepancy between silence and experience has also left local political leaders 'ambivalent' about addressing HIV/AIDS, resulting in the local political discourse to some extent mirroring the national discourse.

The political questioning of traditional HIV/AIDS science has influenced HIV stigma by contributing to popular uncertainty and questioning of transmission mode - again reinforcing a pre-existing tendency to 'deny' this threat. Moreover, the political response has contributed to stigma by strengthening the association between HIV/AIDS and death. This has occurred through the delayed and reluctant roll out of ARVs and the continued questioning of their efficacy, safety and side effects. Local community and political leaders' support for alternative treatment - influenced by their political allegiance; their rejection of ARVs as 'pharmaceutical colonialism'; as well as the need to express their 'rights' - has also contributed to the questioning of treatment choice.

The impact of ARVs on changing HIV stigma, by changing the conceptualisation of the condition as treatable, has been limited. Treatment choice is embroiled in a complex web of cultural politics, rejection of 'Western' science, and assertion of self-determination; but it is also influenced by witnessing people regain health on ARVs. Thus, disclosure is important in reconceptualising HIV/AIDS as a treatable condition. But the relationship between disclosure and HIV stigma is complex and can be described as a catch-22 situation: low disclosure levels prevent the re-conceptualisation of HIV as a treatable disease, because it does not facilitate the association between ARVs and living positively with HIV. HIV stigma, on the other hand, prevents PLHAs from disclosing.

While the political leadership has not managed HIV stigma well, the dominant position of denial and silence has been challenged, both from within the ruling party and from civil society. However, in this particular township, there is limited HIV-activism and, therefore, a lack of alternative frameworks that would enable PLHAs to resist and challenge stigma.

Having argued that HIV stigma is multidimensional, I have suggested a multifaceted approach to addressing stigma. This should clearly include HIV-activism that challenges stigmatising beliefs, such as the individualisation of risk and the conceptualisation of HIV as an 'immoral' disease. It should also include awareness-raising, so as to reduce the confusion about transmission mode and illness causation. Particularly, this study has pointed to the importance of understanding the difference

between HIV and AIDS, and clarifying that HIV/AIDS, while incurable, can be managed with treatment.

I have stressed the importance of replacing a discourse of death and despair – HIV as a lethal and untreatable disease - with a discourse of hope, and suggested that this is possible through ensuring access to quality health care. This includes removing barriers that limit access to health care, such as ensuring confidentiality at health clinics, which will enable people both to test and seek treatment without risking 'exposure'.

Finally, I have highlighted the importance of addressing the conditions that exacerbate the tendency to stigmatise as a way of denying risk. This means a stronger political commitment to addressing HIV/AIDS along with social inequality in post-apartheid South Africa.

I have questioned whether higher disclosure levels will lead to changing risk perceptions, arguing that; on the one hand, 'knowing someone with HIV' seems to be a prerequisite for mitigating risk. Yet, personal knowledge of someone with HIV seems to lead to stigmatisation as denial of risk in this context: a community with high prevalence and where HIV is conceptualised as a disease that the community, as well as the individual, is defenceless against. While research (Derlega et al. 2004) suggests that people may discard misperceptions about HIV when they know someone with HIV/AIDS, this research does not directly address the question of whether it leads to a change in perceptions of one's own risk. Further research is needed to understand how, and in which context, personal knowledge of someone with HIV/AIDS facilitates a change in risk perceptions and behaviour.

While this thesis points to the gendering of blame, stigma, and disclosure, further research is needed to draw out the strongly gendered dimension of disclosure. Despite women being stigmatised for 'immoral' behaviour, they seem to find disclosure easier or more preferable than men, who were reluctant to disclose. This presents us with a conundrum: If men are less likely to be stigmatised for 'immoral' behaviour, why are they much more reluctant to disclose? Thus, additional research needs to be conducted to understand the gendered aspect of disclosure and HIV stigma.

Notes

ⁱ Shisana et al. (2005) found that half of HIV-positive people had not perceived themselves at risk.

ⁱⁱ According to Ipsos Markinor's *HIV/AIDS Risk Assessment* (Ipsos Markinor 2005), 30 percent of South African belong to a group they call 'high risk'.

ⁱⁱⁱ This figure is according to DAG's 2003 survey.

^{iv} This figure is from The South African Department of Health Study 2006, cited in South African HIV and AIDS statistics 2006.

^v See for instance Cosatu land-grab irks DA leader. 2007. *Mail & Guardian Online*.

^{vi} Marion Frank is based in the community centre. She provides support for people in need, and assists the support group.

^{vii} The study by Chandra, Deepthivarma and Manjula pointed to the importance of family as the primary support system in India. It is reasonable to assume that, amongst poor South Africans, families continue to be the primary support system despite the availability of social security grants.

^{viii} This distinction between 'innocent' and 'responsible' victims has defined the AIDS epidemic since its advent 25 years ago; with 'innocent' victims being haemophiliacs and children, and 'guilty' victims being homosexuals, prostitutes, drug users and 'promiscuous' adults.

^{ix} Limited knowledge and incorrect information seem to be pervasive. According to Ipsos Markinor's survey, 23 percent of South Africans believe that HIV can be spread by mosquitos. 14 percent said they do not really know how one gets HIV/AIDS. See HIV/AIDS Risk Assessment 2005. *Ipsos Markinor News*.

^x A survey by Kalichman et al. (2004) in a black township in Cape Town found that 11 percent believed that AIDS is caused by spirits and supernatural forces, while 21 percent were unsure if it is caused by these.

^{xi} To what extent HIV stigma, in the broader context, functions as a way of reproducing social difference is beyond this thesis.

^{xii} A similar response to the AIDS epidemic was seen in the US, where it was initially seen as a 'gay disease', something that led heterosexuals to deny their risk.

^{xiii} I distinguish between denialism, the rejection of conventional AIDS science, and denial - the denial of the severity of the AIDS crisis. While denialism inevitably leads to a denial of the severity of the crisis, it is possible to deny the severity of the AIDS crisis without being a denialist *per se*.

^{xiv} A charge which, according to Paul Farmer, is evident in much AIDS research that focuses on sexual behaviour without linking this to issues such as poverty and gender inequality. (see Farmer 1999)

^{xv} Illustrative of Mbeki's denial of the severity of the crisis is an article in City Press. Mbeki responded to a report about a crisis in the public sector due to many AIDS deaths in the following way: "People die from anything... no one has sounded the alarm where I work daily in the presidency and nobody has said there is a particularly alarming tendency of people dying." (Seepe and Sibanda 2006: para.6)

^{xvi} Nattrass (2006) argued that, "The Health Minister has undermined the HAART rollout by interfering with the ability of provinces to raise money from the Global Fund, by dragging her heels over drug procurement, and by failing to address adequately the human resources crisis in the health sector".

(ibid 2006: 17). Natrass called the government's ARV programme a comfortable hiding zone, arguing that the government on paper has a comprehensive AIDS policy that it uses to shield it from criticism.

^{xvii} Commentator Jeremy Gordin argued, for instance, that an abyss between Mbeki and rank and file members of the ANC was partly caused by his support for Health Minister Tshabalala-Msimang and his firing of Madlala-Routledge, outspoken former Deputy Health Minister. (Gordin 2007: para. 26)

^{xviii} In his State of the Nation address, 2008, Mbeki mentioned HIV/AIDS once, "Accelerating our advance towards the achievement of a goal of health for all includes intensified implementation of the National Strategic Plan against HIV and AIDS." (Mbeki 2008: para 81)

^{xix} This political reluctance is mirrored by a broader popular reluctance to disclose, with Judge Edwin Cameron and TAC chairperson Zackie Achmat being amongst the exceptions.

^{xx} Natrass (2007) argued that the number of people on HAART lack behind operational targets set by the Health Ministry. In 2006, 213.828 South Africans received HAART in the public sector. The target was 600.000. (Natrass 2007:133)

^{xxi} While ARVs have the potential to impact on HIV stigma through changing the perception of HIV/AIDS as a deadly, untreatable disease, it is important to bear in mind that it addresses only the instrumental concern, not the symbolic component of HIV stigma - its association with immorality - as Campbell et al. (2005) reminds us.

^{xxii} The importance of hope in sustaining safe sex practices has been explored by Gibson and Nadasen (2007). Here the importance of hope is seen in relation to imagining living with HIV and responding to risk in other ways than denial and stigmatisation

Bibliography:

- Alonzo, A. and Reynolds, N. 1995. Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory. *Social Science Medicine*. 41(3): 303-315.
- Ashforth, A. 2001. AIDS, witchcraft and the problem of power in post-apartheid South Africa. Occasional Paper Nr. 10. Princeton. New Jersey: Institute of Advanced Study, School of Social Science.
- Campbell, C. et al. 2005. I have an evil child at my house: stigma and HIV/AIDS management in a South African community. *American Journal of Public Health*. 95(5): 808-815.
- Cameron, E. 2005. *Witness to AIDS*. Cape Town: Tafelberg Publishers.
- Chandra, P.S., Deepthivarma, S. and Manjula, V. 2003. Disclosure of HIV infection in South India: patterns, reasons and reactions. *AIDS CARE* 15(2): 207-215.
- Comer, L. et al. 2000. Illness disclosure and mental health among women with HIV/AIDS. *Journal of Community & Applied Social Psychology* 10: 449-464.
- Cosatu land-grab irks DA leader. 2007. *Mail & Guardian Online*. January, 15. [Online]. Available at: http://www.mg.co.za/articlePage.aspx?articleid=295804&area=/breaking_news/breaking_news__national/ [2008, February 14].
- Development Action Group. 2003. Imizamo Yethu survey 2003. (Unpublished).
- Delius, P. and Glaser, C. 2005. Sex, disease and stigma in South Africa: historical perspectives. *African Journal of AIDS Research* 4(1): 29-36.

-
- Derlega, V. et al. 2004. Reasons for HIV disclosure/nondisclosure in close relationships: testing a model of HIV-disclosure decision making. *Journal of Social and Clinical Psychology* 23(6): 747-767.
- Deacon, H. 2005. *Understanding HIV/AIDS Stigma: a theoretical and methodological analysis*. Cape Town: HSRC Press.
- Farmer, P. 2003. *Pathologies of power .health, human rights, and the new war on the poor*. Berkeley: University of California Press.
- Farmer, P. 1999. *Infections and inequalities: the modern plagues*. Berkeley: University of California Press.
- Farmer, P. 1992. *AIDS and accusation. Haiti and the geography of Blame*. Berkeley: University of California Press.
- Gibson, D. and Nadasen, K. 2007. I have plans: scrutinising the meaning, production and sustaining of hope in safe sexual practices among young men in Khayelitsha, Cape Town. *Anthropology Southern Africa* 30(1&2). In print.
- Gevisser, M. 2007. *The dream deferred: Thabo Mbeki*. Jeppestown: Jonathan Ball Publishers.
- Goffman, E. 1963. *Stigma: notes on the management of spoiled identity*. New Jersey. Prentice Hall.
- Gordin, J. 2007. The people have taken back the party. *Sunday Independent*. December, 23. [Online]. Available on:
http://www.iol.co.za/index.php?set_id=1&click_id=3054&art_id=vn20071223090535215C406763 [February 14, 2008].

-
- Green, E. 1999. *Indigenous theories of contagious disease*. Walnut Creek: Altamira Press. Sage Publication.
- Grundlingh, L. 1991. HIV/AIDS in South Africa: a case of failed responses because of stigmatization, discrimination and morality, 1983-1994. *New Contree* 46: 55-81.
- Hassan, F. 2006. Is there still denialism about HIV/AIDS in South Africa? Paper presented at the Harold Wolpe Memorial Trust's 50th open dialogue. (Unpublished).
- Henderson, P. C. 2005. A gift without shortcomings: healers negotiating the intersection of the local and global in the context of HIV/AIDS. *Social Dynamics* 31(2): 24-54.
- Herek, G. M. 2002. Thinking about AIDS and stigma: a psychologist's perspective *Journal of Law, Medicine & Ethics* 30: 594-607.
- Herek, G. and Capitano, J. 1998. Symbolic prejudice or fear of infection? A functional analysis of AIDS-related stigma among heterosexual adults. *Basic and Applied Social Psychology* 20(3): 230-241.
- HIV/AIDS Risk Assessment. 2005. *Ipsos Markinor News*. May, 20. [Online]. Available: <http://markinor.co.za/news/hivaids-risk-assessment> [2008, February 14].
- Ijumba K., et al. 2004. Sexual risk behaviours are influenced by knowing someone with HIV/AIDS. *South African Medical Journal* 94: 522-23.
- Joffe, H. 1999. *Risk and 'the other'*. Cambridge University Press.

-
- Jewkes, R., Levin, J. and Penn-Kekana, L. 2003. Gender inequalities, intimate partner violence and HIV preventive practices: finding of a South African cross-sectional study. *Social Science & Medicine* 56: 125-134.
- Kalichman, S.C. and Simbayi, L. 2004. Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. *AIDS Care* 16(5): 572-580.
- Lawless, S., Kippax, S. and Crawford, J. 1996. "Dirty, diseased and undeserving": The positioning of HIV positive women. *Social Science Medicine* 43(9): 1371-1377.
- Leclerc-Madlala, S. 2002. Youth, HIV/AIDS and the importance of sexual culture and Context: *Social Dynamics* 28(1): 20-41.
- Leclerc-Madlala, S. 2001. Virginty testing: Managing sexuality in a maturing HIV/AIDS epidemic. *Medical Anthropology Quarterly* 15(4): 533-552.
- Levine, S. and Ross, F. 2002. Perceptions of and Attitudes to HIV/AIDS among Young Adults in Cape Town. *Social Dynamics* 28(1): 89-108.
- Levine S. 2007: Media as medical intervention: HIV/AIDS and the new struggle for women's reproductive health care in South Africa. [Online] Available: www.medicuscundi.es/catalunya. [2008, February 14].
- Mbeki, T. 2008: *State of the nation address 2008 (08/02/2008)*. February 8. [Online] Available on: www.polity.org.za/article.php?a_id=12651. [2008, February 14].
- Nattrass, N. 2004. *The Moral Economy of AIDS in South Africa*. Cambridge University Press.

-
- Nattrass, N. 2006. AIDS, Science and governance: The battle over antiretroviral therapy in post-apartheid South Africa. *Aids and Society Research Unit Working Paper*. [Online] Available: www.asru.uct.ac.za [2008, February 14].
- Nattrass, N. 2007. *Mortal Combat. AIDS denialism and the struggle for antiretrovirals in South Africa*. Pietermaritzburg. University of KwaZulu-Natal Press.
- Norman, A., Chopra, M. and Kadiyala, S. 2007. Factors related to HIV disclosure in 2 South African communities. *American Journal of Public Health* 97(10): 1775-1781.
- Parker, R. and Aggleton, P. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for actions. *Social Science & Medicine* 57: 13-24.
- Paxton, S. 2002. The paradox of public HIV disclosure. *AIDS CARE* 14(4): 559-567.
- Robins, S. 2004. "Long live Zackie, long live": AIDS activism, science and citizenship after apartheid. *Journal of Southern African Studies* 30(3): 652-672.
- Robins, S. 2006. From "rights" to "ritual": AIDS activism in South Africa. *American Anthropologist* 108(2): 312-323.
- Rosendal Østergaard, L. and Samuelsen, H. 2004. Muted voices: HIV/AIDS and the young people of Burkina Faso and Senegal. *African Journal of AIDS Research* 3(2): 103-112.
- Seepe, J. and Sibanda, M. 2006. 'There is no govt. aids crisis'. *City Press*. February, 26. [Online]. Available: http://www.news24.com/News24/South_Africa/News/0,,2-7-1442_1888671,00.html [2008, February 14].

-
- Shisana, O. et al. 2005: *South African national HIV prevalence, HIV incidence, Behaviour and Communication Survey*. Cape Town. Human Science Research Council.
- Simbayi, L.C. et al. 2007. Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. *Sexually transmitted infections* 83: 29-34.
- Simoni, J. et al. 1995. Women's self-disclosure of HIV infection: Rates, reasons, and reactions. *Journal of Consulting and Clinical Psychology*. 63(3): 474-478.
- Sontag, S. 2002. *Illness as metaphor and AIDS and its metaphors*. London. Penguin Books.
- South African HIV and AIDS statistics 2006. [Online]. Available: <http://www.avert.org/safricastats.htm> [2008, February 14].
- Van der Vliet, V. 2004. South Africa divided against AIDS: a crisis of leadership. In *AIDS in South Africa: the social expression of a pandemic*. K. D. Kauffman and D.L. Lindauer. Eds. New York: Palgrave Macmillan. 48-96.