University of Cape Town

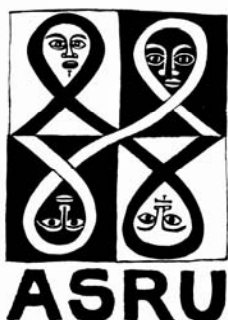# CENTRE FOR SOCIAL SCIENCE RESEARCH

BEYOND THE DISEASE OF DISCRIMINATION: A CRITICAL ANALYSIS OF HIV-RELATED STIGMA IN KTC, CAPE TOWN

Elizabeth Mills

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Aids and Society Research Unit

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Abstract

The aim of this paper is to explore the nature and dynamics of HIV-related stigma in the KTC with a view to understand the impact of stigma on the lives of HIV+ people and their social environment. This paper draws on qualitative research methods, including focus groups, interviews and participant observation. Research was conducted in KTC, a shack settlement in Cape Town, with a group of home-based carers, and their HIV-positive clients, in 2003 and 2004. The complex matrix of factors, like socio-economic and gender inequality, which perpetuate HIV-related stigma in the context of KTC, is explored through this paper. This paper argues that social networks in KTC can play both a constructive and destructive role in facilitating care, and HIV-related stigma respectively. Finally, the research and findings of this paper point to the need to shift away from the notion that stigma is experienced by the individual to a more multifaceted understanding of the impact of HIV-related stigma on the HIV+ individual's social environment.

HIV is an epidemic of global proportions and at the same time it cuts into the heart of individual experiences of illness. In South Africa, despite significant changes that have taken place in the last eleven years of democracy (for example the transformation of the public health care system), people are still dying of AIDS-related illnesses when they could be living healthy lives with the assistance of antiretroviral treatment and adequate food. Another significant aspect of the HIV epidemic, nationally and internationally, is the extent to which individuals and their families are affected by stigmatising discourses and behaviours.

This paper aims to bring out some of the experiences of people living with HIV, or dying of AIDS-related illnesses in KTC, an informal shack settlement in Cape Town, South Africa. The research that forms the basis of this paper was

conducted in 2003 and 2004 with a home-based care (HBC) organisation, called Luvuyolwethu. This organisation provides HBC for over 80 HIV+ people living in KTC. The experiences of both the carers and the clients of Luvuyolwethu form the basis of this critical exploration into the myriad ways in which the HIV epidemic plays out in the lives of HIV+ people and their families, and focuses particularly on the shape, derivation and consequences of HIV-related stigma in this area of South Africa.

Stigma and HIV-Related Stigma

The term 'HIV-related stigma' and not simply 'stigma' is used throughout this paper in order to highlight the particular relationship between HIV and stigma that may, and in many cases does, differ from other forms of bigotry, like homophobia or racism. According to Stein, HIV-related stigma differs from other forms of bigotry in so much as

> 'the stigmatized person is someone who is part of a group but has a spoiled identity in relation to that group because in some respect, s/he has become deviant or abnormal' (2003: 5).

In the case of homophobia, or racism, stigma is predicated on the basis that the 'other' is identified as a member of a group of people that is different from the group of people with which the bigot identifies. The extent to which this theory of stigma can be applied in the context of KTC is explored through the discussion around risk groups below.

For the purpose of this paper, Goffman's (1963) definition of stigma is used as a starting point for the subsequent discussion around the particular nature of HIV-related stigma internationally and in South Africa. According to Goffman, a stigmatised person is someone who is seen to possess disgraceful characteristics (1963). However, Goffman (1963) goes on to argue that stigma exists through relationships and is not simply a consequence of what is perceived to be a discrediting characteristic:

> 'stigma … will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is needed' (1963:13).

State Health Care and Home-Based Care

The development of home-based care (HBC) is, in part, a product of the post-1994 government's decision to decentralise the National Health System (NHS). In 1994 the African National Congress (ANC) drew up policy that would govern the NHS throughout South Africa. This plan argued for the decentralisation of the "management of the delivery of services to provinces, districts and institutions in order to create efficiency, local innovation, empowerment and accountability." (ANC, 1994: 59). This document argues for a 'continuum of care' between the different levels of health services in order to facilitate the provision of care to people who had been discriminated against under the apartheid government (ANC, 1994 and Buch, 2000).

The notion of a 'continuum of care' between the various levels of health services formed part of the rationalisation that supported the development of HBC. The formal recognition of HBC is part of the South African government's response to the HIV epidemic. In a document detailing the South African government's response to the current HIV epidemic, the Department of Health states "To relieve the burden on the public health care system, one strategy pursued for the care and treatment of all chronic patients, including HIV/AIDS patients, is the development of quality home-based care." (Department of Health, 2003).

Locating Luvuyolwethu

As mentioned above, the research was mainly conducted in KTC, a low-resource area that is geographically located in the centre of Cape Town's unicity. The following map indicates the location of KTC in relation to Cape Town.

The low-income and high unemployment level of this area are partially a result of the residue of Apartheid laws that encouraged the development of a cheap non-white labour force on the periphery of central business and industrial areas (Wilson and Mafeje, 1963 and Magubane, 1979). The relationship between past experiences of health, illness and health care under Apartheid and current living (and dying) conditions experienced by informants in KTC indicates that, according to one informant "Apartheid hasn't really left us, it just looks different now. Our lives are still the same… and sometimes worse."

Luvuyolwethu was officially registered as a non-profit HBC organisation in 2003. Its inception, however, dates back to 2000. Selina Poswayo, the founder

and co-ordinator of Luvuyolwethu, and the other carers of Luvuyolwethu have not received any formal financial support, and therefore provide care (and resources wherever possible) as unpaid volunteers.
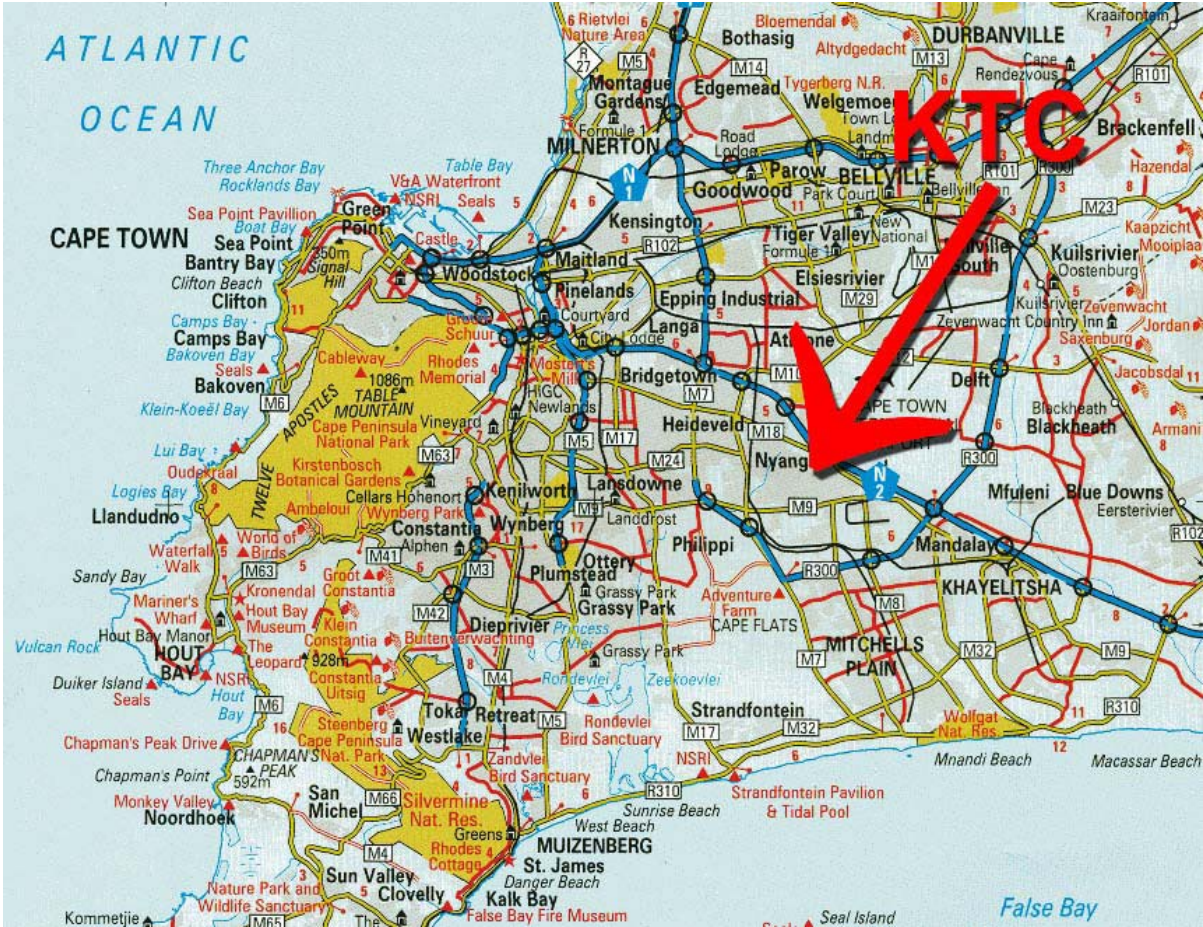
The following excerpt from an interview conducted with Selina Poswayo describes how she first became involved in HBC. This excerpt highlights Selina's initial discriminatory attitude towards HIV+ people in KTC; this attitude shifted, however, when she became aware of the damaging effects that HIV-related stigma had had on the life of her neighbour who had been abandoned by her family as she died of AIDS-related illnesses.

> Selina laughed as she said: "I used to tell my niece and sisters that HIV is a dangerous disease and I won't help anyone who has this. I said that I'll put you outside in the sun and do my own thing.
>
> 'I started getting involved with HIV when I visited a neighbour who was dying of AIDS. She lived in New Crossroads, down the street from me. Her family had left her and were ignoring her because she had AIDS. She was messing in her bed, and she couldn't care for

herself ... I started to care for her … After a while I started to care for more people in KTC'.

'My sister was studying social work. She told me that I was doing home-based care. I didn't know this. But I thought – OK, I'm doing home-based care'.

In 2004 five Luvuyolwethu carers, Selina, Lorraine, Dunyiswa, Cecilia and Lumke provide HBC for approximately 40 HIV+ people and 40 people who are seriously ill (in the fourth stage of the disease[1]) and taking antiretroviral treatment. During my fieldwork I spent more time with Selina and Lorraine; they had taken on the position of being the main carers for Luvuyolwethu. This was partially due to their ability to balance the time spent on income-generating work, and time spent on work as Luvuyolwethu carers. All of the Luvuyolwethu carers are in their late thirties or early forties. They all have children, and other jobs in order to support themselves and their families, and the income they generate subsidises their unpaid work as carers in KTC.

The Luvuyolwethu carers refer to themselves and the work that they do, in isiXhosa, as *nceda abantu*, which literally means 'help people'. In turn, the carers refer to the people to whom they provide HBC as 'clients'. The carers specifically use the term 'client' to denote a professional relationship between themselves and the people who have approached them for assistance. Luvuyolwethu's decision to describe the people they care for as 'clients' relates, according to Selina, to their desire to reinforce their clients' belief in themselves not as victims, or patients, but as agents seeking out a service. The process of going to visit clients is described by Luvuyolwethu carers as 'doing rounds'. These words formalise the form of work that the Luvuyolwethu carers provide, and it also places a distance between visiting 'friends' or 'neighbours' as a friend and formal procedures of administering care as a professional.

The Luvuyolwethu carers visit the clients who are ill at least three times a week, and up to three times a day if the client is seriously ill or dying. Their visits range from sitting down with the client and listening to their concerns, to offering advice or arranging a time to go with them to the clinic, to preparing food and providing intensive care for clients when they are too sick to move and have little or no social support.

Once a week the Luvuyolwethu carers receive and distribute food parcels to the clients who are in the third stage of treatment. This food is donated to

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[2] This stage is reached when the CD4 cell count drops below 200, and antiretroviral drugs are needed to fight HIV (Whiteside and Sunter, 2000:21).

Luvuyolwethu by Woolworths, a South African food chain. After collection, the food is taken into KTC where it is packed and then distributed to Luvuyolwethu's clients. The distribution of food is one of Luvuyolwethu's most important services: many clients depend solely on the food they receive from Luvuyolwethu and the administration of ARVs is made more effective through this distribution as ARVs need to be taken with food.

Participant observation, focus group discussions, informal semi-structured, open-ended interviews and conversations constitute the main methods that I used in the course of my fieldwork and research with Luvuyolwethu's clients and carers. Many of the conversations and focus group discussions were conducted in a mixture of English, Afrikaans and Xhosa with Selina and Lorraine translating where necessary[2].

Significations of HIV-Related Stigma

From Past to Present: Tracing the Trajectory of HIV-Related Stigma

When asked what they understood 'stigma' around HIV and AIDS to mean, the Luvuyolwethu carers and clients offered the following definitions: "Stigma is like a label"; "It is a disgrace"; "Stigma is like the daily news … all the neighbours talk about you"; "It is as if you have HIV+ written across your shirt". These understandings of HIV-related stigma resonate with the ancient Greek use of the word 'stigma': in ancient Greece if a person contravened a social law they were branded with a tattoo; this tattoo was called a 'stigma' (Crawford, 1996 in Stein, 2003). However, unlike the physical depiction of deviance – a stigma branded on one's body – in ancient Greece, HIV-related stigma is a like a metaphorical label that depicts social deviance.

The conception that HIV is related to social deviance has characterised, to a large extent, the way in which people all over the world have treated and continue to treat HIV+ people. Notions of what is socially acceptable or socially deviant are created through powerful discourses, evident in the media and espoused through education campaigns like the ABC campaign, condemning certain behaviours and accepting others. Weeks (1989) comments on some the

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[2] In some cases the clients indicated a desire to remain anonymous. For this reason, some of the clients are referred to using pseudonyms.

factors that have shaped and continue to influence the construction of the HIV+ person as 'other':

> 'AIDS has become the symbolic bearer of a host of meanings about our contemporary culture: about its social composition, its racial boundaries, is attitudes to sexual marginality…What gives AIDS a particular power is its ability to represent a host of fears, anxieties and problems in our current post-permissive society'. (1989:2)

Research into HIV-related stigma over the past twenty years has highlighted a number of discourses that identify specific groups of people as socially deviant and at risk of contracting HIV. HIV-related stigma is largely interconnected with and built on discriminatory discourses and practices, like racism:

> 'HIV-stigmatising discourses quickly incorporated racist discourses too, as the illness began emerging among minorities in the USA and then quickly reaching large numbers in Africa, accompanied by racist 'othering' notions such as the claim of the virus originating in Africa and the old racist link between promiscuity and blackness' (Ratele and Shefer 2002:186).

Initially, as the above quote states, minorities, like homosexuals, Haitians and Africans, were blamed for contracting the virus through deviant sexual behaviour.

> 'AIDS was seen as the result of sexually excessive and degenerate individual behaviours, which originated among aliens' (Strebel, 1997: 17).

For example, the United States of America (USA) initially blamed the Haitians for the increasing rates of transmission of HIV in the USA. Medical experts in the USA claimed that Haitians contracted the virus through 'voodoo practices' involving sexual intercourse with animals and then transmitted the virus through sex work to US citizens (Farmer, 1998). The stigmatisation of minorities became part of a prevailing discourse around HIV and AIDS that identified certain groups of people, like homosexuals and Haitians, as having a higher chance of contracting and transmitting HIV.

According to Baer, Singer and Susser (1997) the epidemiological construction of 'risk groups' was a result of conceptually isolating HIV and AIDS from a large array of factors that contribute towards the transmission of HIV. Consequently, the concept of 'risk groups' separated people who fell outside of the identified groups from those who were classified as belonging to a 'risk

group'. Furthermore, people who did identify themselves with a particular 'risk group', because they were Haitian or homosexual for example, were labelled as likely to be HIV+, or at risk of contracting the virus. Therefore, the creation and perpetuation of 'risk groups' demonstrate that the HIV+ other is not necessarily, as Stein (2003) claims, someone who has been a part of a group and has a 'spoiled identity' in relation to that group. Identified risk groups, like homosexuals or Haitians, are stigmatised by groups or people belonging to groups that do not identify themselves with t he 'risk group'.

Along with the racist underpinnings of HIV-related stigma, moralistic constructions of sexuality create a rich environment for stigma to take root and blossom into discrimination. Stein (2003) argues that discourses around sexual morality are evident in HIV education campaigns like the ABC campaign, which reinforces instead of undermining HIV-related stigma.

The A and the B in the ABC HIV-awareness campaign in South Africa promoted Abstinence and encouraged people to Be Faithful. The C in this campaign stood for Condomise. The ABC campaign communicated to South Africans that if a person abstained from sexual intercourse, was monogamous and used a condom, they would not contract HIV. By implication, if a person did not abstain, did not have only one sexual partner and did not use condoms, s/he was likely to contract HIV (Stein, 2003 and Joffe, 1999).

Aside from obscuring the myriad factors that influence the transmission of HIV, the ABC campaign placed the responsibility for contracting HIV onto the shoulders of the individual. Sexually prescriptive discourses, exemplified for example by the ABC campaign, have played a role in shaping the responses that Luvuyolwethu's clients receive when they disclose their HIV+ status; in some cases the clients were told that they deserved to be HIV+ because they "had too much sex" and "too many boyfriends or girlfriends". As a result of the stigma attached to being HIV+ and the inferences made about their promiscuity or unfaithfulness, Luvuyolwethu's clients were alienated in their social environment.

Stigma-Sign Language

The 'spoiled identity' of an HIV+ individual is enunciated, as Goffman (1963) proposes, through relationships between people and groups of people. Goffman argues that stigma highlights the relationship between power and the representation of the HIV+ individual as 'other' through powerful 'truths' of exclusion. Said has theorised the nature of the relationship between power and

representation in his book Orientalism (1972). Said's theories on the construction of the 'Orient' bears significance in this discussion of the ways in which HIV+ people are imagined through the lens of HIV-related stigma. As discussed above, the power of stigma lies in its ability to represent a host of fears associated with HIV and AIDS. Stigma isolates the HIV+ individual from the person or group that stigmatises, thus isolating them from the disease and the fears that are associated with HIV and AIDS. As with Said's assertion that Orientalism provides the viewer with a standpoint to see, but not to be seen (1972), so too does stigma provide a platform from which the stigmatised HIV+ 'other' can be viewed, obscuring the position of the person or group that stigmatises.

Said argues that

> 'the Orient is an idea that had a history and a tradition of thought, imagery and vocabulary that have given it reality and presence in and for the West'. (1978:132).

Similarly, HIV-related stigma is mired in a language of discrimination that stretches back to the beginning of the HIV-epidemic and reaches forward to the present concretely affecting and influencing the ways in which the HIV+ other is viewed and treated.

In the course of my research in 2004, I asked the Luvuyolwethu carers and clients to tell me how they have, and continue to, experience and witness stigma as it is enacted in KTC. A long conversation ensued in which the informants described an elaborate language of hand signals and metaphors that has been developed to identify particular people as HIV+. This language is used to label HIV+ people - branding them as 'other' – and for this reason these metaphors and hand signals are referred to in this paper as 'stigma sign language'. In addition to the visible signals and verbal phrases, one of the carers, Lorraine, said that it was important to also understand the power of a single look: She said, "people can use their eyes to speak." Lorraine proceeded to show me, with her eyes, how she would identify one of the other people in the room as HIV+.

The language of stigma that the carers and clients described during our focus group discussions illustrates the misconceptions around HIV and AIDS that fuel HIV-related stigma in KTC. It also highlights the way in which language can be used to separate and distance the stigmatised 'other' from the individual or group stigmatising the HIV+ 'other'. The informants described how, in a group of three people, two people can furtively communicate using sign language, that the third person in the group is HIV+. Showing three fingers, or making the sign of a cross with the two index fingers indicates that the person to whom the

person is referring is HIV+. The informants offered the following explanations of these hand signals: in the case of the former sign, each of the three fingers stands for each letter in HIV. The latter sign indicates a common false conflation of HIV with AIDS: the sign of a cross was symbolic, according to the informants, of the crosses that are put on the fresh graves in the graveyard, suggesting that HIV is understood as a life-threatening disease.

Part of the construction of HIV as a life-threatening disease is connected, according to the Selina and Lorraine to the failure, on the part of education campaigns in KTC and in South Africa, to differentiate between HIV and AIDS. AIDS is understood to imply death, and the conflation of HIV with AIDS results in the belief that HIV, too, is an indicator of imminent death. The equation (HIV = AIDS) highlights immortality and obscures the possibilities of living a long, healthy life as an HIV+ person. One consequence of this false equation and the fear that it evokes is that HIV+ people are more likely to be stigmatised, as illustrated by the hand signal of the cross.

In addition to the hand signals, the Luvuyolwethu carers and clients said that there are also a number of phrases that indicate perceptions and misconceptions around HIV, reinforcing the stigmatisation of HIV+ people. Some of the phrases that are used to communicate a person's HIV status include: "Po"; "s/he has a Z3"; "s/he has won the lotto"; "s/he has been run over by a 4X4". The informants explained that "Po" is an abbreviation of 'positive' and is used in the same way that the three finger hand signal is used to point out a person who is HIV+. A potential explanation for the second and third phrase is association of an HIV+ diagnosis with access to state disability grants. A second possible interpretation of these phrases is that the wealth implied in both of these phrases does not signify material wealth, but a plethora of secondary infections associated with HIV and AIDS. According to the main co-ordinator of Luvuyolwethu, Selina, this extends to popular beliefs in KTC that if a person has a lung infection, diahorea, nausea and vomiting for example, they are HIV+. This association of various sicknesses with HIV indicates the extent to which people experience AIDS as a syndrome of illnesses, and not as an illness in itself. This also underlines the extent to which HIV is conflated with AIDS, and therefore with the syndrome of diseases that transpire as a result of a depleted immune system.

The phrase "s/he has been run over by a 4X4" has many potential analogies. According to the Luvuyolwethu carers, 4X4 relates to the four letters in the acronym AIDS. A 4X4 is also a large vehicle that is able to dominate many different and difficult terrains. In KTC, AIDS has been seen to 'take over the bodies of people who have appeared to be healthy, and seemingly 'immune' to physical illness. According to the Luvuyolwethu carers, the many deaths

attributed to AIDS-related illnesses have demonstrated the power of AIDS to override the immune systems of healthy bodies in a similar fashion to a 4X4 crossing rough and ragged landscapes.

This language of hand signals and phrases is an under-researched area of HIV-related stigma, and this paper proposes that further research be conducted to verify the potential explanations and sources of this form of stigma-sign language in and beyond KTC. Furthermore, these phrases and hand signals reinforce Goffman's (1963) assertion that stigma exists in and through a language of relationships. Stigma sign language in KTC is, in many cases, predicated on misconceptions that fuel stigma, reinforcing the distance that characterises the relationship between the HIV+ other and the stigmatising individual or group. The following section moves on to explore the dialectical relationship between HIV-related stigma and structural inequality, focusing in particular on gender inequality.

Highlighting the Shadows of Stigma

According to Said (1978), 'othering' provides the viewer with a standpoint to see (and to judge) but not to be seen, as demonstrated in the above discussion on stigma-sign language, highlighting the way in which HIV-related stigma shifts the focus onto the stigmatised person, or group of peoples, obscuring the status of the person who initiates the stigma. For example, 'risk groups' enable people outside a 'risk group' to ideologically isolate themselves from people who have been categorised as likely to contract and transmit HIV. The numerous ways in which people outside so-called 'risk groups' could contract HIV are obscured. Thus the creation of risk groups not only perpetuates stigma, it also provides people with a platform to ideologically isolate themselves from the potential that they themselves might be HIV+ or vulnerable to contracting HIV.

HIV-related stigma functions to separate the self from the 'other' and in so doing, also highlights the complex social, political and economic factors that enable the power relationship between the stigmatised individual, or group of people, and the individual or group of people who stigmatise. Stein (2003) argues that one of the main critiques of social science research on stigma is that stigma is explained in terms of individual psychology rather than in terms of structural social inequalities.

This paper argues, in line with Stein (2003), that HIV-related stigma intersects with a number of critical factors that shape and are shaped by the life of HIV+ individuals. This is demonstrated through the following case study of one of

Luvuyolwethu's clients, Beauty. The triple oppression of African women (see Cock 1980, Sack 1989 and di Leonardo, 1991) as a result of their race, class and gender, contributes towards women's vulnerability to HIV infection (Farmer, 1992 and Strebel, 1997). The following example of Beauty's 'double-infection' highlights the ways in which these factors intersect and influence her experience of HIV and of HIV-related stigma.

Beauty lives in Barcelona, a low-income area adjacent to KTC, with her boyfriend. When I first visited Beauty, she pointed out the boils on her body and said, "I am double-infected. My boyfriend infects me again and again." When Beauty found out that she was HIV+, she had spoken to her boyfriend and suggested that they use condoms when having sex. Beauty's boyfriend refused, saying that his president (Thabo Mbeki) did not believe that HIV was a big problem and therefore he did not believe that Beauty was sick as a result of being HIV+. The following cartoon (Zapiro, 2002) reflects a perception that President Thabo Mbeki, and indirectly his government, were not taking cognisance of life-threatening nature of the HIV epidemic in South Africa (see also Brink, 2000 and Strode, 2004).

Beauty was unable to convince her boyfriend that he needed to protect himself from contracting HIV (assuming he was not already HIV+), and protect her from the re-infection of HIV that could occur when two HIV+ people have unprotected sexual intercourse.

The various illnesses that Beauty experienced made it difficult for her to work and earn money. Beauty's only surviving relative, her aunt, refused to have any contact with her because she was HIV+. As a result of her HIV status, and her alienation from her only family, Beauty relied on the financial support of her boyfriend. As a result of her financial dependence on her boyfriend, she felt that she could not afford to risk insisting on safe sex in case he terminated their relationship. The difficulty that Beauty experienced in protecting herself from 'double-infection' is partially a result of her dependence on her partner for food and accommodation, and partially a result of her boyfriend's failure to acknowledge the implications of HIV, or Beauty's HIV+ status. A few months later Beauty's boyfriend tested positive for HIV.

Shortly after Beauty found out she was HIV+, she joined a support group and subsequently decided to declare her status openly. Partly as a result of disclosing her status in KTC, Beauty's boyfriend's sisters knew that she was HIV+. After hearing that their brother was HIV+, they blamed Beauty for transmitting the virus to him, calling her a witch. This is an example of what Herek and Capitanio (1988 in Stein 2003) describe as 'symbolic stigma'. Herek and Capitanio (1988) differentiate between symbolic stigma and instrumental stigma. Instrumental stigma, they argue, is based on a fear of infectivity, and of the potentially terminal nature of HIV, whereas symbolic stigma arises from a value-based ideology and involves varying degrees of morality censure as demonstrated in the above case study (1988).

Beauty was stigmatised by her boyfriend's sisters because they believed she had purposefully infected their brother, which they deemed to be immoral. Prompted by his sisters' stigmatisation of Beauty, Beauty's boyfriend attacked her. He beat her up and stabbed her in her arm. Beauty's aunt refused to give her shelter because she was HIV+ and her aunt did not want to be associated with an HIV+ person. Beauty's financial dependence on her boyfriend, compounded with having nowhere else to live, resulted in her continuing to live, and have unprotected sex, with her boyfriend in KTC.

In their article on the social construction of STDs, Ratele and Shefer (2002) explore the gendered implications of HIV-stigma, and argue that women in South Africa are often blamed for transmitting HIV (see Fox, 2003 and Jewkes et al, 2003). Beauty's open disclosure about her HIV+ status is contrasted by her boyfriend's insistence that he was invulnerable to HIV. Beauty was aware that

her boyfriend had multiple sexual partners; this fact together with his insistence on having unprotected sexual intercourse with Beauty increased his chance of contracting HIV and then transmitting HIV to his partners.

Beauty's disclosure of her HIV status and her boyfriend's refusal to acknowledge HIV placed Beauty in the spotlight, masking the potential that her boyfriend may have transmitted HIV to Beauty. This example also highlights the potentially gendered nature of stigma, which was coupled by Beauty's inability to earn money making her financially dependent on her boyfriend. Furthermore, President Thabo Mbeki's ambiguous stance on HIV and AIDS in South Africa was used by Beauty's boyfriend to justify his refusal to have safe sexual intercourse with her. Thus the stigma and blame that Beauty experienced from her boyfriend, his sisters and her aunt were interconnected with issues around gender inequality and the South African government's politically ambiguous stance on HIV and AIDS (see Brink, 2000; Strode, 2004; Nattrass and Geffen, 2003).

Beauty's experience of HIV-related stigma highlights the subtle, yet pervasive and powerful social inequalities that enable and perpetuate stigma and discrimination. HIV-related stigma is dialectically related to social norms and to structural social inequality. Beauty's experience of HIV-related stigma points to the gendered nature of stigma and the discourses that function to reproduce unequal power relations between the 'self' and the 'other'.

Decentring Stigma: Moving Beyond the Individual

In the same way that HIV-related stigma is communicated by individuals as well as groups of people, it is also experienced by both the HIV+ individual and their social environment, variously consisting of family and/or friends. Goffman (1963) argues that stigma is not only experienced at the level of the individual, but also at the level of the collective in what he calls "courtesy stigma" (Goffman, 1963 in Alonzo and Reynolds, 1995). Courtesy stigma, according to Goffman (1963) extends out from the individual to the family and wider social community. In the case of HIV-related stigma, the social community of the individual is stigmatised along with HIV+ individual because of their association with and perceived support of the HIV+ person. Similarly, Helman (2000) and Kleinman (1995) argue that illness moves beyond the confines of the individual's physical body into their social environment. The following example of one of Luvuyolwethu's clients, Lungi, and her family's experience of HIV-related stigma demonstrates the connection between 'social suffering' and

'courtesy stigma', as defined by Kleinman (1995) and Goffman (1963) respectively. This example also illustrates that one of the consequences of HIV-related stigma is that it

> 'often results in a special kind of downward mobility" wherein stigmatised people "lose their place in the social hierarchy' (Coleman, 1986: 214 in Alonzo and Reynolds, 1995:312).

Lungi lived with her mother, Grace, and her three younger sisters in a brick house in one of the wealthier areas of KTC. Lungi's mother had been able to afford a brick house with her income as a high school teacher. However, she had been made redundant in 2001 and had been struggling to cover her family's basic living costs. She received a small amount of money from her children's father, and occasionally her neighbours would give her money to buy food for her children.

In 2003 Lungi became seriously ill and, after undergoing a barrage of tests, discovered that she was HIV+. Grace spoke to Selina's (the co-ordinator of Luvuyolwethu) mother about her daughter's HIV status, and told her that she was struggling to care for her family because of her limited financial resources. Selina's mother told Selina about Grace's concerns and Selina subsequently approached Lungi and asked her if she wanted to receive HBC from Luvuyolwethu. Lungi agreed and thereafter Luvuyolwethu carers visited her and delivered food parcels to Lungi's family each week. These food packages were an important aspect of the care provided by Luvuyolwethu. According to Grace, they were often the only source of food that her family received during the week.

When I first went 'on rounds' with Selina and Lorraine in KTC, we went to visit Lungi. During this visit, Lungi volunteered that she was HIV+. This disclosure surprised Selina and Lorraine; Lungi's mother was concerned about HIV-related stigma and therefore she dissuaded her daughter from disclosing and speaking about her HIV status. In particular, Grace was concerned that her neighbours would find out that her daughter was HIV+ and that they would then 'broadcast' Lungi's status to the wider community in KTC. Selina said that Grace was concerned that if people found out that Lungi was HIV+ and that she could not afford to feed her children, they would judge her and stop being her friend. Grace's status as an educated woman and a high school teacher afforded her a place high on the social hierarchy in KTC. She was embarrassed that she could not provide food for her children; this embarrassment was compounded by the fear that her friends and neighbours would stigmatise her because she had an HIV+ daughter.

When Lorraine and I went to visit Lungi for a second time, Lungi's mother said that Lungi was living with her boyfriend. Lungi was pregnant and had chosen to move in with her boyfriend because he lived close to Somerset Hospital, where she was apparently receiving medical care. After this visit, Lorraine said that Lungi's mother had been suggesting for a few weeks before I started my fieldwork that she would prefer it if Luvuyolwethu carers did not visit her daughter.

Lorraine said that Lungi's mother did not want the carers to visit Lungi because her neighbours had started to ask who the Luvuyolwethu carers were and she was afraid that they would find out that Lungi was receiving HBC from an organisation that cared for HIV+ people in KTC. Grace said that she was also concerned that if her neighbours discovered that her daughter was HIV+ they would stop communicating with her and refuse to give her anymore food or money. Thus, HIV-related stigma affects and moves beyond the HIV+ individual; Lungi's mother was afraid that her social environment might discriminate against her, resulting in a downward mobility on the social hierarchy in KTC. Furthermore, Lungi's family would be affected if Grace's friends and neighbours terminated their contact with them and stopped offering to support them with food or money. The way in which 'suffering' extends beyond Lungi into the lives of her family members illustrates Kleinman's assertion that social suffering needs to be considered alongside the suffering experienced by the individual. In this case, HIV-related stigma creates the suffering related to being HIV+ or having a family member that is HIV+.

A catch-22 situation arose: if Lungi's family continued to draw on the support and care offered by Luvuyolwethu, they might be ostracised and stigmatised by the people in their community and if they refused Luvuyolwethu's HBC, then they would stop receiving the weekly food parcels that they distributed. The Luvuyolwethu carers were concerned that Lungi and her family needed the food parcels and were loathe to stop visiting Lungi. The following week Selina and Lorraine took a food parcel to Lungi's family, and as neither Lungi nor her mother were at home, Selina told Lungi's sister that Lungi should contact Selina if she wanted Luvuyolwethu to continue visiting her. Lungi did not contact Luvuyolwethu.

In this case, public health care, offered by Somerset Hospital, was seen to offer protection against the possible disclosure of Lungi's HIV status. The visits of the Luvuyolwethu carers were perceived as threatening, particularly by Lungi's mother, because they had the potential to 'expose' Lungi's HIV+ status, making Lungi and her mother vulnerable to discrimination from both neighbours and friends in KTC.

According to Selina and Lorraine, Lungi's decision to receive medical care from Somerset Hospital and not the local Masincedane clinic was related to her concern that her status would be disclosed by doctors and nurses who worked at the clinic. This concern was not unfounded and highlighted a number of problems associated with accessing medical care for HIV and AIDS-related illnesses through one's local clinic.

In the course of my research, I witnessed a number of instances where the staff in the clinic or the hospital were treated with distrust because of their alleged disclosure of HIV+ people, and people sick with TB. It was during this period that Patricia became seriously ill and I transported her, her mother, Selina and Lorraine to the district hospital for treatment.

After waiting for five hours the doctor still had not consulted Patricia. When I approached him he told me firmly that he was 'trying' to do his job. However, after he had finished with his current patient, he moved on to Patricia. The doctor stated that Patricia needed to stay in hospital, and he proceeded to tell her, in front of Peggy, Selina, the rest of the patients in the waiting room and myself, that her HIV+ status would not facilitate her quick recovery. The disclosure of Patricia's status by the doctor, was both unethical and improper medical practice. Selina was shocked and angry that the doctor had disclosed Patricia's HIV status so openly, and without Patricia's consent. Selina told me that up until that time Patricia had not explicitly told Peggy that she was HIV+. This example suggests that the perception that one's HIV status is not always kept confidential by medical staff is not unfounded

Networks of Social Interaction and Disclosure

As argued above, the biomedical model that locates illness in the body of the individual bolsters the rationale that HIV+ individuals are responsible for accessing health care resources, which include antiretrovirals. The antiretroviral 'roll-out' is currently underway in South Africa. Nattrass and Geffen (2003) arguethat the effective administration of ARVs does not only significantly affect the physical bodies of HIV+ people, but can also play a role in challenging the notion that HIV equals death. ARVs encourage people to reconsider HIV as a chronic illness rather than a signifier of imminent death: the ARV roll-out has significant implications for HIV-related stigma in South Africa. However, the conception that the individual is responsible for accessing medical treatment, like ARVs, needs to be reassessed. There are, as is demonstrated by the following examples, a number of factors that influence HIV+ people's access to treatment. HIV-related stigma is a noteworthy factor that needs to be addressed

within the clinics in order to facilitate the effective administration of ARVs in South Africa.

Social networks present an infrastructure that facilitates care for and also stigma directed towards HIV+ people in KTC. Since I first started researching Luvuyolwethu, the number of people who have solicited their HBC because they were in the final stage of AIDS has more than quadrupled from eight to forty people. In order to meet the demands of visiting these clients on a regular basis, the Luvuyolwethu carers take on individual responsibility for caring for the people that live in close proximity to their houses.
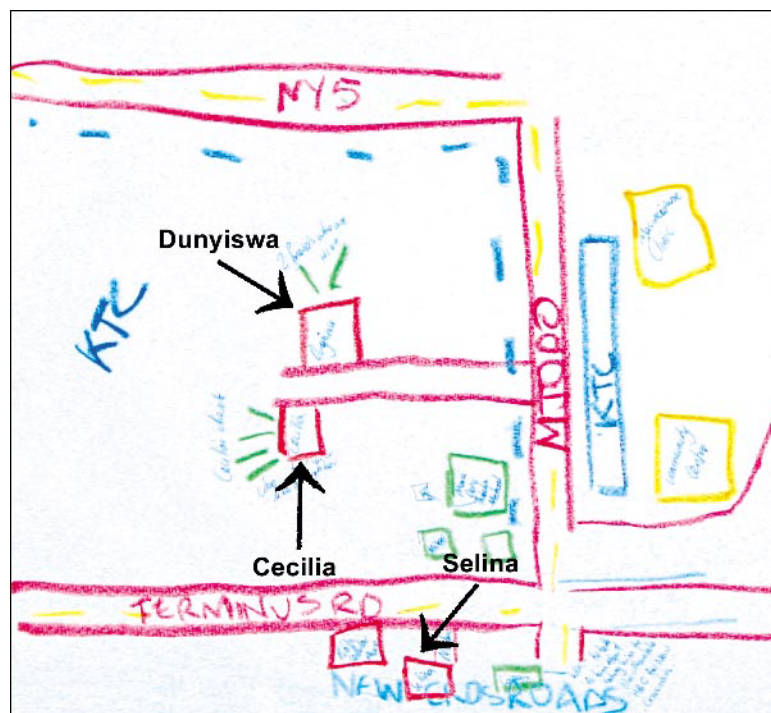
The map (above) was drawn up with Selina. She drew the places where each of the home carers live in order to show their relation to the 'neighbours' (represented by the lines moving out from the carer's homes) for whom they provide care. Dunyiswa visits two friends who lived across the road from her, and who were HIV+. Cecilia is responsible for caring for four clients who live near her home in KTC. Selina said that Dunyiswa and Cecilia's clients trusted them because of their close proximity - they were thought of as neighbours more than as care-workers.

Similarly, a man living in New Crossroads near Selina's house (his house is represented by the small square to the left of Selina's house) had asked Selina to provide home-based care for him. Selina had been caring for him for the past three months, but she was considering transferring him to Nocuthembelo, the HBC organisation for New Crossroads. She said that as each week passes, new

people in KTC contact Luvuyolwethu for home-based care. The growing demands placed on the five care-workers in Luvuyolwethu make it difficult for them to take on more responsibility for caring for people in areas that are officially covered by another home-based care organisation[3]. However, Selina asserted that it was important that the man be given the choice regarding whether or not to transfer to another home-based organisation. These examples illustrate the ways in which social networks facilitate care by connecting the Luvuyolwethu carers with their clients, and their client's friends who are in need of HBC.

Many people in KTC solicited the Luvuyolwethu's care because they were concerned about the potential stigma they might experience from state health care workers in the clinics and hospitals around KTC. These people, unlike Lungi's mother, felt that the Luvuyolwethu carers would treat their status confidentially. This perception might relate to the belief that the staff in state clinics and hospitals disclosed the status of their patients to other people living in KTC. Luvuyolwethu underlined the distinction between the care they were able to offer, as a community-based organisation, and the medical care offered through state health care institutions. Perhaps their clients were more confident in Luvuyolwethu's ability to keep their client's status confidential because of the way it distanced itself from state medical institutions.

In order to protect the status of their clients, the carers were careful to wear casual clothes (and not 'blues and whites' because these colours were indicative of the colour of the clothes nurses wore) and, if asked, to say that they were visiting their friends or neighbours. Acting as 'neighbours' rather than official carers enabled Luvuyolwethu to provide care for their clients, and this simultaneously protected their client's HIV status from their neighbours, or friends living in KTC.

The Luvuyolwethu carer's attempts to provide care as 'neighbours' has both positive and negative consequences. Despite their attempt to protect the status of their clients by claiming to be friends and neighbours, Luvuyolwethu carers have begun to be recognised by people in KTC as belonging to a home-based care organisation. The networks of social interaction between the people who lived in a similar area 'disclosed' the status of Selina and the other members of Luvuyolwethu as home-based carers. For example, Luvuyolwethu carers had been visiting a family comprised of a mother, Mavis, (with TB), her daughter, Thembi, (who was taking antiretrovirals), her niece Patience (who was HIV+)

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[3] She explained that the home-base care policy only permits one HBC organisation in each area; Luvuyolwethu is the official HBC organisation in KTC, even though it serves clients in surrounding areas.

and her grandson (who was HIV+). After a few months of visiting this family, Selina and Lorraine were introduced to a friend of Thembi's, Rose, who lived two shacks away, and was also HIV+. Thereafter the Luvuyolwethu carers took food parcels to Rose and visited her when she was sick.

One day, after visiting Thembi and her family, Selina was approached by a man who ran the Spaza shop at the entrance to the compound in which this family lived. He had not spoken to any of the Luvuyolwethu carers, but had been informed by people living in the compound that they provided home-based care for HIV+ people. He told Selina that a friend of his called Patience was married to a man, Sipho, who had become increasingly sick. Patience asked the man from the Spaza shop if he could bring one of Luvuyolwethu's carers to speak to her and her husband. Patience had sought out Luvuyolwethu after hearing about their visits to other 'sick' people in the compound around the Spaza shop. She was concerned about her husband because he had stopped taking his TB medication. She did not say that he was HIV+.

The networks of communication in this small compound of shacks provided people, like Rose and Patience, with information about how they could access care and support. This indicates that even though the carers were solicited on the basis that they would not draw attention to their clients' status, over time the identity of the Luvuyolwethu carers became known: people began to recognise the carers, not just as neighbours, but as members of an HBC organisation.

Later in the week, the man from the Spaza shop took us to Patience and Sipho's home. Sipho grudgingly conceded to talk to Selina, mainly, he said, because he knew that his wife was worried. He told Selina that he used to receive TB medicine from the Masincedane Clinic that was located less than fifty metres up the road from where he lived. However, due to the close association between HIV and TB, he had decided to stop going to the clinic for treatment, fearful that the people who lived in the area around his clinic would label him HIV+.

The association between HIV with TB, as well as the fear that one's HIV status will be disclosed after visiting the local Masincedane clinic is underlined through the experience of Patricia, a client of Luvuyolwethu's who died in 2003. As a result of testing positive for TB, Patricia was advised to take her chest x-rays to the Masincedane clinic (which was located a few blocks away from her home), in order to prove that she was eligible for TB treatment. One day as Patricia walked home, she encountered a group of people; they started taunting her, shouting to her neighbours that Patricia was HIV+ because she had TB. Patricia claimed that the nurses in the clinic also lived in the area in which she lived and that they had disclosed her status to the other young people living in the area around the Masincedane Clinic.

Patricia's belief that her TB status was disclosed to people in KTC by the staff of the Masincedane clinic supports Sipho's fear of the potential HIV-related stigma that he might experience because of receiving treatment for TB from the Masincedane Clinic. In this case, the biomedical connection between HIV and vulnerability to TB reinforces the fears that Sipho has about the disclosure of his TB status. Patricia and Sipho's experiences suggest that the spatial proximity of clinics to people in the community does not necessarily encourage people to attend the clinics for medical treatment that is related to a TB infection or to HIV. On the contrary, people did not attend the clinic because they feared that their HIV, or TB status would be disclosed to other members of the community and put them at risk of being stigmatised and discriminated against by people living in KTC.

Selina told Sipho that it was important to take TB medicine consistently, and she suggested that he go to the Guguletu day hospital because it is located further away from his place of residence. She said that many people go to the Guguletu day hospital because it services more people than the Masincedane clinic and there was less risk of meeting neighbours, friends, or acquaintances. According to Selina, Sipho's concern about being labeled 'HIV+' was killing him – his TB had made him more sick, and vulnerable to other secondary infections and his weak immune system would be put under further strain. Luvuyolwethu carers continued to visit Sipho until he died - four months later.

The extent to which fear of stigma associated with TB, and by association, HIV plays a role in discouraging people from accessing health care is a critical and under-researched issue in South Africa. In the following statement McNiel (1999 in Ratele and Shefer, 2002: 185) underlines the importance of addressing stigma in order to enable more HIV+ people to access public health care:

' [I]t is clear that the stigmatization of STDs, particularly HIV/AIDS, is still very central in the social construction of these illnesses and necessarily acts as an inhibiting factor in respect of seeking health care. Given such a context, it is not surprising that tackling STDS, both in terms of prevention and treatment is then still an uphill battle, as the problem continues to be marginalized'.

The descriptions of the social networks between the man from the Spaza shop, Thembi, Rose, Sipho and the Luvuyolethu carers disrupts the notion that Luvuyolwethu carers are not recognised as carers by the people in KTC. This also indicates that information passed along social networks connects people in need of care with Luvuyolwethu carers. The care provided by Luvuyolwethu carers was seen, in the case of the man who stopped taking his TB medication, as preferable to public health care because he believed that his HIV+ status

would be better protected by Luvuolwethu carers than by the people working in the Masincedane clinic. Furthermore, these examples also suggest that social networks between the medical staff at the local clinic and the people living in and around KTC convey confidential information about the client's HIV and TB status, making people who access the clinic susceptible to discrimination and HIV-related stigma. Consequently, access to medical treatment like ARVs is undermined by this form of HIV-related stigma in KTC's local clinic.

Conclusion

> 'Creation of alterity, or 'otherness', allows those in power to dehumanize, to scapegoat, to blame and thus to avoid responsibility for sufferers' (Schoepf, 2004: 27).

HIV is not simply a disease of the body, it extends beyond the body into the social psyche of the HIV+ individual, their family, friends and their wider social community. The disease of HIV, when compounded by HIV-related stigmatisation, shifts into a disease of the social psyche.

The research that formed the basis of this paper indicates that suffering due to HIV and AIDS-related illnesses does not only pertain to the physical manifestations of the disease; suffering includes the psychosocial elements that affect the way in which the individual, their immediate and extended family and their friends – their social environment - experience illness. HIV-related stigma, as argued throughout this paper, significantly affects the way in which individuals and their friends and family experience HIV.

The biomedical model that pathologises the HIV+ individual contributes to the perception that the individual is to blame for contracting HIV. It is critical to consider the socio-economic and political factors that influence the transmission of HIV and that also contribute to the perpetuation of HIV-related stigma. Structural inequality, like gender inequality, is highlighted by the stigmatisation and blame of women for contracting and transmitting HIV to men. As this paper has argued, stigma fuels and is fuelled by structural inequalities and social norms; HIV-related stigma takes on a particular shape in relation to social norms and inequalities, and can be used to highlight the particular relationships of power that enable HIV-related stigma in KTC.

Furthermore, the biomedical model that locates illness in the body of the individual underlies the biomedical premise that individuals are solely responsible for accessing health care resources to treat HIV and AIDS-related

illnesses. The so-called antiretroviral 'roll-out' currently taking place in South Africa is partially based on the premise that HIV+ individuals simply need to have ARVs made available to them through their district clinic in order to be able to access them. A major flaw in this premise centres on the pernicious nature of HIV-related stigma, and the fear of disclosure by staff working in state-run clinics and hospitals. Health policy makers and state health care professionals need to take into account that the effective administration of ARVs and medical treatment is not only a matter of access to state clinics and medicine, but also a matter of challenging and uprooting HIV-related stigma in South Africa.

The creation of a language of stigma around HIV in KTC suggests room for future research into the factors that motivate people to stigmatise against HIV+ people. Recognising the impact that stigma has on the lives of their clients, the Luvuyolwethu carers work with their clients to actively challenge HIV-related stigma. However, issues like financial dependence and a history of gender and racial inequality in South Africa continue to undermine the national and local measures taken to undermine and educate people about HIV-related stigma. Thus, in order to transcend the suffering, both social and physical, related to HIV, these fundamental issues regarding structural inequalities need to take centre stage on the platform of the struggle against the HIV-epidemic in South Africa, and at an international level.

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