A Multidimensional Quantitative Evaluation of HIV/AIDS-related Stigma in Cape Town, South Africa

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To Nicoli Nattrass

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Abbreviations

AAS	AIDS Attitudes Scale
AIDS	Acquired ImmunoDeficiency Syndrome
ANOVA	ANalysis Of VAriance
APN+	Asian Pacific Network of people living with HIV/AIDS
ARV	AntiRetroViral
ASSA	Actuarial Society of South Africa
ATWAS	Attitudes Towards Women with HIV/AIDS Scale
BSS	Behavioural Surveillance Survey
CAPS	Cape Area Panel Study
CAS	Cape Area Study
CSSR	Centre for Social Science Research
DHS	Demographic and Health Survey
EA	Enumeration Area
FHI	Family Health International
GRID	Gay-Related Immune Deficiency
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
ICRW	International Center for Research on Women
KPS	Khayelitsha Panel Study
MEASURE	Monitoring and Evaluation to Assess and Use REsults
MICS	Multiple Indicator Cluster Survey
MSF	Médecins Sans Frontières
MTCTP	Mother to Child Transmission Prevention
NGO	Non-Government Organisation
OLS	Ordinary Least Squares
PLWHA	People Living With HIV/AIDS
PSU	Primary Sampling Unit
SCI	Social Cohesion & Integration Unit (of HSRC)
SSA	Sub-Saharan Africa
STDs	Sexually Transmitted Diseases
S&DIWG	USAID Stigma & Discrimination Indicator Working Group
TB	Tuberculosis
UNAIDS	(Joint) United Nations (Programme on HIV/)AIDS
USAID	United States Agency for International Development
UNICEF	United Nations Children's Fund
WHO	World Health Organization

Abstract

A Multidimensional Quantitative Evaluation of HIV/AIDS-related Stigma in Cape Town, South Africa

This study arose out of a concern that previous South African national surveys may have underestimated the levels of HIV-related stigma because of limitations in the questions employed. It thus provides a more comprehensive evaluation of the extent and nature of HIV-related stigma through the measurement of several different dimensions of stigma (and regression analysis is used to conduct an exploratory examination of the factors associated with each dimension). It also presents the first assessment in South Africa of changes in stigmatising attitudes and behaviours towards people living with HIV/AIDS (PLWHA) over time.

Multi-item stigma modules from seven surveys were used to measure stigma from the perspective of both the general population and PLWHA on highly active antiretroviral therapy (HAART). Within the general population, instrumental, symbolic, resource-based, and perceived stigma, and behavioural intentions towards PLWHA were measured. Among PLWHA, experienced, perceived, and internalised stigma were evaluated. Results show that the extent of stigma varied between the different dimensions and that the kinds of questions typically adopted by national surveys fail to capture subtle but important aspects of the problem.

Behavioural intentions towards PLWHA were demonstrably more positive towards family/friends than strangers. Within the general population, instrumental and symbolic stigma was more frequently reported than negative behavioural intentions or resource-based stigma. Among young adults, despite the roll-out of HAART, stigma increased between 2003 and 2006. Although relatively few PLWHA reported many experiences of stigma, most indicated some experienced stigma. Consistent with qualitative research in Cape Town, experienced stigma was more commonly subtle (e.g. gossip) than overt (e.g. losing friends). Importantly, most people perceived PLWHA to live in a highly stigmatising environment.

This study highlights the importance of a multidimensional approach in the measurement of HIV-related stigma, which captures the perspective of both the general population and PLWHA. The increase in stigma measured among young adults shows that stigma may change in unexpected ways and needs to be monitored over time. Finally, regression results indicate that different factors are associated with different dimensions of stigma and hence analyses of stigma, and efforts to reduce stigma, should take cognisance of such variation.

Brendan Maughan-Brown
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Chapter 1. Introduction

Combating stigma is widely recognised as a key ingredient in the multi-layered struggle against HIV and AIDS, and very important for improvements in public health in general (Aggleton & Chase, 2001, Aggleton *et al.*, 2003; Brown *et al.*, 2003; Herek *et al.*, 1996; Malcolm *et al.*, 1998; Piot, 2001; Piot & Seck, 2001). Yet the concept of stigma has proved frustratingly difficult to pin down and to operationalise in quantitative studies. This is particularly the case in South Africa, which is home to the greatest number of HIV-positive people in the world.[1]

This study emerged out of a concern that quantitative studies of HIV/AIDS[2]-related stigma[3] in South Africa were not capturing its multidimensional nature and hence that the emerging conventional wisdom – that stigma levels were low in South Africa and probably falling now that highly active antiretroviral therapy (HAART) is available – may be based on shaky conceptual and empirical foundations. For example, a widely cited national survey from 2002 (Shisana & Simbayi, 2002) concluded on the basis of a limited number of questions probing behavioural intentions (such as whether respondents would purchase groceries from an HIV-positive shopkeeper) that there was a high level of tolerance in the general population towards people living with HIV/AIDS (PLWHA). Critics have (justifiably) argued that the very narrow conceptualisation of stigma used in the survey was inadequate – and have further hypothesised that such measurement error is responsible for the apparent contradiction between these low levels of reported stigma and anecdotal evidence suggesting that HIV-related stigma is, in fact, a problem in South Africa (see e.g. Deacon *et al.*, 2005; Stein, 2003). However, until we develop a more appropriate set of quantitative measures of stigma, the 'true' extent and character of stigma in South Africa remains an open empirical question.

[1] See Whiteside (2008) for an excellent and pithy overview of the HIV/AIDS epidemic.
[2] HIV is Human immunodeficiency virus, and AIDS is Acquired immunodeficiency syndrome.
[3] The term HIV-related stigma will be used in the rest of this dissertation to refer to HIV/AIDS-related stigma.

Although stigma is inherently difficult to capture through quantitative methods, it is important to persist with the challenge of designing new and better quantitative instruments in order to obtain rigorous and reliable estimates of the problem. This is relevant not only in South Africa, but also in sub-Saharan Africa (SSA). As Lorentzen and Morris note, this relative "lack of scientific research on the manifestations of HIV/AIDS-related stigma in SSA presents a serious challenge to the understanding, alleviation and prevention of HIV/AIDS-related stigma" (2003, p. 33).

Anecdotal and ethnographic evidence can provide useful pointers to the character of stigma and its implications for PLWHA. But such studies are, by their very nature, context specific and one should not rely on them to draw conclusions about the extent and distribution of stigma (Link *et al.*, 2004; Vanlandingham *et al.*, 2005). Only quantitative methods enable us to draw conclusions about the shape and extent of stigma in society. The challenge is thus to learn from qualitative studies as to what kinds of questions to ask, to test these questions in the field, and then to explore through statistical analysis whether they are indeed probing the underlying dimensions of stigma we expected them to.

This dissertation attempts to move our understanding forward by exploring different quantitative measures of stigma, analysing their potential determinants and seeing how these change over time. The empirical work was conducted in Cape Town using several samples of adults in the broader metropolitan region and in the African township of Khayelitsha. All surveys were conducted by teams of researchers from the Centre for Social Science Research at the University of Cape Town. As I was involved in the design of most of the questions on stigma, I was able to experiment with different measures of stigma, and to learn from the experience of earlier surveys to adjust and adapt questions in later surveys. More specifically, I was able to use data from two cross-sectional surveys of adults in the Cape Metropolitan region, a panel study of young adults (also across the whole of Cape Town), and two panel studies based in Khayelitsha (of all adults, and of PLWHA on HAART) respectively.[4] I was thus uniquely placed to develop a multidimensional approach to stigma that could explore the nature and extent of stigma (and whether it varied by race and age) in the

[4] Khayelitsha is the largest informal urban settlement in Cape Town.

broader population – i.e. the potential 'stigmatisers' – as well as capture the differences between perceived and experienced stigma amongst PLWHA in Khayelitsha – the potentially stigmatised.

In essence, this study makes a contribution to our methodological approach to measuring stigma, as well as to our emerging understanding of the nature of stigma in South Africa (and its recent changes over time). The few available quantitative studies in SSA are limited by their focus on behavioural intentions towards PLWHA, and very few pay any attention to the individual and socio-economic factors which may underpin or determine such stigmatising behaviour (Nyblade, 2006). None has yet evaluated changes in HIV-related stigma over time. This is particularly problematic given that the social context for PLWHA is continually changing, most notably with the increasing availability of HAART. As a HAART roll-out gained pace in the Western Cape during the study period, we are in a position to explore whether this was associated with changes in stigma – both in the general population and as experienced by PLWHA on HAART.

Furthermore, most quantitative research on HIV-related stigma focuses on social attitudes towards PLWHA whereas there is relatively limited research on the experiences of PLWHA. It is generally not, therefore, possible to assess whether measured stigmatising attitudes and negative behavioural intentions towards PLWHA are consonant with the lived experiences of PLWHA. Importantly, there is no systematic research on levels of stigma being experienced by the growing cohort of people in developing countries who have had their health restored by HAART. This is particularly problematic given that stigma has been known to undermine adherence to treatment regimens (Kalichman *et al.*, 1999; Ware *et al.*, 2006) – thereby threatening the success of the HAART roll-out itself.

According to a recent review of the literature on measuring health-related stigma: "despite extensive knowledge regarding the consequences of stigma and discrimination, comparatively little progress has been made in systematically addressing these in public health programmes" (van Brakel, 2006, p. 308). This may be a result of the complexity of HIV-related stigma which plays to deep-rooted social fears and anxieties, is influenced by a wide range of social, psychological and

economic factors and is culturally mediated and varies across place and time. Until we are able to develop measures of stigma which are sensitive to social context and which capture its multidimensionality, quantitative research will be unable to contribute productively to the urgent task of developing more innovative and effective intervention strategies (Aggleton & Parker, 2002; Castro & Farmer, 2005; Goldin, 1994; Piot, 2000).

With regard to the general population, a multidimensional approach is used to measure different dimensions of stigmatising attitudes, behavioural intentions towards PLWHA, and perceptions of stigma in the broader social environment. I describe the various surveys used to probe stigma (some of which were more comprehensive than others) and then report the results of exploratory regression analysis of the potential determinants of stigma (i.e. factors that affect stigma). One of these surveys, that of young adults in Cape Town, was designed as a panel study and included a set of stigma-related questions which were repeated across two waves. This allows us to conduct a systematic assessment of changes in stigma over time. Not only is this the first study of its kind in SSA, but it has particular relevance given that the time frame overlaps with a substantial HAART roll-out in Cape Town. We are thus able to explore whether this changing biomedical context for PLWHA was associated with a fall or a rise in stigma.

This dissertation also provides the first systematic research in SSA on HIV-related stigma experienced by a cohort of PLWHA on HAART. Survey data from this sample of people (collected in 2004 and 2006) is used to explore the extent and nature of experienced stigma, perceived stigma and internalised stigma. Potential determinants of these dimensions of stigma are also investigated using exploratory regression analysis. The specific empirical questions addressed in this study can be summarised as follows:

1. What is the extent and nature of behavioural intentions and stigmatising attitudes towards PLWHA in the general population of Cape Town?

- 1.a. What is the extent of negative behavioural intentions towards PLWHA?
- 1.b. What is the extent of instrumental stigma, symbolic stigma and resource-based stigma?
- 1.c. What are the perceptions of the social environment for PLWHA, i.e. the extent of perceived stigma?

2. What is the extent and nature of stigma experienced by HIV-positive individuals in Cape Town?

- 2.a. What experiences of stigma do PLWHA have?
- 2.b. To what extent do PLWHA report internalised stigma?
- 2.c. What are the perceptions of the social environment for PLWHA, i.e. the extent of perceived stigma?

3. What social and psychological factors influence stigmatising behaviours and attitudes, and experiences of stigma?

- 3.a. What predicts negative behavioural intentions? In particular, what effect do stigmatising attitudes have on behavioural intentions?
- 3.b. What are the determinants of instrumental stigma, symbolic stigma and resource-based stigma? In particular, does holding prejudice towards other groups influence stigma towards PLWHA?
- 3.c. What determines the level of stigma experienced by PLWHA?
- 3.d. What determines the degree of internalised stigma?
- 3.e. What determines perceived stigma among PLWHA?

4. How has HIV-related stigma responded to changes in the social context for PLWHA during the study period?

- 4.a. Has HIV-related stigma decreased, remained constant, or increased between 2003 and 2006?
- 4.b. What could have affected changes in stigma? In particular, what effect does meeting someone living with HIV or knowing someone who died of AIDS have on stigmatising behaviours and attitudes?

The dissertation is structured as follows:

Chapter 2 & Chapter 3 provide a literature review. Chapter 2 outlines the various approaches that have been taken to understanding and conceptualising stigma in general – and HIV-related stigma in particular. It also reviews the relevant evidence on the extent and impact of HIV-related stigma. Chapter 3 completes the literature review with a review of the quantitative research previously undertaken to measure HIV-related stigma (i.e. how other people have assessed stigma).

Chapter 4 provides an overview of the research methodology, touching on the various survey designs and highlighting how each dataset can be harnessed to improve our understanding of HIV-related stigma in Cape Town. The chapter also highlights the limitations of the study and the ethical considerations relevant to the research.

The remainder of the dissertation comprises two sections. The first section (Chapters 5, 6, 7 and 8) assesses stigma in the general population (i.e. representative samples of adults with no distinction being made between HIV-positive or HIV-negative people). Chapter 5 measures stigma and assesses the potential determinants of stigmatising attitudes and behaviours among young adults in Cape Town; Chapter 6 extends the analysis from the young adults to adults of all ages in Cape Town; Chapter 7 provides the first longitudinal analysis of changes in stigma that has been conducted in South Africa (using the panel study of young adults first introduced in Chapter 5). Chapter 8 then measures the extent of perceived stigma in the general population (i.e. perceptions held by survey respondents about the level of HIV-related stigma in the social environment).

The second section (Chapters 9, 10 and 11) assesses stigma from the perspective of individuals on HAART. Chapter 9 examines experiences of stigma; Chapter 10 looks at perceived stigma; and Chapter 11 analyses internalised stigma. The potential determinants of each of these dimensions of stigma are also explored.

The final chapter provides concluding remarks and considers the implications of the study's findings for future research and for the development of policy.

Chapter 2. Stigma and HIV-related stigma

This chapter is the first of two that form the literature review for this study. To highlight the importance of this research it begins with a review of the evidence and potential impacts of HIV-related stigma. Some background is then provided about the concept of stigma: how the concept has evolved and why HIV is a stigmatised disease. The potential functions that stigma serves are then discussed and used to highlight the different manifestations of stigmatising attitudes that can develop to fulfil these functions. A distinction is drawn between these manifestations (stigmatising attitudes towards PLWHA) and the manifestations of stigma from the perspective of the stigmatised (i.e. PLWHA). The chapter then outlines the different dimensions of stigma that structure the multidimensional approach to measuring stigma in this dissertation.

2.1 Evidence and effects of HIV-related stigma

HIV-related stigma has been reported worldwide: it is "universally pervasive, occurring in every country and region of the world" (Aggleton & Parker, 2002: 4). Initially termed gay-related immune deficiency (GRID) in 1981 after the first reported cases of *Pneumocystis carinii* pneumonia among five homosexual men (Sepkowitz, 2001), HIV-related stigma has been layered upon other stigmas associated with, *inter alia*, homosexuality, sexually transmitted diseases, drug use, race, gender, prostitution, poverty and homelessness (Castro & Farmer, 2005; Herek *et al.*, 2003; Sandelowski *et al.*, 2004; Swendeman *et al.*, 2006). PLWHA have been blamed for becoming infected or infecting others, and consequently condemned as careless or malicious (WHO, 2000). PLWHA have been associated with conduct perceived to be immoral, such as pre-marital or extra-marital sex, promiscuity, 'deviant' sex, substance abuse and witchcraft (Aggleton & Chase, 2001; Balabanova *et al.*, 2006).

A judgmental discourse has established a clear divide between, on the one hand, the 'innocent victims' such as babies infected by their mothers or adults who contracted HIV through blood transfusions, being raped, or who have partners that are unfaithful,

and, on the other hand, those considered guilty who 'deserve it', such as promiscuous individuals, homosexuals, injection drug users or individuals who engage in pre-marital sex (Aggleton & Chase, 2001; Balabanova *et al.*, 2006; Busza, 2001, 1999).

International evidence from both developed and developing countries finds manifestations of HIV-related discrimination at both individual and community levels. Individuals have been gossiped about and treated badly within their homes, communities, religious organisations, work places and places of health care (Aggleton *et al.*, 2003; Busza, 2001; Holzemer & Uys, 2004; Malcolm *et al.*, 1998; WHO, 2004). Examples from SSA include verbal abuse and gossip (Almeleh, 2006; Kohi *et al.*, 2006; Mills, 2004; Mlobeli, 2007); denial of health care (Sherr *et al.*, 2003); divorce (Policy Project, 2005); termination of employment and expulsion from home (Kohi *et al.*, 2006; Simbayi *et al.*, 2007a;); and exclusion from schooling and the military (Skinner & Mfecane, 2004). In extreme cases individuals have been physically assaulted and murdered after disclosing their HIV positive status. In South Africa cases include the murders of Gugu Dlamini[5] (1998), Mpho Motloung[6] (2000) and, in 2004, the rape and murder of Lorna Mlofana.[7]

Stigma is in essence a social construct in which understandings about the stigmatised condition are developed as part of socialisation (Link & Phelan, 2001). Both the stigmatised and stigmatisers enact social roles, which leave the stigmatised with a 'spoiled identity' (Goffman, 1963). But although stigma 'resides in the structure and relations of society' (Herek, 2002, p. 595), it is experienced and processed at the individual level.

[5] Gugu Dlamini was a South African woman from KwaMancinza, a town in eastern KwaZulu- Natal province, who was stoned and stabbed to death after she disclosed that she had HIV on a Zulu language radio programme on Worlds AIDS Day.

[6] Mpho Motloung was a female teacher from Soweto, South Africa. She and her mother were shot dead by her husband (also a teacher from Soweto) who then killed himself. On her body was the note: "HIV positive Aids."

[7] Lorna Mlofana was a female member of the Treatment Action Campaign from Khayelitsha, South Africa. She was raped by a group of young men who then murdered her after they discovered she had HIV.

PLWHA may respond proactively to stigma by joining HIV support groups and activist organisations, but the more typical reaction is social withdrawal.[8] One strategy for avoiding the stigmatised social role is to keep one's HIV status a secret. This is most likely to be the case when PLWHA believe that they are living in a highly stigmatising environment. As Goffman (1963) pointed out, the stigmatised person's central concern during interactions with people is the management of information. They are constantly wary of their condition being discovered and are intent, as Goffman (1963, p. 4) terms it, on "passing" as normal. This is particularly relevant if the condition is not immediately apparent to others, such as in the asymptomatic stage of HIV, when the individual is "discreditable" rather than automatically "discredited" (*ibid.*). The vigilance required to remember what one has told to whom and to hide one's status is likely to result in psychological stress for PLWHA (Alonzo & Reynolds, 1995; Herek, 2002; Sandelowski *et al.*, 2004). Qualitative research in Cape Town, South Africa reported one HIV-positive participant's description: "if you [are] hiding something then it is going to distress you everyday because you feel alone" (cited in Almeleh, 2004, p. 24).

Having a stigmatised condition can result in a psychological phenomenon whereby PLWHA become overly sensitive to the reactions of others. People may feel that they are more closely scrutinised by others and that the condition to which stigma is attached is readily observable to others. In Uganda an individual indicated such experience through an analogy between being poor and having HIV:

> If you do not have money, you may think everyone knows about it, similarly if you have AIDS, you feel that everyone knows you have it, even if no one knows about it (cited in Muyinda *et al.*, 1997, p. 144).

In Scotland an individual living with HIV provided a further example by stating "I've become more reserved with people and I walk about convinced that I have a stamp on my head: 'HIV' " (Green, 1995, p. 557). This is a particularly vivid and compelling

[8] Robins, for example, argues that combined with the extremity of the experiences of full-blown AIDS, it is the profound stigma associated with the later stages of the disease, "that produce the conditions for HIV/AIDS survivors' commitment to 'new life' and social activism" (2006, p. 312).

description of stigma given that the root of the word stigma is stigmata, literally a mark on the body (see further discussion later).

Stigma or fear of stigma can be so pervasive that even high-profile, financially secure individuals with large and caring support networks may be motivated to conceal their status. Such was the case with Edwin Cameron (a South African judge) who reports how long it took him, and how stressful it was, to disclose his status – and how surprised he was by the overwhelming support he received from almost all spheres of society when he finally did so (Cameron, 2005).

Stigma can also be relevant for people who are associated with those living with HIV or even just associated with the disease. Goffman suggests that 'normals' (those without the stigmatised condition) can be given 'courtesy' membership of the stigmatised group. By association with the stigmatised group these individuals may also experience stigma – somewhat counter-intuitively termed "courtesy stigma" (1963, p. 28-30).[9] Such stigma may be experienced by family members, friends and partners of PLWHA, as well as by professionals and volunteers who are associated with PLWHA or with the disease as a result of transference of ideas of contagion or negative personal characteristics onto these people (Muyinda *et al.*, 1997; Wight *et al.*, 2006).

For people associated with HIV, stigma can lead to direct forms of discrimination (Brown *et al.*, 2003; Cao *et al.*, 2006). A qualitative study conducted in Cape Town revealed that stigma towards the caregivers of people living with AIDS was a common experience and tended to heighten distress levels (Orner, 2006). For PLWHA courtesy stigma can also have a significant psychological effect – they may fear that their status may adversely affect those they care about and this may inhibit behaviours such as disclosure. This is illustrated in the following remarks by an individual living with HIV in Cape Town:

[9] Courtesy stigma is also referred to as "secondary stigma" or "stigma by association" by other authors.

> You know, if they can throw stones on you, you don't worry about that. But I can't disclose to them because I am worried about my family…I don't want the other people can throw stones to my family…(cited in Almeleh, 2004, p. 15).

Stigma and discrimination may result in self-devaluation, depressive symptoms, anxiety, low self-esteem and generally reduced well-being (Arkell *et al.*, 2006; Cameron, 2005; Deacon *et al.*, 2005; Herek, 2002; Kang *et al.*, 2006; Link *et al.*, 1997; Scambler, 2004; Wright *et al.*, 2000). Furthermore, rather than being transitory, Kang *et al.* (2006) found that strong relationships between HIV-related stigma and psychological distress were sustained over a two year period. In the extreme, these experiences, attitudes and fears may create such strong pressure to 'pass' that PLWHA might openly reject or attack others who are known to be HIV positive (Herek, 2002); or they might even lead PLWHA to attempt suicide (Balabanova *et al.*, 2006; Muyinda *et al.*, 1997; Thomas, 2006). In an example from South Africa, Vuyani Jacobs testified that after being diagnosed HIV positive he felt so guilty because his family had chosen him to attend University instead of his twin brother that he tried to kill himself (Policy Project, 2005).

HIV-related stigma is a problem not only for those who experience it, but also for the management of the epidemic.[10] As van Brakel puts it "stigma has indirect but strongly negative implications for public health efforts to combat the disease..." (2006, p. 307). A growing body of evidence indicates that HIV-related stigma is known to impede prevention efforts and the adequate provision of treatment, care and support (see e.g. Aggleton & Chase, 2001; Aggleton *et al.*, 2003; Brown *et al.*, 2003; Campbell *et al.*, 2005; Herek *et al.*, 1996; Itano, 2007; Malcolm *et al.*, 1998; Piot & Seck, 2001). Stigma is associated with negative attitudes towards HIV testing and discourages people from being tested, which may interfere with early treatment and the prevention of new infections and reinfection[11] (Chesney & Smith, 1999; Hamra *et al.*, 2006; Herek *et al.*, 2003; Hutchinson & Mahlalela, 2006; Kalichman & Simbayi,

[10] It is important to note that for each of the outcomes affected by stigma that are described here stigma may not be the only or the most important factor. Castro and Farmer (2005) point out, for example, that there are a number of structural factors that influence health behaviours. These include access to health services in general, access to mother to child HIV transmission prevention (MTCTP), access to antiretroviral treatment and socioeconomic status.

[11] HIV reinfection (or 'superinfection' as it is sometimes called) occurs when an individual with one strain of HIV gets infected for a second time with another strain of HIV.

2006; Lee *et al.*, 2005; Lindberg *et al.*, 2006; Liu *et al.*, 2005; Mathole *et al.*, 2006; Wolfe *et al.*, 2006). Fear of stigma may also act as a deterrent to safer sex. A study conducted in the United States showed that stigma was a predictor of high risk sexual behaviour among men who have sex with men (Preston *et al.*, 2004). In South Africa, evidence also indicates that young people make strong associations between condoms and disease (i.e. using condoms is seen as a signifier that you have a disease), which undermines safer sex practices (Leclerc-Madlala, 2002).

Stigmatising attitudes may increase sexual risk behaviour if these attitudes serve the function of distancing the self from the disease associated with the stigmatised group (Boer & Emons, 2004; Deacon *et al.*, 2005; Joffe, 1999; Wailoo, 2001). In such cases HIV is perceived as a disease of 'outsiders' – groups stereotyped to be at risk due to certain behaviours. This could situate the 'in-group' as 'safe' from infection if their behaviour is perceived to be dissimilar to the stereotyped HIV risk behaviour. Stigmatising attitudes could, therefore, increase the risk of HIV infection by falsely decreasing perceptions of risk.

The South African National HIV prevalence, HIV incidence, behaviour and communication survey found a significant minority of females (12.8%) and males (7.5%) that tested HIV positive despite reporting low self-perceptions of risk of HIV infection (Shisana *et al.*, 2005). Although the factors determining self-perceived risk were not examined in Shisana *et al.*'s research, it is possible that these unrealistically low perceptions of personal risk covaried with more stigmatising attitudes – as found to be the case in Namibia (Smith & Morrison, 2006). A similar pattern was found in China where stigmatising beliefs towards PLWHA were positively associated with having had a sexually transmitted disease or having multiple partners, and negatively associated with condom use (Liu *et al.*, 2005).

In addition, stigma can deter people from becoming involved in HIV-related work. For example, Campbell *et al.* (2005) found that many young adults in South Africa were unwilling to associate with HIV-prevention work for fear of being stigmatised. Stigma may therefore impede the mobilisation of resources necessary to respond adequately to the disease.

Once diagnosed with HIV, fear of stigma may also impede access to treatment and other health-care services (Cao *et al.*, 2006; Holzemer & Uys, 2004; Wolfe *et al.*, 2006). Delays in treatment can result in more severe morbidity and poorer treatment prognosis (Piot & Seck, 2001). This can be compounded if the psychological stress caused by stigma weakens the immune system, speeds disease progression and negatively influences treatment effectiveness and/or adherence (Kalichman *et al.*, 1999).

Adherence to HAART has been shown to be the most important factor in achieving undetectable viral loads in PLWHA (Flynn *et al.*, 2004). Good adherence is therefore important for the well being of PLWHA. In addition, it is also important for public health, as poor treatment adherence increases the risk of the development of drug resistance (Bangsberg *et al.*, 2000, 2004; Wahl & Nowak, 2000). Poor treatment adherence may result if individuals hide their medicines from others to avoid being identified as HIV positive (Ware *et al.*, 2006). Quantitative research in France has linked experiences of discrimination from sexual partners to poorer adherence to treatment regimes (Peretti-Watel *et al.*, 2006). Fear of stigma was found to have a similar impact on treatment adherence through qualitative research conducted in the United States in which participants reported that they skipped doses of their AIDS medication because they feared family or friends would discover their status (Rao *et al.*, 2007).

Stigma discourages HIV serostatus disclosure in general (Brandt, 2007; Clark *et al.*, 2003; Derlega *et al.*, 2002; Skhosana *et al.*, 2006; Wolfe *et al.*, 2006; Yang *et al.*, 2006) thereby reducing the access of PLWHA to the necessary support and care. But it also discourages HIV serostatus disclosure to sexual partners and drug-use partners (Cao *et al.*, 2006; Nachega *et al.*, 2005; Simbayi *et al.*, 2007a), thus increasing the risk of transmission of new infections and reinfection. A study done in Cape Town showed non-disclosure to sexual partners to have been closely associated with unprotected sex with sero-discordant partners (Simbayi *et al.*, 2007a).[12]

[12] A 'sero-discordant partnership' refers to a partnership in which one person's HIV-status is positive and the other's is negative (i.e. they have a different HIV status).

Concealment of HIV serostatus may result in behaviour that places either oneself or others at risk of HIV infection. Fear of being labelled HIV positive has resulted in mothers choosing to breast-feed their babies rather than using formula feeding, even when the risk of mother-to-child transmission through breast milk is known to be higher than exclusive formula feeding (Muko *et al*., 2004). Not breastfeeding a baby is seen to be such an obvious deviation from what is expected that it will inevitably tend to raise difficult questions (Preston-Whyte, 2003). Such fears can also make it difficult to negotiate safe sex with sexual partners to whom PLWHAs have not disclosed their status.

For those HIV-positive people who do disclose to their health care workers, stigma can reduce the quality of care they receive. Qualitative work in the United States found that among a group of HIV-positive women 20% reported experience of discrimination from health care-providers, including mistreatment, indifference and not wanting to care for or touch them (Sandelowski *et al.*, 2004). In South Africa, qualitative research amongst health clinic staff points to a similar effect with reports of cases where patients suspected to be HIV-positive were avoided by health care workers (Sherr *et al.*, 2003).

To further underline the point, in addition to impeding the fight against the HIV/AIDS epidemic, HIV-related stigma also impedes the management of other diseases. A study conducted in Zambia found such a strong link between HIV and tuberculosis (TB) that people with TB were automatically assumed to have HIV. This deterred people from accessing treatment and care for TB (Bond & Nyblade, 2006). HIV-related stigma therefore has broad public health implications, which extend beyond the realm of HIV.

2.2 The stigma concept

The potential impact of HIV-related stigma on individual quality of life and health interventions is now widely recognised. With this focus has come the realisation that, to date, stigma is poorly understood and is often marginalised in responses to HIV and

AIDS (Parker & Aggleton, 2003). This is, in part, because stigma has been conceptualised differently by different academic disciplines, has been applied to a broadening range of contexts and has been identified as the reason for an increasing number of problems (Deacon *et al.*, 2005; Link & Phelan, 2001; Parker & Aggleton, 2003). The lack of a common or coherent theory of disease stigma makes the comprehension of stigma increasingly confusing, and it has been suggested that the use of the word "stigma" could now be obscuring more than it is enlightening (Deacon *et al.*, 2005, p. 2).

Parker and Aggleton suggest that the inadequacy of previous attempts to confront stigmatisation is, in part, due to the "relatively limited theoretical and methodological tools available to us" (2003, p. 14). This could explain why many investigators provide no explicit definition of stigma, at even the most rudimentary level (Link & Phelan, 2001; Parker & Aggleton, 2003). Methodologies employed to measure stigma have consequently been extremely varied, often limited and sometimes focused on phenomena related to stigma (discrimination, for example) rather than stigma itself.

In order to develop methodologies to measure stigma it is necessary, therefore, to be clear about what stigma is, and is not, understood to mean; what functions it fulfils; and what its possible manifestations might be.

The concept of stigma has evolved from being "a construct largely grounded in the individual to one rooted in the social space" (Yang *et al.*, 2007, p. 1524-1525). The origins of the word 'stigma' can be traced to ancient Greece where outcast groups were branded, or physically marked, as a permanent measure of their discredited status (Aggleton & Parker, 2002). This was first experienced by slaves caught during escape attempts. They were branded on their foreheads with the first letter of the word for fugitive (Funk, cited in Weiner *et al.*, 1988, p. 738). The word stigma is derived from the same Greek roots as the verb 'to stick', and referred to the 'sticking' of a mark onto someone – by piercing, tattooing or branding – thereby signalling that the bearer was criminal, villainous, or otherwise deserving of social ostracism, infamy, shame, and condemnation (Herek, 2002).

Goffman's seminal piece on stigma defined stigma as "an attribute that is significantly discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one" (1963, p. 3). The stigmatised individual is thus seen to possess "an undesirable difference" that results in a devalued status. This undesirable difference is seen as a deviation from some socially developed ideal or expectation, "from what we would have anticipated" (1963, p. 5). It is the divergence of what is actual from the expected that 'spoils' the social identity and is key in the construction of stigma.

The use of the word 'attribute' added an important dimension to the ancient Greek use of the word stigma. It indicates that the difference being discredited need not be a physical mark. It encompasses all mental, physical, spiritual and behavioural features and/or characteristics that people could view as being discreditable. However, the term has led many authors to conceptualise stigma as a relatively static characteristic or feature of people (Link & Phelan, 2001; Parker & Aggleton, 2003). In this way, stigma continued to be seen as something inherent in the stigmatised person: "a characteristic of persons that is contrary to a norm of a social unit" (Stafford & Scott, 1986, p. 80); a "mark" that defines the stigmatised as "deviant, flawed, limited, spoiled or generally undesirable" (Jones *et al.*, 1984, p. 6).

This rather static conceptualisation of stigma was, however, a consequence of a limited reading of Goffman who, to the contrary, "was very much concerned with issues of social change and the social construction of individual realities" (Parker & Aggleton, 2003, p. 14). Rather than viewing stigma as a fixed attribute, Goffman (1963, p. 4) conceptualised stigma as a relationship between an "attribute and a stereotype", and thus "it should be seen that a language of relationships, not attributes, is really needed" (*ibid.*, p. 3). It was therefore "not to the different that one should look for understanding our differentness, but to the ordinary" (*ibid.*, p. 127).

Katz (1981) was one of the first authors to follow Goffman's observation in suggesting that the devaluation the individual undergoes is not driven by attributes that violate accepted norms, but by majorities choosing to call certain attributes, and the people associated with them, deviant. By contrast with the static model of stigma, a sociological model also emerged to describe stigmatisation as a social process of devaluation within a particular culture or setting. Such a model posits that the process

of devaluation is caused by an action on the part of the stigmatiser. Gilmore and Somerville (1994, p. 1341) highlighted this action using the term 'identification' in their definition of stigma: "identification of a bad or negative characteristic, in a person, or group of persons and treating them as not deserving of respect."

Importantly, Gilmore and Somerville (1994, p. 1341) recognise stigmatisation as a process comprising at least four components:

> These include the problem, itself, which triggers the stigmatizing reaction; identifying the person or group who are targeted for stigmatization; identifying the stigma – that is, recognition of the stigma in, or assigning of it to, the stigmatized person; and a reaction or response to the stigmatized person...

Although their definition of stigma as a 'bad or negative characteristic' situates stigma as an attribute that is recognised in the individual, this process model of stigmatisation also indicates that it could be something assigned to the stigmatised person. This idea situates stigma as something that is projected onto the stigmatised rather than something within them.

Herek and Capitanio (1998, p. 232) state this explicitly when they define AIDS-related stigma as "prejudice, discounting, discrediting and discrimination directed at people perceived to have AIDS or HIV, their loved ones and associates, and the groups and communities with which they are affiliated." Stigma is thus clearly seen as something that originates independently of the stigmatised individual and is "directed at" them. It is not a thing, not something inherently ingrained within someone, but a dynamic social association. As Aggleton *et al.* emphasise:

> Undesirable differences and spoiled identities do not naturally exist, they are actively created by individuals and by communities. Stigmatization therefore describes a systematic process of devaluation rather than a "thing" (2003, p. 4).

Link and Phelan further developed the social/process model of stigmatisation whereby stigma exists when "elements of labelling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows the components of stigma to unfold" (2001, p. 367). In the first instance human differences are distinguished by

people and labelled. Those possessing such differences become associated with the label, as, for example, when the person in question is HIV positive. Secondly, labelled differences are linked to stereotypes and those to whom the label has been attached are associated with these stereotypes. HIV is linked to sexual promiscuity, for example, and people are then seen to be sexually promiscuous because they have HIV. Those labelled with some inherent difference are assigned a separate category – 'them' as distinct from 'us', the 'non-labelled'. Importantly, this separation implies a devaluation.

Consistent with Herek and Capitanio's (1998) definition, Link and Phelan's (2001) definition also stipulates that discrimination is an essential part of the stigma concept. This has been a fairly common practice as the concepts of stigma and discrimination are closely related and therefore often used interchangeably (Buzsa, 1999). This is problematic, however, as it amalgamates cause and effect, and plays a key role in the obfuscation of stigma (Deacon *et al.*, 2005). Deacon *et al.* point out that not all stigma (for example self-stigmatisation) leads to discrimination, and that factors other than HIV-related stigma can cause the discrimination. Despite recognising that discrimination can be directly caused by stigma (termed 'enacted stigma'), they highlight the fact that there is no direct, one-to-one relationship between the two, and therefore a definition should avoid framing stigma as something that necessarily leads to discrimination.

Herek's (2002) introduction to social psychological theory of stigma explicitly distinguishes stigma from both prejudice and discrimination. Prejudice is seen as a negative attitude and discrimination as behaviour. Stigma is defined as "an enduring condition, status, or attribute that is negatively valued by society and whose possession consequently discredits and disadvantages the individual" (*ibid.*, p. 595). Holding prejudicial views and engaging in discriminatory behaviour is not, therefore, stigmatising *per se* – such attitudes and behaviours are stigmatising only when they also reflect society's negative judgement of the target (*ibid.*).

Consistent with Herek (2002) and with influential work done by Miles (1989), who defined racism as a social construct that differentiates and devalues a group but which need not explicitly justify or result in discriminatory action, Deacon *et al.* (2005)

propose a definition of stigma which excludes the concept of discrimination. They define disease stigma as negative social "baggage" associated with a disease (Deacon *et al.*, 2005, p. 18).

Recognising that it is insufficient simply to explain stigma as negative meanings associated with the disease, they further an understanding by assessing how the process of stigmatisation occurs. They use the 'blaming' model (Crawford, 1994; Joffe, 1999), suggesting that associations are made to alleviate anxiety about risk, to understand how stigma is created by individuals as active agents, and that it is a social process that shapes stigmatisation. They define disease stigmatisation as:

> A *social process* by which people use shared representations to distance themselves and their in-group from the risk of contracting a disease by (a) constructing it as preventable or controllable; (b) identifying 'immoral' behaviours causing the disease; (c) associating these behaviours with 'carriers' of the disease and other groups; and (d) thus blaming certain people for their own infection and justifying punitive action against them (Deacon *et al.*, 2005, p. 21).

2.3 Stigma: the social construct

Stigma is a social construct that is culturally mediated, resulting in a high degree of diversity in different cultural settings (Busza, 1999; Deacon *et al.*, 2005; Parker & Aggleton, 2003). Cultural differences may affect both the extent to which the individual is set apart as different from the rest of society and the process of devaluation. The salient differences that identify someone as having HIV or AIDS may also vary – a significant difference in one community might be seen as insignificant in another, and vice versa (Link & Phelan, 2001). In different societies different 'signals' have been developed to identify and label people who are said to have HIV. In many societies PLWHA are identified as such by symptoms like weight loss and wasting, TB or lesions. Behaviours such as feeding formula milk to an infant instead of breastfeeding (Muko *et al.*, 2004), attending specific clinics (Bond & Nyblade, 2006) or attempting to negotiate safe sex (Leclerc-Madlala, 1997) might also lead individuals in certain communities to label a person as HIV positive. In

other communities it is an association with certain groups, the gay community for example, that invites the HIV positive label.

An illustrative example is provided by an individual living with HIV in South Africa who suggests that a government disability grant or the decision to avoid breastfeeding may be interpreted as an indicator of HIV:

> My neighbour asked me why I didn't breastfeed my child. I just told her I have got a problem to my breast. So she just spread it to the other people, why I am not breastfeeding my child. When I found out she was talking bad about me, I told myself I am not going to tell the community about myself. And the other thing, they are always asking me why I have got the formula milk, and "where do I get the formula milk because I am not working and also my boyfriend is not looking after me?" So I told myself, where I am staying now, I am not going to disclose to them because they are very curious. They want to know what is going on in your house so that they can say bad things outside about you (cited in Almeleh, 2006, p. 12).

The formation of negative stereotypes occurs when the dominant cultural beliefs link labelled persons to undesirable characteristics (Link & Phelan, 2001). Therefore, societies will develop "their own meanings and explanations for sickness, ideas about disease transmission and sexual behaviour…. Fears associated with illness, disease, and sex therefore need to be viewed in this broader social and cultural context" (Malcolm *et al.*, 1998, p. 351). In other words, someone perceived as having HIV may be viewed differently in different contexts. As noted earlier, HIV has, for example, been associated with negative religious connotations in Burkina Faso, with extra-martial sexual relations and prostitution in India and with truck drivers, migrants and witchcraft in Zambia.

South Africa's particular historical and political context needs to be considered when thinking about HIV-related stigma. The HIV epidemic in South Africa began to take hold towards the middle of the 1990s, in the historical aftermath of apartheid – a system of government based on racialised and racist ideologies. Under apartheid, racist ideologies entered some social discourses about the origins of HIV that replicated colonial mythologies about animalistic 'Africans' unable to control their sexuality. There were also deep-rooted concerns about 'interracial' relationships that began to focus on HIV (Squire, 2007). In post-apartheid South Africa, despite the lack

of any research-based evidence, a racialised focus on 'virgin rape' as a curative practice (*ibid.*) has assumed the status of an urban legend.

Opposing theories emerged in response to these racist constructions. At the international level, one theory ascribed HIV to a CIA programme of biological warfare against Africa. In South Africa, for many, this raises the memory of apartheid-era plans for biological warfare against the supposed (black) enemies of the State (*ibid*). HIV was also viewed by some as a Western rationale for reducing Africa's population through condomisation. By contrast, condoms have also been said to have been made deliberately faulty, or even implanted with HIV (Squire, 2007). Such beliefs may be especially pertinent in South Africa where many people had already been subjected to programmes of sexual control under apartheid (*ibid.*). In addition, as the rapid growth of the HIV epidemic occurred around the same time as the fall of apartheid, the epidemic is sometimes viewed as an attempt by whites to regain control of the country by reducing the black population of South Africa. This narrative arose several times in Steinberg's ethnographic research conducted in the Eastern Cape, South Africa:

> "Some people believe that the whites have developed a cure for AIDS, but that they are holding it back. They are waiting for enough black people to die so that when we all vote in an election the whites will win and F.W. de Klerk will be the president again."
> I laughed, and his eyes widened with anger.
> "I am not telling you a joke. I am telling you what many people believe," Sizwe said. (Steinberg, 2008: p.138)

> "And as for AIDS, the *umlungus*[13] definitely have a cure. I know absolutely for sure that they do. And they are holding it back. The *umlungus* are so clever. It is not possible that they don't have a cure. They want the blacks to die so that life can be more comfortable again. Tell me, why did people start dying of this thing after democracy came in 1994? And why does it only affect the blacks?" (Steinberg, 2008: p307-308)

[13] *Umlungus* is the Xhosa word for 'white people'.

It is argued that the seriousness and consistency of government responses to HIV have an effect on the progress of HIV epidemics (Barnett & Whiteside, 2006). The first post-apartheid government paid some attention to HIV, but issues around HIV were overshadowed by other socioeconomic problems. The lack of strong leadership on HIV in the Mandela government was followed by a more destructive stance on HIV from the Mbeki government. In 2000, the government under Mbeki began to voice the possibility that antiretrovirals were useless remedies imposed on Africa in potentially exploitative and racist ways. This began the legacy of political distancing from HIV and AIDS denialism within the South African government. In Nattrass's (2007) compelling narrative of AIDS denialism in South Africa, popular newspaper political cartoons by Jonathan Shapiro were used to illustrate how the President of South Africa and the previous Health Minister, Manto Tshabalala-Msimang, repeatedly questioned the science around HIV/AIDS and antiretrovirals, often referring to them as "toxic" and "colonising".

Given this context of AIDS denialism, it was unsurprising that high profile people gave many incorrect and confusing messages about HIV. For example, in 2006, during his trial on charges of rape, former Vice-President Jacob Zuma justified unprotected sexual intercourse with an HIV-positive woman on the grounds that men were less at risk, and that he had showered afterwards (Squire, 2007). AIDS denialism at the highest levels, and continuing government ambivalence about HIV transmission and treatment, have created uncertainties about HIV and undermined the credibility of HIV-prevention messages and other HIV-related information.

The government's questioning of the science around HIV and AIDS began around the same time that HIV awareness campaigns in South Africa had begun to gain momentum. Squire (2007: p.14) describes the dramatic change in awareness about HIV over the last decade:

> HIV has moved from being almost unmentionable to being spoken about everywhere... Awareness seemed to grow from a series of incidents highlighted in the media; from dramatic increases in popular representations of HIV since the late 1990s; and from the activities of a large number of local and national community-based, NGO and government organisations.

Given the historical and political context, it is thus likely that, at least to some extent, the increased awareness about HIV and AIDS has been coupled with ambivalence, scepticism or even outright denial. This could have had serious consequences for HIV-related stigma by undermining the credibility of HIV-related information, and thus reinforcing and perpetuating fears, myths and incorrect beliefs about HIV.

Contemporary South Africa is extremely diverse and has a great variety of ethnic, religious and medical traditions. These have "interacted over many generations in ways that preclude any authoritative account of a singular 'system of belief'" (Ashforth, 2002, p. 126). This means "that traditional healers, traditional medicine and the belief systems of sickness and health can vary according [*sic*] from region to region and clan to clan" (Richter, 2003, p. 13). In addition, "contemporary South Africa enjoys a pluralist system of health provision, in which two main paradigms – biomedicine and African traditional healing – operate at arms' length, in parallel but always at a distance" (Wreford, 2005a, p. 55). It is therefore quite possible for an individual to move between communities and suddenly be faced with quite different negative reactions to the same condition, or even to have relatively little significance placed on the condition in the new community.

Different cultural conceptions of illness and healing, in particular, may be significant mediating factors for HIV-related stigma. The traditional African healing paradigm links symptoms with disease, and their absence with being healthy (Leclerc-Madlala, 2001; Mills, 2005; Richter, 2003; Wreford, 2005a). For example, Leclerc-Madlala reports that some Zulu informants did not believe HIV existed because there was no visible 'proof' of illness. Qualitative research from Cape Town also provides an example of this belief among Xhosa traditional healers:[14]

> Mnguni's belief that traditional healers can offer a cure for HIV and AIDS might relate to his perception that his clients are cured when their health improves. Curing illness, therefore, is measured through visual and experienced improvement in health (Mills, 2005, p. 141).

[14] The Zulu are the largest South African ethnic group with an estimated 10-11 million people (24% of the population) most of whom live in the province of KwaZulu-Natal. Xhosa people are the second largest ethnic group, making up approximately 18% (8 million) of the South African population. Most black South Africans living in Cape Town are Xhosa.

The idea that someone can have HIV but appear healthy, or that someone can be restored to health through HAART but remain HIV-positive, is therefore not a well-developed notion in the traditional African way of conceptualising illness. This suggests that if PLWHA are thought to have HIV only once they become ill, PLWHA may experience HIV-related stigma only when they are visibly sick and not when they are healthy.

Stigma may also be moderated by beliefs about the origins of illness. As with the Zulu, if one can speak in generalities, the Xhosa have traditionally sought explanations for events that signal imbalance (e.g. sickness, misfortune, and drought), as nothing is seen to be without cause (Hodgson, 1982; Ngubane, 1977). Questions inevitably arise about why people are suffering and who is to blame (Ashforth, 2002; Mills, 2005, Nattrass, 2005; Wreford, 2005b). Although there are perceived to be a number of possible causes for such events, they are often (particularly in the case of untimely illness or premature death) attributed to witchcraft (Ashforth, 2002, 2005; Stadler, 2003; Wreford, 2005b). According to Ashforth, witchcraft "typically means the manipulation by malicious individuals of powers inherent in persons, spiritual entities and substances to cause harm to others" (2002, p. 126). In the case of AIDS, Ashforth goes on to argue that "a disease or complex of symptoms better suited to interpretation within the witchcraft paradigm than AIDS would be hard to imagine" (2002, p. 128). This is because the common symptoms of AIDS, especially abdominal pains, wasting syndrome (involuntary weight loss), diarrhoea and respiratory problems, are often similar, if not identical, to those associated with being cursed through witchcraft (Ashforth, 2002, 2005; Wreford, 2005a).

The belief that AIDS is caused by witchcraft and thus that PLWHA are cursed has been captured in surveys among the Xhosa in South Africa (Kalichman & Simabyi, 2004) and among other groups elsewhere in Africa (Ndeki & Klepp, 1994). Being cursed would be likely to be, at the very least, embarrassing and shameful as people would question what the person did to get the curse, or what duty or obligation they neglected, such as honouring their ancestors, which may have undermined the ancestors' inclination to protect them from evil influence (Mills, 2005; Ashforth, 2002). Furthermore, Ashforth argues that PLWHA who are 'victims' of witchcraft may be judged to be "yearning for revenge and thus more inclined to perform

witchcraft themselves. Such people should therefore be treated with caution if not shunned completely" (2002, p. 135). This means that PLWHA may be stigmatised both because they are blamed for being cursed and because their 'curse' makes them a threat to others.

Traditional concepts of illness and healing may also have a bearing on changes in stigma that run counter to the rationalist perspective, which hypothesises that a HAART roll-out could have the capacity to reduce stigma. This would be the case if people come to learn that PLWHA on HAART are also cursed because they are in fact still 'sick'. Ashforth also suggests that the struggle against AIDS (a constantly mutating retrovirus) is remarkably analogous to the struggle against witchcraft: "Like witchcraft, the disease of AIDS ... can never be finally and irrevocably defeated but must rather be constantly protected against and fought" (2002, p. 129). HAART's capacity to suppress HIV mutation without removing the virus from the body could also result in PLWHA coming to be judged as being bewitched, which could lead to their experiencing more stigma over time.

2.4 HIV/AIDS and stigma

The character of the African HIV epidemic is shaped by the origin and nature of the virus, the sequence of its global expansion and the multitude of circumstances into which it has spread (Barnett and Whiteside, 2006; Iliffe, 2006).[15] Similar factors have shaped responses to the epidemic, and often contributed to HIV being stigmatised.

Initially, HIV was commonly associated with, and blamed on, the people who first displayed symptoms of the disease. In Africa, HIV spread through, *inter alia*, mobile networks of militia, migrants and truck drivers; commercial sex workers; and expanding sexual networks made possible by rapid trade and urbanisation. Thus,

[15] Circumstances which might affect the HIV epidemic include, for example, the mobility of the population, the percentage of the population with a sexually transmitted disease, the percentage of the male population who have been circumcised, the percentage of the population who have sexual intercourse with sex workers, and the percentage of the population who have multiple concurrent sexual partners.

> Immigrants and refugees from other African countries were widely held responsible. Villagers blamed townsmen. Elders blamed the young.... Everyone blamed sex workers" (Iliffe, 2006, p. 80-81).

In South Africa the first real warning of HIV was signalled when a group of African mineworkers were tested in 1986. Few South Africans tested positive (0.02%), but 3.76% of Malawian workers tested positive. This led to the Malawians being stigmatised and recruitment of miners from Malawi was abandoned (Grundlingh, 1999). In the United States the disease was first viewed as a homosexual disease, but subsequent diagnoses revealed a high percentage of infected Haitians, who themselves where then categorised as a risk group (Sepkowitz, 2001). By contrast, in many parts of Europe, like the Ukraine for example, HIV has been associated with and blamed on injection drug users (Aggleton & Chase, 2001).

As scientific knowledge about HIV, especially modes of transmission, increased and was disseminated, PLWHA were increasingly seen as personally responsible for their condition. In the case of AIDS, the attribution of personal blame for the immunodeficiency is implied in the name of the condition, being something that is 'acquired'. A disease or condition perceived as being contracted through voluntary and avoidable behaviours, especially behaviours evoking social disapproval, is likely to be stigmatised (Herek, 2002). Guided by attribution theory, Weiner *et al.* (1988) found that physically-based stigmas were perceived as onset-uncontrollable and elicited pity and offers of help. Mental-behavioural stigmas, on the other hand, were perceived as onset-controllable and elicited the opposite reactions. Mak *et al.* (2006) tested this theory on HIV-related stigma in Hong Kong and found that the attributions of controllability, personal responsibility, and blame were applicable in explaining HIV-related stigma.

A judgmental discourse has thus arisen that establishes a clear divide between the 'innocent victims' and those who 'deserve it.' As touched on earlier, the former would include the victims of rape, contaminated blood transfusions, unfaithful partners and children infected via mother to child transmission; while the latter would include homosexuals, intravenous drug users and people perceived to be sexually promiscuous (Aggleton & Chase, 2001; Balabanova *et al.*, 2006; Busza, 2001, 1999; Farmer *et al.*, 2001).

In these ways disease stigma often attaches itself to existing stigmatising frameworks (Aggleton *et al.*, 2003; Herek & Capitanio, 1997; Sontag, 1988). France (2004), for example, found gendered moralistic judgements to be common in research conducted in East and Southern Africa:

> In almost all interviews, women were cited as suffering more from stigma – "they are blamed for the spread of HIV by their partners and families which is related to notions of promiscuity. Women suffer because they come out whereas men hide their status and blame women.... If a woman is HIV+, she is blamed for infecting the man. If the man is sick it is seen as an unfortunate stroke of luck – he is given sympathy and not blamed" (France 2004, p. 2).

HIV is thus often associated with behaviours labelled as deviant because they transgress moral codes (promiscuity or adultery, for example) and with already marginalised and stigmatised groups. In his address at the 2001 UNAIDS World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, Piot pointed to the range of factors that influence stigma:

> HIV/AIDS-related stigma comes from the powerful combination of shame and fear - shame because the sex or drug injecting that transmit HIV are surrounded by taboo and moral judgement, and fear because AIDS is relatively new, and considered deadly.

As indicated by Piot (2001), AIDS is also a stigmatised disease because it is a transmissible, lethal and incurable condition (Brown *et al.*, 2003; Herek, 2002). Diseases that are debilitating, disfiguring and fatal have historically produced reactions of fear and discrimination (Alonzo & Reynolds, 1995). Quantitative studies have shown that negative and discriminatory attitudes towards people with illnesses are a direct function of the severity of the illness (Crandall, 1991; Crandall & Moriarty, 1995). Since the earliest days of the epidemic, AIDS has been widely perceived to be a fatal condition (Herek, 2002). For example, in Xhosa, the predominant African language in Cape Town, the name for AIDS is *gawulayo*, which means killer. These perceptions were also fuelled, in part, by government messages aimed at preventing new infections. In Zimbabwe, for example, the initial messages "AIDS kills" and "AIDS cannot be cured" were understood to mean imminent death; this encouraged hopelessness and instilled fear (Meursing, 1997, p. 119). This is

exemplified in the range of metaphors used to depict AIDS and people living with AIDS. These extend from the Grim Reaper (Sontag, 1988) to *Yamira akveera* from Uganda: "one who has swallowed a piece of polythene bag" (Muyinda *et al.*, 1997, p. 144).[16]

Associations with an undesirable and an unaesthetic form of death increase the perception of the severity of HIV/AIDS. In the later stages of AIDS the symptoms can be highly visible and greatly disfiguring, as, for example, when it manifests as lesions, lipodystrophy[17], AIDS wasting syndrome[18] or kaposi sarcoma[19] (Alonzo & Reynolds, 1995). The disfigurement accompanying the threat of death in HIV/AIDS is more severe than for most other infectious diseases, TB for example, and has added to the fears and fantasies surrounding HIV/AIDS (Malcolm *et al.*, 1998).

Finally, the biology of HIV is extremely complex and difficult to communicate adequately – especially to those with poor educational backgrounds. Most importantly, by contrast with previous diseases of epidemic proportion, HIV has an exceptionally long latency period during which the disease generally remains asymptomatic. Thus people may have the virus but remain looking healthy, which means that the disease can remain hidden. As mentioned earlier, for those who associate illness with known and identifiable symptoms, the very concept of someone being sick with a dangerous disease – and infectious – may be difficult to grasp and accept, both by HIV positive people themselves and by those around them. This is

[16] The saying "one who has swallowed a piece of polythene bag" implies that the plastic swallowed by PLWHA will suffocate them, i.e. death is inevitable.

[17] Lipodystrophy is a medical condition characterized by abnormal or degenerative conditions of the body's adipose (fatty) tissue. Lipodystrophies manifest in various regions of the body as the excess of fat, such as in 'humps' on the back of the neck, or as a lack of fat, such as in 'sunken' cheeks. They are often seen as a symptom of AIDS or as side-effects from antiretroviral drugs (MedicineNet.com, 2002).

[18] AIDS wasting syndrome is the involuntary weight loss of 10% of baseline body weight plus either chronic diarrhea (two loose stools per day for more than 30 days) or chronic weakness and documented fever (for 30 days or more, intermittent or constant) in the absence of a concurrent illness or condition other than HIV infection that would explain the findings (MedicineNet.com, 2004,).

[19] Kaposi sarcoma is a relatively rare tumour of the skin that tends to afflict elderly people or, especially, those with an abnormal immune system as is the case with AIDS. It is characterised by soft purplish plaques and papules that form nodules, which typically start on the feet and ankles and then slowly spread across the skin of the legs, hands and arms. In AIDS patients, these tumours can also develop internally and cause severe internal bleeding (MedicineNet.com, 2001).

likely to occasion confusion and uncertainty. Furthermore, Ashforth suggests that even the latency of HIV is conducive to the witchcraft hypothesis, as the victim of witchcraft is said to be "in a constant struggle against the invisible forces depleting his or her life" (2002, p. 133). Under these conditions, the length of time that elapses between HIV infection and the onset of symptoms, increase the chance of HIV being a stigmatised disease.

It is hardly surprising, in view of its complex pathogenesis and fearful consequences, that social myths about HIV have abounded in societies affected by HIV. Myths among young children in Mali include the notion that AIDS results from sexual encounters between young women and dogs belonging to white people in Cote d'Ivoire (Castle, 2004). In a recent speech in America, Jeremiah Wright (United States presidential candidate Barack Obama's former pastor) charged the United States Government with manufacturing the AIDS virus to kill black people (Kincaid, 2008).[20] In South Africa, it has been reported that some people believe that HIV can be purged from the body by having sex with a virgin (Leclerc-Madlala, 1997). Other incorrect beliefs attribute HIV transmission to urinating in a place where someone with HIV has already urinated; shaking hands; sharing food; touching rusty metal; coming into contact with tears; and sleeping in the same room as someone with HIV (Castle, 2004).

2.5 Dimensions of stigma

2.5.1 The perspective of the general population (i.e. the stigmatisers)

Previous research has divided HIV-related stigma into two main dimensions: symbolic stigma (i.e. negative moral judgement) and instrumental stigma (i.e. negative judgement based on inflated fears of infection) (Bishop *et al.*, 1991; Herek, 2002, Herek & Capitanio, 1998; Le Poire, 1994; Pryor *et al.*, 1989, 1999). This distinction relates to the different psychological functions that symbolic stigma and

[20] Jeremiah Wright's accusation appears, in part, to be informed by a 1996 book by Leonard Horowitz, Emerging Viruses: AIDS and Ebola.

instrumental stigma are theorised to serve. In addition to these two dimensions, this dissertation also explores a third potential dimension of stigma: resource-based stigma (i.e. negative judgements based on resource concerns).

Symbolic stigma

Symbolic stigma is informed by deeply held values "based on the metaphorical social meanings attached to AIDS, the people who get it, and the ways in which it is transmitted" (Herek, 2002, p. 598). Symbolic stigma is based mainly on "judgemental attitudes towards those perceived to have put themselves at risk of infection through immoral and/or irresponsible behaviours" (Stein, 2003, p. 8).

Symbolic stigma acquires much of its potency from associations made between the disease and already stigmatised minority or disliked groups. As mentioned already, HIV has been associated with, *inter alia*, homosexuals, prostitutes, injection drug users, migrants, the poor and different population groups (Aggleton & Chase, 2001; Castro & Farmer, 2005; Gilmore & Somerville, 1994; Herek et *al.*, 2003; Sandelowski *et al.*, 2004; Swendeman *et al.*, 2006). By virtue of these associations and the negative meanings attached to the disease, symbolic stigma associated with HIV can be used as a powerful vehicle for expressing additional hostility towards groups that were already stigmatised prior to the epidemic. This can lead to what is referred to as 'double-stigma' where people who were already targets of stigma are now also stigmatised because they are associated with HIV (Castro & Farmer, 2005; Deacon *et al.*, 2005; Kowaleski, 1988; Reidpath & Chan, 2005).

In addition, like other sexually transmitted diseases, HIV has served to signal pollution and contamination, and consequently PLWHA have been associated with dirt and uncleanliness (Goldin, 1994; Nyblade *et al*., 2003). As mentioned earlier, HIV/AIDS has also become a symbol of suffering and death.

One of the potential psychological functions performed by symbolic stigma is the psychological protection of stigmatising individuals from fear and anxiety. This occurs when individuals distance themselves from a fear of HIV-infection by

assessing that their own behaviour does not put themselves at risk of HIV-infection. This inclination to distance oneself psychologically from HIV is similar to the response that has been associated with other dread-diseases throughout history (Joffe, 1999; Wailoo, 2001). Weitz (1989, p. 273) illustrates how individuals can disavow the potential of infection by holding attitudes such as "AIDS attacks only physically weak, 'promiscuous' persons, who choose their partners unwisely" – in essence "AIDS occurs only elsewhere." HIV is accordingly perceived as a disease of 'outsiders', which situates the 'in-group' as safe from infection.

Instrumental stigma

Instrumental stigma also arises from the desire for protection, but in this case, the stigmatising behaviours (and the beliefs that underpin them) are rooted in perceptions of real physical risk posed by HIV/AIDS. It arises from the perception that interacting with PLWHA poses a direct threat to one's own physical wellbeing. This may well be an incorrect perception: for example, a person might 'know' how HIV is transmitted and therefore be aware that one cannot become infected via casual contact, but yet might nevertheless refrain from hugging someone who is known to be HIV positive. Instrumental stigma reflects personal self-interest and an underlying need to understand the social world in terms of direct utility or harm to oneself (Herek & Capitanio, 1998). Previous research has indicated that instrumental stigma is associated with stigmatising behavioural intentions – such as avoiding contact with HIV-positive people (Bishop *et al.*, 1991; Lau & Tsui, 2005; Nyblade *et al*., 2003).

An example of instrumental stigma is provided by ethnographic research conducted in KwaZulu-Natal (one of the nine provinces of South Africa) that looked at the case of a little boy whose family refused to touch him after his mother had died:

> He was four years old and he wasn't being washed or held. He was dirty and had flies all over him....The reason the child was being neglected was because they were afraid they would catch AIDS from him (cited in Itano, 2007: p.174).

The following quotation recounting the experience of an HIV-positive woman in Masiphumelele (a low-income, informal urban settlement in the Cape Peninsula, South Africa) provides another example of instrumental stigma:

> In the first place I disclosed to my family. It was very hard … and I felt at … first … so angry and sad because they were funny to me…. they didn't even eat my food; they didn't even want me to wash with the basin ... even the teaspoons, cups and things. They were very funny and I was so sick at that time because I was so angry and stressed (cited in Kahn, 2004, p. 6).

Resource-based stigma

Qualitative research conducted in Zambia found that PLWHA are considered a "burden" (cited in Bond, 2006, p. 185) because "they are not able to contribute to household income when they are sick and they undermine the income generation and progress of the household. During periods of illness they soak up money, energy and time" (Bond, 2006, p. 185-186). The simultaneous loss of income-earning power (of the now sick adult) and need for health-related expenditures can result in a simultaneous double blow to families and could result in PLWHA being blamed for the household's financial predicament. If this leads to fewer resources being allocated to the HIV-positive person and/or to other forms of ill-treatment than would be the case if the person had been sick with a different disease, then we could say that the person is experiencing a form of resource-related stigma.

In Steinberg's recent ethnographic study conducted in the Eastern Cape in South Africa Doctor Hermann Reuter (a pioneer of the first pilot HAART programme in South Africa) argues that resource concerns are the main sources of stigma.[21] This is evident in Reuter's response to Steinberg's reflection about feeling that a skeletal AIDS-sick man he saw being treated was already a corpse:

> I am pleased you noticed that.... It is one of the two main causes of stigma. The family sees the patient is getting thinner and thinner and soils his bed and can't eat. They think, He's dead anyway. Why waste our time? [Steinberg: And the other main cause of stigma?] Money. The patient is a financial burden on the family. We don't have sugar because of you. You are killing us (cited in Steinberg, 2008, p. 265).

[21] Details about the HAART pilot project are provided in Chapter 4.

This study accordingly explores a third potential source of stigma – resource-based stigma. The concept derives from earlier research (e.g. Bond, 2006; Stein, 2003) pointing to the potential existence of this problem. As this aspect of stigma is rarely measured, a set of innovative and experimental questions was designed to probe its existence amongst various population groups in Cape Town.

Previous empirical work on resource-based stigma is primarily qualitative. It has been reported that individuals in Zambia complained about the special needs of PLWHA, including special foods, which can use a week's budget in a few days. Complaints were heard that "your resources are milked" and "a lot of money or wealth will be wasted during that nursing period, and, as a result of the illness, you tend to borrow a lot and tell lies" (cited in Bond, p. 186). As a result of periods of long illness, and beliefs amongst care givers that the patient will die anyway, fatigue sets in and negative attitudes develop towards PLWHA. It was sometimes even reported that people wanted the patient to die or were advised to let the patient die. Patients were sometimes neglected as people began raising money for the coffin and funeral instead of providing food and care (*ibid.*).

Another potential source of resource-based stigma was identified in a qualitative study conducted in rural China, which concluded that family members and friends may want to stay away from PLWHA in order to avoid being asked for financial assistance. Similarly, marriage into a family with a person living with HIV is likely to be costly as families share problems (Cao *et al.*, 2006).

Resource-based stigma does not necessarily have to be accompanied by negative or judgemental attitudes towards HIV-positive people. All that is required is that fewer resources are allocated to HIV-positive people *because* they are HIV-positive. In other words, the HIV-positive person is discriminated against on the basis of his or her HIV status, even though the stigmatiser may not be judging them negatively as individuals. Thus, a purely rational economic calculus – which may even make sense at a broader social level – is nevertheless categorised as a form of stigma in that the HIV-positive person experiences it as a direct form of discrimination. This is evident in the argument provided by a 19 year-old woman in her final year of high school in the Cape Town Metropolitan Area:

> You know, it's not like every [country] can afford it [ARVs[22]]; and the country really, in a sense they can't really afford it, you know, because they can barely pay pensions and things like that, you know? Education – for, you know, people. I mean, yes, I feel really sorry for people who have got AIDS; I feel really sorry for the people who didn't ask for it, you know what I'm saying? But who are we going to focus on more: the young people who aren't getting and [*sic*] education, or people who are going to die anyway? (cited in Kahn, 2006, n.p.)

Perceived stigma

In addition to exploring the above three potential dimensions of stigma, this study also discusses 'perceived stigma' i.e. perceptions on the part of individuals about the nature and level of stigma in the broader social environment. This is a generalised perception of how people in one's community feel and react towards PLWHA (Green, 1995; Zelaya *et al.*, in press). For example, a person might believe that when PLWHA disclose their status to someone they will generally be treated unfairly or badly because they have HIV. Perceived stigma in the broader society, i.e. in the 'general population', is a product of social learning and is exacerbated by reported incidents of stigmatising experiences (Scambler & Hopkins, 1986). Although perceived stigma may be an accurate reflection of the social context PLWHA experience, it may also, therefore, be an exaggerated perception of the extent of stigma in the social environment.

2.5.2 Stigma Experienced by PLWHA

The discussion so far has distinguished several dimensions of stigmatising attitudes amongst stigmatisers – i.e. those who stigmatise PLWHA. Some of these stigmatising attitudes may be kept hidden and could have no impact at all on the lives of PLWHA. This would be the case, for example, if someone believed privately that PLWHA were morally to blame for their condition, but acted 'normally' when coming into contact with PLWHA and took no action to deny PLWHA access to resources. However, it is possible that even in such cases, PLWHA may be picking

[22] ARVs stands for antiretrovirals.

up subtle forms of judgmental behaviour – which perhaps the stigmatisers themselves are unconscious of, or unaware that the PLWHA is picking up (e.g. the fact that the PLWHA knows that the stigmatiser is saying unkind things behind his/her back).

It is thus useful to study HIV-related stigma by exploring both its manifestations in the broader/general population, and the way that PLWHA living in the same environment experience stigma. This study achieves this by contrasting the experience of stigma on the part of a sample of PLWHA (those that have been on long-term HAART) in Cape Town with evidence from a representative sample of adults about the nature and extent of stigmatising attitudes in the general population.

Previous research has drawn distinctions between the lived experience of stigma ('enacted' stigma on the part of stigmatisers) and what Scrambler and Hopkins (1986) call 'felt' stigma in their research on epilepsy (e.g. Aggleton *et al.*, 2003). Felt stigma is clearly an important component of HIV-related stigma among PLWHA and can usefully be divided into (1) internalised stigma and (2) perceived stigma.

Internalised Stigma

Link and Phelan (2001) describe the social psychological processes operating through the stigmatised person. They suggest that people develop conceptions of a stigmatised condition such as HIV as part of socialisation into their culture. Expectations therefore develop of how people with the condition are to be valued or treated. This coincides with Goffman's (1963) view that the stigmatised and the 'normal' (the non-stigmatised) are social roles in which *all* actors (including the stigmatised) know the expectations associated with each role. The psychological processes involved in accepting such a stigmatised social role can result in internalised stigma whereby HIV-positive people devalue themselves in their own eyes (Deacon *et al.*, 2005; Scambler, 2004). Self-devaluation may be accentuated for stigmatised conditions, such as HIV/AIDS, which can be 'acquired' by people after they have already formed their own stigmatising ideas about such a condition. In such cases, their stigmatising attitudes towards others may be internalised (and directed at themselves in a form of self-hatred).

In addition, the stigmatisers are generally the dominant or majority group in society and will find ways to justify their stigmatising attitudes. For example, a person who acquires HIV does so as a result of some moral flaw. This belief has the potential to be processed by the stigmatised in a manner that leads them to believe that the justifications are correct and that they are, indeed, in some way morally flawed. This is the process that Goffman (1963) is referring to when he describes how stigmatised persons internalise standards from the wider society and discredit themselves.

Internalised stigma can manifest as a range of emotions including shame, guilt, anger, self-hatred and feelings of worthlessness (Berger *et al.*, 2001; Lee *et al.*, 2002; Mak *et al.*, 2007; Simbayi *et al.*, 2007b; Swendeman *et al.*, 2006; Wight *et al.*, 2006). Internalised stigma is illustrated by an individual living with HIV in Scotland: "I felt dirty and unclean and I thought I would never be able to kiss my wean" and "I know a lot of moral society would be against me sleeping with anybody so I have guilt from that feeling" (cited in Green, 1995, p. 557).[23]

Perceived stigma

As mentioned earlier, perceived stigma refers to beliefs about the existence of HIV-related stigma in the broader social environment. For PLWHA, perceived stigma refers to "how much HIV-infected persons believe that the public stigmitises someone with HIV" (Derlega *et al.*, 2002, p. 415). It is noted that some authors have used 'perceived stigma' to refer to feelings about being stigmatised: "how often participants had thoughts and feelings that they were being stigmatized or put in jeopardy because of their illness" (Sowell *et al.*, 1997, p. 305). When defined in this way, measures of 'perceived stigma' generally include questions probing internalised stigma, experienced stigma and fears about being stigmatised.[24] Sowell *et al.*'s

[23] 'Wean' is a Scottish dialectal term for a very young child.

[24] For example, Sowell *et al.*'s (1997) measures of perceived stigma included "Thought illness was punishment for things done in past" (internalised stigma); "Felt people avoiding me because of my illness" (experienced stigma); and "Feared my family would reject me if they learned about my illness" (fears about being stigmatised).

conceptualisation of stigma was thus not used in this dissertation as it conflates different dimensions of stigma.

Perceived stigma among PLWHA may result from personal experiences of stigma-related prejudice and discrimination, but (as with the general population) it is also a product of social learning and is exacerbated by reported incidents (in the media and through social networks) of stigmatising experiences (Scambler & Hopkins, 1986). In other words, someone living with HIV may not have experienced stigma personally, or know of many people who have, but may still think that the social context for PLWHA is highly stigmatising. If so, then an appropriate policy response may be to provide better education to PLWHA about the 'true' nature and extent of stigma. However, if this apparent disconnect between the way that PLWHA perceive stigma in the social environment and its actual manifestations within the broader population is a product of poor measurement of stigma, then the appropriate response is to improve our measurement of stigma and collect better data. As the assessment of the extent of stigma cannot be made independently of the measure, the best we can do under the circumstances is to collect data on stigma using as multidimensional a concept as possible. Not only will this help us to avoid drawing too quick (and erroneous) conclusions about HIV-related stigma, but it may also produce new information of relevance for those designing stigma-related interventions.

2.5.4 Summary of the different dimensions of HIV-related stigma

Table 2.1 summarises the dimensions of stigma that will be explored in this dissertation – both within the general population and from the perspective of PLWHA. Stigmatising attitudes within the general population can be divided in three different dimensions: instrumental stigma, symbolic stigma and resource-based stigma. When this translates into stigmatising actions (sometimes termed 'enacted stigma') this is felt directly by PLWHA (as experienced stigma).

This study analyses data from PLWHA on the actual experiences of stigma and explores some indicators of internalised stigma. Ideally one would like to compare experiences of stigma with data on stigmatising actions on the part of stigmatisers.

However, as it is impossible to collect accurate data on actual acts of discrimination, data was collected on behavioural intentions – as operationalised by hypothetical questions such as 'would you share a room with an HIV-positive person?' These are discussed in more detail in Chapter 3.

Finally, perceived stigma refers to perceptions about the nature and extent of stigma in the social environment. We measure this amongst PLWHA and in the broader population.

Table 2.1 Different dimensions of HIV-related stigma

Stigma within the general population	Stigma within PLWHA
Attitudes towards PLWHA • Instrumental stigma • Symbolic stigma • Resource-based stigma	Attitude towards self because of HIV status • Internalised stigma
Perceptions of a stigmatising environment • Perceived stigma	Perceptions of a stigmatising environment • Perceived stigma
Enacted stigma • Behavioural intentions	Experiences of stigma • Experienced stigma

Chapter 3. Measuring HIV-related stigma: a literature review

This chapter highlights the major developments in quantitative research on HIV-related stigma globally, and provides a comprehensive review of studies conducted in South Africa.[25] In the review of the international studies I discuss the measurement of stigmatising attitudes and behavioural intentions towards PLWHA (this includes general populations and subsects of the population such as nurses, dentists and volunteers in Non-Government Organisations (NGOs) providing AIDS-related services). I also highlight the most important studies assessing stigma from the perspective of PLWHA, which includes a review of the limited number of parallel studies that have measured stigma among PLWHA and the general public. The review of quantitative stigma studies conducted in South Africa then also separates studies among the general population and those among PLWHA. The focus of this chapter is on study design and methods, and not on findings *per se*. The chapter describes the design of the pioneering research on stigma and how these measures evolved over time, but also shows how some measures of stigma have endured despite subsequent advances. The chapter concludes with a discussion of the gaps that remain in the quantitative assessment of HIV-related stigma (i.e. which aspects of stigma still need to be measured), with a particular focus on South Africa.

3.1 Global quantitative research on HIV-related stigma among general populations

As the first cases of AIDS were diagnosed in the United States, it is unsurprising that the first studies of AIDS-related attitudes were concentrated there. According to Singer *et al.*'s 1987 meta-analysis of public opinion polls relating to HIV/AIDS, the first survey to assess the public's opinion about AIDS occurred in the United States in June 1983. Over the course of the following three years about 22 opinion polls were conducted, many via nationwide telephone surveys. The content of these polls can be categorised into six main dimensions: awareness of the disease; concern about

[25] Please note that this review is limited to studies published in English. It also excludes studies on HIV-related stigma conducted among children.

HIV/AIDS as a serious medical problem in general and for oneself in particular; perceptions about the likelihood of its spread;[26] beliefs about methods of transmission; attitudes towards coercive measures or policies for protecting the public; and reported changes in one's own behaviour to avoid exposure.

HIV-related stigma falls into the last two categories. Opinions about coercive policies towards PLWHA in varied settings (including work, education, housing, sexual activity) were assessed. Typical questions or statements included:

- "Do you think employers should be able to fire someone who has been diagnosed with AIDS, or not?"
- "Do you favour or oppose allowing students with AIDS to attend school if health officials say there is no danger?"
- "People with AIDS should be put into quarantine in special places to keep them away from the general public."

Questions about behavioural measures taken to reduce the risk of HIV-infection were initially framed in terms of precautions being taken to avoid homosexuals or places where homosexuals might be present.[27] Most of the early questions had a gay-centric focus since, as mentioned in Chapter 2, the first cases of AIDS were diagnosed among homosexuals and the disease was initially seen as a gay disease.

Some of the questions first asked in 1985 polls were repeated in 1986, providing the first measures of changes in these opinions over time (Singer *et al.*, 1987). This work provided the first look at the extent of the public's stigmatising attitudes and how these attitudes change over time. Given the measures used to in these early studies, many other studies which followed measure HIV-related stigma solely in terms of discriminatory intentions towards PLHWA. However, despite the early research on changes over time, studies of this nature have rarely been repeated since.

[26] Questions in this dimension were quite different from knowledge about actual modes of transmission. One question, for example, asked: "So far, most of the people with AIDS have been homosexual men and intravenous drug users. Do you think AIDS will spread beyond those groups who already get it so that many people in the rest of the population will get AIDS, or don't you think so?"

[27] For example: "Have you personally or people you know taken any of the following precautions to try to reduce the chances of contracting AIDS: (1) Avoiding people you know or suspect to be homosexual? and (2) Avoiding certain places where homosexuals may be present?"

At about the same time as public opinion polls began probing opinions about AIDS, surveys in the health professions started to do the same. One of the first was conducted in July of 1983 among nurses at the Westchester County Medical Center in New York (Blumenfield *et al.*, 1987). Nurses were asked to respond to ten statements about their willingness to treat patients with HIV[28] and around fears of catching HIV.[29] As with the early polls, surveys such as these based their quantitative analysis on percentage answers to each question. Such analysis provides an indication of the extent of stigma, but provides no understanding about potential factors related to stigma. Many subsequent surveys among health practitioners asked similar questions about willingness to treat patients and fears of contagion, and conducted similar analyses (see e.g. Bennett *et al.*, 1995 (United States); Gerbert *et al.*, 1991 (United States); Manz *et al.*, 1994 (United States); Plant & Foster, 1993 (Scotland)).

Johnson (1989) was among the first to examine the attitudinal and cognitive factors underlying public attitudes towards AIDS. Johnson used three cross-sectional samples in the United States in 1985, 1986 and 1987. He found that those most likely to discriminate against AIDS victims were members of the Christian Right and those who maintained a more individualistic as compared to community oriented focus. Most of the studies on HIV-related stigma which occurred after this explored factors related to stigma either through basic cross tabulations or regression analyses. Price & Hsu (1992), for example, revisited poll data collected by the Los Angeles Times Newspaper in 1985 and 1987 to improve on initial analysis by assessing whether opinions about coercive policies towards PLWHA were associated with knowledge about HIV transmission and attitudes towards homosexuals.[30]

In the early 1990s the first scales to measure HIV-related stigma were developed in the United States. Snell *et al.* (1991) were among the pioneers of multidimensional measurement of AIDS stereotypes via the development of the Stereotypes about

[28] For example, "I would have to ask for a transfer to another unit if I had to care for an AIDS patient on a regular basis."

[29] Statements such as "I would not hesitate to do mouth-to-mouth resuscitation on AIDS patients for fear of contracting the disease"; and "My awareness of AIDS has made me fearful about caring for homosexual patients."

[30] These surveys asked three questions about opinions towards restrictive policies: (1) requiring persons exposed to AIDS to carry identification cards; (2) quarantining AIDS patients; and (3) tattooing people exposed to AIDS.

AIDS Questionnaire.[31] This questionnaire has four main categories: (1) 'global stereotypic beliefs about AIDS'; (2) 'personal attitudes about AIDS'; (3) 'medical issues about AIDS': and (4) 'sexual issues about AIDS'. The second category ('personal attitudes about AIDS') asked 35 statements with response options along a 5-point Likert scale ranging from strongly disagree to strongly agree. These statements were divided into 5 subscales called (1) 'the desire to avoid those afflicted with AIDS'; (2) 'AIDS was not perceived as self-relevant'; (3) 'a close minded approach to AIDS'; (4) 'the issue of AIDS is being exaggerated'; and (5) 'the notion that AIDS is a moral punishment.'[32]

Snell *et al.* (1991) were the first to argue that opinions towards AIDS take various dimensions and that each dimension may be tapped into with different questions. Two of the subscales they identified can be seen as tapping HIV-related stigma: 'the desire to avoid those afflicted with AIDS', and 'the notion that AIDS is a moral punishment.' Although their moral dimension related specifically to punishment for immorality and not moral judgement more broadly (this subscale excluded the statement probing opinions about blame: "People who get AIDS can blame only themselves") this work was the first to make the clear distinction between behavioural intentions/support for coercive policies and moral judgements.

In 1992 the AIDS Attitudes Scale (AAS) was developed in the United States to measure attitudes of nurses towards PLWHA (see Froman & Owen, 1997; Froman *et al.*, 1992). This scale separated questions into four categories which were named: (1) 'homophobia'; (2) 'blaming the victim'; (3) 'fear of HIV and unrealistic concerns about HIV'; and (4) 'empathy' (e.g. "I would like to do something to make life easier for people with AIDS.") The questions in the AAS covered three of the dimensions of stigma discussed in Chapter 2 of this dissertation: enacted stigma (behavioural

[31] The full questionnaire was retrieved May 15, 2008, from http://www4.semo.edu/snell/scales/SAAQ.htm.

[32] The following are examples of questions from each subscale: subscale 1: "I don't want to talk or interact with anyone with AIDS" and "Children with AIDS should not be allowed to attend public schools." Subscale 2 "AIDS is not a threat to me." Subscale 3 "Only people from California have been affected by AIDS." Subscale 4: "People are blowing the issue of AIDS way out of proportion." Finally, subscale 5: "People who die from AIDS are being punished for their past wrongs."

intentions/support for coercive policy), instrumental stigma and symbolic stigma. However, questions from the different dimensions were included in both of the final two scales created (the 'avoidance scale' and the 'empathy scale'). For example, the avoidance scale included the question "Most people who have AIDS have only themselves to blame", which measures symbolic stigma, and "I'm worried about getting AIDS from social contact with someone", a measurement of instrumental stigma. Thus, there was no clear divide between each of the different dimensions of stigma. The AAS (which, according to Froman and Owen (1997), had been employed by 30 additional studies by 1997) therefore simply gives an indication of general stigma, but does not provide a useful measure of the different dimensions of stigma identified.

In 1992 Schondel and Shields developed a questionnaire to measure the attitudes towards PLWHA among volunteers at United States based NGOs that offered AIDS-related services. This 37-item scale was divided into five dimensions. The dimension containing HIV-related stigma measures ('comfortableness with proximity to gay/HIV index') factored separately from the others that measured 'societal responsibility', 'comfortableness with death', 'societal denial of problem' and 'societal perceptions to terminal nature of AIDS'. As with Froman *et al.*'s (1992) indices, the 'comfortableness with proximity to gay/HIV' index conflated different dimensions of stigma: behavioural intentions (e.g. "I wouldn't want to work next to someone infected with the HIV virus"); opinions about coercive policies (e.g. "People with AIDS should be quarantined"); symbolic stigma (e.g. "AIDS should prove to people that homosexuality is unnatural") and instrumental stigma (e.g. "Casual contact with a person infected with HIV would not put you at risk of getting AIDS.")

A similar critique can be made about the Attitude towards AIDS Scale developed by Goh (1991) and tested among United States college students. The 25-item index was created by summing responses along a 5 point Likert Scale to questions such as: "There is no need for the average person to be concerned about AIDS"; "I would avoid having contact with persons with AIDS"; "I would feel embarrassed if one of my family had AIDS"; "There should be separate public facilities (i.e. restroom toilets) for people with AIDS"; and "Persons with AIDS deserve support from their

families and community." Again, while multiple dimensions of stigma are assessed, the scale as a whole can only be used to examine general stigma.

About this time, the first study of attitudes towards PLWHA among nurses in Africa was conducted in Tanzania (Kohi & Horrocks, 1994). Like many before it, this study used questions to capture many of the dimensions of stigma: fear of infection, willingness to treat patients and moral judgement.[33] Again, however, as no distinction was made between the different dimensions of stigma they were combined into a single scale measuring attitudes towards AIDS in general.

In 1993 Herek and Capitanio published the results of their HIV-related stigma study which collected data between September 1990 and February 1991 from a random sample of interviewees in the 48 Continental United States through computer assisted telephone interviews. This study was important for three main reasons. First, it made a clear distinction between four different dimensions of stigma. Negative feelings towards persons with AIDS were assessed with three questions about the extent of feelings of anger, fear or disgust towards PLWHA; support for coercive AIDS policies was measured with two questions about quarantine and publicising the names of PLWHA; blame for persons with AIDS was measured with the question "People who got AIDS through sex or drug use have gotten what they deserve"; and avoidant behavioural intentions were measured with four scenarios such as, for example, a scenario in which the owner of a neighbourhood grocery store where the person being interviewed liked to shop had AIDS.

Second, the four distinct dimensions were analysed separately. Indices for negative feelings, support for coercive policies and avoidant behavioural intentions were analysed by summing the answers to the questions in these categories; and the blame question stood alone as an indicator variable. The analysis showed that the different dimensions of stigma measured covaried with different factors (e.g. blacks scored higher than whites on the coercive policy scale, while whites scored higher on the

[33] Moral judgements were measured by responses to statements such as "people who have AIDS are promiscuous heterosexuals"; "most people with AIDS have the disease through their own fault"; and "people who have HIV/AIDS are immoral."

negative feelings scale and blame item). Herek and Capitanio were thus the first to argue that different dimensions of stigma may be influenced by different factors.

Finally, this survey formed the baseline for repeat surveys conducted by Herek and Capitanio in 1997 and 1999. These surveys formed the first assessment of different dimensions of HIV-related stigma over time (Herek & Capitanio, 1999; Herek *et al.*, 2002).

Despite these advances in stigma research in the early 1990s (when stigma research began to quantify different dimensions of stigma) it remained fairly common for surveys to focus on one particular dimension of stigma. The HIV-related Discrimination Scale, for example, was used in a 1993/1994 survey among general medical practitioners in New South Wales, Australia, to assess opinions about the rights of PLWHA (Bermingham & Kippax, 1998).[34] In Tanzania, Ndeki and Klepp (1994), evaluated attitudes towards PLWHA among young adults with responses to four behavioural intentions questions.[35] As a further example, Lee *et al.* (1999) reported on the Victim Blaming Scale used in survey conducted in 1990 that asked college students in the United States to "Think about people who have AIDS. Do you think they are victims or the cause of their own suffering?" Answers were measured on a 5-point Likert scale: "victims", "somewhat victims", "uncertain", "somewhat cause of own suffering", "cause of own suffering."

Up until 1998 no clear theory had been used to separate the different dimensions of stigma. Herek and Capitanio (1998) conducted a functional analysis of AIDS-related stigma among heterosexual adults to determine whether attitudes were primarily instrumental or symbolic.[36] Two of the main findings would inform many future

[34] The 18-item HIV-related discrimination scale asked questions such as "Medical students with HIV should have the right to complete their degree"; and "People infected with HIV have the right to a full and satisfying sex life."

[35] "I would visit a friend I knew had the AIDS virus"; "Children with AIDS virus should be allowed to attend school with other children"; "I would be friends with someone who has AIDS"; and "I would be willing to look after a relative who has AIDS."

[36] It is noted that in Herek and Capitanio (1998) the AIDS stigma scale was formed by summing responses to the following three statements: (1) "People who got AIDS through sex or drug use have gotten what they deserve"; (2) "People with AIDS should be legally separated from others to protect the public health"; and (3) "The names of people with AIDS should be made public so others can avoid them." The first question was itself a probe of

measures of HIV-related stigma. First, stigma may serve different functions for different individuals (i.e. stigma may be driven by the desire to distance oneself physically from risk of infection or to create a moral distinction between PLWHA and oneself). On the other hand, for many of the respondents, AIDS-related stigma may simultaneously serve both instrumental (termed 'evaluative' by Herek and Capitanio) and symbolic ('expressive') functions. These two findings demonstrated the importance of considering different attitude functions independently.

Most of the studies discussed so far (with the exception of the studies in Tanzania by Kohi & Horrocks, 1994; and Ndeki & Klepp, 1994) were designed specifically to measure stigma. These studies were mainly conducted in the developed world and often used either telephone or mail surveys. Around the turn of the century four large organisations developed general population surveys containing questions on various subjects including stigma that could be administered via personal interviews in developing countries.[37] These were: (1) the Demographic and Health Survey (DHS) sponsored by the United States Agency for International Development (USAID); (2) HIV/AIDS/STD Behavioural Surveillance Surveys (BSS) sponsored by Family Health International (FHI); (3) the UNAIDS MEASURE[38] Evaluation General Population Survey; and (4) the United Nations Children's Fund (UNICEF) Multiple Indicator Cluster Survey (MICS).

As was the case with Ndeki and Klepp's research these surveys probed HIV-related stigma solely in terms of behavioural intentions towards PLWHA. Furthermore, although there was some variation in the questions, many of the questions repeated the same theme across the surveys. Typical questions included: "If you knew that a shopkeeper or food seller had the AIDS virus, would you buy vegetables from them?"

moral judgment towards PLWHA (i.e. symbolic stigma), while the other questions measured opinions about coercive policies towards PLWHA. As with many previous scales, this one also conflated different dimensions of stigma. However, in Herek *et al.* (2002) the questions from the 1997 and 1999 surveys had been clearly divided into distinct dimensions of stigma. For example, the question "People who got AIDS through sex or drug use have gotten what they deserve" was combined with two others probing symbolic stigma (i.e. "Most people with AIDS don't care if they infect other people with the AIDS virus"; and "Most people with AIDS are responsible for having their illness.")

[37] All four surveys were retrieved May 10, 2008, from http://www.emro.who.int/GFATM/guide/stigma/stigma1.html

[38] MEASURE stands for Monitoring and Evaluation to Assess and Use REsults.

(UNAIDS MEASURE Evaluation, 2000); "If a relative of yours became sick with the virus that causes AIDS, would you be willing to care for her or him in your own household?" (DHS, 2000); "If a teacher has the AIDS virus but is not sick, should he or she be allowed to continue teaching in school?" (UNICEF, 1999); and "If a student has HIV but is not sick, should he or she be allowed to continue attending school?" (FHI, 2000).

These questionnaires formed the basis for the majority of the HIV-related stigma studies conducted to date in developing countries. The FHI questionnaire, for example, has been administered in Lesotho, Swaziland, Kenya, Ethiopia, Ivory Coast, Niger, Benin, Burkino Faso, and Cameroon.[39] The DHS survey has been used in Ghana, Kenya, Malawi, Uganda, Zambia and Zimbabwe.[40] Other subsequent surveys in developing countries have used stigma questions similar to those asked in these four surveys, see for example the 2001 Botswana AIDS Impact Survey (Letamo, 2003); and the Lea Toto survey in Kenya (Hamra *et al.*, 2006). Furthermore, continued revision and administration of these surveys (such as the 2008 release of MICS,[41] which contained four behavioural intentions questions similar to those mentioned above) indicates the staying power and lasting influence of these original four surveys on global research on HIV-related stigma in the developing world.

The focus on behavioural intentions as a measure of stigma is, however, seriously problematic. As outlined in Chapter 2, it conflates stigma with discriminatory actions (actual or hypothetical). Behavioural intentions towards PLWHA become the measured proxy for stigma. As Deacon *et al.* (2005) highlight, the main problem with this approach is that it makes the assumption that stigma and behavioural intentions are interchangeable measures. Although stigma can lead to negative behavioural intentions (discrimination that people say they will enact), it is not necessarily a one-to-one relationship. Not all of the negative behavioural intentions are a product of stigmatising attitudes, and not all stigmatising attitudes will lead to negative

[39] Reports on each of these surveys are available at http://search.fhi.orgusing the search criteria "BSS" and the name of the country of interest.
[40] Reports on each of these surveys were retrieved May 28, 2008, from http://www.measuredhs.com/aboutsurveys/search/search_survey_main.cfm?SrvyTp=country
[41] The 2008 MICS was retrieved May 15, 2008, from http://www.childinfo.org/mics/mics3/index.php

behavioural intentions. A respondent's statement that, for example, he/she was not willing to look after a close family member with AIDS could well be motivated by anxieties about time constraints or a lack of the necessary skills. Negative behavioural intentions in such a case bear little relationship to stigma.

Furthermore, reported behavioural intentions that express the willingness to interact with PLWHA might not always indicate the absence of stigma (Nyblade, 2006). Returning to the example about willingness to care for a family member with AIDS, Nyblade *et al.* (2003) conducted qualitative research in three African countries that showed that although care is almost always given, the type and quality of care varies, and is often accompanied by stigma. Under such circumstances, the *fact* that care is given does not in and of itself provide an adequate proxy for the absence of stigma. It would be better to probe the relative quality of care and explore a broader set of attitudes towards PLWHA.

A third problem with measuring stigma purely in terms of behavioural intentions is that the underlying cause of the stigmatising behaviour cannot be determined (Nyblade, 2006; Stein, 2003). This is a problem not only for a general understanding of stigma, but also for the formation of appropriate policy. Nyblade points out: "understanding why a person engages in a particular stigmatizing behaviour is especially critical to developing effective programs to reduce stigma" (2006, p. 340).

The development of the Attitudes Towards Women with HIV/AIDS Scale (ATWAS) (O'Hea *et al.*, 2001) was among the next important advances in HIV-related stigma research. This scale comprised multiple items with four main factors that, like other scales in the past, did not make a clear distinction between the sources of different attitudes. The 'myths/negative stereotypes' factor probed moral judgements (symbolic stigma) with statements such as "Most women with HIV/AIDS have slept around a lot." The other factors probed opinions about support for coercive policies (such as, "Women who transmit HIV to their unborn baby should have their baby taken away"), but also conflated other issues (with statements such as "Women with HIV/AIDS are unfit mothers.") Despite its limitations, the development of this scale was critical as it highlighted the need for scales probing stigma towards a single population category. Specific measures mean that stigma towards the group of

interest (in this case women with HIV/AIDS) is captured independently of prejudices held towards other groups (for example homosexuals and foreigners).

In 2003 Herek *et al.* published a paper that used data from their 1999 national telephone survey illustrating the extent to which support for HIV surveillance policies connects with HIV-related stigma. This paper used a question which was one of the first to probe perceived stigma among the general population of the United States. The question asked respondents how much people with AIDS had been unfairly persecuted over the years – whether they face "a great deal" of unfair persecution, "some," "a little bit," or "no unfair persecution at all." They then repeated the question in the context of the modern day. This not only provided one of the first assessments of perceived stigma among the general population, but also gave an indication of how these perceptions can change over time.

Most of the other stigma surveys conducted worldwide after 2003 have followed similar patterns to the previous surveys by either measuring a limited domain of stigma (see for example Lau & Tsui, 2005 (Hong Kong); Liu *et al.*, 2005 (China)) or conflating different domains into one scale (see for example Mahendra *et al.*, 2006 (India); Mak *et al.*, 2006 (Hong Kong)).

However a few studies since 2003 have made the distinction between forms of stigma clear and conducted analysis using different dimensions of stigma. Lee *et al.* (2005), for example, measured symbolic stigma, instrumental stigma, behavioural intentions and support for coercive policy. Although this study was limited in that it only asked a single question to measure each dimension, and therefore may not have captured the full extent of each dimension, the analysis provided correlates of each of these dimensions separately. This study thus not only provided an indication of the extent of the dimensions of stigma measured, but also what factors were related to each dimension.

Another important survey was administered in Tanzania in 2005 to test indictors of HIV-related stigma that had been developed by the USAID Stigma and Discrimination Indicator Working Group (S&DIWG). This study conducted an extensive evaluation of three dimensions of HIV-related stigma: (1) fear of casual

transmission and refusal of casual contact with PLWHA (i.e. instrumental stigma); (2) values: shame, blame, and judgment (i.e. symbolic stigma); and (3) enacted stigma (discrimination) (Tanzania stigma-indicators field test group, 2005). This was one of the first studies in a developing country that made the distinction between these dimensions of stigma and asked multiple questions to probe each dimension. Zelaya *et al.* (in press) subsequently develop a comprehensive 24-item stigma scale in India that contained six questions in each of the three dimensions highlighted by the Tanzanian study described above, and an additional six questions to probe perceived stigma. As will be described in the next section, perceived stigma has been measured in studies that surveyed both PLWHA and the general population, and among samples of PLWHA only. However, Zelaya *et al.*'s study was one of the first to develop a multi-item scale to measure perceived stigma in the general population.[42]

Finally, in one of the most recently published research papers, Pulerwitz *et al.* (in press) measured stigma among truckers in Brazil using a 15-item scale that comprised two similar categories to the surveys mentioned above: (1) fear of casual contact; and (2) blame of PLWHA. This study is noteworthy, however, in that it also measured a third category of stigma named "fear of discrimination from others", which included statements that measured perceived stigma.[43] It was thus quite clear from these recent surveys that the importance of quantitative measures of perceived stigma is now becoming more widely recognised.

In sum, there has not been a clean evolution of the design of studies to measure HIV-related stigma as some of the limitations of earlier studies (such as conflating dimensions of stigma into one scale, or not capturing the multidimensional nature of stigma) continue to characterise more recent studies. A broad trend can, however, be discerned. HIV-related stigma was initially measured in terms of enacted stigma

[42] The scale for perceived stigma comprised the following questions: (1) "People living with HIV/AIDS in this community face neglect from their family"; (2) "People want to be friends with someone who has HIV/AIDS"; (3) "People living with HIV/AIDS in this community face ejection from their homes by their families"; (4) "People living with HIV/AIDS in this community face rejection from their peers"; (5) "People living with HIV/AIDS in this community face verbal abuse or teasing"; and (6) "People with HIV/AIDS in this community are abandoned by their spouse or partner."

[43] These statements were (1) "If I had AIDS, people would avoid me"; (2) "If I told my regular [sexual] partner that I have HIV/AIDS, she/he would leave me"; and (3) "If I had AIDS, I would be fired from my job."

(support for coercive measures and negative behavioural intentions towards PLWHA). Analysis of such data initially used only response frequencies to indicate the extent of stigma, but soon started to employ cross-tabulations, ANOVA and regression analysis to assess covariates of stigma. Negative moral judgements towards PLWHA and fear of HIV-infection from PLWHA were then recognised as important dimensions of stigma and measures of symbolic stigma and instrumental stigma were accordingly designed. It was also recognised that each of these dimensions incorporates many aspects and studies began to include multiple survey items to measure each dimension. Scales were then formed to combine these questions for analysis, but in the process the initial scales generally conflated the different dimensions of stigma. The importance of creating a clear distinction between the different dimensions of stigma was then established and studies began to distinguish between enacted stigma, symbolic stigma and instrumental stigma in both measurement and analysis. More recently, perceived stigma was recognised as an important dimension that needed to be measured. The latest, comprehensive studies of HIV-related stigma among general populations thus form separate, multi-item scales to measure enacted, symbolic, instrumental and perceived stigma.

3.2 Global quantitative research on HIV-related stigma among PLWHA

Far fewer studies have assessed stigma from the perspective of PLWHA. This is in part related to the fact that there are no public sample frames (lists of names from which to draw a sample) of PLWHA and hence obtaining a sample of PLWHA is generally quite difficult. As a result the studies measuring stigma among PLWHA are not randomised, generally have small samples and are collected mainly via convenience sampling or snowball sampling techniques.

One of the first studies of HIV-related stigma among PLWHA was conducted by Green (1995) in Scotland. This study stands out for a number of reasons. In addition to undertaking pioneering research among PLWHA it also was the first of very few studies to measure stigma concurrently from the perspective of both PLWHA and the general public. The survey used 15 statements to probe symbolic stigma (e.g. “People

with HIV are as intelligent as anybody else"), instrumental stigma (e.g. "It is safe for people with HIV to work with children"), and opinions about coercive policies towards PLWHA (e.g. "People with HIV must expect some restrictions on their freedom.") The statements about symbolic stigma (other examples were: "People with HIV are dirty"; "People with HIV are not to be trusted"; and "People with HIV should be ashamed of themselves") provided an indication of negative attitudes towards PLWHA when presented to members of the general population, but when asked to PLWHA also measured internalised stigma (what Green termed 'felt stigma'). This provided the first measurement of internalised stigma among PLWHA. Furthermore, all respondents (both PLWHA and others) were asked what they thought the general public's response to each statement would be. The study thus provided an assessment of perceived stigma from the perspectives of both the general public and PLWHA, which could then be compared. Although all 15 questions were combined into one scale, thus conflating the various dimensions of stigma measured, the descriptive analysis provides a good comparative commentary on the answers to each question.

In 1996 researchers in the United States started adapting quality of life scales to make them applicable specifically to PLWHA. Cella *et al.* (1996), for example, developed the Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) quality of life instrument from the Functional Assessment of Cancer Therapy – General Questionnaire. However these scales tend to measure general well-being such as emotional (e.g. "I feel sad"), functional (e.g. "I am able to enjoy life") and social/family well-being (e.g. "I feel distant from my friends") and are not good indices for the measurement of HIV-related stigma. For another example see Holmes and Shea (1997).

1996 and 1997 saw the publication of two research pieces that would shape much of the future research on HIV-related stigma among PLWHA. In 1996, in the United States, Westbrook and Bauman developed two 24-item scales: one to measure internalised stigma among PLWHA and the other to measure perceived stigma, applicable to both PLWHA and the general public. The full instrument is presented in Appendix A as it is not readily available on the internet.

The internalised stigma scale comprised statements about internalised *symbolic* stigma (e.g. "I think less of myself because I have HIV"; "I feel ashamed that I have HIV"; and "I must have done something to deserve getting HIV"), as well as statements about internalised *instrumental* stigma, i.e. the feeling that as a person with HIV they present a health risk to other people (e.g. "Because of my HIV, I should not hold a new infant"; and "People are right to be afraid of me because I have HIV.") Although these are two different aspects of internalised stigma, the scale conflates them.

The perceived stigma scale is a comprehensive scale tapping perceptions about how stigmatising the general public is in terms of moral judgements (e.g. "Most people believe that if you have HIV, you must have done something to deserve it"), fear of infection (e.g. "Most people think that someone with HIV should not take care of other people's children"), and discrimination (e.g. "Most people would reject the friendship of a person with HIV.") These two scales were pivotal as they made a clear distinction between internalised and perceived stigma and highlighted that each dimension can be tapped with multiple items. These scales have been used to measure stigma among PLWHA (see e.g. Derlega *et al.*, 2002; and Pequegnat *et al.*, 2001) and in comparative studies between PLWHA and the general public (e.g. Project Accept conducted in Thailand, Tanzania, and Zimbabwe between 2005 and 2007).[44]

In 1997, Sowell *et al.* published research that used questions to determine disclosure patterns, perceived stigma, and the adequacy of resources among rural women with HIV in South Carolina, United States. Importantly, they used a different conceptualisation of perceived stigma to Westbrook and Bauman (1996). Instead of viewing perceived stigma as the degree to which PLWHA think the general public stigmatises PLWHA (the conceptualisation used in this dissertation), Sowell *et al.* used perceived stigma to encompass "thoughts and feelings that they were being stigmatized or put in jeopardy because of their illness" (1997, p. 305). These included

[44] Project Accept was conduct by the National Institute for Mental Health (NIMH), an overview of the project was retrieved May 15, 2008, from http://www.cbvct.med.ucla.edu/overview.html

questions to measure internal stigma (e.g. "Felt ashamed of illness", and "Thought illness was punishment for things done in past") and fears about stigma (e.g. "Feared I would lose my friends if they learned about my illness.") Although they did not make a clear distinction between the different dimensions of stigma measured in the survey, in their analysis of responses to different questions they pointed out that questions measured "different types of stigma" (*ibid.*, p. 307) and they analysed covariates of each question separately.

Sowell *et al*'s. (1997) study is important to note as many subsequent studies of stigma used the same definition of perceived stigma and combined Sowell *et al.*'s questions into an index to measure 'perceived stigma', thus conflating different dimensions of stigma (for two recent examples see Emlet, 2006 (United States); and Wight *et al.*, 2006 (United States)). Similarly to Sowell *et al.*, Swendeman *et al.* (2006) also defined perceived stigma as a stigmatised person's fear or anticipation of discrimination/rejection and internal sense of shame and used Sowell *et al.*'s statements to measure 'perceived stigma'.[45] Importantly, Swendeman *et al.* used factor analysis with Sowell's questions and found that the questions measuring internal sense of shame (internalised stigma) separated from two other dimensions measuring fear of social rejection and feelings about being avoided. This indicated that Sowell *et al.*'s survey was indeed measuring different dimensions of stigma, which need to be distinguished.

The first heavily cited study to develop a scale to measure enacted (experienced) stigma was conducted in the United States to compare the impact of stigma among PLWHA and people with cancer (Fife & Wright, 2000). Fife and Wright's experienced stigma scale combined the responses to nine statements about experience of social rejection. The first statement probed whether the respondent *had* experienced discrimination ("My employer/co-workers have discriminated against me"), while the others probed whether the respondent *felt* he/she had experienced enacted stigma (e.g. "I feel others avoid me because of my illness"; and "I feel some friends have rejected me because of my illness.") Although their scales, which were created to measure internalised shame and social isolation, conflated different

[45] Swendeman *et al.* (2006) also adapted Sowell *et al.*'s questions into eleven questions to measure enacted (experienced) stigma.

concepts within each, this study is also noteworthy as it measured and analysed experienced stigma, internalised shame and social isolation with separate multidimensional scales.[46] This highlighted the need for measures of stigma among PLWHA to capture different dimensions of stigma, as was the case with measures of stigma among the general population.

The most commonly used stigma measure among PLWHA was published by Berger *et al.* in 2001. They developed an extensive 40 item scale which grouped stigma into four categories: personalised stigma (i.e. experienced stigma)[47]; disclosure concerns[48]; negative self image (i.e. internalised stigma)[49]; and concern with public attitudes about people with HIV (i.e. perceived stigma).[50] This study thus highlighted the clear distinction between the three main dimensions of stigma from the perspective of PLWHA: i.e. experienced stigma, perceived stigma and internalised stigma. For recent examples of other studies that have used these scales, or adaptations thereof, see Bunn *et al.*, 2007 (United States); Rao *et al.*, 2008 (United States); and Wright *et al.*, 2007 (United States).

Of the two main studies conducted in Asia to measure stigma among PLWHA, one measured experiences of stigma (Asian Pacific Network of PLWHA, 2004) and the other internalised stigma (Mak *et al.*, 2007). The 2004 study was conducted in India, Indonesia, Philippines and Thailand and is notable for its multi-item measurement of experiences of stigma and discrimination in many separate contexts (i.e. family, community, health care, employment, education). The study highlighted the fact that different degrees of stigma can occur in different contexts. The Mak *et al.* study is notable for being one of the first studies to research internalised stigma outside the United States and United Kingdom.

[46] The internalised shame scale, for example, included statements which measured internalised stigma ("I feel I am at least partly to blame for my illness"), perceived stigma ("I feel others think I am to blame for my illness") as well as feelings about disclosure ("I feel I need to keep my status a secret.")

[47] Experienced stigma was measured with statements such as: "I Have lost friends by telling them I have HIV"; and "People I care about stopped calling after learning I have HIV."

[48] Disclosure concerns were measured with questions such as: "Telling someone I have HIV is risky"; and "In many areas of my life, no one knows I have HIV."

[49] Internalised stigma was measured with questions such as "Having HIV makes me feel I'm a bad person"; and "Having HIV makes me feel unclean."

[50] Questions to measure perceived stigma included "Most people believe a person who has HIV is dirty"; and "People with HIV are treated like outcasts."

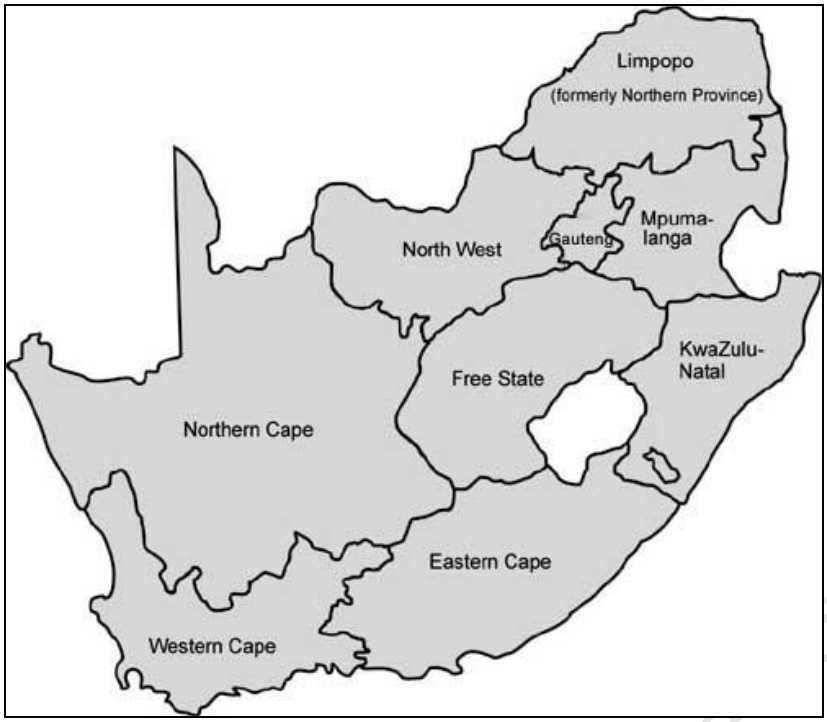
In sum, although the initial studies of stigma among PLWHA did not make clear distinctions between different dimensions of stigma, and some of the initial scales combined different dimensions of stigma together, it is now recognised that separate, multidimensional scales are required to measure experienced stigma, internalised stigma and perceived stigma.

3.3 Measurement of HIV-related stigma in South Africa

In similar vein to research on HIV-related stigma elsewhere in the world, research in South Africa has focused mainly on stigmatising attitudes and behavioural intentions towards PLWHA, with the first studies among PLWHA emerging only in 2006. In total, 20 studies have measured HIV-related stigma in South Africa: 13 among general populations, 3 from both the general population and among PLWHA, and 4 among PLWHA only. Unlike many studies from developed nations, South African studies typically do not use telephone surveys and mail surveys as a large percentage of the population do not have these services. Self-completed questionnaires are also generally inappropriate due to high illiteracy rates. The surveys conducted in South Africa to measure HIV-related stigma therefore employ personal face-to-face interviews.

Figure 3.1 displays a provincial map of South Africa as the studies in South Africa will be situated by province.

Figure 3.1. The nine provinces of South Africa



3.3.1 Assessment of stigma in the general population

The first study to include measures of HIV-related stigma was conducted by the HSRC in 1992 and consisted of 5,360 structured interviews across South Africa. Given the trend in international stigma research at the time, this study is particularly notable for including questions on symbolic stigma[51] and perceived stigma[52] among the many that measured behavioural intentions[53] and opinions on coercive policies towards PLWHA[54] (Du Plessis *et al.*, 1993). Furthermore, factor analysis was used to show that the eleven stigma items grouped separately from the various other questions in the study and could thus be combined into a scale. Although this study also fell into the trap of conflating different aspects of stigma, as was occurring in stigma research on the international level, it remains the first scale used in Africa to measure HIV-related stigma. It was also the first study in Africa to use statistical analysis

[51] These questions were "Do you think that people who have the AIDS virus should be blamed for their own condition?"; and "If a family member has been infected with the AIDS virus will you be ashamed of him/her?"
[52] For example: "Do you think your friends would avoid you if you contracted AIDS?"
[53] For example: "Would you remain friends with someone who contracted the AIDS virus?"
[54] For example: "Should people who contract the AIDS virus be compelled to resign from their jobs?"

(analysis of variance) to assess covariates of this stigma scale. Despite its ground breaking work, this study is only available in hard copy via the HSRC library and consequently has not been accorded the much wider recognition it deserves.

The next several years saw no studies of HIV-related stigma, possibly because social science research focused on issues around the political transition from the Apartheid State to a democratic government. Between 1998 and 1999 the UNAIDS MEASURE Evaluation field-tested the instrument it was developing (see page 44 for a discussion of the final instrument) in eight countries, including South Africa (UNAIDS MEASURE Evaluation Indicator Field Test Group, 2001). This instrument contained three questions that probed behavioural intentions towards PLWHA;[55] one on disclosure concerns;[56] and one on prioritising health care.[57]

The majority of subsequent surveys in South Africa measured stigma almost entirely on the basis of behavioural intentions towards PLWHA. These included two national surveys conducted by the HSRC, one in 2002 (Shisana & Simbayi, 2002) and the other in 2005 (Shisana *et al.*, 2005); and one commissioned by the Department of Health (Parker *et al.*, 2002).[58] Provincial level data measured stigma in a similar way in the rural areas of Limpopo Province (Pelzer, 2003) and in KwaZulu-Natal Province (Robinson *et al.*, 2004).

These studies identified apparently low levels of 'stigma' by using general tolerance towards PLWHA as a proxy measure. As mentioned previously, using behavioural intentions as a proxy for stigma is problematic in a number of ways. Beyond these

[55] The following questions were asked in this study: (1) "If a relative of yours became sick with the AIDS virus, would you be willing to care for him or her in your household?"; (2) "If a teacher has the AIDS virus but is not sick, should he or she be allowed to continue teaching in school?"; and (3) "If you knew that a shopkeeper or food seller had the AIDS virus, would you buy food from them?"

[56] The question was: "If a member of your family got infected with the AIDS virus, would you want it to remain a secret?"

[57] The question was: "Should people with AIDS receive less, the same or more health care than other seriously ill people?"

[58] The following statements, for example, probed stigma in the 2002 HSRC study: (1) "I will sleep in the same room as someone with HIV/AIDS"; (2) "I will share a room with someone who is HIV positive"; (3) "I will talk to someone with HIV/AIDS"; (4) "I will treat a family member who has HIV/AIDS well"; and (5) "I will not get infected by being in the same room as an infected person."

known limitations, the few questions that did not measure stigma in terms of behavioural intentions were also not good measures of stigma. One question in the HSRC study, for example, asked the participants to indicate their agreement with the statement: "I will not get infected by being in the same room as an infected person" (Shisana & Simbayi, 2002). This question used a measure about knowledge of HIV-transmission to proxy for stigma. Accordingly, the validity of these findings has been questioned with respect to the methods of measurement employed as none of symbolic, instrumental, resource-based,[59] or perceived stigma were measured (Deacon *et al.*, 2005; Stein, 2003).

The first study to form a multi-item index for symbolic stigma was undertaken by the AIDS Law project in 2002 (Jennings *et al.*, 2002). This study, conducted in Gauteng and KwaZulu-Natal Provinces, was designed to evaluate the nature and extent of discrimination towards PLWHA. Discrimination was measured based on responses to six statements about coercive policies towards PLWHA, such as "Tests for HIV/AIDS should be compulsory when people apply for jobs." The study's model for understanding discrimination identified three factors that influence discrimination, including deviation from perceived societal norms. "Deviance" was measured by means of responses to the following statements: (1) "AIDS only affects homosexuals"; (2) "AIDS is a punishment from God"; and (3) "An HIV positive person brought it upon himself or herself – they should not expect to be treated well by community members." In addition respondents were asked whether they agreed or not with the following scenario:

> Mary is dying of AIDS. She used to be an independent young woman who always got what she wanted. Mary had many relationships with different men. Although there are those who sympathise with her, most people in the community feel that she got what she deserved.

These questions were combined to form an index which, although not termed so by the authors in the study, can be seen as the first index of symbolic stigma in South Africa. Basic cross-tabulations were conducted to assess the influence of 'deviance'

[59] As will be discussed later, the 2005 HSRC study did include one question that was probably intended to measure resource-based stigma.

on discriminatory attitudes – it was found that the more 'deviant' a person was seen to be, the more this sample discriminated against her or him.

The Siyam'kela ("We are accepting") project in South Africa published a toolkit of indicators for measuring HIV-related stigma in 2004.[60] Although the two categories into which they divided the 12 different sets of stigma indicators suffered from conceptual conflation – e.g. the external (enacted) stigma category included themes around discrimination/avoidance of PLWHA and moral judgements towards PLWHA – the different indicators reflected the multidimensionality of stigma. Of particular importance was the indicator set titled 'Unwillingness to invest in PLWHAs'. This set of indicators was based on the belief that it is a waste to invest resources in PLWHA because they are not productive and will not live long. This was the first time that a specific indicator had been developed for resource-based stigma. The following year the HSRC 2005 study was the first, and to date only, study to include a question intended directly to elicit resource-based stigma ("It is not a waste of money to train or give a promotion to someone with HIV/AIDS", Shisana *et al.*, 2005).

Results from the first HIV-related stigma survey conducted in Cape Town were published in two separate research papers in 2003 and 2004 (Kalichman & Simbayi, 2003, 2004). The twelve stigma items used were adapted from the work by Herek *et al.* (2002) and designed to measure negative beliefs about PLWHA and the endorsement of social sanctions against PLWHA. Although the questions were not combined into indices, these studies provided the first extensive set of questions measuring HIV-related stigma in South Africa. Importantly, the set of questions probing symbolic stigma (what Kalichman and Simbayi (2004) termed 'repulsion') included the first question in HIV-related stigma research to assess negative attitudes towards PLWHA based on the premise that people with HIV may have HIV as a result of witchcraft and are therefore cursed ("People who have AIDS are cursed.") Their 2004 study also provided the first, and as yet only, research in South Africa to test the relationship between HIV-related stigma and traditional beliefs about the

[60] The Siyam'kela project was a joint project of the Policy Project (South Africa), The Centre for the Study of AIDS (University of Pretoria), USAID, and the South African Department of Health. The study was retrieved May 13, 2008, from http://www.policyproject.com/siyamkela.cfm

cause of AIDS using, in this instance, the question: "Is AIDS caused by spirits or supernatural forces?"[61]

Building on this work by Kalichman and Simbayi, Kalichman *et al.* (2005) developed the AIDS-Related Stigma Scale. Although Du Plessis *et al.* (1993) had used a stigma scale in their study, Kalichman *et al.*'s was the first multi-item scale (nine items) to measure stigma in Africa that was tested for validity and reliability across different cultural contexts. The scale was designed to reflect various dimensions of stigma without confusing stigmatising beliefs with knowledge about HIV transmission. The scale includes items which reflect symbolic stigma (including negative attitudes based on traditional beliefs (e.g. "People who have AIDS are cursed"), instrumental stigma (e.g. "It is safe for people who have AIDS to work with children"), and enacted stigma (e.g. "I do not want to be friends with someone who has AIDS"; and "People who have AIDS should not be allowed to work.") Although the brief scale is well placed for inclusion in surveys that have limited space for stigma questions, the scale does not probe resource-based stigma and it conflates all the other dimensions, thereby precluding a separate analysis of these dimensions.

In 2006, two studies were published that provided the first measures of perceived stigma in South Africa. Phaswana-Mafuya and Peltzer created a 2-item stigmatisation of HIV/AIDS index to measure stigma among staff in tertiary institutions in the Eastern Cape Province.[62] They asked respondents "If you think about the behaviour of your colleagues, is there stigma (feeling of shame) attached to HIV/AIDS at your work place?" and "Do you think there is a stigma (feeling of shame) attached to HIV/AIDS in the community where you live." The study found a sizeable percentage of respondents reported stigma in the workplace (28.5%) and in the community (42%). However it is difficult to know what these figures really represent as a result of uncertainties about how the term 'stigma' would have been interpreted.

[61] Multiple logistic regression analysis showed that controlling for other factors apart from HIV knowledge, individuals who believed that AIDS is caused by spirits or supernatural forces were significantly more likely to express negative attitudes towards PLWHA and endorse social sanctions against PLWHA. However, this relationship was no longer significant when the models controlled for knowledge about HIV/AIDS.

[62] Tertiary institutions provide further education after the completion of high school (secondary school). Tertiary institutions include universities, technikons, and further educational and training colleges.

In 2006, I assessed whether the term 'stigma' might be used in survey questions to provide an accurate measure of stigma. I asked 224 PLWHA to respond to three questions. First, I asked: "Do you know what stigma is?" Respondents who said they did were then asked the following open-ended question: "Please tell us what you think stigma is." Finally, after everyone had been given a definition of stigma[63], which tried to capture all dimensions of stigma, everyone was asked "Have you ever experienced stigma?" Eighty-seven respondents (39%) said they knew what stigma was. Of these individuals only a few mentioned aspects of symbolic stigma (e.g. "It is when people think he/she is better than you because of your status"), a couple of people mentioned discrimination in general (e.g. "Its when people treat those who are HIV badly because of their status"), but most related stigma to experiences of gossip (e.g. "Stigma is when people talking [*sic*] bad things about people living with HIV/AIDS.") Importantly, only 48 respondents (21%) indicated that they had ever experienced stigma, despite 80% reporting experienced stigma in one of the survey questions probing actual events in their lives (see Chapter 9 for detailed analysis of experienced stigma). It was therefore quite clear that even among PLWHA (who are presumably more likely to have thought about issues of stigma), the term 'stigma' was defined and understood in different ways by different people, and generally did not capture the full range of our research definition of stigma encompassed. It was thus concluded that using the term 'stigma' in survey questions would not yield results that could be easily interpreted.

A study conducted in Tshwane[64] Metropolitan Area in Gauteng Province adapted questions from Green (1995), Herek and Capitanio (1993), and Westbrook and Bauman (1996) (see above for a description of these surveys) to develop a 'personal stigma' index and a perceived stigma index (Visser *et al.*, 2006). Although these researchers identified three clear factors (what they called 'human rights', 'personal interactions', and 'blame and judgement') and provided a good descriptive analysis based on each question, they summed responses to all the questions in both indices and thus conflated instrumental stigma, symbolic stigma and enacted stigma.

[63] "Stigma refers to horrible things that people think about, say to or do to you or your family because you have HIV. Stigma also refers to when people stop thinking, saying or doing nice things about/to you or your family because you have HIV."
[64] Tshwane is also known as Pretoria.

3.3.3 Measurement of stigma among PLWHA

The first published study to measure stigma among PLWHA in South Africa analysed stigma within the Anglican Church in Southern Africa (the other countries involved were Angola, Lesotho, Mozambique, Namibia and Swaziland; see Deacon & Simbayi, 2006). This study measured experiences of stigma among PLWHA by means of questions probing the full spectrum from more subtle manifestations of stigma, such as gossip, to more overt manifestations such as being beaten, punched or kicked purely by virtue of HIV positive status. This pioneering work on stigma experienced by PLWHA was also the first to assess stigma towards PLWHA among the same sample frame (i.e. members of particular congregations). The questionnaires attempted to tap into all dimensions of stigma apart from resource-based stigma, and analysis was based on frequencies and cross-tabulations.

The only other research completed in 2006 measured experienced stigma, internalised stigma and perceived stigma among a sample of HIV positive women in Tswhane, Gauteng Province (Mdlalose, 2006). This study adapted Westbrook and Bauman's (1996) scales as the basis for questions designed to probe stigma.[65]

Three papers have emerged from a survey designed to measure experienced stigma and internalised stigma among PLWHA in Cape Town, Western Cape (Kalichman *et al.*, 2008; and Simbayi *et al.*, 2007a, 2007b). Three questions were asked about experiences of stigma/discrimination: (1) "I was treated differently by my friends and family once they found out I have HIV"; (2) "My HIV status has caused me to lose a job or a place to stay"; and (3) "I have experienced discrimination because I am HIV positive" (Simbayi *et al.*, 2007a, 2007b). It is, however, difficult to interpret the nature and extent of experienced stigma from these questions because being 'treated differently' in Question 1 could actually indicate positive experiences; positive responses to Question 2 could reflect individuals having lost their jobs simply because

[65] These scales are also currently being used in Project Accept by NIMH in two sites in South Africa (Gauteng and KwaZulu-Natal) to assess the impact of interventions to prevent HIV. A report on this randomised control trial was retrieved May 15, 2008, from http://www.cbvct.med.ucla.edu/overview.html

they were too sick to work; and responses to Question 3 might well have been informed by widely differing interpretations of discrimination.

Internalised stigma was measured in this survey on the basis of responses to seven statements that were adapted from Kalichman *et al.*'s (2005) AIDS-Related Stigma Scale. Two of the questions in the scale may not be good measures of internal stigma *per se* ("It is difficult to tell other people about my HIV infection" and "I hide my HIV status from others") as there could well be other reasons, such as perceived stigma, for agreeing with these statements. However the other five questions provide good indications of negative self perceptions and self abasement based on HIV status (see Simbayi *et al.*, 2007b).[66] Six of these statements (the statement "It is my own fault that I am HIV positive" was excluded) were used to form the Internalized AIDS-Related Stigma Scale (IA-RSS) that was shown to have good scale properties that were relatively stable across three culturally different samples: one in South Africa, one in Swaziland and one in the United States (Kalichman *et al.*, 2008).

Probably the most comprehensive study of stigma yet to be conducted in South Africa adapted Westbrook & Bauman's scales to develop comparative measures of stigma among the general public and stigma among a sample of HIV positive women in Tshwane, Gauteng Province (Visser *et al.*, in press). By contrast with the other studies in South Africa that used these scales, Visser *et al.* used factor analysis to identify two main factors emerging from these questions to create two scales (tested for reliability and validity): (1) "blame and judgement" and (2) "interpersonal distancing." The blame and judgement scale (six items) measured aspects of symbolic stigma and the interpersonal distancing scale (six items) measured behavioural intentions towards PLWHA (with the exception of the statement "I think less of someone because they have HIV.") These statements were adapted (i.e. prefaced by "Most people...") to measure perceived stigma in the community. The same perceived stigma questions were asked to the HIV positive women, and the blame and judgement scale was adapted to measure internalised stigma among these women. The only real gap in this research was the absence of a direct measure of

[66] (1) "Being HIV positive makes me feel dirty"; (2) "I feel guilty that I am HIV positive"; (3) "I am ashamed that I am HIV positive"; (4) I sometimes feel worthless because I am HIV positive"; and (5) "It is my own fault that I am HIV positive."

experienced stigma. For example, one statement measuring behavioural intentions ("If I was in public or private transport, I would not like to sit next to someone with HIV") was adapted and posed to PLWHA as: "If I was in public or private transport and someone knew I had HIV they would not sit next to me." Among PLWHA these questions therefore measured perceptions about how they might be treated rather than actual experiences.

3.4 Measurement gaps in research on HIV-related stigma

Overall, the majority of quantitative HIV-related stigma studies have been conducted in developed countries, especially in the United States, and have been overwhelmingly focused on social attitudes towards PLWHA. Most of this research uses cross sectional surveys and only a limited number have measured changes in stigma over time. We therefore know very little about how HIV-related stigma changes over time and what factors influence these changes. There is thus an urgent need to evaluate changes in the magnitude and character of social attitudes towards PLWHA (Weiss *et al.*, 2006). There is also relatively limited research on the experiences and perspectives of the stigmatised and only a handful of studies that measure stigma from both the perspective of the stigmatisers and stigmatised to allow comparison. Importantly, there is no systematic research on stigma experienced by the growing cohort of people in developing countries who have had their health restored by HAART.

Following the trend in research on social attitudes towards PLWHA, previous South African studies (see e.g. Parker *et al.*, 2002; Shisana & Simbayi, 2002) have also tended to measure HIV-related stigma mainly in terms of behavioural intentions towards PLWHA. There is relatively little research, especially in Sub-Saharan Africa, that makes a clear distinction between different dimensions of stigma and even fewer that use multi-item scales to measure each dimension separately.

In terms of specific dimensions of stigma, resource-based stigma has only, to the best of my knowledge, been measured by one question in one study (see Shisana *et al.*,

2005). Perceived stigma has also only been measured in a limited number of studies, particularly in SSA. This is an important area of research as fear of stigma affects health behavioural outcomes, such as the uptake of voluntary counselling and testing (Chesney & Smith, 1999; Hamra *et al.*, 2006; Herek *et al.*, 2003; Hutchinson & Mahlalela, 2006; Kalichman & Simbayi, 2006; Lee *et al.*, 2005; Lindberg *et al.*, 2006; Liu *et al.*, 2005; Mathole *et al.*, 2006; Wolfe *et al.*, 2006).

In terms of factors that affect HIV-related stigma, identifying the determinants of stigma and their implications for health policy was included in Weiss *et al.*'s (2006, p. 285) recommendations for the future stigma research agenda in the following terms: "stigma may be motivated by exaggerated or inappropriate fears and dangerousness, moral judgements ... magico-religious ideas about the cause ... or other factors." Given that few studies have distinguished between different dimensions of stigma, it follows that hardly any have examined determinants of the different dimensions separately.

In particular, the relationship between pre-existing stigmas and HIV-related stigma is a factor that stands out as lacking measurement (Nyblade, 2006, p. 341). Despite being recognised as an important component for future research agendas in 1996 (Herek *et al.*, 1996), the interaction of HIV-related stigma with other kinds of stigma has only been measured in a few studies in developed countries (see e.g. Herek & Capitanio, 1999; Lee *et al.*, 1999). In SSA there appear to be no studies attempting to measure this.

In addition only one study (see Kalichman & Simbayi, 2004) has analysed the relationship between traditional beliefs and stigma. The importance of assessing the relationship between traditional beliefs and HIV-related stigma has recently been brought to life in Steinberg's (2008) ethnographic research. Research in this area is sorely lacking, as understanding this relationship may play an important role in understanding stigma in South Africa.

Chapter 4. Study methods

Chapter 4 presents an overview of the methods used in this study. The chapter starts with a description of the study site and describes the method of data collection before giving an outline of the surveys used in this dissertation. Each survey is situated in relation to the contribution it makes to the aims of the study, as well as by reference to previous research on HIV-related stigma (informed by the review presented in Chapter 3). Greater detail about each survey will be provided in later chapters. This chapter also highlights key aspects of the statistical analyses undertaken and concludes with a discussion of the ethical considerations informing this research.

4.1 Study Site

South Africa has the highest number of people living with HIV/AIDS in the world (Whiteside, 2008) which makes it an ideal study site for HIV-related stigma. Given this, it is surprising that relatively few quantitative HIV-related stigma studies have been conducted in South Africa (or anywhere else in SSA). Within South Africa, Cape Town is an appropriate site for two main reasons. Primarily, because the first pilot HAART programme in South Africa was launched in May, 2001 in Cape Town's largest informal urban settlement – Khayelitsha. Cape Town is thus particularly well situated for an assessment of stigma amongst individuals who have been on relatively long-term HAART.

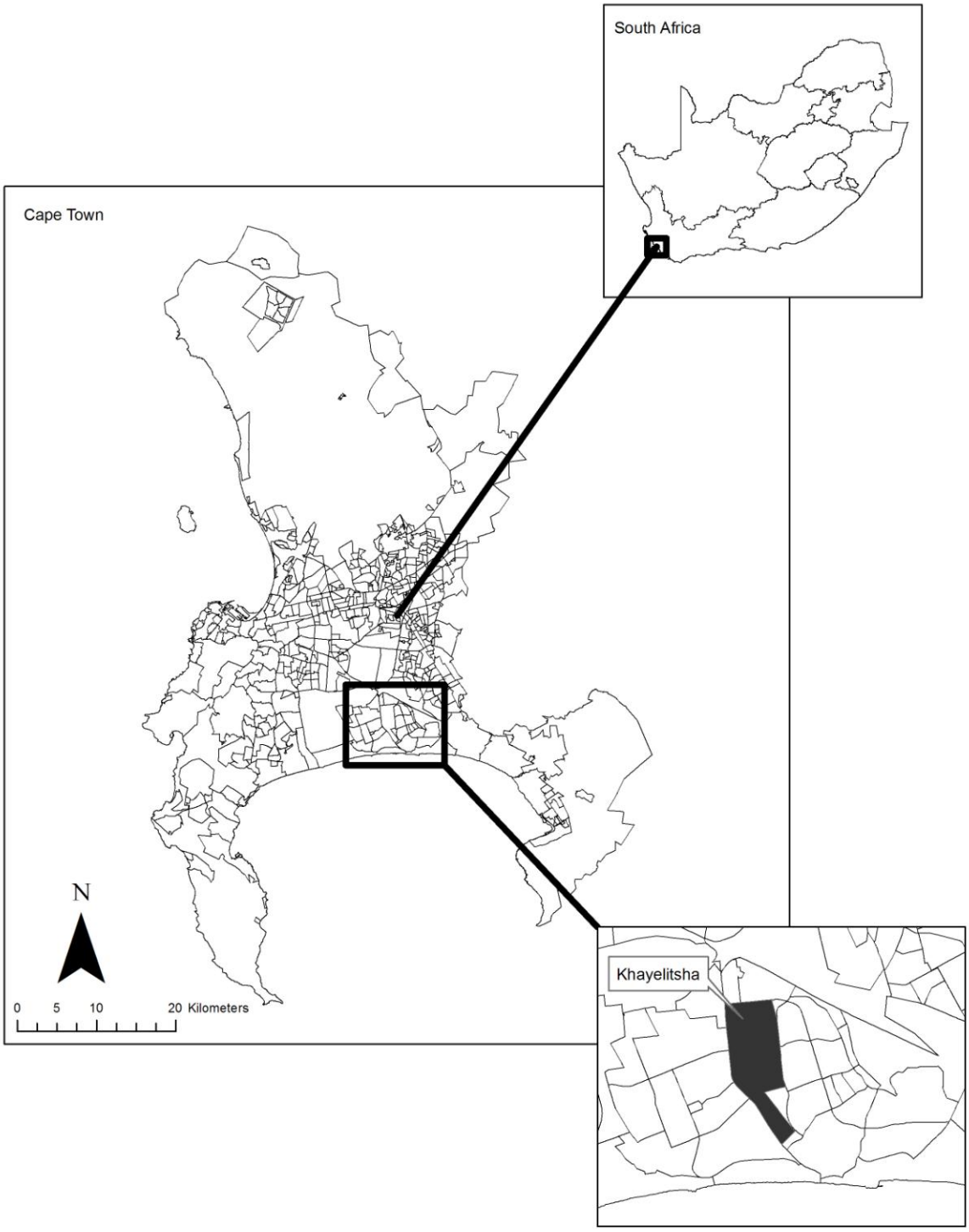
The pilot HAART programme was conducted by Médecins Sans Frontières ('Doctors without Borders') in collaboration with the Western Cape Provincial government. At the time the pilot was initiated it was known that middle-class people in developed countries who became AIDS-sick could expect to receive lifelong treatment. However, there was uncertainty about whether public health systems in developing countries could manage to deliver treatment to the poor. The pilot programme aimed to demonstrate that it was feasible to provide HAART in a primary health care setting in impoverished areas. Khayelitsha was chosen as the pilot site as it was in the only South African province (i.e. the Western Cape) that would cooperate with MSF and

because it was a poor, crowded conglomeration of former township 'shoebox' houses and shanty-town shacks where high adult HIV prevalence rates were the norm. This programme, the first public provision of HAART in Africa, was a great success. By 2004 more than a thousand Khayelitsha residents had started treatment, clinical outcomes were positive and adherence was exceptionally high. (For more details about the history, selection criteria and clinical outcomes of the programme see: Coetzee *et al*., 2004a, 2004b; Médecins Sans Frontières *et al*., 2003).

As this study uses a sample from the MSF HAART pilot programme, it is important to note that – as is the case with most HAART programmes in developing countries – the vast majority of those who participated in the programme were women. There was thus an element of selection bias in the programme. The overrepresentation of women probably reflects the fact that health-seeking behaviour is socially constructed and constitutive of gender identity: gendered norms make it difficult for men to admit any health-related weakness and seek medical attention (Nattrass, in press). In addition, at the time of the pilot, pregnancy appeared to be a primary determinant of a person participating in voluntary counselling and testing. This would have contributed to greater participation of women by virtue of more women knowing their HIV-status (Coetzee & Nattrass, 2004).

The second reason for Cape Town being chosen as a study site is that it is a multi-cultural South African city with a high degree of segregation between the different population groups (Seekings *et al.*, 2005). Given that stigma is context-specific, Cape Town is thus also an appropriate site for measuring stigmatising attitudes within, and comparing stigmatising attitudes between, the different population groups. Figure 4.1 situates Cape Town within South Africa, and Khayelitsha within Cape Town.

Figure 4.1. The study sites: Cape Town and Khayelitsha (source: City of Cape Town)



Cape Town is the third largest city in South Africa by population and the largest city in the Western Cape Province.[67] According to the latest census (City of Cape Town, 2003), the population of Cape Town was almost three million (2,893,251) in 2001.[68] Just under half (48.1%) reported their population group as 'coloured',[69] 31.7% as 'black', 18.8% as 'white' and 1.4% as 'Indian'. The 2001 census showed a higher percentage of females (52%) relative to males (48%).

Cape Town is a city of stark contrasts. Its spectacular topography, featuring the unique dominance of the landscape by Table Mountain, results in its often being regarded as one of the world's most beautiful cities. Figure 4.2, which shows a view of Cape Town when approached from the sea, demonstrates why this might be so. But the picturesque view from a distance, often reinforced for visitors by scenes of idyllic beaches fringing wealthy suburbs such as Camps Bay in Figure 4.3, does not withstand close-up scrutiny. The picture-postcard scenes all too often serve to obscure, or at the very least act as a distraction from, the extreme disparities in wealth and living conditions that characterise this part of the Western Cape.

High property prices in the more sought-after residential areas, which would include suburbs like Seapoint in Figure 4.2, result in these being mainly occupied by whites who, on average, as displayed in Table 4.1 earn considerably more than either coloureds or blacks. Blacks, on average, have the lowest *per capita* income, at less than a seventh of the average income of whites. Coloureds have a greater *per capita* income than blacks, but still less than a sixth of the income of whites.

[67] Approximately 65% of the population of the Western Cape, one of the nine provinces in South Africa, reside in Cape Town (Rhoode, 2005).
[68] It is noted that the figures presented here are based on the 2001 Census and would thus not accurately reflect the population of Cape Town today.
[69] 'Coloureds' is a term commonly used in South Africa to describe people of mixed race.

Figure 4.2. The suburb of Seapoint with Table Mountain in the background

Figure 4.3. Camps Bay beach and Lion's Head, Cape Town

Table 4.1 Population distribution, HIV prevalence and *per capita* income for the three largest population groups in the Western Cape, South Africa

Population group	[a] Population	[a] HIV positive	[a] % HIV positive (total population)	[a] HIV prevalence rates for adults (15-49 yrs old)	[b] Average *per capita* monthly income
Black	1,306,748	152,322	12%	18%	R877
Coloured	2,529,615	41,912	2%	3%	R1,000
White	904,349	9,574	1%	2%	R6,511

Source: [a] Estimates for July 1 2003 from the ASSA 2003 HIV/AIDS Projection models (ASSA, 2005)
[b] Calculated from the 2001 South African Census

The majority of blacks and coloureds in Cape Town reside in distinctly unpicturesque, and very much less hospitable areas, including shanty-towns on the sands of the Cape Flats and townships such as Khayelitsha (described below). These are usually some distance from the city centre (often as a result of forced removals under the Apartheid Group Areas Act) and are subject to frequent flooding in the winter and, for the shack-dwellers, devastating fires driven by the Southeaster in the heat of the summer. In addition to general racial segregation, previous research has shown that such inequalities in income, as well as inequalities in infrastructure, schooling and health care leave the majority of blacks and many coloureds in a position of relative, and often absolute, poverty (Makinen *et al*., 2000; Seekings *et al*., 2004b; Seekings & Nattrass, 2004; Turok, 2001; Van der Berg, 2002).

Pillay (2007) argues that wage-earning differentials between population groups in the Cape Town area are largely a result of labour market disadvantage (i.e. differences in skills and experiences) rather than discrimination per se. Differences in unemployment rates highlight this, with unemployment measured in the 2001 census as being: 49.8% among blacks; 25.9% among coloureds; and only 4.7% among whites. Labour market inequalities are one product of South Africa's long history of racial inequality. It has been shown that from as early as the eighteenth and nineteenth centuries the British colonial government developed a system that favoured coloured over black ('native') labour (Goldin, 1987). Racial discrimination was, however, most obvious under apartheid, the National Party government's policy of racial segregation, which officially began in 1948 and ended in 1994. Racial segregation was enforced through control of, among other things, travel, residence, employment and education (Pillay, 2007). The long history of racial discrimination created distinct socioeconomic and socio-cultural contexts for different population

groups, which linger on to a large extent today in the form of labour market disadvantage (Seekings & Nattrass, 2005).

Table 4.1 also shows that HIV prevalence in the Western Cape in 2003 was greatest in the black population, with 12% of the total population estimated to be HIV positive and 18% of adults between 15 and 49 years old infected. The prevalence rate was considerably lower among the coloured population (2% of the population and 3% of adults between 15 and 49 years) and lowest amongst whites (1% of the population and 2% of adults between 15 and 49 years). This suggests that the salience of issues related to HIV is likely to differ between the population groups.

4.1.1 Khayelitsha

Khayelitsha is Cape Town's largest black township, home to 36% of blacks living in Cape Town. Khayelitsha is situated 21 kilometres (13 miles) southeast of central Cape Town. It comprises a mix of formal housing and informal (shack type) houses, but most residents live in corrugated iron shacks without running water. Figure 4.4 provides an illustration of a shack in Khayelitsha and Figure 4.5 gives a distinctly different prospect of Table Mountain from the distanced view in Figure 4.2. The 2001 population census recorded the number of people living in Khayelitsha as 329,002 in 85,614 households. Almost all residents of Khayelitsha were black and almost everyone (96.8%) spoke Xhosa as their home language (City of Cape Town, 2005). Unemployment was about 51% and income distribution in Khayelitsha approximated that for blacks as a whole in Cape Town (Magruder & Nattrass, 2006).

The Western Cape has the lowest provincial HIV prevalence rate in South Africa (ASSA, 2005). However, area-level antenatal surveys indicate 2004 HIV prevalence among antenatal clinic attendees in Khayelitsha to be 33%, which is significantly above the provincial average of 14.9% (Shaikh *et al.*, 2006). As is the case with Khayelitsha, antenatal HIV prevalence is significantly above the provincial average in other black townships around Cape Town, such as Guguletu and Nyanga (29.1%, *ibid.*) and in other black townships countrywide, such as in Rietvlei (28%), Eastern Cape province, and Umlazi (47%), KwaZulu-Natal province (Jackson *et al.*, 2007).

Figure 4.4. A shack in Khayelitsha

Figure 4.5. A section of Khayelitsha with Table Mountain in the background

4.2 Data collection

The survey data used in this research was collected through four studies conducted by the Centre for Social Science Research (CSSR) at the University of Cape Town: The Cape Area Panel Study (CAPS) of young adults; the Cape Area Study (CAS) of adults; the Khayelitsha Panel Study (KPS) of adults in Khayelitsha; and the HAART Panel Study of adults on HAART in Khayelitsha. Data relevant for this dissertation were collected in the 2003 and 2006 waves of CAPS, in CAS 2003 and 2005, in KPS 2004, and in the 2004/05 and 2006 waves of the HAART Panel Study. Joanne Stein, a former CSSR researcher with expertise in stigma, compiled the stigma questions asked in the 2003 surveys. Stein designed these questions to probe different dimensions of stigma (namely instrumental, symbolic, resource-based and perceived stigma) based on the conceptual framework outlined in 2003 (Stein, 2003). These questions were ground breaking as most previous surveys in South Africa had measured stigma using behavioural intentions questions and no survey had investigated resource-based stigma (see Chapter 3 for details about previous measures of HIV-related stigma). The current study, which commenced in April 2004, analyses this data for the first time.

I designed, or had a role in designing, all other stigma questions used in this dissertation. I was assisted greatly by colleagues in the CSSR who challenged my questions and suggested alternatives. Each questionnaire was designed through a three-stage process. First, relevant questions were taken from previous stigma studies from around the world. Second, these questions were piloted with trained CSSR fieldworkers to test transferability from other regions and to ensure they were clearly understood in the local context. Questions probing experiences of stigma were piloted with a group of CSSR fieldworkers who were themselves HIV positive, and many were on HAART. Third, each pilot was followed up with a focus group consisting of the same fieldworkers to discuss important aspects of stigma that were not covered by the initial set of questions. New questions were developed and piloted with the fieldworkers.

For the Khayelitsha surveys the questions were translated into the local language (Xhosa) and back translated during training to validate the translation and to improve the fieldworkers' understanding of each question. This training helped standardise how each interview was conducted by the fieldworkers. All questionnaires were designed with careful consideration of the potential context effects raised by Sudman *et al.* (1996).[70] The questions from each survey are provided later, in the relevant analysis sections.

I personally trained the CSSR fieldworkers to conduct the stigma modules within each survey. I was also responsible for the quality control process for each of the stigma modules. The quality control managed through the CSSR aimed to reduce missing data and detect interviewer effects (i.e. patterns in responses by interviewer).[71] No discernable interviewer effects were found. Raw data from the questionnaires were captured in a Microsoft Excel spreadsheet by trained CSSR data capturers.

The following section provides a brief description of each survey and the contribution it makes to this research. Detailed descriptions, including the sample characteristics and sampling techniques, are provided later, where relevant.

4.2.1 The Cape Area Panel Study (CAPS)

CAPS is a longitudinal study that follows the lives of a large and representative sample of adolescents in Cape Town as they undergo transitions to adulthood (Lam *et al*., 2005). CAPS commenced in 2002 with respondents between the ages of 14 and 22. In 2003 the second wave of CAPS (n = 1,371) included a stigma module designed to probe behavioural intentions and stigmatising attitudes (symbolic stigma,

[70] Context effects suggest that answers to survey questions can be affected by prior questions in the same survey, which may provide respondents with cognitive cues that are used to answer subsequent survey items. As an example, questions about perceived stigma in the HAART surveys may have influenced answers about individual experiences of stigma. The experienced stigma questions were therefore asked prior to the perceived stigma questions, which were also buffered by two modules that were unrelated to stigma.

[71] The quality control process for each survey was completed when a random subset of 20% of the questionnaires was captured for the second time.

instrumental stigma, resource-based stigma and perceived stigma) towards PLWHA. As mentioned above, this was the first survey in South Africa to probe all four of these dimensions of stigma.

Additional survey questions were designed to provide demographic, sociological, psychological and economic variables to assess potential determinants of stigma. In particular, a module on prejudice towards different groups was designed to assess the interaction between HIV-related stigma and other kinds of stigma. The analysis of this data makes this study the first in Southern Africa to assess this important relationship.

The third wave of CAPS in 2005 did not ask any questions about stigma. In 2006, however, the fourth wave of CAPS (n = 1,075) repeated part of the 2003 stigma module. The 2003 and 2006 datasets were combined to create a panel dataset to evaluate changes in different dimensions of HIV-related stigma (behavioural intentions, instrumental stigma and symbolic stigma) over time. This analysis is the first of its kind in South Africa, and among the few to investigate such changes internationally.

4.2.2 The Cape Area Study (CAS)

CAS comprises a series of cross-sectional surveys of adults in the Cape Metropolitan Area covering a wide range of topics in the social sciences. In 2003 CAS interviewed 588 individuals with a survey that focused on social and political attitudes and behaviour. This survey included a module of questions probing attitudes and behavioural intentions towards PLWHA. The majority of these questions were an identical sub-set of questions from CAPS 2003. These questions were designed to assess whether stigma among adults in Cape Town showed similar characteristics to stigma in the young adult population of Cape Town.

In 2005 CAS interviewed a different group of 1,202 individuals with a survey that included a question probing perceived stigma. This question was designed to provide

an indication of whether the extent of perceived stigma among adults in Cape Town was similar to perceived stigma among young adults.

4.2.3 The Khayelitsha Panel Study (KPS)

KPS follows the lives of adults living if Khayelitsha. The study commenced in 2000 with a representative sample of 966 individuals. The second wave of KPS (2004, n = 570) asked about opinions on the social context experienced by people living with HIV. Questions in this module were designed to measure the nature and extent of perceived stigma. Despite a significantly smaller sample in the second wave, Magruder and Nattrass (2006) argued that attrition bias was not evident – at least not so far as labour market calculations were concerned. Caution is still however needed in interpreting these data. Together with the perceived stigma questions in CAPS and the CAS surveys these were the first questions to measure perceived stigma among the general population of Cape Town.

4.2.4 The HAART Panel Study

The HAART Panel Study was designed to investigate the impact of long-term antiretroviral treatment on the lives of people living with AIDS. Between August 2004 and February 2005 a snowball sample of 242 individuals who had been on HAART for at least a year was recruited through word of mouth and contacts with clinics and support groups. The study aimed to recruit as many individuals as possible that had participated in the pilot HAART programme conducted in Khayelitsha. Although this was not a random sample, and was therefore non-representative, over two thirds of the starting (2001) cohort from the pilot HAART programme was recruited into the study. Furthermore, over a third of the total known cohort of people in Khayelitsha who had been on HAART for longer than a year was included in the sample.

The stigma module in the HAART 2004/05 survey was designed to examine the experiences and perceptions of HIV-related stigma. This was the first survey in Cape

Town to investigate perceived stigma among PLWHA. Demographic and socio-economic questions were included to provide variables for the statistical analysis of potential determinants of experienced and perceived stigma. In 2006, the HAART survey contained another module on experiences of stigma to assess how relevant the issue of stigma remained in the lives of these individuals. This was the first panel analysis of experienced stigma in Africa. In addition, the 2006 survey included a module designed to measure the nature and extent of internalised stigma. An analysis of the potential determinants of internalised stigma was again made possible through the inclusion of questions to elicit factors that could affect internalised stigma.

Table 4.2 provides an overview of the four studies used in this dissertation and the contribution made by each survey.

Table 4.2. Overview of the studies used in this dissertation

Cape Area Panel Study (CAPS)	**Cape Area Study (CAS)**
Representative sample of young adults in Cape Town 2003 (n = 1,371) • Attitudes towards PLWHA • Determinants of stigmatising attitudes • Perceived stigma 2006 (n = 1,075) • Changes in stigma over time.	Representative cross sectional surveys of adults in Cape Town 2003 (n = 588) • Attitudes towards PLWHA • Determinants of stigmatising attitudes 2005 (n = 1,202) • Perceived stigma
Khayelitsha Panel Study (KPS)	**HAART Panel Study**
Large sample of adults in Khayelitsha 2004 (n = 570) • Perceived stigma	Snowball sample of individuals on HAART in Khayelitsha 2004/05 (n = 242) • Experienced stigma • Perceived stigma • Determinants of experienced and perceived stigma 2006 (n = 224) • Experienced stigma • Internalised stigma • Determinants of internalised stigma

4.3 Data analysis

The raw data from each survey were exported from Microsoft Excel to STATA/SE 9.1 for analysis. The specific statistical techniques used will be described in the relevant chapters. It is, however worth noting that as a rule, probit regression models were used with binary dependant variables; ordered probit regression models were used with dependant variables comprising a maximum of six values; and Ordinary Least Squares (OLS) regression models were used with dependant variables comprising seven or more values.

It is also worth noting upfront that concerns about using OLS regression techniques (employed in a number of the chapters) with attitudinal data have been considered. OLS regression is optimal under the assumption that the dependent variables are continuous. In this study, this was not strictly speaking the case, as the dependent variables could not take on any value. In addition, many of the dependent variables were formed from responses along a 5-point Likert scale. The difference between the response options used to create the dependent variables could not be said to be equal. The difference between "strongly agree" and "agree", for example, cannot be assumed to be the same as the difference between "neither agree nor disagree" and "agree." Furthermore, there is some debate about whether probit or logit regression is the better technique.

Sensitivity analysis was therefore conducted to test the robustness of the OLS, ordered probit and probit regression results using ordered probit, ordered logit and logit regressions respectively. All sensitivity analyses showed only marginal differences in the significance of the coefficients across technique. In a few instances the marginal change in the significance of the coefficients between the regression techniques altered the level of significance of the variable. However, given that these cases involved very small changes (i.e. the significance of a variable might change from $p < 0.049$ (5% level of significance) to $p < 0.051$ (10% level of significance)) it was concluded that the significance of the coefficients, for all practical purposes, was robust across regression technique. It was therefore concluded that the choice of

regression techniques did not bias the results. The results of each sensitivity analysis is provided in the appendix and referred to where relevant.

4.4 Limitations of the study

The use of survey data to measure stigma has several limitations. First, an understanding of the nature and extent of stigma is limited to those aspects of stigma which are probed by the particular survey questions that were asked. As there is always a trade-off between the number of questions and quality of survey data (as a result of interview fatigue), there is always pressure on survey designers to reduce the number of questions asked. This can be a problem for multidimensional variables like stigma, especially (as in this study and almost all other stigma studies in South Africa) when the stigma modules contribute a small portion to a larger study on a variety of topics. CSSR surveys are always team efforts with many researchers vying for space in the questionnaire. I was thus at times obliged to drop and adapt questions in ways that were not always optimal for my specific research interests.

Second, especially in the case of face-to-face interviews which is the survey mode almost always used in stigma research in South Africa, stigma may be underestimated as a result of social desirability bias. Social desirability bias is the phenomenon whereby respondents give answers that they deem to be socially expected or acceptable and that portray the respondent in a more favourable manner rather than disclosing what they truly intend or feel. Pisani (2008) provides an astute account of the real-world challenges in collecting behavioural and epidemiological data for social science research, in which she refers to the phenomenon of participants providing socially desirable responses as "The tell-the-interviewer-what-you-think-they-want-to-hear lie" (p.100). Desirability bias can thus affect the measurement of behavioural intentions and stigmatising attitudes.

Third, questions probing behavioural intentions are almost always hypothetical in nature. This is problematic because many people might not know how they would act in certain situations and might not even be aware of the prejudices they harbour.

What they report as their (likely) action in such a hypothetical example may thus be a poor indicator of how they would act in a real life situation. In other words, behavioural intentions are not the same as behaviours – the association between stigmatising attitudes and behavioural intentions may actually be greater than the association between behavioural intentions and actual behaviours. When interpreting associations between behavioural intentions and stigmatising attitudes in this dissertation, it is therefore important to note that there is the potential for a degree of redundancy between measures of instrumental stigma and behavioural intentions.

Fourth, without the use of qualitative data to validate the interpretation of the survey answers the assumption has to be made that the respondents interpreted the questions as the research design intended. This, however, is not always the case – even where careful piloting of the questionnaires takes place (as was the case in the Cape Town surveys). For example, in one of the surveys used in this study the following statement was posed to the individuals on HAART: "The disability grant helps people with HIV be more accepted by their families." A positive responsive was assumed to indicate the perception that money received through this government welfare programme contributes to lower levels of stigma experienced by PLWHA. However, during fieldwork training for the subsequent survey, one of the fieldworkers said that in her case she would agree to this statement, but it would not indicate a reduction in stigma. In her case her family was 'more accepting' of her when she received the money because she no longer needed to ask them for money and therefore she no longer needed to visit them, which they did not want her to do because of her HIV-positive status. So, at least in terms of this individual, the answer received would not have been interpreted correctly. For this reason, this question was not used in this research. However, in the absence of such fortuitous qualitative checks on the meaning of the questions, we have to assume that the research questions were measuring stigma as intended.

In addition, three factors in the design of the surveys limit this research. First, as with all surveys with HIV positive participants, no sample frame was available to randomise the selection of participants. The survey of people on HAART therefore used a snowball, convenience sample. As this is a non-probability sample inferences cannot be made about individuals on HAART in general. Furthermore, this sample

was recruited mainly via word of mouth through HIV-positive support groups. Access to support groups and HAART might, in and of itself, indicate this sample to be living in a social environment that is less stigmatising than for other PLWHA.

Second, the survey questions asked to the adult population of Metropolitan Cape Town were not designed specifically to examine potential determinants of stigma. Some factors found to be significantly associated with stigma among young adults, such as knowledge about HIV transmission, were missing from the models of stigma among adults. These models therefore suffer from omitted variable bias.

Third, the surveys' questions probing stigma among the general population were asked before Kalichman & Simbayi published their important paper in 2004 on the potential link between traditional beliefs and HIV-related stigma. Consequently, no questions in this study were designed to assess the extent to which individuals (predominantly black individuals) believed that HIV was caused by witchcraft. It was thus impossible to investigate the relationship between stigma and the belief that PLWHA are cursed.

4.5 Ethical considerations

Several measures were taken to ensure that no harm occurred to any of the participants (survey respondents or fieldworkers) involved in this research. First, prior to the commencement of each survey, ethics approval was obtained from the University of Cape Town. Furthermore, CAPS was a collaborative project with Princeton University and Michigan State University. CAPS was therefore reviewed, and approved, by the International Review Boards at these institutions as well.

Second, special care was taken to ensure the safety of fieldworkers. Where possible, fieldworkers conducted interviews in areas familiar to them, and in which they felt safe to work on their own. In unfamiliar or less safe areas, fieldworkers worked in pairs.

Third, particular efforts were made to ensure the anonymity of participants, especially those who were living with HIV/AIDS. Fieldworkers were trained about the importance of minimising the possibility of involuntary disclosure of HIV status. Interviews with PLWHA were scheduled in advance and at a location comfortable to both respondents and fieldworkers. In addition, all survey participants received a token of appreciation for their contribution to this research. In 2003, the CAPS respondents were, for example, given small bags or baseball caps. It was subsequently discovered that respondents, and the research they were involved in, could possibly be identified by these gifts. Respondents in the HAART survey were therefore given food vouchers instead of material goods to avoid any chance of involuntary disclosure.

Fourth, special care was taken to ensure that the written consent obtained from each respondent was fully understood (i.e. informed consent was obtained). Consent forms for KPS and the HAART study were, for example, translated into Xhosa and designed to emphasise the key issues as simply as possible (see appendix B for an example of one of these consent forms). The consent forms were signed by fieldworkers once they had satisfied themselves that the respondents understood and agreed to their contents. The fieldworkers were thus responsible for ensuring that the consent obtained was fully informed consent.

Last, every attempt was made to understand, respect and maintain the integrity of the data used. As alluded to above, particular care was taken in the selection and testing of statistical methods to ensure that the information provided by the participants was not incorrectly interpreted.

Assessment of HIV-related stigma in the general population of Cape Town

Chapter 5. HIV-related stigma among young adults in Cape Town

As mentioned earlier, previous quantitative studies of HIV-related stigma in general populations have tended to focus on the measurement of behavioural intentions towards PLWHA and consequently have been criticised for adopting such a narrow approach to stigma measurement which fails to account for the complex multidimensional nature of stigma (Berger *et al.*, 2001; Crandall *et al.*, 1997; Deacon *et al.*, 2005; Fife & Wright, 2000; Herek & Capitanio, 1998; Stein, 2003). These studies have also been criticised for conflating negative judgement of PLWHA and negative behavioural intentions, thereby making it impossible to explore whether stigmatising attitudes may be a 'determinant' (in the sense of co-vary with) of negative behavioural intentions.

Studies that have probed different dimensions of stigma have found that stigma may serve different functions for different individuals. Qualitative research conducted in Russia (Balabanova *et al.*, 2006) and Namibia (Thomas, 2006) clearly revealed that the basis of HIV-related stigma involves both fear related to health consequences of interacting with PLWHA and the disease's association with behaviour and populations deemed to be immoral. This supported previous quantitative research in the United States which showed that stigma simultaneously served symbolic and instrumental functions for 30% of the sample (Herek & Capitanio, 1998). Another study conducted in Hong Kong showed that both symbolic stigma and instrumental stigma were an important source of discriminatory attitudes (Lau & Tsui, 2005). Such studies highlight that it is important, therefore, to consider different dimensions of stigma independently.

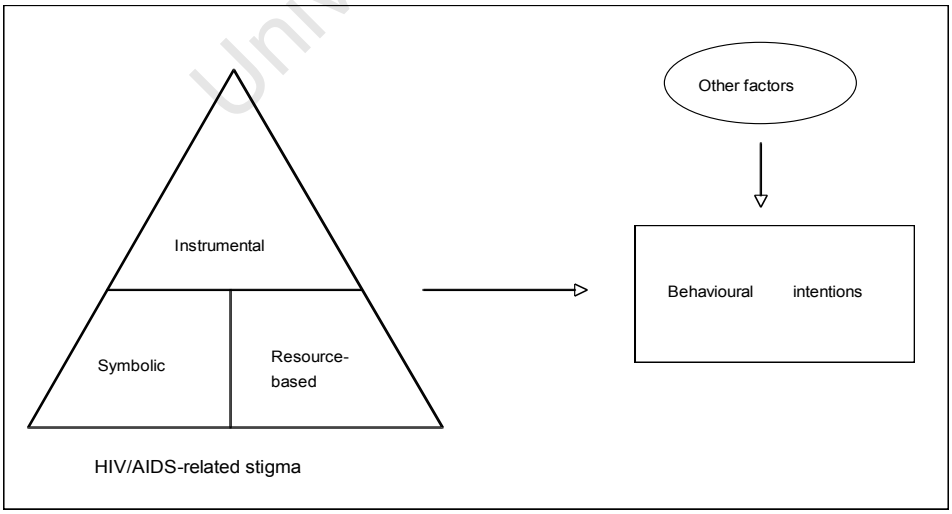
5.1 Method

This chapter provides a new and more inclusive understanding of HIV-related stigma in South Africa using a multidimensional approach to assess the stigmatising attitudes among the young adult population of Cape Town. Three different dimensions of

stigma were measured: (1) symbolic stigma (that is, a negative moral judgement of PLWHA); (2) instrumental stigma (that is, negative judgement based on irrational fear of infection); and (3) resource-based stigma (that is, negative judgement towards PLWHA based on resource concerns). Importantly, behavioural intentions (positive or negative) towards PLWHA were measured separately. Given the multifaceted nature of each dimension of stigma and the various manifestations of negative behavioural intentions, indices of each were formed using a number of different questions. Statistical analyses were then undertaken to determine the potential factors influencing the stigmatising attitudes. Importantly, the potential determinants of the behavioural intentions were explored in order to probe the extent to which behavioural intentions were influenced by different dimensions of stigma.

Figure 5.1 displays the theoretical assumptions used in this chapter. Stigma was depicted as three components: instrumental, symbolic and resource-based. Behavioural intentions were conceptualised as a potential product of stigma. However, as illustrated, behavioural intentions might also have been influenced by other factors besides stigmatising beliefs. For example, someone who says they are not willing to take care of a family member with AIDS might not feel they have the adequate skills for such an important task. In such a case their behavioural intentions are not a result of stigma.

Figure 5.1. Theoretical assumptions used for stigma measurement



The different dimensions of stigma were explored using data from the 2003 Cape Area Panel Study (CAPS) of young adults.[72] The first wave of CAPS, conducted in 2002, interviewed 5,000 young adults, aged between 14 and 22 years. CAPS had a complex survey design. The sample was stratified by race (black, coloured and white). The primary sampling units (PSUs) were the enumeration areas (EAs), comprising clusters of households, from the 1996 general census.[73] Four hundred and forty PSUs, about 10% of the enumeration areas in Cape Town in the 1996 census, were selected based on probabilities proportional to size. Simple random sampling, using aerial photographs of each enumeration area, was then used to select 25 households within each PSU. Finally, a maximum of three individuals between the ages of 14 and 22 were selected from each household. It was uncommon for more than three individuals within this age range to reside in one household, but when it occurred, the three individuals with the most recent birthdays were selected. This wave of CAPS collected demographic, behavioural and attitudinal information.

In 2003 the second wave of CAPS re-interviewed 1,371 of the respondents from the first wave. Selection of respondents for the second wave was based on systematic selection of PSUs within the black and coloured strata, and individuals in the white strata. In each case a random starting point was selected and then every third unit was selected.

Table 5.1 displays the key demographic information of the CAPS 2003 sample. More than half the sample was black and less than 10% white. The sample was slightly biased in favour of women. Most respondents had completed at least grade 7 and the majority was still in secondary school. The significant majority of respondents (86%) were affiliated to a religious organisation. The sample was weighted so that the proportions in each racial group were representative of the population structure in Cape Town at the 2001 population census (City of Cape Town, 2003).

[72] A full description of the survey design for CAPS and the CAPS survey instruments is available at http://www.caps.uct.ac.za/ [retrieved June 12, 2008].
[73] An enumeration area is the geographical area enumerated by one census representative. An EA is the smallest geographical area for which census data are reported.

Table 5.1. CAPS 2003 sample characteristics

		n	percent	mean
All respondents		1,371	100%	
Race	black	782	57%	
	coloured	460	34%	
	white	128	9%	
			100%	
Gender	men	625	46%	
	women	746	54%	
			100%	
Education	< grade 8	226	16%	9.63
	grade 8 to 11	872	64%	
	grade 12	204	15%	
	some tertiary	66	5%	
			100%	
Income	*per capita* household (pcy)			R876
	Less than average pcy	1,028	75%	
	more than average pcy	343	25%	
			100%	
Religion	no	185	14%	
	yes	1,173	86%	
			100%	

Note: The total number of respondents differs between variables due to missing data

The second wave included a module of questions probing attitudes and behavioural intentions towards PLWHA, which are relevant to this chapter. As mentioned previously (see Chapter 4) using survey questions to probe such aspects does have limitations due to social desirability bias and the hypothetical nature of many questions. This study hypothesised that these factors were likely to result in an underestimation of stigma as peoples' reported intentions are likely to be more positive than their interactions with PLWHA would actually be. As it was not feasible to control for these effects the reader needs to be cognisant of their potential to influence the results.

The questions used to measure stigma and behavioural intentions towards PLWHA, together with responses to them, are displayed in Table 5.2. Questions were combined into three indices (instrumental stigma, symbolic stigma and behavioural intentions) and into indicators of resource-based stigma. The questions allocated to each index/indicator are indicated in superscript in Table 5.2. These indices were used as a measurement of stigma and as the dependent variables (Y) in multiple regression models assessing potential determinants of stigma. The following section outlines the formation of each of the dependent variables (each index/indicator).

Table 5.2. Survey questions used to form stigma and behavioural intentions indices

	Definitely Yes	Probably yes	Probably no	Definitely no	Don't Know	Total
[r] Q1. Do you think the government should provide free health care for people who need it?	92% (1,261)	6% (85)	1% (7)	1% (16)	0% (0)	100%
[r] Q2. Do you think the government should provide free health care for people with AIDS?	92% (1,257)	7% (91)	1% (11)	1% (10)	0% (3)	101%
[r] Q3. Would it be a good idea for the government to give job training to unemployed young people?	89% (1,226)	8% (114)	1% (15)	1% (11)	0% (5)	100%
[r] Q4. Should youth who are infected with HIV get this job training?	76% (1,042)	16% (223)	3% (36)	4% (57)	1% (12)	100%
[r] Q5. Should all people who are too sick to work get a welfare grant from the government?	81% (1,113)	14% (192)	2% (31)	2% (30)	0% (6)	99%
[r] Q6. Should someone with AIDS who is too sick to work get a welfare grant from the government?	81% (1,104)	14% (188)	3% (41)	2% (24)	1% (11)	101%
[b] Q7. Would you be willing to look after a close family member with AIDS?	85% (1,165)	10% (135)	2% (23)	3% (35)	1% (9)	101%
[b] Q8. Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them?	92% (1,260)	5% (75)	1% (14)	2% (22)	0% (0)	100%
[b] Q9. If you knew that a shopkeeper had HIV/AIDS, would you buy fresh vegetables from him or her?	66% (901)	18% (241)	4% (58)	11% (150)	1% (14)	100%
[b] Q10. Imagine you meet someone you really like and he/she tells you that he/she is HIV positive, would you still go out on a "date" with him/her?	59% (798)	25% (346)	5% (73)	9% (123)	2% (21)	100%
[b] Q11. Do you think a school pupil with HIV should be allowed to attend school?	87% (1,184)	7% (92)	1% (20)	4% (61)	0% (4)	100%
[i] Q12. Would you drink from the same bottle of water as an HIV infected friend?	64% (875)	15% (204)	6% (80)	14% (197)	1% (14)	100%
[i] Q13. Would you rather not touch someone with HIV/AIDS because you are scared of infection?	15% (202)	6% (76)	12% (164)	67% (911)	1% (11)	101%
[I] Q14. Do you worry that HIV is much easier to catch than we are told?	41% (555)	12% (162)	10% (134)	36% (491)	1% (20)	100%
[i] Q15. Would you prefer to know who has HIV/AIDS in your community so that you can be careful not to get infected by them?	53% (714)	14% (190)	9% (122)	23% (310)	2% (23)	101%
[i] Q16. Do you think that a school pupil with HIV puts other pupils in their class at risk of infection?	8% (107)	8% (112)	15% (200)	68% (934)	1% (15)	100%
[s] Q17. Do you think HIV/AIDS is a punishment for sleeping around?	15% (206)	11% (147)	13% (172)	60% (820)	2% (21)	101%
[s] Q18. Do you think that many people who get HIV infected through sex have only themselves to blame?	26% (353)	14% (185)	12% (161)	47% (645)	2% (21)	101%
[s] Q19. Do you think that some people with HIV/AIDS want to infect other people with the virus?	15% (210)	21% (288)	16% (218)	43% (590)	4% (59)	99%

Note: [r] Resource-based index [b] Behavioural index [I] Instrumental index [s] Symbolic index
Percentages do not always total 100% as a result of rounding effects
Numbers in parentheses indicates number of respondents

5.1.1 Formation of indices

Questions from the stigma module were assigned to different indices in a two step process. Firstly, a theoretical approach was used to group questions into indices based on face validity, that is, what I expected a question to be measuring based on theoretical understandings, the empirical literature and pilot testing of the questionnaire. Four indices were identified (displayed in Table 5.3): the behavioural (BI), symbolic (SI), instrumental (II) and resource-based (RI) indices.

The first thing to notice in Table 5.3 is that the six questions probing resource-based stigma were used to create three new variables (i.e. each of the three pairs of questions were combined): 'Q1&Q2', 'Q3&Q4' and 'Q5&Q6'. As can be seen in Table 5.2 (which lists all the questions) Question 1 was a general question in that it asked the respondents if he or she was in favour of providing free health care to those who need it. Question 2, by contrast asked specifically if the respondent favoured providing free health care for people with AIDS. This pair of questions allows us to create a new variable which isolates those who are biased specifically against PLWHA from those who do not support free health care to anyone (including those with AIDS). Only those who favoured free health care in general but not for people with AIDS were categorised as stigmatising. The same logic was applied to the paired Question 3 and Question 4 (about job training) and Question 5 and Question 6 (about welfare grants).

The second noteworthy aspect of Table 5.3 is Question 11, which includes a set of question marks in the index columns. This is because Q11 ("Do you think a school pupil with HIV should be allowed to attend school?") could arguably be measuring symbolic, instrumental or resource-based stigma. The respondent could be judging the child as unworthy (morally), or as a potential threat to other children, or as a waste of scarce educational resources (given that the child is unlikely to survive into adulthood). It could also be picking up behavioural intentions, i.e. if it was up to the respondent, the pupil would not be allowed to attend school. At this stage (which relied on face validity to allocate questions to indices) this question was accordingly not allocated to any index.

Table 5.3. The allocation of questions into indices and factors

		BI	II	SI	RI	F1	F2	F3
Q1&Q2	Discrimination of PWHA with respect to the provision of free health care.				√			
Q3&Q4	Discrimination of PWHA with respect to the provision of job training.				√			
Q5&Q6	Discrimination of PWHA with respect to the provision of a welfare grant.				√			
Q7	Would you be willing to look after a close family member with AIDS?	√				√		
Q8	Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them?	√				√		
Q9	If you knew that a shopkeeper had HIV/AIDS, would you buy fresh vegetables from him or her?	√				√		
Q10	Imagine you meet someone you really like and he/she tells you that he/she is HIV positive, would you still go out on a "date" with him/her?	√				√		
Q11	Do you think a school pupil with HIV should be allowed to attend school?	?	?	?	?	√		
Q12	Would you drink from the same bottle of water as an HIV infected friend?		√				√	
Q13	Would you rather not touch someone with HIV/AIDS because you are scared of infection?		√				√	
Q14	Do you worry that HIV is much easier to catch than we are told?		√				√	
Q15	Would you prefer to know who has HIV/AIDS in your community so that you can be careful not to get infected by them?		√				√	
Q16	Do you think that a school pupil with HIV puts other pupils in their class at risk of infection?		√				√	
Q17	Do you think HIV/AIDS is a punishment for sleeping around?			√				√
Q18	Do you think that many people who get HIV infected through sex have only themselves to blame?			√				√
Q19	Do you think that some people with HIV/AIDS want to infect other people with the virus?			√				√

Note: BI: Behavioural Index
II: Instrumental Index
SI: Symbolic Index
RI: Resource-based Index
F1: Factor 1 and Final Behavioural Index
F2: Factor 2 and Final Instrumental Index
F3: Factor 3 and Final Symbolic Index

Exploratory factor analysis was then used to see which questions appeared to be measuring the same underlying dimension of stigma - thereby testing the coherence of the stigma indices.[74] The factor analysis identified three 'factors', or groupings of

[74] Factor analysis is a statistical technique used to represent a set of variables in terms of a smaller number of hypothetical variables (Kim & Mueller, 1978). This technique analyses the correlation between each of the questions in Table 5.2 and factors (groups) together questions that are highly correlated (answered in similar ways) (Field, 2000). Each group of

questions, which respondents answered in similar ways.[75] The questions within each factor are displayed in the last three columns in Table 5.3. As the questions in each factor were the same as those grouped together using the face validity approach, the factor analysis therefore corroborated the theoretical formation of the behavioural intentions (factor 1, $\alpha = 0.67$), instrumental stigma (factor 2, $\alpha = 0.61$) and symbolic stigma (factor 3, $\alpha = 0.59$) indices.[76] The factor analysis indicated that Question 11 should be included in behavioural intentions index because it factored better with that group of questions than the others.

The questions initially allocated (based on face validity) to the resource-base index did not, however, factor together and showed very low reliability as an index ($\alpha = 0.19$). It is possible that these questions were probing different aspects of resource-based stigma, regarding health, training and welfare respectively. These variables were therefore initially analysed separately and not combined into a composite 'index'.

5.2 Measures of HIV-related stigma

Responses to the stigma questions were coded so that a score of 0 indicated no stigma reported and a score of 3 indicated maximum stigma reported. It was difficult to interpret the "don't know" responses. For example, a "don't know" response to Question 19 ("Do you think some people with HIV/AIDS want to infect other people with the virus") could indicate that the respondent was uncertain about the moral character of PLWHA (i.e. they did not say no to this question) and thus it could indicate some degree of stigma. On the other hand it could be a completely non-judgemental response based on not knowing the intentions of PLWHA and therefore not being in a position to give an answer. Given that it was impossible to separate respondents in these two categories and as relatively few respondents answered "don't

questions (each factor) is then examined to assess which dimension of stigma (hypothetical variable) it is measuring.

[75] The factor analysis used Varimax rotation and eigen values greater than one.

[76] Cronbach's Alpha (α) measures how well a set of items (or variables) measures a construct-it is a coefficient of reliability (or consistency). It is generally accepted that an alpha of about 0.6 or greater indicates a reliable index.

know" (Question 19 was most affected with 4% of respondents selecting this answer) all 'don't know' responses were excluded from analysis.[77] The 5-point Likert Scale was therefore reduced to a 4-point scale. Where questions were grouped together in an index, the answers to each question were summed to form the overall stigma score for each index. A 'general stigma' score was created by summing all the stigma questions.

Table 5.4 displays the levels of stigma measured within each index. Four levels of stigma are shown in the table. 'No stigma' represents respondents who scored the lowest possible score in each index, that is, no stigma on any question. Low, moderate and high levels of stigma record respondents scoring within the lower third, second third and upper third of each index respectively.

Levels of stigma among young adults in Cape Town were shown to vary significantly depending on the dimension of stigma being evaluated. With regard to the behavioural intentions index, the majority of respondents had a relatively high tolerance towards PLWHA, with 89% expressing no or low levels of negative behavioural intentions. A much greater percentage of respondents (50%) showed moderate-high symbolic stigma and the majority of respondents showed moderate-high levels of instrumental stigma (58%). This indicates that negative attitudes towards PLWHA based on fears of infection and negative moral judgement towards PLWHA are more prevalent than intentions to discriminate against PLWHA.

The resource-based stigma indicators measured low levels of this dimension of stigma amongst the young adult population of Cape Town. It must be noted, however, that the questions asked in CAPS were among the first attempts to measure this dimension of stigma, and as the factor analysis indicates, these questions may well not be probing any consistent notion of resource-based stigma.

The general stigma index, which simply sums the scores for all stigma questions, reveals that the vast majority of respondents (97%) were found to reveal some degree

[77] A total of 2% of respondents answered "don't know" to any of the resource-based stigma questions; 3% to any of the behavioural intentions questions; 5% to any of the instrumental stigma questions; and 6% to any of the symbolic stigma questions.

of stigma towards PLWHA. Furthermore more than a quarter of respondents reported moderate (27%) or high (2%) levels of stigma on the majority of questions. This is worrying given that *any* level of stigma is potentially damaging for PLWHA. Furthermore, actual levels of stigma are likely to be higher, given potential response bias, which as mentioned earlier was likely to result in an underestimation of stigma, and therefore potentially undermining of both HIV prevention efforts (for e.g. creating disincentives for disclosure) and treatment (by undermining adherence).

Table 5.4. Measures of stigma among young adults in Cape Town

	No stigma	Low levels	Moderate levels	High levels	Total
Behavioural intentions	35%	54%	9%	1%	99%
Instrumental stigma	9%	33%	47%	11%	100%
Symbolic stigma	18%	33%	36%	14%	101%
Resource-based stigma (health)	94%	5%	1%	0%	100%
Resource-based stigma (training)	80%	14%	3%	3%	100%
Resource-based stigma (welfare)	91%	6%	3%	1%	101%
General stigma	3%	68%	27%	2%	100%

Note: Percentages do not always total 100% as a result of rounding effects

5.2.1 Relationship between stigma indices

Having constructed the stigma indices, an analysis was then conducted to assess the relationships between the different dimensions of stigma. Of particular interest was the extent to which individuals who reported one dimension of stigma were also likely to report another. Correlation analysis was conducted with the behavioural intentions, instrumental stigma and symbolic stigma indices. Table 5.5 shows a strong positive correlation between these indices.

As noted above, the separate resource-based stigma indicators did not factor together and therefore could not reasonably be summed into one index. As correlation analysis was not suitable for the individual indicators, a binary variable was created to indicate which individuals reported resource-based stigma on at least one of the questions. The binary variable included 339 (25%) respondents who reported some resource-based stigma and 1001 (75%) that reported none. Further analysis of resource-based stigma in this chapter uses this binary variable. One-way analysis of variance (ANOVA) indicated that individuals who reported resource-based stigma were more

likely than their counterparts to report negative behavioural intentions ($p < 0.000$), instrumental stigma ($p < 0.000$) and symbolic stigma ($p < 0.000$).

These findings indicated that individuals who reported one dimension of stigma were also likely to report another. That is, as found by Herek and Capitanio (1998), many individuals simultaneously held different stigmatising attitudes and intentions.

Table 5.5. Correlations between behavioural intentions, instrumental stigma and symbolic stigma

	Behavioural intentions	Instrumental stigma	Symbolic stigma
Behavioural intentions	1		
Instrumental stigma	0.52	1	
Symbolic stigma	0.35	0.42	1

5.3 Determinants of stigma

OLS regression models, the results for which were confirmed by ordered probit analysis (see Appendix C for these results), were used to assess factors that influenced behavioural intentions towards PLWHA, instrumental stigma and symbolic stigma. Probit regression models, the results for which were confirmed by logit analysis (see Appendix C), were used to assess factors that influenced resource-based stigma. All models were adjusted to account for the survey design of CAPS (stratification and clustering effects) as well as for non-response.

Table 5.6 displays the explanatory (independent) variables examined as factors that could influence stigma and behavioural intentions towards PLWHA. As noted in Chapters 2 and 3, HIV-related stigma is a complex social phenomenon, which is moulded by cultural and contextual factors. The analysis in this chapter divides the sample into three population groups – blacks, coloureds and whites – to assess whether racial differences in Cape Town (see section 4.1) exist for the different dimensions of stigma. Race is an obvious potential determinant given that HIV prevalence rates vary a great deal between the race groups (see Table 4.1), and because race is a proxy for language and cultural differences which may well have implications for how HIV-related stigma is manifest and determined.

Table 5.6. Explanatory variables used to assess potential determinants of behavioural intentions, instrumental stigma, symbolic stigma and resource-based stigma

Behavioural intentions	Instrumental stigma	Symbolic stigma	Resource-based stigma
Racial groups	Racial groups	Racial groups	Racial groups
Gender	Gender	Gender	Gender
Age	Age	Age	Age
Education	Education	Education	Education
HIV knowledge	HIV knowledge	HIV knowledge	HIV knowledge
Religious affiliation	Religious affiliation	Religious affiliation	Religious affiliation
Know someone with HIV	Know someone with HIV	Know someone with HIV	Know someone with HIV
Know someone who died of AIDS	Know someone who died of AIDS	Know someone who died of AIDS	Know someone who died of AIDS
General bigotry	Household income	General bigotry	General bigotry
Household income		Household income	Household income
Instrumental stigma			
Symbolic stigma			
Resource-based stigma			

Gender is another potential determinant of stigma given that attitudes towards PLWHA have been found to vary between men and women (Greene *et al.*, 2003; Herek & Capitanio, 1993; Lee *et al.*, 1999; Lee *et al.*, 2005). A study of HIV-related stigma in Botswana showed that generally women were more tolerant of PLWHA than men, supposedly because women are the principal caregivers (Letamo, 2003). Similar results have been found in Portugal (Dias *et al.*, 2006). Accordingly, it was thus hypothesised that young men in Cape Town would reveal more stigmatising attitudes and negative behavioural intentions than their female counterparts.

Age is another potential determinant of stigma, although research investigating the relationship between HIV-related stigma and age has yielded inconsistent results. The Nelson Mandela/HSRC study (Shisana & Simbayi, 2002) found that stigma levels in South Africa varied according to age. Those in the oldest category (>49 years old) displayed the greatest stigma, followed by those in the youngest group (15-24 years old). A study in Hong Kong also found older respondents to be more stigmatising (Lau & Tsui, 2005). It must be noted, however, that this study compared different age groups: 18-35 years old with 36-50 years old. Similar results were found elsewhere in China (Lee *et al.*, 2005). Conflicting evidence from Botswana (Letamo, 2003) and Kenya (Hamra *et al.*, 2006) showed that younger respondents were significantly more stigmatising than older respondents.

With regard to young adults in Cape Town, it seemed plausible to expect older respondents to stigmatise more as they probably knew less about HIV, and might have perceived themselves to be less at risk from HIV than the younger respondents. However, it seemed equally plausible that younger respondents might be more stigmatising because HIV affects younger people disproportionately and they might therefore have a greater tendency to distance themselves psychologically from risk of HIV infection by blaming others and defining HIV-risk in terms of 'out-groups' that did not include them.

As intimated above, knowledge about HIV and about risk in general is likely to be an important factor influencing stigma. Thus education and knowledge about HIV ought to be captured in regression models on stigma. Previous studies in South Africa (Shisana & Simbayi, 2002), Botswana (Letamo, 2003), Kenya (Hamra *et al.*, 2006) and China (Lee *et al.*, 2005; Liu *et al.*, 2005) have shown higher levels of education to be equated with lower levels of HIV-related stigma. It was thus hypothesised that a similar result would be found in this analysis. The level of education of each respondent was based on the number of years of education successfully completed. In coding the education variable, a year of education was assigned for each level of schooling successfully completed.[78]

Previous research has also highlighted a direct relationship between an individual's knowledge of HIV and his/her attitudes towards PLWHA (Boer & Emons, 2004; Crandall *et al.*, 1997; Dias *et al*., 2006; Herek & Capitanio, 1994, 1998; Lau & Tsui, 2005; Letamo, 2003; Le Poire, 1994; Lew-Ting & Hsu, 2002; Liu *et al.*, 2005; Kohi & Horrocks, 1994; Parker *et al.*, 2002). Inaccurate knowledge about HIV, especially with regard to HIV transmission, has been linked to both instrumental and symbolic stigma, as well as to negative behavioural intentions towards PLWHA.

To investigate this, an index was formed of HIV knowledge based on the respondents' opinion on whether HIV could be transmitted by (1) "using a public toilet?", (2) "sharing a bath?", (3) "sharing a bottle of water?", (4) "shaking hands?", (5) "kissing

[78] Note that grade one was the first year of education counted. Also note that levels of education were based on each year of schooling successfully completed and not each year completed at school. In other words, grade six is counted as one year of education, even if it took three years to complete.

on the lips?", (6) "deep kissing? (Putting your tongue in their mouth?)", and (7) "touching someone's genitals (penis or vagina) with your hand?"[79] Respondents received a score of zero for incorrect answers or one for correct answers. The scores for individual questions were summed to obtain an index from 0-7, with 7 indicating a correct understanding on all questions.

As noted in Chapter 2, stigma is a product of socialisation and is shaped by social values. The norms and values that are held by individuals may be moulded by religious organisations. This is definitely the case in South Africa where the latter have a strong social role (Levy *et al.*, 2005). Reaction to HIV/AIDS from religious organisations in South Africa have ranged from divine retribution discourse, at one end of the scale, through to the most tolerant and non-judgemental discourse, at the other (Delius & Glaser, 2005). On the one hand, HIV is seen as a punishment for immorality and demands repentance (Levy *et al.*, 2005). On the other, Deacon and Simbayi (2006) argue that churches offer a place for progressive theological reflection and practical action on moral formation and social justice. The Anglican Archbishop for Southern Africa, for example, was among the first religious leaders to publicly counter HIV-related stigma (Deacon & Simbayi, 2006, p. i).

Religious organisations can also establish safe spaces in which people can discuss their knowledge, fears and experiences and therefore increase awareness about HIV. In South Africa the large-scale active participation of churches in creating HIV awareness was launched in 2001 when the National Religious Association for Social Development cooperated with the National Department of Health to run HIV education workshops. At the provincial level, the Anglican Church in the Western Cape has been at the forefront with particularly vocal activism from Archbishop Desmond Tutu.[80] One of the most successful church programmes, Fikelela (whose slogan is 'The Church is HIV/AIDS friendly') was founded by St Michael's Church in Khayelitsha. Fikelela was so successful that all Anglican churches are mandated (by the Anglican Church of South Africa) to emulate the programme (Levy *et al.*,

[79] It could be argued that under certain circumstances the correct answer to the question "deep kissing? (Putting your tongue in their mouth?)" is unclear. If both parties involved had, for example, cuts in their mouth and stomach ulcers. Sensitivity analysis showed that results (sign and significance) are robust with the exclusion of this question.
[80] Desmond Tutu was the Archbishop of Cape Town from 1986 to 1996.

2005). Affiliation to a religious organisation was therefore included in the regression analyses, but neither theory nor any previous research findings provided any clear prior expectation about how religious affiliation would be found to be associated with stigma.[81]

The 'religion' variable begins to probe the respondent's social location and its resulting implications for stigma. This can be taken further by exploring the contact that respondents may have had with PLWHA. According to Goffman (1963) the more contact a person has with people living with a particular disability, the more 'normalised' the disability becomes to the person. This is consistent with the contact hypothesis, which states that:

> Prejudice (unless deeply rooted in the character structure of the individual) may be reduced by equal status contact between majority and minority groups in pursuit of common goals. The effect is greatly enhanced if this contact is sanctioned by institutional supports (i.e., by law, custom, or local atmosphere), and if it is of a sort that leads to the perception of common interests and common humanity between members of the two groups (Allport, cited in Herek & Capitanio, 1997, p. 2).

Herek and Capitanio's (1997) research in the United States showed that direct contact with PLWHA was associated with less stigma and discriminatory attitudes towards PLWHA. In South Africa (Shisana & Simbayi, 2002) and Kenya (Hamra *et al*., 2006) a greater acceptance of PLWHA has also been found to result from knowing PLWHA. It thus makes sense to include a variable indicating contact with PLWHA as part of the set of potential determinants of stigma. This analysis assesses the influence that knowing someone with HIV/AIDS has on stigma via answers to the question "Do you personally know anyone who has HIV/AIDS?"

In addition to interrogating knowledge of someone living with HIV, this chapter reports on the first research undertaken to assess the impact on stigma of knowing someone who had died of AIDS. The question that was used to separate respondents

[81] CAPS asked respondents "What is your religion?" Individuals who reported a religion were considered affiliated to a religious organisation. It is noted that affiliation to a religious organisation is a fairly blunt indicator of the influence of religion in the respondents' lives. Unfortunately other indicators, such as the frequency of attendance at religious services, were not measured.

who did, from those who did not, know someone who had dies of AIDS asked: "Do you personally know anyone who has died or you think died of AIDS?" Given the theory that HIV-related stigma might be a manifestation resulting, at least in part, from a fear of HIV/AIDS (see Chapter 2), it was hypothesised that individuals who knew someone who died of AIDS would have expressed more stigma than those who did not.

It should be noted that knowing some with HIV, or who has died of AIDS, is not a sensitive measure of personal contact. Personal contact might need to be at a much closer and more intimate level, such as with a close family member, friend or trusted colleague, to effect change in stigma. It is also noted that the two questions probing personal contact were asked in the first wave of CAPS in 2002, a year before the stigma questions were asked to the same respondents. It is likely, therefore, that some respondents would have experienced personal contact during the interval between the surveys. As new personal contact experienced between 2002 and 2003 was not measured it is likely to bias the results.[82]

In their research on racism in America, Sniderman and Piazza (1993) found that a person's negative characterisation of black people remained embedded in a broader tendency to denigrate an array of out-groups in general. They point to the concept of ethnocentrism as a possible factor leading to reactions against blacks, which is seen as blind and irrational because it has nothing intrinsically to do with blacks and may just as well manifest itself against any of many other out-groups. Kraft and Rise (1995) found that attitudes towards minorities also had a direct effect on opinions about coercive AIDS policy, such as quarantining PLWHA and banning PLWHA from having sexual intercourse. Castro and Farmer (2005) further emphasise this point in their argument that in societies marked by profound racism[83] and sexism these prejudices will shape HIV-related stigma.

[82] This bias is likely to result in an underestimation of the effect of personal contact on stigma as the stigma scores of the individuals who experienced new personal contact between 2002 and 2003 would be added to the scores of the individuals who reported no contact. Consequently, some of the effect of personal contact with PLWHA on levels of stigma would be 'hidden'.

[83] With the history of Apartheid, South Africa is to the forefront in this category.

A variable called 'bigotry' was thus formed to explore whether comparable relationships exist between HIV-related stigma amongst young adults in Cape Town and general tendencies to denigrate out-groups. This variable measures the number of out-groups that the respondents themselves do not belong to and towards which some dislike is expressed. The respondents were asked, on an 11-point Likert scale, the degree to which they like/dislike blacks, coloureds, whites, Indians, Jews, illegal immigrants and homosexuals. A binary variable was created from each question to indicate if any dislike was expressed towards that group or not. The separate binary variables were then summed to create the variable 'bigotry', which showed the number of groups that each respondent disliked.[84] After controlling for the racial group of each respondent, this resulted in a scale from 0 (no dislike shown towards any group) to 6 (some dislike shown to every group).

Economic class is another potential determinant of stigma. Research conducted in China showed that, after controlling for, *inter alia*, education, age, gender and place of work, individuals with lower monthly incomes had a higher degree of stigmatising beliefs towards PLWHA (Liu *et al.*, 2005). The authors did not justify the inclusion of this variable nor did they comment on the finding. Given the age of the sample in CAPS, and the consequent low levels of employed respondents, the (log of) household *per capita* income of each respondent was included in this analysis with a view to exploring two potential effects this variable could have on stigma.[85] First, poorer respondents may view PLWHA as a financial burden (on households or the community) and as a result form more negative judgements towards PLWHA (that is, resource-based stigma). Second, household income could serve as a proxy for the

[84] It is noted that a lack of information regarding the respondents' sexual preferences or immigration status meant that this variable might not correctly represent views towards out-groups, as some of the respondents might have been homosexuals or illegal immigrants themselves. It is likely, however, that the effect of this error is small as the respondent would have to be a member of the target group and express dislike towards his/her own group for the index to be affected.

[85] Various adult equivalent incomes were used in sensitivity analyses. It was found that substituting these incomes made no difference to the models. Per capita income was used in the final models due to ease of interpretation. This variable was created from the household module of the CAPS survey, which asked how much money the household earned in a typical month from everybody. The log of incomes was used to limit the impact of extreme values and to increase the normality of distribution. Respondents with zero income were recoded with one rand of income to avoid excluding them from the models.

quality of education the young adult may have received – better quality education leading to lower levels of stigma. Either way, it was hypothesised that individuals living in a household that had lower income would report more stigmatising attitudes and more negative behavioural intentions than individuals in wealthier households.

Finally, previous research has found that instrumental stigma and symbolic stigma add to the predictive power of models of AIDS tolerance or discriminatory opinions (Herek & Capitanio, 1998; Lau & Tsui, 2005; Le Poire, 1994). Accordingly, the attitudinal dimensions of stigma (instrumental, symbolic and resource-based) were included in the analyses to assess the degree to which behavioural intentions are influenced by these attitudes. This chapter provides the first-ever empirical exploration of how resource-based stigma might help 'explain' behavioural intentions towards PLWHA in the explanatory regression models.

Table 5.7 provides summary statistics of the unconditional variation (i.e. the differences in mean values) for the behavioural intentions, symbolic and instrumental indices for the variables discussed above. Table 5.7 also displays the difference in the percentage of respondents reporting some resource-based stigma for these variables. The differences between the mean values and percentages are tested for statistical significance.[86] The values represent the average score for the first group minus the average score for the second. The value of -1.30 for 'black - coloured' for the behavioural intentions index means, for example, that the average score for blacks was 1.30 less than the average score among coloureds – i.e. young black adults in Cape Town, on average, expressed significantly less in the way of negative behavioural intentions towards PLWHA than coloureds.

The results show that across all indices blacks, on average, expressed lower levels of stigma than either whites or coloureds; and coloureds, on average, more instrumental, symbolic stigma and resource-based stigma than whites. Men, on average, expressed significantly greater levels of stigma than did women. The younger half of the sample (15 to 18 years old) expressed more negative behavioural intentions, instrumental stigma and resource-based stigma than the older half (19 to 23 years old). Compared

[86] T-tests were used to assess differences in the mean.

to those with less than the average years of completed education (i.e. 9 years or less), those with more than the average (10 years or more) reported less negative behavioural intentions towards PLWHA and lower levels of instrumental stigma and resource-based stigma. The effect of knowledge about HIV transmission was more pronounced than general levels of education, with respondents displaying perfect knowledge about HIV transmission manifesting significantly lower levels of stigma than those with incomplete knowledge. With regard to religion, those respondents who were affiliated to a religious group expressed, on average, more instrumental stigma, symbolic stigma and resource-based stigma than those stating no affiliation.

Table 5.7. Mean scores of different dimensions of stigma by respondents' characteristics

		Behaviour	Instrumental	Symbolic	Resource-based
Range of scores		0-15	0-15	0-9	0/1
		mean	mean	mean	percent with 1
All respondents		1.79	5.49	3.06	25%
Race	*blacks - coloureds*	**-1.30*** **	**-2.69*** **	**-2.80*** **	**-30%*** **
	blacks - whites	**-1.03*** **	**-1.21*** **	**-1.77*** **	**-19%*** **
	coloureds - whites	0.26	**1.47*** **	**1.03*** **	**12%*** **
Gender	men - female	**0.45*** **	**0.54** **	**0.64*** **	**8%*** **
Age	younger half - older half	**0.22***	**0.65*** **	0.11	**7%** **
Education	below average - above average	**0.23** **	**0.62** **	0.08	**4%** **
HIV Knowledge	incomplete - complete	**1.15*** **	**1.54*** **	**1.22*** **	**16%*** **
Religious affiliation	no - yes	-0.11	**-0.55** **	**-0.72*** **	**-5%***
Know someone with HIV	*no - yes*	**0.40** **	0.20	**0.32***	**10%*** **
Know someone who died of AIDS	*no - yes*	**0.23***	**0.64*** **	**0.66*** **	**6%** **
Bigotry	*below average - above average*	**-0.79*** **	n/a	0.21	n/a
Income	poorest half - richest half	-0.16	**-0.34** **	**-1.07*** **	**-8%*** **
Instrumental	low - high	**-2.07*** **	n/a	n/a	n/a
Symbolic	low - high	**-1.61*** **	n/a	n/a	n/a
Resource-based	*no - yes*	**-1.67*** **	n/a	n/a	n/a

Note: ***Significant at the 1% level **Significant at the 5% level *Significant at the 10% level
n/a: Not applicable

Respondents who knew someone living with HIV or knew someone who had died of AIDS expressed, on average, lower levels of stigma than those who did not report

these experiences. Those who expressed above average levels of bigotry were found, on average, to manifest more negative behavioural intentions towards PLWHA than those who expressed below average levels of bigotry. With regard to income, those with higher *per capita* household income were found, on average, to manifest more instrumental stigma, symbolic stigma and resource-based stigma. Finally, behavioural intentions were found, on average, to be more negative among those who expressed more instrumental stigma, symbolic stigma and resource-based stigma.

5.3.1 Regression results

Table 5.8 displays the regression models used to evaluate potential determinants of negative behavioural intentions towards PLWHA, instrumental stigma, symbolic stigma and resource-based stigma. A few factors were consistent across all models in Table 5.8. First, blacks were associated with significantly less stigma than either coloureds or whites. Second, individuals who reported better knowledge about HIV transmission were, as expected, predicted to manifest lower levels of stigma.[87] Last, for the relevant models (all except instrumental stigma), individuals who reported more bigotry were associated with greater levels of stigma.

Additional factors predicted to influence behavioural intentions towards PLWHA (model 5.8.1) were: knowing someone with HIV, instrumental stigma, symbolic stigma and resource-based stigma. Individuals who reported personally knowing someone with HIV were associated with less negative behavioural intentions, i.e. more tolerance towards PLWHA. Instrumental stigma was negatively associated with behavioural intentions, i.e. greater fear of infection was predicted to lead to more negative behavioural intentions. Similarly, greater levels of symbolic stigma were predicted to lead to more negative behavioural intentions. Last, individuals that reported resource-based stigma were also more likely to report more negative behavioural intentions towards PLWHA.

[87] It is noted that the sensitivity analyses for the resource-based stigma model (i.e. logit regressions to test the results of the probit model, see Appendix C) found HIV knowledge to be a non-significant covariate of resource-based stigma. This was the only coefficient in the entire sensitivity analysis to change from a significant to a non-significant relationship (and none changed from a non-significant to a significant relationship).

Table 5.8. Regression models of determinants of stigma among young adults in Cape Town

	Behavioural intentions	Instrumental stigma	Symbolic stigma	Resource-based stigma
Model	**5.8.1**	**5.8.2**	**5.8.3**	**5.8.4**
Regression	**OLS**	**OLS**	**OLS**	**Probit**
Coloured (base = black)	**0.415***	**2.929*****	**2.893*****	**0.565*****
	[0.198]	**[0.317]**	**[0.176]**	**[0.148]**
White (base = black)	**0.928****	**2.252*****	**2.215*****	**0.643***
	[0.383]	**[0.593]**	**[0.317]**	**[0.341]**
Gender (base = women)	0.018	0.305	**0.508*****	**0.238***
	[0.149]	[0.215]	**[0.127]**	**[0.144]**
Age	0.021	-0.046	0.006	0.018
	[0.032]	[0.050]	[0.038]	[0.031]
Years of education	-0.032	**-0.221*****	-0.067	-0.057
	[0.038]	**[0.056]**	[0.044]	[0.038]
HIV knowledge	**-0.278*****	**-0.721*****	**-0.282*****	**-0.072***
	[0.055]	**[0.072]**	**[0.042]**	**[0.040]**
Religion (base = no affiliation)	-0.192	-0.234	0.117	0.167
	[0.226]	[0.349]	[0.179]	[0.189]
Know someone with HIV (base = no)	**-0.523*****	**0.690****	**0.571****	-0.099
	[0.153]	**[0.267]**	**[0.227]**	[0.173]
Know someone who died of AIDS (base = no)	-0.122	0.021	0.074	-0.126
	[0.150]	[0.234]	[0.188]	[0.145]
Bigotry	**0.254*****	n/a	**0.103*****	**0.180*****
	[0.047]	n/a	**[0.039]**	**[0.031]**
Log *per capita* household income	0.027	**-0.301***	-0.027	-0.011
	[0.092]	**[0.162]**	[0.088]	[0.086]
Instrumental stigma	**0.252*****	n/a	n/a	n/a
	[0.025]	n/a	n/a	n/a
Symbolic stigma	**0.096****	n/a	n/a	n/a
	[0.037]	n/a	n/a	n/a
Resource-based stigma	**1.144*****	n/a	n/a	n/a
	[0.284]	n/a	n/a	n/a
Constant	**0.645**	**12.995*****	**3.404*****	**-1.684***
	[0.880]	**[1.412]**	**[0.724]**	**[0.880]**
n	1142	1256	1252	1305
R-squared	0.38	0.27	0.30	n/a
Prob > F	0.000	0.000	0.000	0.000

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors
n/a: Not applicable

With respect to instrumental stigma (model 5.8.2), fear of infection was predicted to decease with increases in years of education. Higher levels of *per capita* income (which, as noted earlier, could be a proxy for quality of education) also predicted lower levels of instrumental stigma. The effect of knowing some with HIV was predicted to have the opposite effect on instrumental stigma to the effect it had on behavioural intentions. Individuals who knew someone living with HIV were associated with greater fears of infection than those not knowing someone with HIV.

Gender differences were identified in the model for symbolic stigma (model 5.8.3) and resource-based stigma (model 5.8.4). Men were associated with more symbolic stigma and more likely to report resource-based stigma than women. In addition, as with its effect on instrumental stigma, individuals who knew someone with HIV were associated with more symbolic stigma than individuals who did not know someone with HIV.

5.4 Discussion

This chapter found levels of stigma to have varied depending on the dimension of stigma being measured amongst young adults in Cape Town. The low levels of negative behavioural intentions were consistent with previous South African national studies (discussed earlier), which measured stigma based primarily on behavioural intentions. This study would have concluded that 'stigma' was indeed low, if no further dimensions of stigma had been measured. However, the prevalence and magnitude of negative moral judgements (symbolic stigma) and fear of HIV infection (instrumental stigma) were significantly higher than negative behavioural intentions towards PLWHA. The majority of respondents expressed moderate to high levels of instrumental stigma and half expressed symbolic stigma at these levels. These findings therefore suggest that attitudes towards PLWHA in Cape Town are more complex and negative than indicated by behavioural intentions alone. These findings highlight the importance of a multidimensional approach to stigma measurement.

Recent qualitative research among PLWHA in Khayelitsha provides an indication that much of the stigma experienced does, in fact, involve both instrumental and symbolic

stigma (Almeleh, 2006; Mlobeli, 2007). Several participants in Mlobeli's 2007 study recalled experiences of instrumental stigma, most often involving the sharing of food or personal items:

> At home there is also a stigmatisation because they don't want to share utensils with me. I think in the community there is a fear that a [HIV] positive person will infect them (cited in Mlobeli, 2007, p. 67).

> They think if you stay in the same room and share blankets and clothes you will infect them. Other friend of mine was moved to stay in a horrible old outside room which was not in good condition for her health using her own things that are not used by other family members scared of being infected (cited in Mlobeli, 2007, p. 68).

> When I prepare and dish food my family does not accept the food for the fear that they might be infected (cited in Mlobeli, 2007, p. 69).

With regard to symbolic stigma, Almeleh, in analysing his participants' stories, finds that many "retell experiences where they hear that they are labelled as promiscuous, prostitutes, witches, or 'loose' women" (2006, p. 12). Similarly, participants in Mlobeli's study shared stories involving symbolic stigma: "Where the HIV is bad is when they treat you as if you are nothing and you are the person who sleeps around and now you deserve to be sick" (2007, p. 76).

These qualitative findings, combined with the reported levels of instrumental and symbolic stigma presented in this chapter, beg the question as to why measured behavioural intentions toward PLWHA are so positive. Is it realistic to believe that many individuals would in *no way* discriminate against PLWHA even though they openly expressed instrumental and symbolic stigma? Research on racism shows that even individuals who regard themselves as not being prejudiced and endorse egalitarian values may still discriminate in subtle ways if they hold prejudices that they are not fully conscious of and therefore cannot control (Dovidio *et al.*, 2000, 2002). As people do not even have to be aware of the operation of attitudes for those attitudes to be influential, it seems more realistic to assume that openly expressed symbolic and instrumental stigma would probably lead to some form of discrimination, even if only subtle. This suggests that methods need to be developed to measure more subtle forms of negative behavioural intentions towards PLWHA

than the ones typically used in attitudinal surveys – including the one analysed here. Probing the issue through ethnographic and behavioural studies may also prove fruitful. For example, Mills (2006) reports that people often use subtle hand-signals (3 fingers for HIV positive) to indicate a person's HIV status (or assumed HIV status) to others. Catching sight of such a signal would no doubt be upsetting to the HIV positive person concerned.

The last dimension of stigma measured, resource-based stigma, was reported by relatively few young adults. Given that the questions used to probe resource-based stigma asked opinions about government spending, it is possible that this result was biased by the age of the respondents (who were possibly too young to have formulated clear opinions). A similar analysis was therefore undertaken to retest these results on the basis of the survey responses of a wider sample of adults in Cape Town. This will be reported on in the next chapter.

Overall, there were strong interconnections between all three dimensions of stigma. In other words, many people manifested the same levels of stigma across different dimensions. This provides an initial indication that stigma reduction interventions need to be cognisant of different dimensions of stigma and develop interventions that are sensitive and responsive to this.

The analysis of determinants of stigma found a few factors to apply to all dimensions of stigma. Each dimension of stigma found more widespread expression among coloureds and whites than among blacks. Interpretation of this finding requires caution as many different socio-economic and socio-cultural factors could combine to structure and influence this outcome. As noted in Chapter 4, racial segregation in South Africa has resulted in differences in geographic location of residence, employment opportunities, level of education and levels of poverty. These factors may be among the reasons for higher HIV prevalence rates among black individuals (see Table 4.1). Evidence from China suggests that high HIV-prevalence areas are associated with lower levels of stigma (Cao *et al.*, 2006). This may well also be the case in South Africa. If so then the race dummy variables may simply be picking up differences in community level HIV prevalence. However, the 'contact' variables (knowing someone who has HIV or has died of AIDS) should have picked this up to

some extent. Racial differences can also proxy for a range of other community level variables, such as the quality of 'community' (i.e. the level of 'neighbourliness') see e.g. Seekings (2008). Either way, it is important to note that race clearly affects stigma and further research is needed to determine the underlying factors behind these differences.

Levels of knowledge about HIV transmission were also found to be an important determinant of all dimensions of stigma. Better knowledge was associated with lower levels of stigma. This emphasises the importance of education about HIV as an intervention to reduce stigma. Furthermore, HIV transmission knowledge was measured in terms of incorrect perceptions about modes of transmission, which represents a fairly basic level of knowledge about HIV. This indicates the importance of even rudimentary knowledge about HIV in assisting with reducing stigma. The importance of general education was also evident in the finding that the number of years spent in fulltime education was negatively associated with instrumental stigma. This is intuitive and emphasises the role general education can play in reducing stigma. Furthermore, higher *per capita* household income was associated with lower levels of instrumental stigma. If household income was a proxy for quality of education received by the young adults this could indicate that not only education in general, but better quality education in particular is key to the reduction of instrumental stigma.

The analyses also indicated, however, that although HIV education is necessary for stigma alleviation, it is by no means sufficient. General levels of bigotry were significant in the prediction of negative behavioural intentions, symbolic stigma and resource-based stigma. In other words, individuals who manifested negative attitudes towards other groups were more likely to manifest negative attitudes and behavioural intentions towards PLWHA. This means that in order to reduce HIV-related stigma it is also necessary to address broader tendencies to denigrate an array of out-groups in general. This is consistent with Herek *et al.* (2003) who argue that the link between AIDS stigma and stigma against gay and bisexual men in the United States highlights the importance of combating sexual prejudice and discrimination against gay, lesbian and bisexual people.

The analysis of determinants of behavioural intentions showed that all three dimensions of stigma (instrumental stigma, symbolic stigma and resource-based stigma) were associated with more negative behavioural intentions towards PLWHA. This highlights the importance of creating a clear distinction between stigma (instrumental, symbolic and resource-based) and its potential manifestations (as captured through behavioural intentions). This reinforces the need to address all three dimensions of stigma in order to achieve a comprehensive reduction in discrimination towards PLWHA. In addition, these findings reiterate two of the points made above. First, the influence of fear of infection on negative behavioural intentions towards PLWHA provides further evidence of the importance of education about HIV. Second, the influence of stigma (both symbolic and resource-based) and bigotry on negative behavioural intentions towards PLWHA makes it clear that education alone will be insufficient to alleviate discrimination against PLWHA.

Research conducted in Swaziland concluded that access to resources can influence stigma because lower levels of income were associated with higher levels of stigma (Moon *et al.*, cited in Stein, 2003). Such conclusions may, however, not be warranted as levels of income could potentially be a proxy for a number of other factors, such as the extent or quality of education. This is especially the case since resource-based stigma was not significantly associated with *per capita* household income. This chapter in the dissertation provides the first evidence of a direct measure of resource-based stigma affecting behavioural intentions towards PLWHA and highlights the importance of resource-based stigma for both future research on stigma and efforts to reduce stigma.

The significance of instrumental, symbolic and resource-based stigma in predicting behavioural intentions brings us back to the question raised earlier about the need for a more nuanced measure of behavioural intentions. If stigmatising attitudes strongly influenced behavioural intentions for some people, then why not for others? Or is it more likely that the stigmatising attitudes held by many of the respondents did lead to some form of discrimination but that this was not measured through the questions about behavioural intentions asked in this study?

Last, in terms of behavioural intentions towards PLWHA, respondents who reported personally knowing someone with HIV/AIDS articulated more positive behavioural intentions. This indicates support for the contact hypothesis (i.e. direct contact with members of the stigmatised group will reduce prejudice) and suggests that promoting disclosure might be an effective way to reduce discrimination towards PLWHA.

Contrary evidence was, however, provided by the instrumental stigma and symbolic stigma models. Knowing someone with HIV personally was significantly associated with greater levels of stigma for both these dimensions. Almeleh (2006) found that in Cape Town HIV status disclosure is most common when people are sick and have no other choice but to disclose. Consequently, HIV/AIDS is so strongly associated with illness and death that in the case of many people whose health had been restored by HAART people stopped believing they were HIV positive (Almeleh, 2006). This is consistent with the 'stigma trajectory' theory described by Alonzo and Reynolds (1995). They suggest that PLWHA experience stigma differently at different stages of HIV and AIDS illness, with the latter stages of the disease being characterised by greater degrees of stigma as the physical manifestation of AIDS affects physical appearance and affects everyday activities.

This suggests that interactions with PLWHA may generally involve extremely sick individuals who were dying of AIDS, rather than individuals who were living healthy, positive lives with HIV. Instead of normalising the disease, disclosure on the part of AIDS sick individuals might perpetuate associations between HIV and illness, perpetuate fears of HIV/AIDS and perpetuate moral judgment towards those affected, i.e. perpetuate stigma.

It is difficult to explain these contradictory tendencies. But again it shows the nuances of stigma when different aspects are measured separately. The current finding suggests that interaction with PLWHA may reduce negative behavioural intentions, but that if stigmatising attitudes are to be reduced the nature of such involvement may need to change. This might be achieved by encouraging early disclosure of HIV status (i.e. when the person is still healthy) to help recast HIV as a chronic manageable disease, and thereby reduce fears of HIV and negative moral judgments towards PLWHA.

Chapter 6. HIV-related stigma among adults in Cape Town

Chapter 5 revealed a greater prevalence and magnitude of stigma among young adults in Cape Town than measured in previous national studies in South African studies. To recap: the majority of respondents (96%) were found to reveal some stigmatising attitudes or negative behavioural intentions towards PLWHA. Measures of both instrumental stigma (the most prevalent dimension) and symbolic stigma were found to be much greater than measures of negative behavioural intentions towards PLWHA. This provided evidence supporting the hypothesis that low levels of stigma found in previous national surveys can (at least in part) be ascribed to their methodology, which focused on measuring stigma predominantly in terms of behavioural intentions towards PLWHA. This evidence was, however, far from convincing as the CAPS sample (aged 15 to 23) had a very different age profile to that of the previous national surveys (aged 15 and above) so one cannot be sure whether the different results obtained for different measures of stigma relate only to young adults, or whether the difference holds within the general population.

This chapter assesses whether stigma among a wider sample of adults of all ages in Cape Town shows similar characteristics to stigma in the young adult population. It sets about this by comparing the responses to questions probing behavioural intentions and stigmatising attitudes towards PLWHA among the young adults with responses to the same questions among a small, but representative sample of adults in the Cape Metropolitan Area. The multidimensional measurement of stigma among adults is used to retest the hypothesis that it was as a result of their methodology that previous national surveys found low levels of stigma. This chapter also adds to the current understanding of factors that affect stigma through an extended analysis of a range of potential determinants of stigma such as age, for example.

6.1 Method

The data analysis presented here uses a subset of the questions from CAPS 2003 that was repeated in the 2003 Cape Area Study (CAS) as well as a set of questions about stigma that are unique to CAS. CAS 2003 interviewed 588 adults (18 to 84 years old) in the Cape Town Metropolitan Area on a wide range of topics, including demographics, social environment, beliefs, attitudes and behaviours. The sample was stratified by race (black, coloured and white). The primary sampling units (PSUs) were the enumeration areas (EAs), comprising clusters of households, from the 1996 general census. Seventy PSUs were selected randomly from the database of EAs. Simple random sampling, using aerial photographs of each enumeration area, was then used to select 10 households within each PSU. Finally, within the household the 'next birthday rule', was used to select as the respondent the individual older than 18 whose birthday was due next (see Seekings *et al.* (2004a) for more details).

Table 6.1 displays the key demographic information of the CAS 2003 sample. Coloureds were the most sampled population group, followed by blacks and then whites. Women comprised the majority of the sample. Most respondents had completed at least grade 7 and significant proportions had completed either grade 12 or some tertiary education. The average number of completed years of education was 10.3. Unfortunately, 43% of respondents did not provide information about their household income and individual level income data were not collected. As a result, no income data was available for the analysis. It was, however, possible to ascertain that almost equal numbers of respondents were employed as were not. Last, the vast majority of respondents indicated a religious affiliation. The data was weighted so that the sample matched the gender and race profile of Cape Town at the 2001 population census (City of Cape Town, 2003).

Table 6.1. CAS 2003 sample characteristics

		n	percent	mean
All respondents		588	100%	
Race	black	197	35%	
	coloured	214	41%	
	white	137	24%	
			100%	
Gender	men	213	37%	
	women	357	63%	
			100%	
Age	18 to 23	105	19%	
	24 to 49	313	57%	
	50 to 84	132	24%	
			100%	
Education	< grade 8	110	19%	10.3
	grade 8 to 11	217	39%	
	grade 12	132	23%	
	some tertiary	108	19%	
			100%	
Employment	Yes	264	47%	
	No	292	53%	
			100%	
Income	Not available			
Religion	No	62	11%	
	Yes	506	89%	
			100%	

Note: The total number of respondents differs between variables due to missing data

CAS 2003 included a module of questions probing stigmatising attitudes and behavioural intentions towards PLWHA. The majority of these questions are an identical, but limited, selection of questions from the CAPS 2003. The questions and associated response frequencies from this module are displayed in Tables 6.2 and 6.3. Table 6.2 lists the CAS questions which did not appear in CAPS, while Table 6.3 displays the questions that did.

Table 6.2. Questions probing behavioural intentions towards PLWHA, which did *not* appear in CAPS 2003

How likely is it that you would take part in action to prevent a person infected with HIV/AIDS from....	Very likely	Likely	Not likely	Not at all likely	Don't know	Total
[BS] Q1. teaching your children?	17% (102)	16% (93)	22% (131)	41% (239)	4% (23)	100%
[BS] Q2. moving into your neighbourhood?	11% (64)	14% (83)	24% (141)	49% (286)	2% (14)	100%
[BS] Q3. operating a business in your area?	9% (55)	14% (82)	23% (137)	49% (287)	5% (27)	100%
[BS] Q4. sitting in the same classrooms as your child?	13% (78)	16% (95)	21% (125)	45% (265)	4% (25)	99%

Note: [BS] Behaviour intentions towards strangers
Numbers in parentheses indicate number of respondents
Percentages do not always total 100% as a result of rounding effects

Table 6.3. Questions from CAPS 2003 repeated in CAS (2003), probing attitudes and behavioural intentions towards PLWHA

In your opinion:	Definitely yes	Probably yes	Probably no	Definitely no	Don't know	Total
[R] Q5. Do you think the government should provide free health care for people who need it?	71% (419)	24% (143)	2% (13)	2% (12)	0% (1)	99%
[R] Q6. Do you think the government should provide free health care for people with AIDS?	73% (429)	22% (130)	2% (12)	2% (11)	1% (6)	100%
[R] Q7. Would it be a good idea for the government to give job training to unemployed young people?	78% (456)	21% (125)	1% (4)	0% (1)	0% (2)	100%
[R] Q8. Should youth who are infected with HIV get this job training?	66% (386)	28% (165)	2% (13)	1% (4)	3% (20)	100%
[BF] Q9. Would you be willing to look after a close family member with AIDS?	60% (355)	34% (197)	2% (13)	1% (5)	3% (18)	100%
[BF] Q10. Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them?	63% (371)	32% (186)	1% (8)	2% (10)	2% (13)	100%
[I] Q11. Would you drink from the same bottle of water as an HIV infected friend?	37% (216)	23% (133)	19% (109)	15% (90)	7% (40)	101%
[S] Q12. Do you think that many people who get HIV infected through sex have only themselves to blame?	18% (106)	25% (148)	26% (155)	24% (144)	6% (35)	99%

Note: [R] Resource-based Stigma [S] Symbolic stigma [I] Instrumental stigma
[BF] Behavioural intentions towards family/friends
Numbers in parentheses indicate number of respondents
Percentages do not always total 100% as a result of rounding effects

Following the methodology outlined in Chapter 5, questions were assigned to different stigma indices (based on face validity) and then the indices were tested for consistency using factor analysis. The questions used in each index are indicated in superscript in Tables 6.2 and Table 6.3. The decision process resulting in each index is described below.

6.1.1 Behavioural intentions indices

The following questions were assessed on face value to be measuring behavioural intentions towards PLWHA:

- How likely is it that you would take part in action to prevent a person infected with HIV/AIDS from….
  - Q1. teaching your children?
  - Q2. moving into your neighbourhood?
  - Q3. operating a business in your area?
  - Q4. sitting in the same classrooms as your child?

- Q9. Would you be willing to look after a close family member with AIDS?

- Q10. Imagine that you find out that one of your close friends is HIV infected. Would you still be friends with them?

The exploratory factor analysis identified questions Q1-Q4 ($\alpha = 0.95$) to be measuring a different dimension of behavioural intentions towards PLWHA than questions Q9 and Q10 ($\alpha = 0.74$). This intuitively made sense as questions Q1-Q4 were probing attitudes towards people that are strangers to the respondents, while questions Q9 and Q10 probed attitudes relating to personal acquaintances of the respondents. It is not surprising that people's behavioural intentions would be different towards these two categories of people. Interestingly, despite asking questions about behavioural intentions towards these separate groups, previous studies have not made an *explicit* distinction between strangers and family/friends. The analysis in this chapter, by contrast, formed two separate indices for behavioural intentions towards PLWHA: behavioural intentions towards strangers (BS); and behavioural intentions towards family/friends (BF).

6.1.2 Instrumental indicator

A single question in CAS was identified on face value to be measuring instrumental stigma:

- Q11. Would you drink from the same water bottle as an HIV infected friend?

The assumption underlying the use of this question was that a negative response (i.e. would not drink from the same water bottle) indicated fear of HIV infection. Results derived from answers to this question are interpreted as evidence of instrumental stigma. It must be noted, however, that there are other possible explanations for a negative response to this question, which could be measuring a general health-related orientation, and not necessarily an anxiety specifically about HIV (respondents might be unwilling *ever* to drink from the same glass, cup or mug as anyone else – if so then this would introduce 'noise' into the data).

Although it would have been preferable to have more than one indicator question, it is worth noting that the factor analysis identified this question as separate from all others. This suggests that it is measuring a different dimension of stigma from the other questions. Thus, even though it is a singe indicator of instrumental stigma it is probably a reliable one. It is also worth noting that in the CAPS dataset (analysed in Chapter 5) this variable correlated positively with the other questions probing instrumental stigma. We can thus use it as a single indicator variable with a reasonable amount of confidence.

6.1.3 Symbolic stigma indicator

As was the case with the instrumental stigma indicator, only one question in CAS was assessed on face value to be measuring the respondents' value judgements of PLWHA:

- Q12. Do you think that many people who get HIV infected through sex have only themselves to blame?

As was found for the instrumental indicator, the factor analysis identified this question as separate from all others, indicating it could stand alone as a proxy for a symbolic stigma indicator. One needs to be aware that one question is not an index and neither is it a comprehensive measure of symbolic stigma (which includes a range of negative associations made between HIV/AIDS and already marginalised groups (prostitutes, drug users and homosexuals for example), and negative moral

judgements of PLWHA (irrespective of whether they also belong to these groups)). However, as the answers to this question in CAPS were correlated with other questions measuring symbolic stigma (see Chapter 5), it is probably a reasonable indicator of symbolic stigma for the purpose of analysing stigma in CAS.

6.1.4 Resource-based stigma indicators

As in the CAPS analysis, the following pairs of questions were designed to measure resource-based stigma:

- Q5. Do you think the government should provide free health care for people who need it?
- Q6. Do you think the government should provide free health care for people with AIDS?

- Q7. Would it be a good idea for the government to give job training to unemployed young people?
- Q8. Should youth who are infected with HIV get this job training?

Resource-based stigma is indicated by the opinion that PLWHA are less deserving of government funding. To measure resource-based stigma it was, therefore, necessary to separate respondents who believed that PLWHA are less deserving of government welfare from those who were generally opposed to the government providing welfare to people (whether AIDS-sick or not).

To achieve this, questions Q5 and Q6 were combined into a variable called 'Q5&Q6' to indicate discrimination towards PLWHA with respect to the provision of free health care. This was discussed earlier in Section 5.1.1. To recap: 'Q5&Q6' was created by assigning 'no stigma' scores to respondents who thought that free health care should not be provided for people who need it (Q5), while free health care should be provided for people with AIDS (Q6). Respondents' opinions were scored as 'stigmatising' when they thought that free health care should be provided for people who need it (Q5), but not to people with AIDS (Q6). Respondents who gave the same answer to both questions were assigned 'no stigma' scores as this was seen to indicate general opinions about government welfare and not about PLWHA in particular.

Similarly, questions Q7 and Q8 were combined into the variable 'Q7&Q8' to indicate discrimination towards PLWHA with respect to capacity building.

The working assumption guiding the analysis was that both these variables would give an indication of reluctance to allocate resources to PLWHA and therefore comprise a resource-based stigma index. The factor analysis, however, indicated that these two variables were not probing the same dimension of stigma ($\alpha = 0.04$). This finding is consistent with Chapter 5 (which conducted a factor analysis of the same questions asked in the CAPS 2003). This provides evidence against the hypothesis that it was the relative youth of the young age group in CAPS that was responsible for the inconsistency between the answers to the questions probing resource-based stigma. Clearly both older and younger respondents are answering these questions in ways that suggest that they are not probing our hypothesised single underlying dimension of stigma. It is possible that these questions are probing different aspects of resource-based stigma, regarding health and training respectively. Nevertheless, consistent with Chapter 5, these variables are analysed separately and not combined in a composite 'resource-based' stigma index.

6.2 Measures of HIV-related stigma

Following the same methods used in Chapter 5, responses to the stigma questions were coded so that a score of 0 indicated no stigma reported and a score of 3 indicated maximum stigma reported. As discussed in the previous chapter, all "don't know" responses were excluded from analysis as a result of difficulties in interpreting such responses.[88] The 5-point Likert Scale was therefore reduced to a 4-point scale. Where questions were grouped together in an index, the answers to each question were summed to form the overall stigma score for each index. Also, consistent with the methodology discussed earlier, summing all the stigma questions created a 'general stigma' index.

[88] A total of 3% of respondents answered "don't know" to either of the resource-based stigma questions; 5% to any of the behavioural intentions questions; 7% to the one question probing instrumental stigma; and 6% to the one question probing symbolic stigma.

Table 6.4 shows the degree of stigma within each indicator. Four levels of stigma are shown in the table. 'No stigma' represents respondents who scored the lowest possible score in each indictor. Low, moderate and high levels of stigma record respondents scoring within the lower third, second third and upper third of each indicator respectively.

Table 6.4. Measures of stigma among adults in Cape Town

	No stigma	Low levels	Moderate levels	High levels	Total
Behaviour intentions (friends/family)	53%	43%	4%	0%	100%
Behaviour intentions (strangers)	42%	25%	17%	16%	100%
Instrumental stigma	38%	25%	20%	17%	100%
Symbolic stigma	25%	28%	27%	20%	100%
Resource-based stigma (health)	92%	6%	2%	0%	100%
Resource-based stigma (training)	84%	14%	2%	0%	100%
General stigma	6%	65%	28%	1%	100%

Levels of stigma are shown to vary significantly depending on the dimension of stigma being evaluated. Furthermore, levels of discriminatory behavioural intentions towards PLWHA varied depending on who the target subject was. More specifically, tolerance was generally shown towards family/friends: 96% of respondents reveal no/low negative behavioural intentions towards family/friends, with the remaining 4% displaying moderate levels of negative behaviour intentions. When the target subject was a stranger with HIV/AIDS, greater levels of intolerance were displayed: 58% of respondents expressed some negative behavioural intentions towards strangers, a third displayed moderate/high levels and 16% revealed high levels.

The symbolic and instrumental indices show that these negative attitudes towards PLWHA were expressed more frequently and to greater degrees than negative behavioural intentions. The majority of respondents expressed some symbolic and instrumental stigma, with more than a third expressing moderate to high levels of each of these dimensions. The prevalence and magnitude of symbolic stigma was greater than that of instrumental stigma, indicating that negative moral judgements associated with HIV/AIDS were more prevalent than fear of HIV infection from drinking from the same bottle of water as an HIV-positive person. The resource-based stigma indicators revealed relatively low levels of this dimension of stigma.

The general stigma index indicates that the vast majority of respondents (94%) were found to reveal some degree of stigmatising attitudes or negative behavioural intentions towards PLWHA. Furthermore, 28% of respondents indicated moderate levels and 1% expressed high levels of general stigma.

Table 6.5 displays levels of stigma among CAS (adults) alongside levels of stigma reported for the same questions from CAPS (young adults) in Cape Town. A comparison of the behaviour index for strangers is, however, not possible as these questions were not asked in CAPS. The general stigma index compares stigma reported for all questions from CAS with all questions from CAPS. Results show that stigma among the adults surveyed showed similar patterns to stigma amongst the young adults. Resource-based stigma and levels of negative behavioural intentions towards friends/family were relatively low for both groups. Levels of instrumental stigma and symbolic stigma were considerably higher among both groups.

Overall, the vast majority in both groups expressed some stigma (the general stigma index) and 29% of each group reported moderate or high levels of stigma. The only notable difference was that slightly higher levels of instrumental stigma were measured among adults (CAS) than among young adults (CAPS). These findings suggest that there is little difference between manifestations of stigma among adults and young adults in Cape Town. This also enables us to be confident that these data sets are picking up genuine social attitudes, rather than simply reflecting noise generated in the collection of the data (e.g. through interviewer error, poorly understood questions etc).

Table 6.5. Comparison between stigma reported in CAS and CAPS

		No stigma	Low levels	Moderate levels	High levels	Total
Behaviour intentions (friends/family)	***CAS***	53%	43%	4%	0%	100%
	CAPS	78%	18%	3%	1%	100%
Behaviour intentions (strangers)	***CAS***	42%	25%	17%	16%	100%
	CAPS	n/a	n/a	n/a	n/a	n/a
Instrumental stigma	***CAS***	38%	25%	20%	17%	100%
	CAPS	55%	22%	8%	15%	100%
Symbolic stigma	***CAS***	25%	28%	27%	20%	100%
	CAPS	34%	16%	20%	30%	100%
Resource-based stigma (health)	***CAS***	92%	6%	2%	0%	100%
	CAPS	94%	5%	1%	0%	100%
Resource-based stigma (training)	***CAS***	84%	14%	2%	0%	100%
	CAPS	80%	14%	3%	3%	100%
General stigma	***CAS***	6%	65%	28%	1%	100%
	CAPS	3%	68%	27%	2%	100%

6.3 Determinants of HIV-related stigma

Regression models were used to assess potential determinants of stigma. The dependant variables for four of the models (behavioural intentions towards family/friends, behavioural intentions towards strangers, instrumental stigma and symbolic stigma) are described above. As was the case with the analysis in Chapter 5, the separate resource-based stigma indicators did not factor together and therefore could not be summed into one index. A binary variable was therefore created to indicate individuals who reported resource-based stigma on either of the indicators. The binary variable represented 131 (23%) respondents who reported resource-based stigma and 439 (77%) that reported none.

Consistent with the choice of regression models throughout this study, OLS regression models were used for both behavioural intentions indices as they comprised more than six values. Ordered probit regression models were used for the instrumental stigma and symbolic stigma indicators (four values each) and probit regression model for resource-based stigma (two values). Sensitivity analysis was

conducted by comparing the results of the OLS regression models with ordered probit regression models; the ordered probit regression models with ordered logit regression models; and the probit regression model with a logit regression model. As was the case with the analysis presented in Chapter 5, the significance of the coefficients, for all practical purposes, were robust across techniques (the results of the sensitivity analysis are displayed in Appendix D). Finally, all models were adjusted to account for the survey design of CAS (stratification and clustering effects) as well as for non-response.

Table 6.6 displays the explanatory variables used in the regression models. The table shows two sets of variables. The first set of variables was used to assess potential determinants of stigma among young adults (see Chapter 5). The methods used to create these variables and the motivation for their inclusion in the models remains unchanged. The second set of variables was not used in the previous analysis and will be described after an initial analysis of the variables in Set 1 below.

Table 6.6. Explanatory variables used to assess potential determinants of behavioural intentions, instrumental stigma, symbolic stigma and resource-based stigma

Behavioural Intentions	Instrumental stigma	Symbolic stigma	Resource-based stigma
Set 1	**Set 1**	**Set 1**	**Set 1**
Racial groups	Racial groups	Racial groups	Racial groups
Gender	Gender	Gender	Gender
Age	Age	Age	Age
Education	Education	Education	Education
General bigotry		General bigotry	General bigotry
Instrumental stigma			
Symbolic stigma			
Resource-based stigma			
Set 2	**Set 2**	**Set 2**	**Set 2**
Religious importance[a]	Religious attendance[a]	Religious importance[a]	Religious importance[a]
Employment	Employment	Employment	Employment
Neighbourhood problems	Neighbourhood problems	Neighbourhood problems	Neighbourhood problems
General trust	General trust	General trust	General trust
Social attitudes		Social attitudes	Social attitudes

Note: [a] A distinction is made between religious attendance and the importance the respondents place on religion

Table 6.7 displays the differences in mean values of each of the stigma indicators for the variables listed in Set 1 in Table 6.6. The differences between the mean values were tested for statistical significance with T-tests. The results show that some of the variables in Set 1 display similar variations across all dimension of stigma, but others vary according to the dimension of stigma measured. Blacks reported significantly lower levels of stigma than coloureds on all dimensions except for behavioural intentions towards strangers. Blacks expressed more negative behavioural intentions for both behavioural indices than whites, but less instrumental, symbolic and resource-based stigma. Coloureds expressed significantly more negative behavioural intentions and instrumental stigma than whites. Gender differences were significant only for behavioural intentions towards family/friends: men reported more negative intentions than women. With respect to age, the younger half of respondents expressed more negative behavioural intentions towards strangers; while the older half expressed more instrumental stigma and symbolic stigma.

Table 6.7. Differences in mean scores of stigma indices by variables in Set 1

		Behaviour intentions (family/friends)	Behavioural intentions (strangers)	Instrumental stigma	Symbolic stigma	Resource-based stigma
Range of scores		0-6	0-15	0-3	0-3	0/1
		mean	mean	mean	Mean	percent with 1
All respondents		0.80	3.72	1.33	1.39	23%
Race	blacks - coloureds	**-0.36*** **	**1.79*** **	**-0.94*** **	**-0.41*** **	**-9%*** **
	blacks - whites	**0.18** **	**3.49*** **	**-0.54*** **	**-0.34*** **	**-13%*** **
	coloureds - whites	**0.54*** **	**1.70*** **	**0.39*** **	0.06	4%
Gender	men - women	**0.23*** **	-0.31	0.03	0.09	3%
Age	younger half - older half	0.04	**0.83*** **	**-0.21** **	**-0.17** **	-1%
	18-24 to 25-49	0.09	**1.14*** **	**-0.20** **	0.02	2%
	18-24 to 50-84	-0.14	**0.93** **	**-0.57*** **	**-0.23** **	-3%
	25-49 to 50-84	**-0.23** **	-0.21	**-0.39** **	**-0.25** **	-5%
Education	below average - above average	**0.18** **	**1.42*** **	**0.16** **	0.01	-1%
General bigotry	low - high	**-0.33*** **	**-2.56*** **	n/a	0.09	**-5%***
Instrumental stigma	low - high	**-0.57*** **	0.21	n/a	n/a	n/a
Symbolic stigma	low - high	**-0.37*** **	0.46	n/a	n/a	n/a
Resource-based stigma	low - high	**-0.48*** **	**-0.98*** **	n/a	n/a	n/a

Note: ***Significant at the 1% level **Significant at the 5% level *Significant at the 10% level
n/a: Not applicable

In addition to comparing stigma reported between the younger and older respondents, stigma was compared between 18-24, 25-49 and 50-84 year olds. This age breakdown was similar to that used (15-24, 25-49 and > 49 year olds) in the 2002 Nelson Mandela/HSRC Study of HIV/AIDS (Shisana & Simbayi, 2002). As previously mentioned, the 2002 Nelson Mandela/HSRC Study measured stigma with questions probing mainly behavioural intentions towards PLWHA. Furthermore, based on the two different categories for behavioural intentions identified in this chapter, it appears that the 2002 Nelson Mandela/HSRC Study concentrated largely on measuring behavioural intentions towards family/friends. Similar age categories were created to assess whether behavioural intentions towards family/friends measured in the current study showed similar variations by age as stigma measured in the 2002 Nelson Mandela/HSRC Study. Table 6.7 shows that the 25-49 year old group displayed the least negative intentions towards family/friends. However, the youngest group expressed the most negative behavioural intentions towards strangers, while the oldest group expressed the least. By contrast, younger respondents reported less instrumental and symbolic stigma than older respondents.

Interestingly, the variation in the behavioural intentions towards family/friend index showed similar variation to the Nelson Mandela/HSRC Study stigma index. For each index, the 25-49 year old group was found to be the least stigmatising and the oldest group the most. In addition, variation by race was also found to follow a similar pattern when it came to the behavioural intentions towards family/friends index used in the current study when compared with the stigma index in the Nelson Mandela/HSRC Study. That is, whites expressed the lowest levels of stigma, followed by blacks, with coloureds reporting the highest level of stigma. As already mentioned, these patterns varied substantially for the other dimensions of stigma reported so far, which were not measured in earlier studies (including the Nelson Mandela/HSRC Study). These findings therefore suggest that had the current study measured stigma only in terms of negative behavioural intentions towards family/friends, both the level of stigma measured and the correlates of stigma would be comparable to the Nelson Mandela/HSRC Study. Again, this finding reinforces the argument that a multidimensional approach is required to capture the full extent and the complex nuances of stigma.

Table 6.7 also reveals some results that are comparable to the CAPS study (see Table 5.7). Fewer negative behavioural intentions and lower levels of instrumental stigma were reported among individuals who had completed above average years of education compared to those who completed below average. In addition, behavioural intentions towards PLWHA were more negative among individuals who expressed higher levels of bigotry, instrumental stigma, symbolic stigma and resource-based stigma.

As mentioned previously, the remaining variables were not used in the analysis in Chapter 5. Chapter 5 included religious affiliation as a determinant of stigma, but it was noted that simply being affiliated to a religious organisation was a fairly blunt measure. It was thought that behavioural intentions, symbolic stigma and resource-based stigma were more likely to be influenced by the salience of religion in someone's life, rather than by the simple fact of belonging to a religious group. Fortunately CAS asked a better question in that respondents were asked how important religion is to the respondent and the responses were combined into a binary variable, 'importance of religion.'[89] The importance of considering religion is highlighted by data showing religious organisations to be the only institutions for which the majority (53%) of the CAS respondents indicated membership.

The degree of importance placed on religion was not seen as a potential determinant of instrumental stigma. However, as noted in Chapter 5, religious organisations might often be forums for the discussion of social issues and hence could affect fears about HIV/AIDS. Accordingly, active membership of a religious organisation (i.e. 'religious attendance' rather than 'importance of religion') was included as a control for instrumental stigma.

Household income was a significant covariate of instrumental stigma among young adults, but, as mentioned earlier, most CAS respondents declined to complete the income section of the questionnaire. The binary variable 'employment' was therefore included in the analysis as an indicator of socio-economic status. Previous research found that the employed expressed lower levels of stigma than the unemployed

[89] The base for 'importance of religion' is respondents who indicated that religion was not important in their lives.

(Shisana & Simbayi, 2002). In addition, a variable was created to provide an indication of the quality of living conditions. This variable, 'neighbourhood problems', measured neighbourhood problems based on the frequency with which a certain problem occurred in the respondents' residential area. Neighbourhood problems were assessed using 9 questions ($\alpha = 0.87$) indicating the frequency of noise disturbance, graffiti, loiterers, drunks, vandalism, racial insults or attacks, break-ins of houses or cars and people being attacked.[90] The assumption here was that social problems would be more prevalent in low-income areas, and hence will proxy for income. They may also be useful for capturing neighbourhood effects which in CAPS was proxied for only through the inclusion of the race variable.

A study conducted in the United States to assess public trust associated with AIDS found that the effectiveness of HIV/AIDS intervention campaigns is directly correlated with the extent to which their target audiences perceive them to be credible. Public trust was measured by opinions about three statements: (1) "Many scientists and doctors say AIDS in not spread by casual contact. Do you think what they are telling us is definitely true, probably true, probably false or definitely false?"; (2) "A lot of information about AIDS is being held back from the public"; and (3) "The government is using AIDS as a way of killing off minority groups". It was found that higher levels of AIDS-related distrust were related to greater willingness to avoid and stigmatise PLWHA, and to inaccurate beliefs about HIV transmission (Herek & Capitanio, 1994).

CAS respondents were asked their opinion of the statement "generally speaking, most people can be trusted." Although this statement elicited opinions about trust in general, inhibiting specific inferences, it may suggest a link between trust and stigma. This may be particularly pertinent in South Africa due to the historical and political factors discussed in Chapter 2 that could have undermined the credibility of HIV-related education. Just as more bigoted people have been shown to express more HIV-related stigma, it is plausible that less trusting people are also more stigmatising. Responses to the trust statement were measured on a 5-point Likert scale ranging from "strongly agree" to "strongly disagree", with "neither agree nor disagree" as the

[90] The response options for each question ranged from 0 (i.e. never) to 4 (i.e. very often).

central point. The variable 'general trust' was created so that 0 represented the lowest levels of trust and 5 the greatest.

Finally, CAS 2003 asked a number of questions probing the social attitudes of the respondents. These attitudes could play a central role in the formation of stigma. The primary mode of HIV transmission in South Africa is through sexual intercourse. The nature of associations made between sexual intercourse and HIV, as well as other associations linked to HIV/AIDS, is likely to be influenced by conservative/liberal social attitudes. Responses to two of the statements designed to probe social attitudes factored together with a degree of reliability ($\alpha = 0.65$). These were: (1) "It is okay for a woman to have a child as a single parent if she doesn't want to have a stable relationship with a man"; and (2) "Individuals should have the chance to enjoy complete sexual freedom." Responses to these two statements were combined into a variable called 'social-conservative', scores range from 0-8, with higher scores reflecting more conservative social attitudes.

Variation in stigma by the Set 2 variables is displayed in Table 6.8. No significant difference was found in symbolic stigma or resource-based stigma via these variables. For both behavioural intentions indices, respondents who reported that religion was rather/very important in their lives reported more negative behavioural intentions. Respondents who reported attending religious services reported higher levels of instrumental stigma. Compared to those who were employed, the unemployed expressed significantly more negative behavioural intentions. Similar results were found for the other variable used as a proxy for income. That is, individuals who reported living in neighbourhoods with high incidence of problems reported more negative behavioural intentions. On the other hand, individuals living in neighbourhoods with a higher prevalence of problems reported less instrumental stigma.

As expected, individuals who expressed lower levels of trust in others in general also expressed more negative behavioural intentions towards strangers and more instrumental stigma. The effect of conservative attitudes on behavioural intentions was found to vary with the target subject: respondents who expressed more socially

conservative opinions reported less negative behaviour towards family/friends, but more negative behavioural intentions towards strangers.

Table 6.8. Differences in mean scores of the stigma indices by variables in Set 2

		Behaviour intentions (family/friends)	Behavioural intentions (strangers)	Instrumental Stigma	Symbolic stigma	Resource-based stigma
Range of scores		0-6	0-15	0-3	0-3	0/1
		mean	mean	mean	mean	percent with 1
All respondents		0.80	3.72	1.33	1.39	23%
Importance of religion	'not very' - 'rather/very'	**-0.24****	**-1.56*****	n/a	-0.3	-3%
	'never attend' - 'attend services'	n/a	n/a	**-0.25****	n/a	n/a
Employment	unemployed - employed	**0.12***	**0.93*****	0.09	-0.03	-2%
Neighbourhood problems	low - high	**-0.12***	**-1.83*****	**0.18***	0.08	4%
General trust	low - high	-0.01	**0.77*****	**0.4*****	0.9	4%
Social conservative	liberal - conservative	**0.17****	**-1.39*****	n/a	-0.11	2%

Note: ***Significant at the 1% level **Significant at the 5% level *Significant at the 10% level

6.3.1 Regression results

Table 6.9 displays the regression models used to evaluate potential determinants of negative behavioural intentions towards family/friends (6.9.1), negative behavioural intentions towards strangers (6.9.2), instrumental stigma (6.9.3), symbolic stigma (6.9.4) and resource-based stigma (6.9.5). It is also important to note that HIV transmission knowledge was found to be a highly significant predictor of stigmatising attitudes and behavioural intentions among young adults (see Chapter 5). CAS 2003 did not collect data on HIV transmission knowledge, and thus the models in this chapter do not control for this factor. In other words, the models might suffer from omitted variable bias and the results need to be analysed with caution.

Table 6.9. Regression models of determinants of stigma among adults in Cape Town

	Behavioural intentions family/friends	Behavioural intentions strangers	Instrumental stigma	Symbolic stigma	Resource-based stigma
Model	**6.9.1**	**6.9.2**	**6.9.3**	**6.9.4**	**6.9.5**
Regression	**OLS**	**OLS**	**O-probit**	**O-probit**	**Probit**
Coloured (base = black)	0.086	**-2.149*** **	**0.888*** **	**0.454*** **	0.303
	[0.141]	**[0.862]**	**[0.178]**	**[0.153]**	[0.204]
White (base = black)	-0.173	**-2.185*** **	**0.663*** **	**0.377***	**0.734*** **
	[0.177]	**[0.878]**	**[0.220]**	**[0.202]**	**[0.258]**
Gender (base = women)	**0.286*** **	0.128	-0.060	0.033	-0.020
	[0.090]	[0.335]	[0.113]	[0.107]	[0.153]
Age	0.003	-0.011	0.005	0.003	0.004
	[0.004]	[0.015]	[0.004]	[0.040]	[0.005]
Years of education	**0.028** **	-0.052	-0.004	**0.028***	0.010
	[0.014]	[0.085]	[0.020]	**[0.028]**	[0.023]
Importance of religion (base = not important)	**0.305** **	0.545	n/a	0.093	**0.293***
	[0.119]	[0.533]	n/a	[0.161]	**[0.172]**
Religion (base = no affiliation)	n/a	n/a	0.150	n/a	n/a
	n/a	n/a	[0.117]	n/a	n/a
Employment (base = unemployed)	**-0.140***	-0.117	-0.018	0.024	0.077
	[0.083]	[0.357]	[0.125]	[0.106]	[0.145]
Neighbourhood problems	**0.008***	0.005	0.006	**0.012***	**0.015** **
	[0.005]	[0.035]	[0.006]	**[0.006]**	**[0.007]**
General trust	**0.073***	**-0.463** **	**-0.147*** **	0.018	-0.027
	[0.043]	**[0.218]**	**[0.055]**	[0.048]	[0.055]
Social-conservative	**-0.073*** **	**0.331** **	n/a	-0.001	-0.021
	[0.019]	**[0.138]**	n/a	[0.034]	[0.029]
Bigotry	**0.122*** **	**1.012*** **	n/a	0.023	0.065
	[0.038]	**[0.160]**	n/a	[0.043]	[0.050]
Instrumental stigma	**0.378*** **	0.091	n/a	n/a	n/a
	[0.045]	[0.207]	n/a	n/a	n/a
Symbolic stigma	0.002	-0.132	n/a	n/a	n/a
	[0.039]	[0.202]	n/a	n/a	n/a
Resource-based stigma	0.138	**1.096** **	n/a	n/a	n/a
	[0.127]	**[0.444]**	n/a	n/a	n/a
Constant	**-0.619** **	**4.028** **	n/a	n/a	**-1.780*** **
	[0.292]	**[2.146]**	n/a	n/a	**[0.461]**
n	438	426	474	488	506
R-squared	0.25	0.28	n/a	n/a	n/a
Prob > F	0.000	0.000	0.000	0.083	0.030

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors
n/a: Not applicable

Behavioural intentions towards family/friends

The model for behavioural intentions towards family/friends (6.9.1) predicted four factors to have a statistically significant effect on behavioural intentions in the expected direction. Consistent with Chapter 5, controlling for the other variables in the model, individuals who expressed more bigotry and more instrumental stigma were predicted to report more negative behavioural intentions. Furthermore, the instrumental indicator was found to have a fairly large influence on these behavioural intentions. This was intuitive as instrumental stigma was assumed to be measuring fear of getting infected with HIV from casual contact. These fears are likely to have an effect on behaviour towards those PLWHA with whom people come into close contact, i.e. family and friends. Results from model 6.9.2 appear to support this argument as the instrumental indicator loses significance when the subject of the behavioural intentions was not a personal acquaintance (i.e. behavioural intentions towards strangers).

By contrast with the findings reported from the CAPS survey of young adults, gender appears to play a role in shaping behavioural intentions. Men were predicted to report more negative behavioural intentions towards family/friends with HIV than women. Also, individuals who were employed and individuals who reported fewer neighbourhood problems[91] reported less negative behavioural intentions. This suggests that individuals with a higher socio-economic status were associated with more tolerant behavioural intentions.

There was no clear prior expectation about how behavioural intentions towards PLWHA would be associated with the salience of religion in the respondents' lives. The analysis found that individuals who stated that religion was rather/very important in their lives reported more negative behavioural intentions than those that stated religion was not/not very important in their lives.

[91] It is noted that the significance of the coefficient for the neighbourhood problems variable changed from $p < 0.094$ to $p < 0.109$ when the sensitivity analysis was conducted using ordered probit regression (see Appendix D). Although this is a relatively small change it means that this variable was not statistically significant in the ordered probit model. Importantly, the significance level of all other variables remained unchanged in the sensitivity analysis.

Three factors were found to affect behavioural intentions towards family/friends with HIV in the opposite direction to what one might have expected. First, individuals who had completed more years of education were associated with more negative behavioural intentions. Second, individuals who stated they were more trusting of people in general were associated with more negative behavioural intentions. Last, individuals who expressed more socially conservative attitudes were associated with more tolerant behavioural intentions. No conclusive explanation could be found for these results. They may, however, indicate that other extraneous variables affect behavioural intentions towards individuals with whom the respondents share an emotional bond, as is assumed to be the case with regard to family/friends. For example, the finding that those who are more conservative are more tolerant might indicate that traditional values regarding family and friends over-ride other social attitudes in determining behaviour. More qualitative and quantitative research is necessary to explore these issues further.

Behavioural intentions towards strangers

Model 6.9.2 shows the predicted determinants of behavioural intentions towards strangers living with HIV/AIDS. Interestingly, black respondents were predicted to express more negative behavioural intentions towards strangers than either coloureds or whites. This contrasts with all models in Chapter 5 and, as will be shown, all other models explored in this chapter. Again, as previously mentioned, caution is needed when interpreting differences between race groups. It is very likely that the race variables proxy for various unmeasured factors. As noted in Chapter 5, the race result may proxy for HIV prevalence rates, which are highest among blacks. As a reminder, the incidence of behavioural intentions towards strangers was measured on the basis of the respondents' assertions about the likelihood of their taking action to intervene in particular situations. Speculatively, this may again be a factor of prevalence rates. Fears attaching to the events used in this study to measure behavioural intentions towards strangers (PLWHA moving into their neighbourhood, teaching the respondents' children, sitting in the same classroom as their children, or operating a business in their area) may be far more salient for black individuals than either whites or coloureds.

The other factors found to be significant in the prediction of behavioural intentions towards strangers were all in the expected direction. Respondents who expressed more bigotry towards other out-groups were associated with more negative behavioural intentions towards strangers with HIV. By contrast with the findings for behavioural intentions towards family/friends, individuals who reported less trust in people in general also reported more negative behavioural intentions towards strangers; and those who were more socially conservative were predicted to manifest more negative behavioural intentions towards strangers with HIV. Finally, respondents who expressed resource-based stigma were associated with more negative behavioural intentions towards strangers.

Instrumental stigma

The model (6.9.3) predicting potential determinants of instrumental stigma shows that white and coloured respondents were predicted to display significantly greater fear of infection than black respondents. The only other factor found to have significance was levels of trust. Individuals who reported greater trust in people in general were associated with less instrumental stigma.

Symbolic stigma

The model predicting the potential determinants of symbolic stigma (model 6.9.4) was fairly weak (Prob > F = 0.08). This was not surprising given the complex nature of such attitudes, which are influenced by a myriad of factors. Some of these factors are not included in the model (most notably HIV knowledge which was shown to be a highly significant predictor of stigma in Chapter 5), which is thus weakened by omitted variable bias. It does, however, provide an indication that whites and coloureds expressed more symbolic stigma than blacks. In addition, respondents from neighbourhoods with more problems expressed more symbolic stigma. Counter-intuitively, respondents who had completed more years of education were also associated with greater levels of symbolic stigma.

Resource-based stigma

The model predicting the potential determinants of resource-based stigma (model 6.9.5) was also fairly weak (Prob > F = 0.03). It indicated that whites expressed more resource-based stigma than blacks. Consistent with the symbolic stigma model, respondents from neighbourhoods with more problems expressed more resource-based stigma. In addition, respondents who reported that religion was rather/very important in their lives were associated with more resource-based stigma than those who stated religion was not, or not very, important in their lives.

6.4 Discussion

This chapter shows that stigma among adults in Cape Town showed similar patterns to stigma amongst young adults in Cape Town (Chapter 5). As found in the analysis of young adults, it is apparent that the prevalence and magnitude of stigma varies according to which dimension of stigma is being measured. In particular, behavioural intentions were generally quite positive and relatively low levels of resource-based stigma were reported, while considerably more instrumental stigma and symbolic stigma were measured. The findings reported in Chapters 5 and 6 would appear, therefore, to be representative for the general population of Cape Town in 2003.

A new empirical finding emerging from this analysis is that behavioural intentions towards PLWHA can also be deconstructed into different dimensions. Responses to family/friends with HIV/AIDS differ from responses to PLWHA with whom the respondents are not closely acquainted. Responses towards family/friends were found to be much more positive. This finding is consistent with both qualitative research conducted in Cape Town (Kahn, 2004) and quantitative research conducted in Soweto[92] (Skhosana *et al.*, 2006), which found PLWHA to be supported by most members of their households. This is intuitive, as greater tolerance would be expected towards people with whom an emotional and/or kinship bond is shared.

[92] Soweto (short for South Western Townships) is a large, predominantly black, township situated to the south west of the City of Johannesburg.

This finding suggests that studies of stigma need to be cognisant of the relationship between the respondent and the potentially stigmatised subject.

These findings also add to the emerging evidence that previous national studies conducted in South Africa found low levels of stigma predominantly because of the methods they used to measure stigma. Chapter 5 pointed to the fact that low levels of stigma found in the previous studies probably resulted from the use of behavioural intentions towards PLWHA as the primary measure of stigma. Furthermore, behavioural intentions in previous studies were measured mainly in terms of intentions towards family/friends. This chapter highlights that such a measure will elicit the lowest levels of stigma from individuals. If one wants to measure stigma levels within society, it is important to ask about behavioural intentions towards both family/friends and strangers.

As was the case with the analysis of the potential determinants of stigma among young adults (Chapter 5), this chapter found variations in the magnitude of stigma between the different population groups in Cape Town. Interpretation of this finding again requires further ethnographic and other research. It does, however, indicate that interventions aimed to reduce stigma may need to be sensitive to the social and cultural context of their audiences.

Fear of infection (instrumental stigma) was found to influence behavioural intentions towards family/friends living with HIV/AIDS negatively. This strengthens the evidence from Chapter 5 of the importance of HIV education. However, again consistent with Chapter 5, general bigotry was also found to have a negative influence on behavioural intentions towards PLWHA. This adds further emphasis to the fact that, even with the provision of HIV education, HIV-related stigma is likely to remain a problem until interventions to reduce general levels of xenophobia and bigotry are implemented.

Furthermore, resource-based stigma was also found to have a negative influence on behavioural intentions towards strangers. In other words, individuals who expressed discriminatory opinions about the allocation of state financial resources to PLWHA appeared more likely to discriminate against PLWHA. In conjunction with the

analysis in Chapter 5, this provides the first quantitative evidence of the negative impact this dimension of stigma may have for PLWHA. It is important, therefore, for further studies to include this dimension of stigma and to improve the design of questions to probe resource-based stigma. It is also important for people to be aware of resource-based stigma when designing interventions to reduce HIV-related stigma.

This analysis showed, when controlling for everything else, that age was not a significant determinant of stigma. This finding is important as it stresses that anti-stigma campaigns need to target individuals of *all* ages. Typically, HIV education is targeted at younger individuals who are, on average, more likely to be at risk of contracting HIV. This might explain the findings of the bi-variate analysis in Table 6.7, which showed younger individuals to express less instrumental stigma than older individuals. In addition to stressing the importance of targeting all ages, this seems to suggest that HIV education could be designed with the dual purpose of HIV prevention and HIV-stigma reduction.

In Chapter 5, more men than women were associated with symbolic and resource-based stigma. The present analysis also reveals men to be associated with more negative behavioural intentions toward PLWHA who are either family or friends (as distinct from strangers). Such gender differences are consistent with previous findings in Botswana and South Africa (Letamo, 2003; Visser *et al.*, 2006), one potential reason being that women are "more understanding and sympathetic – in keeping with their gender role" (Visser *et al*., 2006, p. 53). Another potential contributing factor relates more widely to systems of power and inequality (Link & Phelan, 2001; Parker & Aggleton, 2003). According to Link and Phelan (2001):

> Stigma is entirely dependent on social, economic, and political power – it takes power to stigmatize. In some instances the role of power is obvious. However, the role of power in stigma is frequently overlooked because in many instances power differences are so taken for granted as to seem unproblematic (p. 375).

Patriarchal cultures, such as the one in South Africa, reinforce gender inequality, placing men in a position of power over women (Mlobeli, 2007). This power not only allows men to decide what is seen as 'normal' or 'deviant' behaviour, but also more

importantly provides the ability to add to "pre-existing stigmas in the community... [so that] marginalized group like women in the family and society experience multiple stigmas when they are HIV-positive" (Mlobeli, 2007, p. 69).

The finding that men are more stigmatising than women may therefore be tied to the larger issue of systemic gender inequality. This may be particularly relevant in the context of HIV: women are more physiologically susceptible to infection through heterosexual sex and therefore disproportionately affected, which means women are more likely to be held responsible for getting and transmitting HIV, especially through 'sleeping around' (Squire, 2007). However, as we are uncertain of the underlying mechanisms at work here, research on gender and stigma needs to be high on the agenda for future HIV-related stigma research.

A few additional factors, not identified in the previous chapter, are worth highlighting. First, levels of general trust were found to be a significant determinant of instrumental stigma: lower levels of general trust were associated with greater fear of infection. Herek and Capitanio (1994) showed that AIDS-related distrust in the United States was associated with greater willingness to avoid and to stigmatise PLWHA. Given that the analysis undertaken in this chapter did not look at trust as relating specifically to HIV/AIDS information, no specific inferences can be drawn here. The findings do, however, indicate that further research is needed to assess the relationship between confidence in the reliability of HIV information and instrumental stigma more specifically. High levels of instrumental stigma found in this study may, for example, have nothing to do with access to HIV information and everything to do with the credibility of this information.

Second, respondents who placed greater importance on religion were associated with more negative behavioural intentions towards friends/family with HIV and more resource-based stigma. Given the high level of membership of religious organisations, this emphasises the potential role that religious organisations could play in reducing levels of stigma. Targeting church leaders and local priests/preachers with regard to HIV awareness may thus be a potentially productive way of reducing stigma. However, for such interventions to work, they would need to be sensitive to the underlying reasons why religious people appear to be more stigmatising. Without

more in-depth ethnographic research, it is impossible to tell whether it is the messages given by religious leaders that appear to result in intolerant judgemental attitudes, or whether people with these characteristics are attracted to religious organisations. Either way, it is clear that church-based HIV programmes (such as the Anglican programme mentioned in Chapter 5) have a long way to go with regard to addressing HIV stigma.

Third, an increase in years of completed education was found to affect negatively both behavioural intentions towards friends/family and symbolic stigma. It must be noted that, given the age profile of the sample, most of this education would have been completed in a very different context (i.e. Apartheid) to that of the current education system. In addition, this general measure of education does not assess HIV-related education specifically. It is recommended that further research should be cognisant of the potential positive relationship between education (or other factors that education might stand as a proxy for) and stigma.

Finally, higher incidences of neighbourhood problems were associated with greater levels of symbolic stigma and resource-based stigma. Again, neighbourhood problems could proxy for income, and hence quality of education received. It could also proxy for other factors such as HIV prevalence levels and social factors operating at community level. Further research is also required to extrapolate the factors underlying neighbourhood problems that influence stigma.

In sum, this exploratory quantitative analysis found that differences exist in both the prevalence and potential determinants between the different dimensions of stigma. It is thus recommended that research into stigma and interventions to reduce stigma consider all potential manifestations of stigma. Furthermore, individuals involved in the design of campaigns to reduce stigma need to be cognisant that different factors may influence the manifestation of different aspects of stigma.

Chapter 7. Changes in HIV-related stigma among young adults in Cape Town

As argued in Chapter 2, stigma is socially constructed and thus likely to vary across groups and over time. Chapter 5 described stigma among young adults and examined potential determinants of stigma in 2003, but very little is known about how stigma changes over time and the factors that might influence such change. This information is important as stigma intervention strategies need to be cognisant of, and responsive to, the changing social context for PLWHA. As the epidemic matures the social context will change as a result of social responses to HIV prevention and treatment interventions. Research into the dynamics of such changes is rare (see Herek & Capitanio, 1999 for one example in the United States) and in sub-Saharan Africa it is virtually non-existent. There is clearly an urgent need to evaluate changes in the magnitude and character of social attitudes towards PLWHA (Weiss *et al.*, 2006). This chapter makes a contribution by assessing changes in stigma among young adults in Cape Town between 2003 and 2006.

The only previous research conducted in South Africa that claimed to assess changes in HIV-related stigma produced the following recommendation:

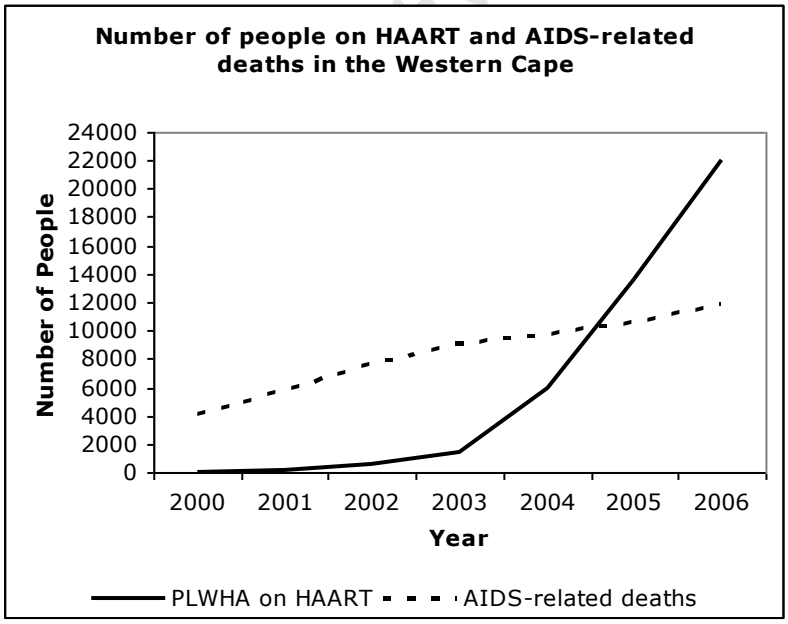
> *Stigmatising attitudes are decreasing*
> As South Africans are becoming more accepting of HIV/AIDS as a reality in South Africa, and accepting of people and family members living with HIV/AIDS, it is critical that service providers capitalise on this window of opportunity to encourage disclosure of HIV-status (Shisana *et al.*, 2005, p. xxxix).

But the methods used to draw these conclusions are highly questionable as two cross-sectional surveys were analysed (when a panel study would have been more appropriate) and different sets of stigma questions were asked in the 2002 (Shisana & Simbayi, 2002) and 2005 (Shisana *et al.*, 2005) surveys. In other words, attitudes and behavioural intentions could not be reliably monitored over time and drawing firm conclusions and making strong recommendations on the basis of responses to these questions was therefore inappropriate.

As a social construct, HIV-related stigma is amenable to change because the meanings attached to HIV/AIDS and its symbolic representations shift over time. There are many theories and counter-theories about the effects of particular interventions or social change on stigma. The development of efficacious treatment has, for example, been seen as contributing to the reduction in health-related stigmatising attitudes and behaviours (Weiss & Ramakrishna, 2006). HAART has the potential to change the perception of AIDS as a death sentence, and thereby reduce stigma (Preston-Whyte, 2003). Access to HAART is believed, for example, to have lessened HIV-related stigma in Haiti (Farmer *et al.*, 2001), among adolescents in Brazil (Abadía-Barrero & Castro, 2005) and in villages in rural China (Cao *et al.*, 2006).

Figure 7.1 illustrates that HAART coverage has increased substantially each year in the Western Cape since 2003. South Africa's public-sector HAART programme was launched in most provinces in 2004 and had been piloted in the Western Cape since 2001. By 2006, HAART coverage in the Western Cape was at 55.7% of the number of people estimated to need HAART (Nattrass, 2007, p. 131).

Figure 7.1. Number of people on HAART and AIDS deaths in the Western Cape



Note: Data from the ASSA2003 model (available on www.assa.org.za)

One would thus expect this to have had some impact on HIV-related stigma over time – especially between 2003 and 2006. Given the purported positive impact of HAART in terms of reducing stigma argued above, one might have hoped stigma would have decreased sharply over the period.

However, Herek (2002) warns that, while disease stigma historically decreases as the disease is better understood and as treatment becomes available, this appears not always to be the case with regard to HIV/AIDS. This may well be the situation in South Africa where access to HAART is only a recent phenomenon and not available to everyone who needs it. Lack of full HAART coverage in South Africa has resulted in continual increases in AIDS deaths. As shown in Figure 7.1, AIDS-related deaths have continued to rise alongside the increase in the number of PWLHA on HAART. Squire (2007: p.10) provides a good description of the context which enabled an increase in the number of people on HAART to go hand in hand with an increase in AIDS-related deaths:

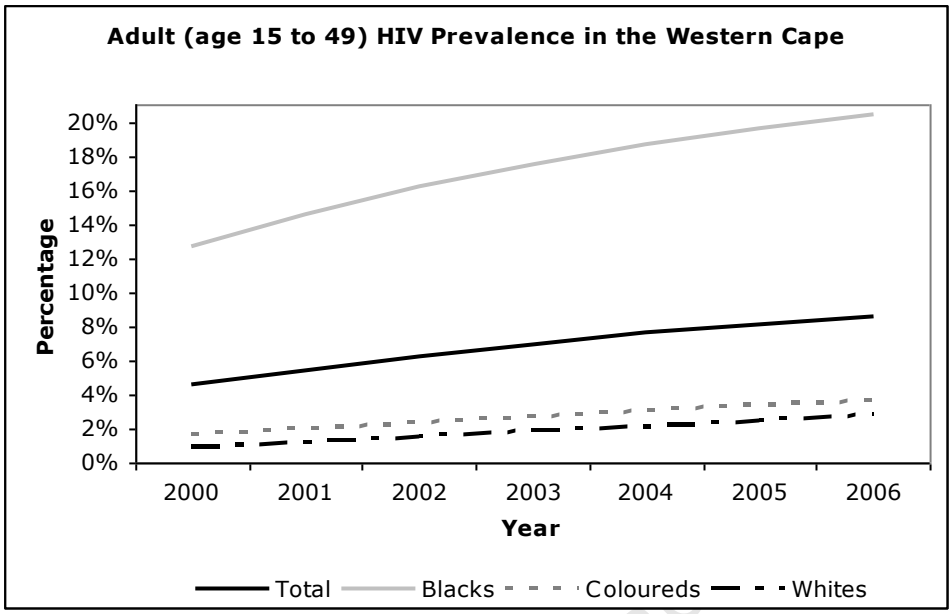
> Despite well-developed public and private health sectors and increasing commitment from government and international programmes, low private health insurance coverage, lack of money to buy private care, and the public sector's continuing partial and patchy delivery of antiretrovirals and other treatments mean that relatively few receive adequate treatment. Nearly 1,000 people die daily.

This trend in AIDS-related deaths could reinforce the associations between HIV and death and lead to increases in stigma – even in the presence of a partial HAART roll-out.

Alternatively, another theory is that levels of stigma will be associated with HIV prevalence levels: based on the contact hypothesis (see Herek & Capitanio, 1997) prejudice is believed to decrease with increased direct contact with members of the stigmatised group. A study conducted in rural China found supporting evidence for this theory: villages where HIV-prevalence was high were associated with lower levels of stigma (Cao *et al.*, 2006). In Kenya, Hamra *et al.* (2006) also found that personal acquaintance with PLWHA was associated with fewer manifestations of HIV-related stigma. Given that HIV prevalence has increased in the Western Cape since 2000 (see Figure 7.2) stigma should, according to this theory, have decreased as

a result. This would be the case among the black population in particular as prevalence rates among this group increased the most.

Figure 7.2. Adult (15 to 49) HIV prevalence in the Western Cape

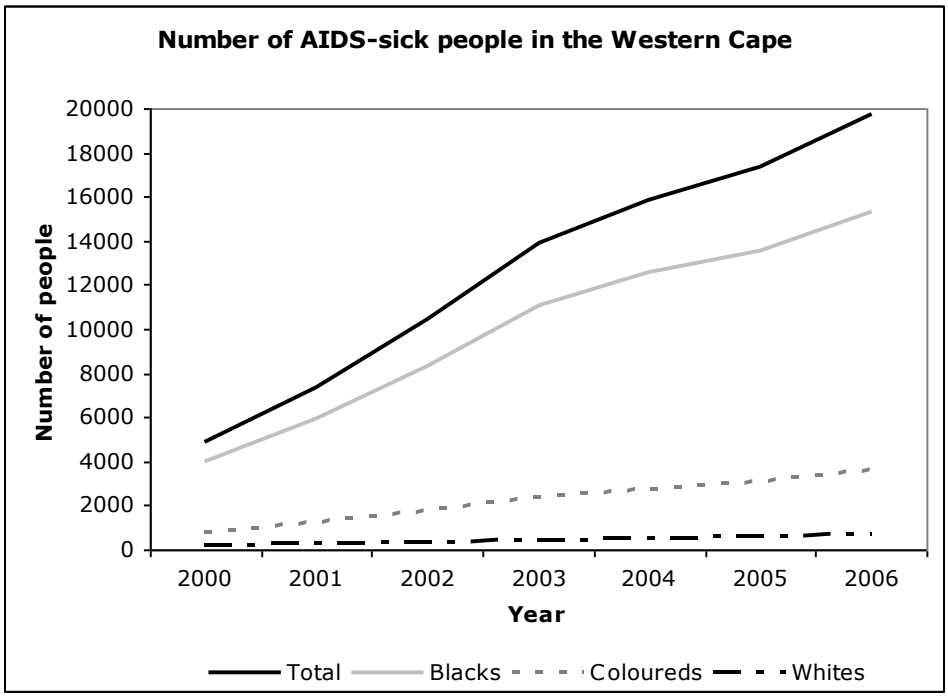


Note: Data from the ASSA2003 model (available on www.assa.org.za)

However, Almeleh's (2006) finding that PLWHA in South Africa generally do not disclose until they are manifestly sick raises the possibility that the increase in the number of AIDS-sick people, especially among blacks (see Figure 7.3), results in more people becoming aware of the negative aspects of HIV, and this could result in the perpetuation of stigmatising ideas. The South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey in 2005 found some evidence for this: "higher levels of negative attitude were related to close contact to people living with HIV/AIDS" (Shisana *et al.,* 2005, p. 96).

It is clear that the social context surrounding HIV/AIDS in the Western Cape has changed considerably in the past few years, primarily as a result of the HAART roll-out in Khayelitsha. It is not clear, however, how stigmatising attitudes and behaviours have changed in response. This chapter fills an important gap in research on HIV-related stigma by evaluating how stigma has changed among young adults in Cape Town.

Figure 7.3. Number of AIDS-sick people in the Western Cape



Note: Data from the ASSA2003 model (available on www.assa.org.za)

7.1 Method

This chapter uses panel data from CAPS 2003 (analysed as a cross sectional survey in Chapter 5) and CAPS 2006. In 2006, the fourth wave of CAPS re-interviewed 1,075[93] of the 1,371 second wave respondents. This survey contained a module designed to evaluate changes in stigma since the 2003 survey. The stigma module repeated eight questions verbatim from the 2003 survey to enable direct comparisons. These questions were selected to cover behavioural intentions towards PLWHA and the two main dimensions of stigma identified after detailed analysis in Chapter 5: instrumental stigma and symbolic stigma. At the questionnaire design stage there was still debate on the effectiveness of the resource-based stigma questions. They were therefore excluded as a result of space constraints in the survey. Table 7.1 displays the eight panel questions asked and the dimension of stigma each probes.

[93] Seven of these individuals responded 'myself' to whether they knew anyone living with HIV/AIDS. These individuals were excluded from the sample.

Table 7.1. Stigma questions asked in 2003 and 2006 CAPS

Please respond to the following questions by answering "Yes" or "No". If you are not sure, chose the "Probably Yes" or "Probably No" response. If you are quite sure chose the "Definitely Yes" or "Definitely No" response. ***Interviewer: Do not read the "don't know" option***	***Dimension of stigma***
1. Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them?	Behavioural intentions
2. If you knew that a shopkeeper had HIV/AIDS, would you buy fresh vegetables from him or her?	Behavioural intentions
3. Do you think a school pupil with HIV should be allowed to attend school?	Behavioural intentions
4. Would you drink from the same bottle of water as an HIV infected friend?	Instrumental stigma
5. Would you rather not touch someone with HIV/AIDS because you are scared of infection?	Instrumental stigma
6. Do you worry that HIV is much easier to catch than we are told?	Instrumental stigma
7. Do you think HIV/AIDS is a punishment for sleeping around?	Symbolic stigma
8. Do you think that many people who get HIV infected through sex have only themselves to blame?	Symbolic stigma

7.2 Analysis & Results

The analysis & results section of this chapter is divided into 3 sections: (1) changes in reported stigma; (2) changes in stigma by gender, race and age; and (3) determinants of stigma transitions.

7.2.1 Changes in reported stigma

This section evaluates transitions that occur within the panel between 2003 and 2006 (i.e. among the individuals who were interviewed in both the surveys). Descriptive statistics (percentage response to each question) provide an initial indication of change. The main part of Table 7.2 displays the response frequencies for each question for 2003 and 2006. At first glance, shifts in response frequencies suggest an increase in stigma for the majority of questions. In particular it is noted that, with the exception of Question 3, there is a significant movement away from the least stigmatising response. In addition, an increase in uncertainty is noted as more respondents answered "don't know" in 2006.

Response options were then coded to enable changes in averages to be tested. The response options ("definitely yes", "probably yes", "probably no" and "definitely no") were coded from 1 to 4 for each question: a score of 1 for the lowest level of stigma and a score of 4 for the highest.

The increase (up to 8% in 2006 for Question 6) in "don't know" responses raised a difficult methodological question about how to use this information. The easiest solution was to exclude the "don't know" responses. This seemed unsatisfactory because someone who, for example, thinks in 2003 that HIV is definitely *not* a punishment for "sleeping around," but in 2006 is uncertain ("don't know") could reasonably be regarded as having developed a more negative attitude. In other words, the "don't know" responses have valuable content that should be captured in any empirical work. Accordingly, the analysis coded the "don't know" response as a mid-point (2.5) between yes and no.[94]

T-tests were conducted to assess whether the average score for each question was significantly different in 2003 as compared to 2006. The T-tests were conducted so that a positive sign indicates an increase in stigma.[95] T-test 7.2.1 in Table 7.2 shows that a significant increase in stigma, on average, was found for the majority of items and no items showed a significant decrease. The behavioural intentions items (which showed low levels of stigma in 2003) changed the least, with a significant increase for Question 1 only. In other words, on average, respondents were more likely to say they would not remain friends with a PLWHA in 2006 than 2003, but attitudes were unchanged about pupils attending school and buying fresh vegetables from an HIV-positive shopkeeper. Two of the instrumental stigma questions (Questions 4 and 5)

[94] The mid-point was selected as it gives less weight to transitions to or from "don't know" than from transitions between stigmatising and non-stigmatising responses. For example, a response shift from definite stigma to "don't know" equates to a drop in stigma by 1.5. A response shift from definite stigma to probably no stigma equates to a drop in stigma of 2. The larger decrease in stigma in the latter scenario seems appropriate due to the uncertainty in the first scenario. It is important to note that sensitivity analysis excluding the "don't know" option yielded results with the same sign and significance, and only marginal changes in the coefficients.

[95] Higher scores for the first four items in Table 7.2 indicate greater levels of stigma. The T-test for the first four items subtracted the 2003 average from the 2006 average. In other words if the 2006 average was higher (more stigma) than the 2003 average then the T-test score will be positive to indicate an increase in stigma. The opposite process for the second four items ensured a similar outcome.

showed a significant increase in stigma between 2003 and 2006, while the increase for Question 6 was non-significant. The symbolic stigma questions showed the greatest average increases in stigma.

The Stuart Maxwell test for homogeneity of the marginal distributions was then used to validate the interpretation of the T-tests. The Stuart Maxwell test assesses whether two samples are independent (Stuart, 1955). It is used to test whether individual responses to questions have changed unsystematically and significantly between 2003 and 2006. It is useful for two main reasons. First, a systematic survey effect, rather than real changes in stigma, could cause the majority of answers to shift in one direction.[96] If this has happened the T-test will identify a significant difference in the averages between the years and lead us to the wrong conclusion. A significant coefficient on the Stuart Maxwell test informs us that significant and unsystematic changes have occurred, giving us confidence that the T-test is picking up real changes. Second, a non-significant T-test does not necessarily indicate that no changes have taken place; it could be that the net result had merely lead to a small change in the average. In other words, a significant Stuart Maxwell coefficient for questions with a non-significant T-test score indicates that significant changes in responses occurred, but that almost the same degree of change happened in both directions. Larger Stuart Maxwell coefficients indicate greater changes between the years.

The Stuart Maxwell coefficients displayed in Table 7.2 were significant for all questions apart from Question 3 (which was the only item in which almost no changes in responses were reported). This validates the T-test results as being indicative of changes in stigmatising attitudes and behaviours rather than simply reflecting any potential survey effects. The significant Stuart Maxwell coefficient for Questions 2 and 6, which showed no significant change in mean response over time, indicates that the distribution of responses to these questions changed significantly. In fact, the largest Stuart Maxwell coefficient is recorded for Question 6, indicating that responses to this question changed the most.

[96] A systematic survey effect occurs when changes in the survey process affect responses (for example, if fieldworkers were trained to be friendlier and establish greater rapport in the 2006 survey then this in and of itself could have changed responses).

Finally, it was important to consider potential effects of survey attrition between 2003 and 2006 as 296 respondents were not re-interviewed in 2006. The 2003 sample was selected to be representative of the young adult population of Cape Town. If the 296 individuals who were not re-interviewed experienced a change in attitude that differed significantly from the rest of the sample then the results reported above might not be representative. In other words, if these 296 individuals had reported a decrease in stigma (by contrast with the increase in stigma reported by the 2006 sample) then the aforementioned results would be biased.

An attrition test was conducted to assess whether the aforementioned results changed in a hypothetical scenario in which stigma was assumed to decrease among the 296 missing 2006 respondents. In other words, the attrition test assesses whether the 296 respondents would have made a difference to the results if stigma trends among this group had run counter to the current findings. A hypothetical sample was created for 2006 by including the attritors as respondents in the 2006 sample. It was then assumed that all the attritors reported lower levels of stigma in 2006 than they did in 2003, i.e. a score of one was subtracted from their 2003 scores. T-tests were used to assess changes in the stigma reported by the 2003 sample and the hypothetical 2006 sample. T-test 7.2.2 indicated the average change in stigma for this scenario. The results were consistent with T-test 7.2.1: significant increases in stigma were found for the same questions. Therefore, as far as these attitudes were concerned we can conclude that there was no discernable attrition bias.

Table 7.2. Changes in stigma between 2003 and 2006

Question	2003					2006					T-test 7.2.1	Stuart Maxwell test	T-test 7.2.2 (attrition test)
	Definitely yes	Probably yes	Probably no	Definitely no	Don't know	Definitely yes	Probably yes	Probably no	Definitely no	Don't know			
1. Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them? **Behavioural intentions**	92% (982)	5% (56)	1% (11)	1% (15)	0% (0)	81% (864)	13% (148)	0% (5)	4% (41)	1% (6)	+0.16***	70***	+12***
			[stigma]					[stigma]					
			n = 1064					n = 1064					
2. If you knew that a shopkeeper had HIV/AIDS, would you buy fresh vegetables from him or her? **Behavioural intentions**	66% (701)	17% (179)	4% (47)	12% (124)	1% (11)	60% (638)	23% (240)	7% (69)	8% (90)	2% (25)	+0.02	29***	-0.02
			[stigma]					[stigma]					
			n = 1062					n = 1062					
3. Do you think a school pupil with HIV should be allowed to attend school? **Behavioural intentions**	87% (918)	7% (73)	2% (16)	5% (49)	0% (3)	87% (925)	7% (73)	1% (7)	5% (50)	0% (4)	-0.01	4	-0.03
			[stigma]					[stigma]					
			n = 1059					n = 1059					
4. Would you drink from the same bottle of water as an HIV infected friend? **Instrumental stigma**	63% (668)	16% (165)	6% (63)	15% (159)	1% (9)	45% (474)	19% (199)	11% (120)	20% (216)	5% (55)	+0.36***	111***	+27.8***
			[stigma]					[stigma]					
			n = 1064					n = 1064					
5. Would you rather not touch someone with HIV/AIDS because you are scared of infection? **Instrumental stigma**	15% (163)	5% (58)	12% (130)	66% (705)	1% (6)	14% (145)	11% (119)	20% (212)	51% (544)	4% (42)	+0.19***	100***	+12.8***
[stigma]						[stigma]							
			n = 1062					n = 1062					
6. Do you worry that HIV is much easier to catch than we are told? **Instrumental stigma**	41% (440)	13% (142)	8% (85)	35% (375)	2% (19)	30% (319)	25% (261)	19% (198)	19% (203)	8% (80)	+0.08	179***	-0.1
[stigma]						[stigma]							
			n = 1061					n = 1061					
7. Do you think HIV/AIDS is a punishment for sleeping around? **Symbolic stigma**	18% (188)	11% (116)	12% (129)	58% (613)	2% (17)	22% (235)	18% (195)	19% (199)	33% (356)	7% (78)	+0.43***	147***	+33.8***
[stigma]						[stigma]							
			n = 1063					n = 1063					
8. Do you think that many people who get HIV infected through sex have only themselves to blame? **Symbolic stigma**	28% (296)	14% (145)	12% (129)	45% (482)	1% (10)	30% (321)	22% (236)	16% (171)	25% (270)	6% (64)	+0.36***	137**	+25.4***
[stigma]						[stigma]							
			n = 1062					n = 1062					

Notes: *10% significance level **5% and ***1% Numbers in () denote number of respondents
Total percentages may not equal 100% due to rounding errors

Table 7.3. Summary of stigma changes within the panel between 2003 and 2006

Please respond to the following questions by answering "YES" or "NO".	Transition			Stigma change
	-	0	+	
1. Imagine that you find out that one of your friends is HIV infected. Would you still be friends with them? (Behavioural intentions)	6%	77%	17%	+11%***
2. If you knew that a shopkeeper had HIV/AIDS, would you buy fresh vegetables from him or her? (Behavioural intentions)	22%	53%	26%	+4%
3. Do you think a school pupil with HIV should be allowed to attend school? (Behavioural intentions)	12%	77%	11%	-1%
4. Would you drink from the same bottle of water as an HIV infected friend? (Instrumental stigma)	18%	42%	40%	+22%***
5. Would you rather not touch someone with HIV/AIDS because you are scared of infection? (Instrumental stigma)	21%	45%	35%	+14%***
6. Do you worry that HIV is much easier to catch than we are told? (Instrumental stigma)	35%	28%	37%	+2%
7. Do you think HIV/AIDS is a punishment for sleeping around? (Symbolic stigma)	21%	34%	45%	+24%***
8. Do you think that many people who get HIV infected through sex have only themselves to blame? (Symbolic stigma)	26%	32%	42%	+16%***

Notes: *10% significance level **5% and ***1%
'-'; '0' & '+' transitions represent the percentage of respondents in 2006 who reported less stigma, equal levels and more stigma respectively

Table 7.3 provides a summary of the changes in responses to the stigma questions between 2003 and 2006. The 'stigma change' column shows the difference between the percentage of respondents reporting an increase in stigma and those reporting a decrease. The largest difference is noted for Question 7, with almost a quarter of respondents reporting an increase in stigma. For this question, 45% of respondents reported a more stigmatising response in 2006 than 2003, while only 21% reported a less stigmatising response. The 'transition' part of the table reveals that although there were overall increases in stigma, many respondents also reported a decrease in stigma.

7.2.2 Changes in stigma by gender, race and age

Chapter 5 and Chapter 6 found the extent and nature of stigma to vary by gender and race. Although little variation was found by age in the previous chapters, such variation has been found in previous research (Shisana *et al.*, 2005; Shisana & Simbayi, 2002). This section assesses whether variation in stigma over time among young adults was affected by these variables too. Following the analysis conducted in Chapter 5, the eight stigma questions used in this chapter were grouped into three indices. Questions 1 to 3 were summed to form an indicator of behavioural intentions. Question 4 to 6 made up an instrumental stigma indicator and Questions 7 and 8 were combined as an indicator of symbolic stigma.

Table 7.4 displays T-test results for the difference in average scores between 2003 and 2006 and the percentage of respondents reporting a change in stigma by gender, race and age. Age is split into those who were 18 or younger in 2003 and those 19 or older in 2003.

Table 7.4. Stigma transitions by gender, race and age

	Behaviour intentions			Instrumental stigma			Symbolic stigma		
Women		+0.12			+0.24***			+0.88***	
	25%$^{-}$	46%^{0}	29%$^{+}$	36%$^{-}$	20%^{0}	44%$^{+}$	25%$^{-}$	20%^{0}	55%$^{+}$
Men		+0.20*			+0.65***			+0.69***	
	27%$^{-}$	40%^{0}	33%$^{+}$	29%$^{-}$	16%^{0}	55%$^{+}$	29%$^{-}$	21%^{0}	50%$^{+}$
Blacks		+0.11			+0.42***			+1.14***	
	24%$^{-}$	54%^{0}	22%$^{+}$	33%$^{-}$	19%^{0}	48%$^{+}$	21%$^{-}$	22%^{0}	57%$^{+}$
Coloureds		+0.23**			+0.42***			+0.36***	
	27%$^{-}$	29%^{0}	44%$^{+}$	33%$^{-}$	18%^{0}	49%$^{+}$	36%$^{-}$	16%^{0}	48%$^{+}$
Whites		+0.10			+0.62***			+0.20	
	32%$^{-}$	29%^{0}	39%$^{+}$	29%$^{-}$	10%^{0}	61%$^{+}$	27%$^{-}$	23%^{0}	50%$^{+}$
<= 18yrs in 2003		+0.08			+0.49***			+0.84***	
	29%$^{-}$	39%^{0}	32%$^{+}$	33%$^{-}$	17%^{0}	50%$^{+}$	24%$^{-}$	22%^{0}	54%$^{+}$
> 18yrs in 2003		+0.24***			+0.37***			+0.74***	
	22%$^{-}$	47%^{0}	31%$^{+}$	33%$^{-}$	20%^{0}	47%$^{+}$	30%$^{-}$	18%^{0}	52%$^{+}$

Note:
T-test *10% significance level **5% and ***1% ; '+' = more stigma on average
%$^{-}$ %^{0} %$^{+}$ Percentage of respondents becoming less stigmatising, overall no change and more stigma respectively

Table 7.4 reveals that although a significant minority reported a decrease in stigma an average increase in stigma was reported by all groups for each dimension of stigma. With respect to gender, men showed a greater average increase for instrumental stigma than women, while symbolic stigma increased more among women than men. In other words, fear of infection increased for everyone, but the increase was greater among men; and negative moral judgements increased for everyone, but the increase was greater among women. The increase in average negative behavioural intentions was non-significant among women and only marginally significant among men.

By race, coloureds were the only group to express an increase in negative behavioural intentions. All groups showed an increase in instrumental stigma, with whites showing the greatest increase. Symbolic stigma increased most significantly among blacks and also among coloureds, while the increase among whites was non-significant. The most notable change in stigma by race was the increase in symbolic stigma among blacks.

Relatively small variation was found between the age groups for each dimension of stigma. The older group reported a significant increase in negative behavioural intentions, while the increase for the younger group was non-significant. On the other

hand, the younger group reported slightly larger increases in both instrumental stigma and symbolic stigma compared to the older group.

7.2.3 Determinants of stigma transitions

We now turn to an exploration of the potential determinants of changes in stigmatising attitudes and behavioural intentions. We consider in particular, the effect on stigma of knowing someone living with HIV/AIDS or someone who had died of AIDS. In this regard, the sample was restricted to respondents who reported not knowing someone living with HIV/AIDS or someone who had died of AIDS in 2002. The impact on stigma of subsequently meeting someone living with HIV or knowing someone who died of AIDS between the baseline 2002 and 2006 was assessed.

The reader is reminded that the stigma questions were first asked in 2003. This means that some of the new experiences reported may have occurred before stigma was measured at baseline. Thus, some of the effect on stigma of these experiences with HIV/AIDS may have occurred before 2003. This would lead to an underestimation of the relationship between these variables in this analysis.

Table 7.5. New contact with HIV/AIDS between 2002 and 2006

	Number of respondents who first met PLWHA between 2002 & 2006	Percent of group who first met PLWHA between 2002 & 2006	Number of respondents who first knew someone to die of AIDS between 2002 & 2006	Percent of group who first knew someone to die of AIDS between 2002 & 2006
Black	124	36%	149	43%
Coloured	26	8%	21	7%
White	5	9%	4	7%
Total	155		174	

Table 7.5 displays the percentage of CAPS respondents who experienced either event between 2002 and 2006. The table shows that significantly more young black adults than either whites or coloureds living in Cape Town reported knowing PLWHA (36%) and knowing someone who died of AIDS (43%). This was expected, as more than 95% of new AIDS cases and AIDS deaths over the intervening period were amongst blacks (see Table 7.6). After excluding missing data, there were insufficient

observations to conduct the analysis for all race groups. Given that the majority of new experiences with HIV/AIDS in the intervening period were amongst blacks it is reasonable to conduct the analysis with only the black individuals from the sample.

Table 7.6. New AIDS cases and AIDS deaths in South Africa between 2002 and 2006

	Black	Coloured	White	Total
New AIDS cases	178,170	5,789	1,526	186,517
Percentage of total	95.5%	3.1%	0.8%	100%
AIDS deaths	111,873	3,736	692	116,944
Percentage of total	95.6%	3.2%	0.6%	100%

Source: Estimates from the 2003 ASSA HIV/AIDS projection models (ASSA, 2005)

As it was impossible to control for all factors that might have influenced changes in stigma, this analysis should be seen as an initial exploration of the potential effect of knowing someone living with HIV/AIDS and knowing someone who died of AIDS on changes in stigma. Individual-fixed effects regression models were used.[97] (Random-effects models were also considered, but the Hausman test suggested that they were inconsistent and gave biased parameter estimates.)

Three different dependent variables were used: behavioural intentions, instrumental stigma and symbolic stigma. The main independent variables of interest were: 'contact with PLWHA' and 'knowing someone who died of AIDS'. The models also included the variable 'contact with PLWHA and knowing someone who died of AIDS' to control for the effect of having both of these experiences.

The following variables controlled for other factors that might influence changes in stigma. Increases in years of education were captured by the variable 'increased education'. The overall trend between the surveys is accounted for by 'survey year'. This variable accounted for factors that might have influenced changes in stigma between 2003 and 2006 that were not controlled for in the model. Four variables

[97] Individual-fixed effects estimators use the difference in scores for the variable of interest between the different time periods. The power of using panel data and fixed effects estimators is that any variable that does not change between the years will have a difference of 0 (2003-2006 = 0) and will not affect the model. Therefore, any factors influencing stigma that can be thought of as static will not bias the model, even if they have not been measured in the survey. See Wooldridge (2006) for a full discussion about individual-fixed effects.

measured at baseline (in 2003) were included.[98] The variable '2003 HIV knowledge' was included because knowledge about HIV transmission was found to influence fear of HIV infection in 2003 (see Chapter 5).[99] Such fears may influence interactions with PLWHA. The variable '2003 general bigotry', measured attitudes towards other groups and was included on the premise that holding prejudiced attitudes towards different groups of people could predispose someone to developing negative attitudes about PLWHA.[100] Age and gender were included given that the previous analysis had shown that changes in stigma varied by gender and, albeit it slightly, by age.

The model for behavioural intentions also included instrumental stigma and symbolic stigma as independent variables. This is because Chapter 5 found that individuals who expressed these stigmatising attitudes were more likely to express negative behavioural intentions towards PLWHA. The analysis presented here tests whether changes in instrumental stigma or symbolic stigma affected changes in behavioural intentions.

Table 7.7 displays the regression results. The results indicate that, controlling for the other variables in the model, having met someone living with HIV/AIDS between 2003 and 2006 was not a significant predictor in changes in any dimension of stigma. Controlling for everything else, personally knowing someone who had died, or was thought to have died of HIV/AIDS, was associated with increases in instrumental stigma and symbolic stigma. Importantly, increased negative behavioural intentions were significantly associated with increased instrumental stigma. In other words, increased fear of infection appeared to decrease tolerance towards PLWHA.

[98] The baseline variables were interacted with the time trend variable, 'survey year'.
[99] The same variable is used from Chapter 5 to measure knowledge about HIV transmission. Knowledge is measured based on whether the respondent thought people can get HIV by (1) "using a public toilet"; (2) "sharing a bath"; (3) "sharing a bottle of water"; (4)" kissing on the lips"; (5) "deep kissing? (Putting your tongue in their mouth?)"; (6) "touching someone's genitals"; (7) "shaking hands"; and (8) "having oral sex."
[100] The same variable is used from Chapter 5 to measure general bigotry. An 11-point scale measures like or dislike towards whites, coloureds, Indians, Jews, Muslims, illegal immigrants and homosexuals. The first 6 groups are selected as the black respondents are not part of these groups themselves. It is not known for certain whether any of the black respondents are homosexual, but as the vast majority of them have reported sexual relations with the opposite sex the error is assumed to be low.

Another interesting finding displayed in Table 7.7 involves levels of HIV knowledge in 2003. The results show that, controlling for the other variables in the model, individuals with better knowledge of HIV transmission in 2003 showed greater increases in instrumental stigma and symbolic stigma between 2003 and 2006. This is probably a product of the fact that individuals with better knowledge of HIV transmission in 2003 expressed significantly lower levels of stigma than others (see Chapter 5), and hence changes in reported attitudes represent a greater shift in stigma for these respondents. This does not, however, explain why, despite having good knowledge of HIV, symbolic stigma and especially instrumental stigma (fear of HIV infection) increased for these individuals. Finally, controlling for the other variables, men showed greater increases in instrumental stigma than women.

Table 7.7 Individual-fixed effects (FE) regression models for changes in stigma among young black individuals in Cape Town

	Behavioural intentions	Instrumental stigma	Symbolic stigma
Model	**7.7.1**	**7.7.2**	**7.7.3**
Regression	**FE**	**FE**	**FE**
Know someone with HIV	0.48 [0.38]	0.71 [0.64]	0.42 [0.48]
Know someone who died of AIDS	-0.49 [0.35]	**0.66*** **[0.39]**	**1.20***** **[0.42]**
Know someone with HIV and know someone who died of AIDS	-0.18 [0.53]	-0.74 [0.78]	-0.89 [0.66]
Increased education	0.05 [0.12]	0.07 [0.21]	**-0.32**** **[0.15]**
2003 HIV knowledge	0.16 [0.11]	**0.38***** **[0.13]**	**0.25***** **[0.09]**
2003 general bigotry	0.01 [0.01]	-0.01 [0.01]	**-0.02**** **[0.01]**
Age	0.09 [0.06]	-0.03 [0.17]	-0.07 [0.06]
Gender (base=women)	-0.16 [0.26]	**0.94***** **[0.37]**	0.45 [0.29]
Survey year	**-2.69**** **[1.29]**	-1.85 [1.98]	1.45 [1.37]
Change in instrumental stigma	**0.17***** **[0.05]**	n/a n/a	n/a n/a
Change in symbolic stigma	-0.06 [0.06]	n/a n/a	n/a n/a
n	607	608	610
R-sqaured	0.10	0.12	0.28
Prob > F	0.000	0.000	0.000

Note: *10% significance level **5% significance level and ***1% significance level
n/a: Not applicable

7.3 Discussion

Overall, stigma increased among young adults in Cape Town between 2003 and 2006. Behavioural intentions became slightly more negative over time, but overall, levels of this manifestation of stigma remained relatively low. As noted in Chapters 5 and 6, this does not necessarily mean, however, that discrimination (or enacted stigma) towards PLWHA is not a problem, or is not increasing, as the more subtle manifestations of enacted stigma, such as gossip or hand signals, may be more prevalent than the overt and extreme manifestations captured by typical survey questions. For example, 60% of CAPS respondents in 2006 reported that they had personally heard other people saying nasty things about PLWHA. Unfortunately this question was asked only in 2006 so we do not know how this more subtle measure of stigma may have changed over time.

The significant increases in instrumental stigma and symbolic stigma are alarming – especially considering that the respondents were in an age group highly likely to be targeted with HIV prevention messages. In addition, the increases in stigma were measured over the same period that South Africa started providing antiretroviral treatment through the public sector – a process that began in Khayelitsha, Cape Town in 2001. This suggests that any potential reduction in stigma achieved through AIDS prevention and treatment initiatives either had no effect on reducing stigma or was overwhelmed by other factors.

Importantly, the analysis reported on in this chapter found no evidence for the contact hypothesis, i.e. that direct contact with members of the stigmatised group will normalise the disease and decrease stigma towards the group. The nature of the interaction between the respondents and PLWHA is, however, not known. As mentioned earlier, Almeleh (2006) found that in Cape Town HIV status disclosure is most common when people are sick and have no choice other than to disclose to potential care-givers and assistants. Consequently, HIV/AIDS is so strongly associated with illness and death that people whose health has been restored by HAART are regarded by some as no longer being HIV positive (*ibid.*).

This suggests that in the minds of respondents, interactions with PLWHA probably refer to extremely sick individuals who were dying of AIDS rather than individuals who were living healthy, productive lives with HIV. Instead of normalising the disease, interactions with PLWHA when they are sick with AIDS might perpetuate associations between HIV and illness, perpetuate fears of HIV/AIDS, and perpetuate negative moral judgement towards those affected, i.e. perpetuate stigma.

This chapter has identified two factors that potentially contributed to increased levels of stigma. The first is knowing someone who had died of AIDS. The public sector provision of HAART had only reached 55.7% of those in need of treatment by 2006 (Nattrass, 2007). This meant that despite the HAART roll-out, the numbers of annual AIDS-related deaths increased between 2003 and 2006. It is thus to be expected that a significant number of respondents reported knowing someone who died of AIDS over this period. This may well have reinforced associations between HIV/AIDS and death, increased fears of HIV/AIDS and increased moral judgement towards those affected, i.e. increased stigma. If so, then it follows that a more rapid and extensive roll-out of HAART to all those who need it could help reduce AIDS-related deaths and stigma.

Second, increases in instrumental stigma were significantly associated with an increase in negative behavioural intentions towards PLWHA. It is reasonable to suppose that if individuals become more fearful of HIV infection over time their willingness to interact with PLWHA might decrease. This finding indicates the direct negative effect that increases in instrumental stigma may have for PLWHA. Chapter 5 indicated that HIV education is still necessary to reduce stigma. There was also evidence from Chapter 5 that interacting with PLWHA was associated with increased fears of infection. The findings in this chapter, especially as stigma increased among individuals with good knowledge of HIV transmission, also suggest the need to weaken associations between HIV and death – preferably by steadily expanding the HAART roll-out and by providing more explanation to people about the ways of avoiding HIV-infection and about the potential to live long and healthy lives on HAART.

Chapter 8. Perceived stigma among the general population in Cape Town

This chapter measures perceived stigma, i.e. the perception that PLWHA are stigmatised, among the general population of Cape Town. Perceived stigma, which has rarely been measured in sub-Saharan Africa, warrants a special focus for two main reasons. First, perceived stigma may have negative consequences for public health initiatives by impeding HIV prevention, treatment and care efforts. The perception that PLWHA are treated unfairly or badly might lead to the anticipation of stigma if one were to test positive. Such anticipation could deter people from testing, discourage disclosure and reduce willingness to present for health care. In other words, irrespective of whether or not actual HIV-related discrimination takes place, or whether PLWHA generally receive support when they disclose their HIV status, perceived stigma can have far reaching consequences for responses to HIV/AIDS.

Second, it is possible that measures of perceived stigma provide a better indication of levels of HIV-related discrimination than do measures of negative behavioural intentions towards PLWHA. This would be the case if people gave responses to questions about their own behavioural intentions towards PLWHA that do not reflect their likely capacity for discrimination. As noted in Chapter 4 this could result from social desirability bias or from the hypothetical nature of many questions. It would also be the case if the questions used in the surveys did not capture important and more subtle aspects of HIV-related discrimination. This concern has already been voiced in the previous three chapters, which suggests that more nuanced and innovative questions are needed to elicit more subtle manifestations of stigma.

Vanlandingham *et al.* (2005) found variation in reactions to PLWHA in Thailand, but their main conclusion was, that overall, these reactions were considerably more positive than is widely assumed. They suggest that in Thailand, as elsewhere, reports in the popular press and in the research literature tend to focus on negative reactions. In South Africa, news media, research papers and activist groups have focussed considerable attention on extreme examples of HIV-related stigma, in particular the

deaths of Gugu Dlamini, Mpho Motloung and Lorna Mlofana.[101] Rather than this being the norm, a reading of Vanlandingham *et al.* (2005) might suggest that these could be atypical cases, which are used to generalise the experience to broader groups. Those who exaggerate the distribution and effects of stigma may well have the well-being of PLWHA at heart, but this is not without cost. As mentioned above, such exaggeration is likely to impact on HIV prevention via heightened fears of stigma that might, for example, deter people from voluntary counselling and testing.

Evidence from different population groups around the world indicates that it is common for people to believe that PLWHA experience stigmatisation. A study in the United States done among men who have sex with men, for example, found that almost two thirds of respondents rated their community's attitudes towards PLWHA as intolerant (Preston *et al*., 2004). The same study found, however, that most people believed that families and health care providers are supportive. In Russia, a qualitative study (Balabanova *et al.*, 2006) found high degrees of perceived stigma in the general population. In another study in the United States, Herek *et al.* (2003) found that the vast majority of people believed that PLWHA have been and continue to be targets of persecution; and Dias *et al.* (2006) found that adolescents in Portugal believe that people with AIDS experience discrimination and social exclusion.

Chapter 5 revealed generally low level of stigma as measured by behavioural intentions towards PLWHA among young adults. Chapter 6 showed similar results for behavioural intentions towards family/friends. Chapter 6 did, however, show that behavioural intentions towards strangers were substantially more negative, with almost a third of respondents reporting negative intentions. This chapter assesses whether negative behavioural intentions towards PLWHA and perceived stigma are reported to similar degrees in Cape Town.

[101] The stories of these women, which were touched on in Chapter 2, are repeated here for convenience. Gugu Dlamini was a South African woman from KwaMancinza, a town in eastern KwaZulu-Natal province, who was stoned and stabbed to death after she disclosed that she had HIV on a Zulu language radio programme on Worlds AIDS Day.
Mpho Motloung was a female teacher from Soweto, South Africa. She and her mother were shot dead by her husband (also a teacher from Soweto) who then killed himself. On her body was the note: "HIV positive Aids."
Lorna Mlofana was a female member of the Treatment Action Campaign from Khayelitsha, South Africa. She was raped by a group of young men who then murdered her after they discovered she had HIV.

8.1 Method

Questions designed to measure perceived stigma were asked in three different surveys. First, in CAPS 2003 (see Chapter 5 for a description of this survey) a single question was asked to the young adults: "Do you think people with HIV/AIDS often get treated unfairly or badly by others?"

Second, in 2005, CAS interviewed 1,202 adults in Cape Town. The sampling procedure and data collection process for this survey was the same as the previous CAS survey in 2003 (see Chapter 6 for details). The sample characteristics for CAS 2005 are displayed in Table 8.1. As in CAS 2003, coloureds were the most sampled population group, followed by blacks and whites; and the sample was heavily weighted in favour of women. The majority of the sample had some secondary school education and almost half had completed secondary school. Finally, CAS 2005 comprised a sample with a wide range of ages: 18 years old to 87 years old.

Table 8.1. CAS 2005 sample characteristics

		n	percent	mean
All respondents		1,202	100%	
Race	black	409	34%	
	coloured	529	44%	
	white	252	21%	
			99%	
Gender	men	466	39%	
	women	736	61%	
			100%	
Education	< grade 8	221	19%	9.8
	grade 8 to 11	474	40%	
	grade 12	484	41%	
			100%	
Age	range from 18 to 87	1,191		40

Note: The total number of respondents differs between variables due to missing data
Percentages do not always total 100% due to rounding effects

CAS 2005 probed perceived stigma with the use of vignettes that described different characteristics of an HIV positive person to different respondents. All the respondents were first told to "imagine that you are visiting a cousin (or another

relative) for a braai."[102] The respondents were then told that while talking to their cousin someone walks into the room and their cousin gives some details about the person. Each respondent received one of the following four descriptions of the person: (1) "that person there who just walked in, John, he is HIV-positive"; (2) "that person there who just walked in, Brenda, she is HIV-positive"; (3) "that person there who just walked in, John, he is sick with AIDS"; and (4) "that person there who just walked in, Brenda, she is sick with AIDS." There were thus two variations in the persons characteristics: (1) the person was either a man or a woman, and (2) the person was either HIV-positive or sick with AIDS. Perceived stigma was then assessed for each scenario with the following question:

> Do you think people like [John] are sometimes treated unkindly or badly by other people because they are [HIV-positive]? (The information in parentheses was changed to match the question to the scenario.)

The different scenarios were used to assess whether perceived stigma varied according to who the target subject was. As mentioned in Chapter 2, previous research has found HIV positive women to experience more stigma than HIV positive men (see e.g. France, 2004). In the first analysis it was accordingly hypothesised that, controlling for whether the respondent was described as HIV-positive or sick with AIDS, the respondent would report higher levels of perceived stigma when the subject was a woman. The second analysis assessed variation in perceived stigma based on the 'stigma trajectory' theory postulated by Alonzo & Reynolds (1995). As described in Chapter 5 Alonzo and Reynolds suggest that PLWHA experience stigma differently at different stages of HIV and AIDS illness, with the latter stages of the disease being characterised by greater degrees of stigma as the physical manifestation of AIDS affects physical appearance and affects everyday activities. It was accordingly hypothesised that, controlling for whether the subject was a man or a woman, individuals described as 'sick with AIDS' would be perceived to experience more stigma than those described as 'HIV-positive'.

Another survey which probed perceived stigma amongst adults was the KPS. However, this survey did not ask scenario based questions and was limited to Africans

[102] 'Braai' is a commonly used term in South Africa for a barbeque.

in Khayelitsha. Nonetheless it helps us paint a more complete picture of perceived stigma within the general (black) population. It also provides a context for reflecting on experienced and perceived stigma among PLWHA in Khayelitsha (see Chapters 9 and 10). As noted in Chapter 4, KPS 2004 interviewed 570 adults living in Khayelitsha in 2004. Although a representative sample of 966 adults were interviewed in KPS 2000, the high degree of attrition between the two surveys suggests that caution is needed in extending inferences to the general population. However, as no attrition bias was found with regard to labour-market characteristics (Magruder & Nattrass, 2006), there are grounds for optimism about the continued representivity of the sample.

Table 8.2 displays the sample characteristics for KPS 2004. Everyone in the sample was black, and everyone reported Xhosa as their home language.[103] As in CAS 2005, more females were interviewed than males; and the sample comprised individuals with a wide range of ages (18 to 81 years) with an average of 35 years. Compared to the adults interviewed in CAS 2005, the adults in KPS had completed, on average, fewer years of education.

Table 8.2. KPS 2004 sample characteristics

		n	percent	mean
All respondents		570	100%	
Race	black	570	100%	
Home language	Xhosa	570	100%	
Gender	men	229	40%	
	women	341	60%	
			100%	
Education	< grade 8	221	28%	8.8
	grade 8 to grade 11	474	45%	
	grade 12	156	27%	
			100%	
Age	range from 18 to 81	570		35

[103] Xhosa is one of the eleven official languages of South Africa. Xhosa is the second most common home language (after Zulu) spoken in South Africa. According to the 2001 Census, Xhosa is spoken by about 18% of South Africa's population. The majority of Xhosa speakers live in the Eastern Cape, followed by the Western Cape.

KPS 2004 measured perceived stigma with responses (on a 5-point Likert Scale: "strongly disagree", "disagree", "neither agree nor disagree", "agree" or "strongly agree") to the four statements displayed in Table 8.3. Given that Chapter 6 measured few negative behavioural intentions towards family/friends, the first question was designed to assess whether people perceive family members to be supportive or stigmatising. Question 2 enables a comparison between perceived stigma reported among young adults in Cape Town from CAPS 2003 and general perceptions about how PLWHA are treated. Question 3 was included for two reasons. First, Chapters 5 and 6 raised the point that measures of more subtle manifestations of stigma may be important. Second, anecdotal evidence (personal communication with PLWHA) indicated that gossip about PLWHA was common, and feared by PLWHA. Question 4 was included to measure perceptions of a more overt form of discrimination.

Table 8.3. Statements asked in KPS 2004 to measure perceived stigma

1. Most people with HIV are supported by their families when they disclose their HIV status
2. People with HIV often get treated unfairly or badly by others
3. People say unkind things about HIV positive people
4. Most people prefer to avoid people with HIV as much as possible

8.2 Measures of perceived stigma

8.2.1 Perceived stigma among young adults in Cape Town

Table 8.4 displays the responses to the perceived stigma question asked in CAPS 2003. The majority of respondents (57%) perceived that PLWHA are treated unfairly or badly. Note the use of the term 'often' in the question. This indicates that the majority of respondents not only perceived PLWHA to be stigmatised, but they perceived stigmatisation to occur frequently.

Table 8.4. Perceived stigma among young adults in Cape Town

1. Do you think people with HIV/AIDS often get treated unfairly or badly by others?	Yes	57% (776)
	No	36% (492)
	Don't know	7% (90)
		100%

Note: Numbers in parentheses indicate number of respondents

8.2.2 Perceived stigma among adults in Cape Town

Table 8.5 displays the responses to the perceived stigma question asked in CAS 2005. Overall, combining answers from all scenarios, the vast majority (71%) thought that PLWHA are treated unkindly or badly; and a further 9% thought this was possible. Note the use of the term 'sometimes' in this question. With the inclusion of 'sometimes' the responses provide an indication that most people perceived PLWHA to be stigmatised, but the perception of the frequency of stigma is unknown. The difference in wording between the CAPS 2003 question and the CAS 2005 question may explain the greater percentage of perceived stigma in CAS 2005.

Importantly, there was no statistically significant difference detected in responses between any of the different scenarios provided.[104] In other words, reported perceived stigma was the same regardless of whether respondents were thinking about stigma experienced by women or men; or whether respondents were thinking about someone with HIV or someone with AIDS. This indicates that there is a perception that in general PLWHA are stigmatised.

Table 8.5. Perceived stigma among adults in Cape Town

1. Do you think that people like [John/Brenda] are sometimes treated unkindly or badly by other people because they are [HIV-positive/sick with AIDS]?	Yes, definitely	49% (591)
	Yes, probably	22% (264)
	Perhaps	9% (108)
	Probably not	5% (56)
	Definitely not	11% (135)
	Don't Know	4% (48)
		100%

Note: Numbers in parentheses indicate number of respondents

8.2.3 Perceived stigma among adults in Khayelitsha

Table 8.6 lists responses to the statements in KPS 2004, listed on page 166, that were used to measure perceived stigma among adults in Khayelitsha. The results indicate that for the first question most of the KPS 2004 sample (80%) believed that PLWHA were supported by their families. However, the other three questions revealed that the

[104] This finding was robust with the use of different statistical tests: T-test, ordered probit, ordered logit, probit or logit regressions. Regression results were robust with the inclusion of control variables: race, age, gender and schooling.

vast majority perceived PLWHA to experience stigma. The perception that PLWHA experience gossip (Question 3) was the form of perceived stigma most frequently reported (by 72% of respondents). Perceived stigma was also, however, relatively high for Question 2 and Question 4: 67% believed that PLWHA were often treated unfairly or badly, and 64% thought PLWHA were often avoided. These results thus indicate that even relatively severe manifestations of stigma are perceived to be common.

Table 8.6. Perceived stigma among adults in Khayelitsha

Please tell us how strongly you agree or disagree with the following statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know	Total
1. Most people with HIV are supported by their families when they disclose their HIV status	0% (1)	1% (7)	17% (96)	68% (381)	12% (69)	1% (8)	99%
2. People with HIV often get treated unfairly or badly by others	0% (2)	13% (75)	18% (102)	51% (289)	16% (90)	1% (4)	99%
3. People say unkind things about HIV positive people	1% (5)	10% (57)	17% (94)	52% (291)	20% (111)	1% (5)	101%
4. Most people prefer to avoid people with HIV as much as possible	2% (9)	6% (34)	27% (149)	48% (262)	16% (87)	1% (7)	100%

Note: Numbers in parentheses indicate number of respondents
Percentages do not always total 100% as a result of rounding effects

8.3 Discussion

This chapter suggests that perceived stigma among the general population of Cape Town and specifically among adults in Khayelitsha is pervasive. That is, the majority of people in Cape Town believe that PLWHA experience stigmatisation. Furthermore, there is evidence that even relatively severe experiences of stigma are perceived to be common. As noted earlier, such perceptions may have extremely negative consequences for interventions aimed at HIV prevention, treatment and care. In particular, high levels of perceived stigma in the general population may deter people from voluntary counselling and testing and presenting at clinics.

This chapter does, however, show that stigma is not perceived to be common within families, who are generally perceived to be supportive of PLWHA. This is consistent with findings in Chapter 5 and 6 that people generally expressed positive behavioural intentions in scenarios involving family members with HIV/AIDS. This strengthens the argument that measures of stigma need to make a distinction between different

groups of potentially stigmatised individuals (i.e. between family/friends and strangers). These findings from the first section of analysis in this study thus suggest that the majority of enacted stigma probably occurs beyond the confines of the household and accordingly people perceive families to be supportive.

On the other hand, a disconnect is apparent between the high levels of perceived stigma found in this chapter and responses to other questions in Chapter 5 and 6 identifying comparatively lower levels of negative behavioural intentions towards PLWHA. One possible explanation for this was that PLWHA experience subtle manifestations of stigma that were not detected in the surveys. The large number of respondents who perceived PLWHA to be gossiped about suggests that this could be true. However, the majority of respondents also thought PLWHA are commonly treated unfairly or badly, and deliberately avoided or shunned. It therefore remains unclear whether the available datasets have adequately assessed behavioural intentions in the general public (due to measurement error or a set of questions that is not sufficiently comprehensive), or whether perceptions of stigma are unrealistically high.

What this means for policy is unclear. Consistent with Vanlandingham *et al.*'s (2005) suggestion, it may be that experiences of stigma are perceived to be more common than they actually are. If so, relevant parties such as the media, HIV activists, and researchers, should be made aware of the dangers of extrapolating too much based on a few cases. On the other hand, it may be that questions used in this study to measure negative behavioural intentions towards PLWHA among the general population do not capture adequately the full extent of the problem. If this is the case different methods need to be developed to measure stigma.

The remaining parts of this dissertation provide a measurement of experienced stigma, perceived stigma and internalised stigma among PLWHA. This will provide a better indication of whether perceived stigma in the general population reflects actual experiences of stigma.

Assessment of HIV-related stigma among individuals on HAART in Khayelitsha, Cape Town

Chapter 9. Experienced stigma among individuals on HAART

Recent research on stigma experienced by PLWHA in Cape Town found that 42% of the respondents reported experiencing HIV-related discrimination and that these individuals were significantly less likely to have disclosed their HIV-status to their sexual partners (Simbayi *et al.*, 2007a). Apart from this study, little research on experiences of stigma has been conducted in sub-Saharan Africa. Importantly, there is no systematic research on levels of stigma experienced by the growing cohort of people in developing countries who have had their health restored by HAART.

This chapter contributes to addressing this gap in the literature by exploring data on experienced stigma from a cohort of HAART patients in Khayelitsha, South Africa. Specifically, the chapter evaluates experienced stigma from three different angles. First, experienced stigma was measured in terms of *any* experience of HIV-related stigma prior to 2004/05.[105] Part 1 (Section 9.2) accordingly measures the nature and extent of experienced stigma; and explores its potential determinants. Given that our earlier analysis found experienced stigma to be strongly associated with illness, Part 2 (Section 9.3) considers experiences of HIV-related stigma for the period just before respondents started HAART; i.e. when they were sick with AIDS.[106] This part of the chapter thus measures the extent and nature of stigma when it seemed likely, on average, to have been experienced most severely. Finally, in Part 3 (Section 9.4) experienced stigma was measured between 2004/05 and 2006. This third section provides an indication of the relevance of experienced stigma after HAART has restored PLWHA to health. In other words, it will assess the degree to which stigma is a persistent phenomenon in certain individuals' lives: to what extent do some individuals remain in bad situations (they experienced stigma before and they continue to do so)?

[105] As described in Chapter 4, the first wave of the HAART Panel Study was collected between August 2004 and February 2005. It asked respondents about their experienced stigma prior to the survey (i.e. prior to 2004/05).

[106] Although it is possible for doctors to put patients on HAART before they become AIDS-sick, the protocol in Khayelitsha was to initiate patients on treatment when their CD 4 count falls below 200. At this stage, most people are extremely vulnerable to opportunistic infections because their immune systems are severely compromised.

9.1 Method

This chapter uses data from the first (2004/05) and second (2006) waves of the HAART Panel Study. The design and sampling technique of this study were provided in Chapter 4. The reader is reminded that the sample – comprising individuals who by 2004/05 had been on HAART for more than a year – was recruited via word of mouth and the results should not be regarded as necessarily representative of all people on HAART. Given that respondents were recruited mainly through HIV positive support groups and social networks it is possible, for example, that these respondents live in more supportive environments than those not recruited into the study. However, as the study managed to recruit two thirds of the initial cohort of HAART patients starting treatment in 2001 when the HAART pilot project began, the data probably captures key aspects of the lived experiences of PLWHA on long-term HAART.

Table 9.1 displays the characteristics of the 2004/05 HAART survey. The vast majority of respondents (79%) were women. The over-representation of women in the HAART sample reflects the gender bias in the HAART pilot programme discussed in Chapter 4.[107] The sample had a mean age of 34 years and was fairly poorly educated (only a third of the sample had completed secondary school).[108] More than two thirds of the sample was unemployed. The majority of personal income was therefore obtained through government welfare via disability grants.[109] Finally, as was the case in the KPS study of the adult population of Khayelitsha, the majority of the HAART sample was affiliated to a religious organisation.

[107] Qualitative research conducted in African townships around Cape Town has found similar gender bias. Consistent with the argument in Chapter 4, this bias was explained by the fact that more women know their HIV-status than men due to VCT services for pregnant women (Squire, 2007).

[108] Most AIDS cases and AIDS deaths in South Africa in 2001 were among 25 to 29 year old women, and among 35 to 39 year old men (ASSA, 2005). Given that the majority of the sample started treatment in 2001, it was expected that the mean age of the 2004/05 sample would be three or four years older.

[109] Individuals with CD4+ counts below 200 who were unable to work were eligible to receive R740 in 2004/05 from the government disability grant program. Disability grants were awarded as either 'permanent' or 'temporary,' with the former coming up for renewal at 5 years and the latter at 6 months.

Table 9.1. The 2004/05 HAART Panel Study sample characteristics

		n	percent	range	mean
All respondents		242			
Gender	men	50	21%		
	women	192	79%		
			100%		
Age				20-64	34 years old
Education	none	5	2%	0-12 years	9.45 years
	primary	42	17%		
	secondary	116	48%		
	grade 12/matric	79	33%		
			100%		
Religious affiliation	no	63	26%		
	yes	179	74%		
			100%		
Working	no	171	71%		
	yes	70	29%		
			100%		
Income	personal income			R0-R5,300	R1,077
Disability grant	no	64	26%		
	yes	178	74%		
			100%		

Table 9.2 displays the sample characteristics for the 2006 wave of the HAART Panel Study and Table 9.3 provides a summary of the attrition between the two surveys. The 2006 HAART survey comprised 224 respondents, with an attrition of only 18 respondents (7.4%) from the first wave. Importantly, no one refused to complete the survey in 2006. Seven of those who could not be contacted for the follow up survey were men and 11 were women. This skewed the gender of the sample slightly further in favour of women, who constituted 82% of the 2006 sample.

The age, education and religious profile of the 2006 sample were similar to that of the 2004/05 sample. This provided an initial indication that, at least in terms of these demographics, attrition did not bias the sample. Subsequent statistical analysis[110] (see Appendix E for these results) showed that age was the only demographic variable significantly associated with attrition, i.e. older respondents were more likely to have dropped out of the sample. Therefore, although most of the attrition appeared to be random, it must be noted that the 2006 sample was biased slightly towards younger

[110] Probit and logit regression models were used to test attrition with the following explanatory variables: gender, age, education, religious affiliation, number of years HIV positive, employment status and personal income.

individuals. The last point to note is that despite the increase in employment, the average personal income decreased. This was because significantly more individuals lost the disability grant (28%) than found employment (12%) between the surveys (see Maughan-Brown *et al.* (2008) for a detailed panel analysis of the effects of losing a disability grant among these respondents).

Table 9.2. The 2006 HAART Panel Study sample characteristics

		n	percent	range	mean
All respondents		224			
Gender	men	41	18%		
	women	183	82%		
			100%		
Age				22-58	35 years old
Education	none	4	2%	0-12 years	9.6 years
	primary	36	16%		
	secondary	108	48%		
	grade 12/matric	76	34%		
			100%		
Religious affiliation	no	61	27%		
	yes	163	73%		
			100%		
Working	no	132	59%		
	yes	92	41%		
			100%		
Income	personal income			R0-R7,000	R1,017
Disability grant	no	120	54%		
	yes	104	46%		
			100%		

Table 9.3. Attrition between the 2004/05 and 2006 HAART surveys

Interviews conducted in 2004/05	242
Interviews conducted in 2006	224
Total survey attrition	18
Percent survey attrition	7.4%
Reasons for attrition:	
Respondent moved and could not be located	10
Respondent unknown at the recorded address	6
Respondent reported as deceased	2

9.2 Part I: Experienced stigma prior to 2004/05

Experienced stigma can usefully be broken down into stigma from household members, and stigma experienced more broadly. According to a Soweto study, most HIV-positive people are supported by household members (Skhosana *et al.*, 2006). Similar trends were evident in the HAART 2004/05 data set: two-thirds of respondents reported that they had disclosed their HIV status to everyone in the household by the time they started HAART, and only three respondents reported that a (single) household member had been unsupportive. This suggests that most experienced stigma within this sample is likely to have occurred beyond the confines of the household.

Broader experiences of HIV-related stigma were then measured using responses to nine statements (ranked on a 5-point Likert scale) about experiences of stigma since HIV diagnosis (see Table 9.4). This, of course, tells us something about whether stigma had been experienced, but not about the frequency of such experiences.

One of the methodological challenges involved in analysing the data entailed making a decision on how to interpret the 'neutral' response option: "neither agree nor disagree." During the initial checking of survey questionnaires in the field it became evident that many respondents were opting to record "neither agree nor disagree." When asked about this, the fieldworkers told the survey managers that respondents were opting to record "neither agree nor disagree" when they believed that sometimes the statement was true, and sometimes not. For example, when asked whether it was true or false that family members were willing to take care of them, they would pick the neutral response if they thought it was true that some family members would, but others would not. Given these circumstances, it was decided that "neither agree nor disagree" was best interpreted with regard to these questions as meaning: both agree and disagree (i.e. some people do while others do not). It was thus understood to represent some experience of stigma.

Four key findings are evident from Table 9.4. First, the percentage of respondents who reported experienced stigma from family members was low (as expected): 93%

disagreed that family members and friends had treated them badly because of their HIV status; and 96% agreed that when HIV made them very sick their close family members were willing to take care of them. This is consistent with the low levels of stigma reported by household members and with the findings from Chapter 6 that few negative behavioural intentions towards family/friends with HIV were reported in the adult population of Cape Town.

Second, it is noteworthy, however, that 10% agreed and a further 5% neither agreed nor disagreed with the statement that they had lost a friend because of HIV. Although this experience was still relatively uncommon, this indicates that a significant minority had experienced a relatively severe manifestation of stigma (i.e. losing a friend). Third, a substantial proportion (17% agree and a further 27% neither agree nor disagree) reported that "people who have no reason to fear still worry that they will catch HIV from me." This suggests that irrational fears of infection may be a significant aspect of the stigmatising environment experienced by these PLWHA. This concurs with findings from both Chapter 5 and Chapter 6 indicating fairly high levels of instrumental stigma in Cape Town. Last, "unkind things said behind the respondents back" (Question 8) was the most common experience of stigma. This is consistent with qualitative research in Khayelitsha and other nearby townships among PLWHA which reveals that gossip and hand signals are common and hurtful forms of stigmatising behaviour (Almeleh, 2006; Mills, 2004, 2006; Mlobeli, 2007):

> It was reported that in Khayelitsha if one is suspected of being HIV-positive or is HIV-positive people give the person names such as Z3, prostitute, won lotto and other negative names. This existential behaviour accounted for most of the stigmatising behaviours from the community (Mlobeli, 2007, p. 73).

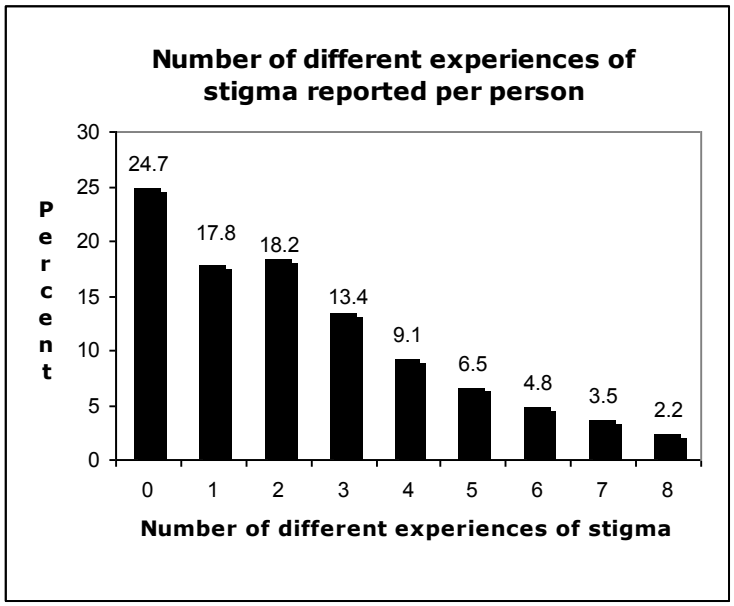
Table 9.4. Items used to assess experienced stigma

To what extent do you agree or disagree with the following?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total
1. I have lost friends because I am HIV positive	15% (36)	70% (168)	5% (13)	10% (24)	0% (1)	100%
2. Family members and friends have treated me badly because I am HIV positive	23% (57)	70% (169)	5% (12)	1% (2)	1% (2)	100%
3. When HIV made me very sick my close family members were willing to take care of me	1% (2)	2% (4)	2% (4)	50% (119)	46% (111)	101%
4. When people find out I am HIV positive, they feel uncomfortable in my presence	6% (15)	64% (154)	26% (65)	3% (7)	0% (1)	99%
5. People are concerned that they could 'catch' HIV from the food I prepare or from touching me	14% (34)	66% (157)	15% (36)	4% (9)	1% (2)	100%
6. People who have no reason to fear still worry that they will catch HIV from me	15% (35)	41% (95)	27% (66)	15% (36)	2% (5)	100%
7. People treat me with less respect when they find out I am HIV positive	23% (56)	59% (142)	12% (29)	6% (15)	0% (0)	100%
8. Because I am HIV positive, people say unkind things behind my back	10% (24)	23% (56)	31% (76)	34% (82)	2% (4)	100%
9. Many people avoid me because I am HIV positive	14% (35)	59% (141)	23% (56)	4% (9)	0% (0)	100%

Note: Numbers in parentheses indicate the number of respondents
Percentages do not always total 100% due to rounding effects

Figure 9.1 shows a histogram of the number of different statements for which each respondent reported an experience of stigma. Conclusive statements about the impact of stigma cannot be made from this information as the severity and nature of stigma may vary dramatically from item to item. Nevertheless, it is noteworthy that 75% of respondents had experienced some stigma, and furthermore that 17% of respondents experienced stigma on the majority of items (i.e. the sum of respondents who reported stigma on five or more of the items).

Figure 9.1. The number of different experiences of stigma reported per person



9.2.1 Formation of the experienced stigma index

The questions listed in Table 9.4, with the exception of Question 3, were recoded so that a response of "strongly disagree" to a particular question was scored as zero to represent no experience of stigma and four when the respondent answered "strongly agree." The response options "disagree", "neither agree nor disagree", and "agree" were then scored one, two or three respectively. In the case of Question 3, the scale was reversed as the response of "strongly disagree" represented experienced stigma while the response "strongly agree" represent no experience of stigma. The values ascribed to each answer were then summed to form the index called 'experienced stigma'. The experienced stigma index thus has a potential range of zero (no experienced stigma) to 36 (experience of stigma reported for every question).

Factor analysis was then conducted to test construct validity of the experienced stigma index. It indicated that the questions were indeed probing one underlying dimension (i.e. experienced stigma). The construct validity of the experienced stigma index was then further tested with a correlation analysis with variables expected to relate to experienced stigma. Stigma scores should be positively correlated with depression or anxiety and negatively related to self-esteem (Berger *et al.*, 2001; Goffman, 1963; Laryea & Gien, 1993). Table 9.5 shows that correlations between the experienced

stigma index and variables forming a rough measure of depression/anxiety[111] and self efficacy/confidence[112] were in the expected direction. These findings thus provide further evidence of the construct validity of the experienced stigma index. In addition to construct validity, the index also displayed internal reliability (α=0.82).

Table 9.5. Correlations between experienced stigma and related constructs

	Experienced stigma
Depression or anxiety	0.44
Self-efficacy or confidence	-0.18

9.2.2 Determinants of experienced stigma

Understanding the specific factors that drive, or at least are associated with, experiences of stigma is of potential value to the design of appropriate interventions to combat stigma. This section describes the hypotheses and variables used to explore potential correlates and determinants of experienced stigma using OLS regression models.[113] Table 9.6 displays the independent (explanatory) variables used in the regression models to assess potential determinants of experienced stigma.

[111] The depression/anxiety index was created with five questions probing how often (never, hardly ever, sometimes, often, or all the time) the respondent experienced various emotions in the past year. These questions were: (1) "Felt that problems are piling up so high that you cannot overcome them?"; (2) "Felt that you cannot stop feeling very sad and depressed – even with help from your friends or family?"; (3) "Felt lonely?"; (4) "Felt nervous or stressed?"; and (5) "Been so worried or anxious that you have felt tired, worn out or exhausted?" All five questions were summed to create an index with a possible range from 0 ('never' on all questions) to 25 ('all of the time' for all questions). Factor analysis indicated construct validity and the index showed internal reliability (α = 0.80).

[112] The self efficacy/confidence index was created with four statements answered on a 5-point Likert Scale from strongly disagree to strongly agree. These statements were: (1) "I can always manage to solve difficult problems if I try hard enough"; (2) "If someone opposes me, I can find the means and ways to get what I want"; (3) "It is easy for me to stick to my aims and accomplish my goals"; and (4) "If I am in trouble, I can usually think of a solution." All four questions were summed to create an index with a possible range from 0 ('strongly disagree' to all statements) to 20 ("strongly agree" to all statements). Factor analysis indicated construct validity and the index showed internal reliability (α = 0.82).

[113] Sensitivity analysis using ordered probit regression models showed the significance level of the coefficients to be robust across technique. The results for the sensitivity analysis are presented in Appendix F.

Table 9.6. Explanatory variables to assess potential determinants of experienced stigma

Experienced stigma
Gender
Age
Education
Religious affiliation
Years HIV positive (time between diagnosis and interview dates)
Experience of illness
Household income
Percentage contribution to household income
Illness effect on household at start of HAART *or* in the 3 months prior to the interview
Clinic where HAART was received
Percentage HIV-status disclosure to household members

As noted earlier, disease stigma often attaches itself to existing stigmatising frameworks – including those related to gender (France, 2004; Herek & Capitanio, 1997; Leclerc-Madlala, 1997, 2002; Sontag, 1988). Accordingly, it was hypothesised that women would report more experienced stigma than men.

Age was included as a potential explanatory variable of experienced stigma on the grounds that HIV is concentrated amongst young adults, and hence young people are more likely to experience stigma than older people. Education was included on the grounds that people with more education might be better able avoid stigma by (1) moving in social circles where there is less stigma and (2) making better decisions about to whom to disclose their HIV-positive status. In addition, people with more education might be better able to shrug off negative social judgements and behaviours and thus be less likely to experience stigma in a negative way (and therefore be less likely to report it).

Deacon and Simbayi (2006) found that some PLWHA were discriminated against by members of their church. In addition, Chapter 6 found that respondents (in the general adult population of Cape Town) who reported that religion was very important in their lives expressed more negative behavioural intentions towards family/friends with HIV. It was thus hypothesised that experienced stigma would be greater among respondents who reported an affiliation to a religious organisation.

Experiences of stigma will probably have some temporal dimension, as the number of people who know someone's HIV status or label that person HIV positive will most

likely increase over time. Experiences of any form of stigma were therefore likely to increase with time since HIV diagnosis. The number of years the respondent had been HIV positive was therefore included to control for this relationship.

As described in the previous chapter, Alonzo and Reynolds' (1995) theory about a 'stigma trajectory' suggests that PLWHA experience stigma differently at different stages of HIV and AIDS illness, with the latter stages of the disease being characterised by greater degrees of stigma as the physical manifestations of AIDS affect physical appearance and everyday activities. Fife and Wright (2000) provided empirical evidence for this, as individuals who reported poorer functional health status were associated with more experienced stigma. It was accordingly hypothesised that respondents who reported more experiences of ill health would report more experienced stigma than those with fewer experiences of ill health.

An illness index was created using two variables: (1) self-perceptions of health during the first six months of HAART; and (2) reported side-effects in the three months prior to the 2004/05 survey. Table 9.7 displays the questions used to assess self-perceptions of health at the start of HAART and then three and six months later. Coetzee (2005) showed that an increase in perceived health among PLWHA mirrored the trend in clinical markers, i.e. perceived health was in line with CD4 counts. Self-perceptions of health are thus taken as a fairly good proxy for actual health. The side-effects that the respondents reported are listed in Table 9.8. Some side-effects probably had relatively obscure symptoms (headaches, feeling sad or depressed, and having trouble remembering, for example) and others were probably detectable by relatively few people (sex-related problems, for example). It was hypothesised, however, that each side-effect could have contributed to general impressions formed by others about the health of the respondent and all were thus included in the index.

The illness index was created in the following way. First, responses to the three self-perceived health questions were summed to obtain an overall perception of health during the six-month period. This 'perception of health' index was then divided into 10 percentiles, with the top percentile coded as the poorest self-perceived health and the bottom percentile as the best perception of health. Second, a 'side-effects' variable was created by adding 1 for each additional side-effect reported. Again, the

side-effects variable was divided into 10 percentiles. Respondents reporting no side-effects scored 0, those that reported less than 10% of the side-effects scored 1, and so on until those that reported 90% or more side-effects scored 9. Finally, the illness index was formed by summing the perception of health index and the side-effects variable.[114]

Table 9.7. Self-perceptions of health at the start of HAART, three months after the start of HAART and six months after the started of HAART

If 10 is the healthiest you have been in your life, what score would you give for how you felt:					
When you had to start ARVs	10	Three months after the start of ARVs	10	Six months after the start of ARVs	10
	9		9		9
	8		8		8
	7		7		7
	6		6		6
	5		5		5
	4		4		4
	3		3		3
	2		2		2
	1		1		1

Table 9.8. Experience of side-effects in the three months prior to the 2004/05 survey

Have you experienced any of the following side-effects from the ARVs in the past three months?
Nausea/stomach problems
Headaches
Fevers, chills, sweats
Felt sad or depressed
Unwanted loss of weight
Problems with having sex such as loss of interest or lack of satisfaction?
Skin problems
Muscle-aches and joint pain
Pain, numbness or tingling in the hands and feet
Feeling dizzy and light-headed
Feeling very tired/exhausted
Trouble remembering

[114] Several other variables were created to test whether the models were robust with the inclusion of an illness variable of a different form. A variable was, for example, created by dividing the sample into 5 categories: very poor health, poor health, fair health, good health and very good health. In addition, calendar data was used to create a variable of the number of months since January 2001 during which the respondent reported suffering any serious illness or injury that stopped him or her from undertaking normal activities. Surprisingly, despite having started HAART during this period, the majority of respondents reported that serious illness never prevented them from undertaking their normal activities. This raised the question of how respondents interpreted 'serious illness' and 'normal activities'. Nonetheless, the regression results were robust (displaying the same sign and significance level (10%, 5% or 1%) of the coefficients) no matter which illness indicator was used.

As discussed earlier in the context of resource-based stigma, it is possible that experienced stigma might be linked to the negative impact that respondents' HIV-related illnesses may have had on the household – e.g. if care-givers had to take time off from work or school to look after the sick person. Qualitative research shows that PLWHA can be accused of wasting time and money, and as a result may have care and support withdrawn. This could arise within the household when caregivers themselves resent the burden of care. Alternatively the burden experienced by their families might make the respondents vulnerable to gossip and stigma from neighbours and others associated with their household. In Uganda, Muyinda *et al.* (1997) found that AIDS-related illnesses (especially mental illness) increased the burden of care and resulted in caregivers developing negative attitudes towards their HIV-positive family members.

The effect illness had on the respondents' household at the time they started HAART was measured with five questions (see Table 9.9). A similar set of questions was used to assess this effect on the respondents' households in the three months prior to the interview. The responses to all questions in both sets were summed to create an index assessing the combined effect that illness had had on the respondents' households at the time they started HAART and on the households in the three months prior to the interview.[115] It was hypothesised that the greater the negative effect illness had on households, the greater the resentment would have been towards the respondent, and hence the greater the stigma likely to be experienced.

[115] The responses to all questions in each set were also summed separately to create two separate indexes. Including either, or both, of these indexes in the regression models instead of the combined index made no difference to the sign or significance level of any of the coefficients in the models.

Table 9.9. Illness effect on the household at the time the respondent start HAART

We would like to ask you some questions about how you think that your illness affected your household. Think back to the time when you were very sick – i.e. the time when the doctor decided it was time to put you on ARVs

	Never	Hardly ever	Some-times	Often	Most of the time	All of the time
How often did anyone miss work to look after you or help you?	1	2	3	4	5	6
How often did a child have to stay home from school to look after you or help you?	1	2	3	4	5	6
How often did physical disabilities or health problems interfere with your ability to work, look for a job, study or work around the house?	1	2	3	4	5	6
How often did your illness interfere with your ability to look after children, play with them and help them with their homework?	1	2	3	4	5	6
How often were your own children, or other children in the household, sad or depressed because of your illness?	1	2	3	4	5	6

AIDS does not, however, only exacerbate poverty through the expenditure of resources (including money and others such as time) needed to care for PLWHA, but also because the economic contribution previously made by PLWHA often diminishes or ceases completely. This may result in a simultaneous double blow to the family, which could result in the PLWHA being blamed for its financial predicament. Castro and Farmer (2005) pointed out that as poor people almost invariably suffer violations of their social rights, poorer PLWHA generally suffer from greater HIV-related stigma. Household income was thus included to test whether economic context influenced experienced stigma. Household income was measured as the average of the household income when the respondent first started HAART and the household income at the time of the interview. Although a fairly blunt measure, this variable gave a general indication of the level of economic circumstances of respondents.[116]

Building on the analysis of household income, it was noted that household income *per se* tells us nothing about the relative contribution made by the respondent within the household. The models therefore included a variable that indicated the average percentage contribution made by each respondent to household income. The average was calculated from the percentage contribution in the household at the time the respondent started HAART and in the household at the time of the interview (and then the two percentages were summed and divided by two). It was hypothesised that

[116] It should be noted that the regression results (the sign and the significance level of the coefficients) remained unchanged whether household income was measured based solely on the household the respondents resided in when they began their HAART programme, or solely on the household at the time of the 2004/05 interview.

respondents from poorer households, and those that made smaller contributions to household income, would be more widely regarded as a burden on their families' financial resources and, as a consequence, more likely to experience stigma.

As argued in the previous chapters, social context is an important determinant of stigma. This is difficult to capture adequately in quantitative studies such as this. However one could introduce certain 'controls' that could capture some aspects of variation in the social context faced by PLWHA. The variable used here for this purpose was the clinic where the respondents received their antiretroviral treatment. Most HAART patients in Khayelitsha obtain their medication from three clinics (Site B, Site C and Michael M) – see Table 9.10. A broad array of factors, within the clinics or within the broader community the clinics serve, could create environments that differ greatly in terms of stigma. Factors include, *inter alia*: the structural design; location of the HIV/AIDS unit; attitudes of staff members; HAART programmes and related support infrastructure; and visibility of the clinic's access points to the surrounding community. The lack of detailed data about each clinic prevented the formation of hypotheses about the degree of stigma within each clinic. However, it made sense to control for clinic type when conducting the stigma analysis.

Table 9.10. Clinics where HAART was received

Clinic	respondents	percentage
Site B	103	42.6
Michael M	34	14.1
Site C	99	40.9
Other (Brooklyn Medical Clinic, KTC Day Hospital, Mitchells Plain, Tygerberg or Vinigar Pharmacy)	6	2.5
Total	242	100

The final explanatory variable – household disclosure of HIV-status – was included in a second, separate model. This variable measured the average percentage disclosure of HIV status to members in the household at the start of HAART and in the household at the time of the interview. Unfortunately no variable was available to provide an indication of general levels of HIV-disclosure (i.e. disclosure to people outside the household). Inclusion of this household disclosure variable was justified on the grounds that it is reasonable to assume that the fewer people who knew the respondent's HIV status, the less likely it was for the respondent to experience stigma.

However, the disclosure variable needed to be included in a separate model as it was also possible that the relationship between disclosure and stigma ran in the opposite direction: the extent of experienced stigma would determine the number of people the respondent was willing to disclose to. If levels of HIV-status disclosure in the household were determined by experiences of stigma (in addition to experienced stigma being determined by levels of disclosure) then the model would produce biased regression estimates as a result of endogeneity.[117] Adding the disclosure variable to a separate second model thus allows the effects of this variable on experienced stigma to be assessed without compromising the validity of the first model.

Regression results

Table 9.11 displays the two OLS regression models of potential determinants of experienced stigma. The first model (9.11.1) shows that controlling for age, gender, education, religious affiliation, household income, personal contribution to household income, and clinic, the experience of illness had a strong and positive relationship with experienced stigma. In other words it was apparent that health played a significant role in experienced stigma: respondents who had experienced poorer health experienced more stigma.

The only other factor found to influence experienced stigma was the clinic where respondents receive their HAART. Respondents that receive HAART from the Site C clinic reported significantly more experienced stigma than respondents from either Site B clinic or Michael M clinic.[118] This suggests that social context at a very localised level can affect experiences of stigma. The quantitative analysis could not

[117] Endogeneity is an econometrics problem that occurs when the independent variable is correlated with the error term in a regression model. This can occur as a result of two-way causality (i.e. when there is feedback between the dependent and any independent variables) and as a result of omitted variables.

[118] The regression models reported here indicate that respondents from Site C reported more experienced stigma than respondents from Site B. In addition, a post regression test indicated that respondents from Site C clinic also reported more stigma than respondents from Michael M clinic ($p < 0.001$). The Wald test for simple linear hypotheses about the parameters of the most recently fitted model was used to compare perceived stigma among individuals who received HAART from Site C clinic and those who received HAART from Michael M clinic.

assess whether such an effect was driven by characteristics of the clinic itself (intolerant/insensitive staff[119] or structural layout, for example) or by characteristics of the community around the clinic (individuals knowing little about HIV/AIDS, or a religious organisation giving certain messages, for example).

Table 9.11 Regression models for determinants of experienced stigma

Model	**9.11.1**	**9.11.2**
Regression	**OLS**	**OLS**
Gender (base = women)	0.204	0.399
	[0.643]	[0.682]
Age	0.007	0.013
	[0.039]	[0.041]
Years of education	-0.052	-0.038
	[0.112]	[0.116]
Religion (base = no affiliation)	0.658	0.975
	[0.586]	[0.601]
Years HIV-positive	0.132	0.167
	[0.125]	[0.142]
Illness index	**0.364*** **	**0.348*** **
	[0.067]	**[0.075]**
Average household income	0.170	0.288
	[0.192]	[0.242]
Percentage contribution to household income	-0.012	-0.008
	[0.008]	[0.009]
Illness effect on household	-0.192	-0.067
	[0.311]	[0.345]
Michael M clinic	-0.067	0.153
	[0.874]	[0.960]
Site C clinic	**2.226*** **	**2.495*** **
	[0.705]	**[0.785]**
Other clinic	0.835	1.163
	[1.225]	[1.361]
Percentage disclosure to household members	n/a	1.250
	n/a	[0.978]
Constant	4.618	1.563
	[2.869]	[3.264]
n	229	206
R-squared	0.31	0.34
Prob > F	0.000	0.000

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors n/a: Not applicable

[119] For example, a participant in qualitative research conducted in Khayelitsha described an instance when she attended the TB clinic when the HIV clinic was not open and the doctor told her in front of the waiting crowd that she could only be treated on the 'other' (HIV) side (Squire, 2007).

Further research is clearly necessary into the precise nature of the 'clinic effect'. However, personal interviews with two participants of the HAART survey who receive treatment at Site C clinic revealed interesting insights about the different clinics that are worth mentioning. When asked what they know about the Site B, Site C and Michael M clinics and the experiences of people who receive HAART at these clinics, both Florence and Andiswa[120] framed their responses around the structural layout of the clinics. Florence observed that Site C clinic is shaped as a large square with different consultation rooms all around the edge and one large central waiting area. HIV patients at Site C clinic are "experiencing problems as they need to hide away from other patients." Hiding away from other patients is almost impossible at Site C clinic as:

> HIV has their own reception. Everyone who goes there are for HIV/TB. They are sharing a building. The consultation rooms are in the middle of the clinic by the other rooms so everyone sees who passes by. People [HIV positive] wait in the centre [of the clinic] where everyone can see them. People from the township see them.

This description of Site C clinic contrasts markedly with that of both Site B and Michael M clinics. At Site B clinic the HIV consultation room was described as being an "enclosed area.... A separate building so it is easier for people to go without being seen." While at Michael M clinic, although the overall structural layout is similar to the layout at Site C clinic, the "HIV rooms are right at the end of the clinic and people don't always see who goes in there."

Andiswa described the experiences of PLWHA at Site C clinic in a similar manner. She observed that "Everyone knows you have HIV if you go to the HIV clinic so people sit far away in a different waiting area and when the Doctor calls them they will come running, so most of the people are still hiding." When asked whether other people in the community find out who goes into the HIV clinic her response was:

[120] Florence and Andiswa are pseudonyms to maintain the interviewees' anonymity. Florence is a 32 year old black woman living in Khayelitsha who has been on HAART since February 2001. Andiswa is a 31 year old black woman living in Khayelitsha who started HAART in January 2002.

> Yes, when they are gossiping they will tell each other whom they saw from the TB/HIV side and when they are talking about that they will say, for example: ndibone u [Andiswa] kwelacala, meaning that they saw [Andiswa] on that side, the HIV side.

These narratives suggest that as a result of the location of the HIV clinic within Site C clinic, the HIV status of PLWHA is highly 'visible' to other patients at the clinic. Furthermore, the HIV status of clients of the Site C HIV clinic may be involuntarily disclosed to others in their community as people who see them visiting the HIV clinic tell others about it. It is therefore possible that respondents from Site C clinic experienced more stigma than respondents from other clinics because more people in their communities knew they were HIV-positive.

The second model (9.11.2) showed the findings in Model 9.11.1 to be robust with the inclusion of the disclosure variable. The percentage of people in the household to whom the respondent had not disclosed their HIV-status was not significantly associated with stigma. This finding, along with two others from the model (discussed below), indicates that these PLWHA were living in supportive households. Similarly, the effect of illness on the household (i.e. the degree to which illness interfered with the normal activities of household members) showed no significance in any model. In other words, no evidence was found that resentment towards PLWHA leads to experienced stigma. Also, neither the average household income nor the average percentage contributed by the respondents to the household income was found to influence stigma. In other words, there was no evidence of resource-based stigma within the household.

9.3 Part II: Experiences of stigma when sick

This section assesses (1) stigma experienced when the respondents were sick, and (2) sources of gossip experienced by respondents when they were sick. The finding from the 2004/05 data, that experienced stigma was significantly associated with health, suggested that most stigma may have been experienced when the respondents were

extremely ill.[121] Based on what was learnt from the 2004/05 HAART survey, the 2006 HAART survey included several questions (see Table 9.12) to form a measure of experienced stigma during the period before respondents started HAART (i.e. when most of them were sick). These questions asked the frequency (never, hardly ever, sometimes or many times) of experienced stigma to assess the extent of stigma during this time. Furthermore, given that subtle manifestations of stigma appeared to be more common than more extreme manifestations (see Table 9.4), three questions were included to measure (1) how often people said unkind things to the respondent; (2) how often people gave the respondent "bad looks"[122]; and (3) how often people gossiped about the respondent.[123]

Table 9.12 displays the questions asked and the response frequencies. Two main points are drawn from the table. First, subtle manifestations of stigma (Questions 4, 5 and 7) were more common than other experiences, with gossip experienced by the greatest percentage (35%) of respondents. Second, although the majority of respondents (55%) reported no experience of stigma, a significant minority (32%) of respondents reported that they 'sometimes' or 'many times' experienced stigma in at least one of the manifestations listed in the table.

[121] Given that individuals living with HIV become eligible for HAART when their CD+ 4 counts decrease below 200, most of the respondents would have been ill just before they started HAART and remained ill until HAART had restored their health.

[122] Personal discussions with several people living with HIV indicated that they often felt other people gave them "bad looks" because of their HIV status.

[123] Given that gossip was initially conceptualised as things said about people (i.e. without the subjects of the gossip being aware of the conversation), it was initially thought that reports by people that they were gossiped about could only be a perception. However, subsequent discussion with several PLWHA informed that gossip is not always 'hidden' (i.e. people will often gossip about someone even when it is obvious that the subject of the gossip can hear). In addition, the person gossiped about is often told about the conversation by others who heard what was said. It is therefore possible for gossip to be personally experienced.

Table 9.12. Stigma experienced prior to HAART when respondents were sick

We would now like you to think back to when you **WERE SICK**, just before you started ARV treatment: Did you experience the following?	Never	Hardly ever	Sometimes	Many times	Total
1. How often did people avoid touching you because you have HIV?	86% (191)	4% (8)	7% (16)	4% (8)	101%
2. How often did people treat you badly because you have HIV?	84% (187)	8% (17)	5% (12)	3% (7)	100%
3. How often did people not eat the food you have prepared or share a meal with you because you have HIV?	89% (198)	5% (11)	4% (8)	3% (6)	101%
4. How often did people say unkind things to you because you have HIV?	73% (162)	7% (16)	15% (33)	5% (12)	100%
5. How often did people give you a bad look because you have HIV?	74% (164)	6% (14)	14% (31)	6% (13)	100%
6. How often were you denied a public service (police, education, etc.) because of your HIV status?	96% (214)	4% (8)	0% (0)	0% (0)	100%
7. How often did people gossip about you because you have HIV?	67% (149)	4% (10)	18% (41)	11% (24)	100%

Note: Numbers in parentheses indicate the number of respondents
Percentages do not always total 100% due to rounding effects

We now turn to an analysis of different sources of the gossip experienced by respondents when they were sick. Given that the analysis reported earlier in this chapter indicated low levels of stigma within the family, the aim here was to assess other potential sources of stigma. The design of this part of the study assumed (correctly) that gossip would be the experience of stigma reported by most respondents in the 2006 survey. The 75 respondents who reported any experience of gossip were thus subsequently asked if any of the people listed in Table 9.13 had gossiped about them, and who had gossiped about them the most.

Table 9.13 shows that relatively few respondents (16%) who reported being gossiped about identified a close family member as a source of gossip, and 11% reported a close family member as the primary source of gossip experienced. Although this indicates that not all respondents were fully supported by their close family, it again gives the impression of general support from the family. The main sources of gossip were reported to be the respondents' neighbours and people from their street: two thirds of the respondents reported gossip from their neighbours and 64% from people in the street. Furthermore, neighbours were the primary source of gossip for 30% of respondents, and people from the street for 34% of respondents. A significant minority of respondents (33%) also reported that a friend gossiped about them, while very little gossip was reported by colleagues at work, someone from church/place of worship, or from someone at the clinic.

These findings indicate that the respondent's immediate neighbourhood appear to be the single greatest source of gossip. This suggests that households are largely supportive, but the immediate 'community' is not.

Table 9.13. Sources of gossip experienced prior to HAART when the respondent was sick

Did any of the following people gossip about you when you **WERE SICK**?	N/A	Yes	No	Total	Circle the person who gossiped about you the most
1. A close family member	0% (0)	16% (12)	84% (63)	100%	11% (8)
2. Other relatives	0% (0)	29% (22)	71% (53)	100%	6% (4)
3. A friend	4% (3)	33% (25)	63% (47)	100%	14% (10)
4. Your partner (spouse/girlfriend/boyfriend)	12% (9)	11% (8)	77% (58)	100%	3% (2)
5. A neighbour	1% (1)	67% (50)	32% (24)	100%	30% (21)
6. Someone in your street	0% (0)	64% (48)	36% (27)	100%	34% (24)
7. A colleague at work	48% (36)	0% (0)	52% (39)	100%	0% (0)
8. Someone from Church/place of worship	23% (17)	3% (2)	75% (56)	101%	0% (0)
9. Someone at the clinic	0% (0)	3% (2)	97% (73)	100%	0% (0)
					98%

Note: Numbers in parentheses indicate the number of respondents
Percentages do not always total 100% due to rounding effects

9.4 Part III: Stigma experienced between 2004/05 and 2006

The first part of this chapter assessed the extent of experienced stigma at any time in the lives of the respondents prior to the 2004/05 survey. It did not, however, provide an indication of whether stigma remains relevant to the lives of these individuals. It is possible, for example, that the stigma reported by individuals was predominantly experienced when sick, but that after being on HAART for a few years stigma became a progressively less significant dimension of being HIV positive for them. To assess the continued relevance of stigma in the respondents' lives, the 2006 HAART survey measured stigma experienced between the 2004/05 survey and 2006 (i.e. when the respondents were on HAART and no longer AIDS-sick) using the same statements asked about experienced stigma in the 2004/05 survey. However, in 2006 each statement was prefaced with the phrase "In the past year...."

Table 9.14 displays responses to the statements in the 2004/05 survey (any stigma experienced before 2004/05), and responses in 2006 (experiences of stigma in the year preceding the 2006 survey). For ease of comparison the "strongly disagree" and "disagree" responses were combined; similarly the "strongly agree" answers were combined with "agree." The results point to three main findings of interest. First, consistent with previous findings, Statement 2 indicated that families were generally supportive during the time between the surveys. In 2006, almost half the respondents (46%) disagreed with the other statement probing experienced stigma within the family (i.e. Statement 3: "When HIV made me very sick my close family members were willing to take care of me.") Given that only 3% had disagreed with this statement in 2004/05, it seemed unlikely that these responses were indicating experienced stigma. Follow up discussions with several of the respondents revealed that they had not been sick during the last year and thus they were disagreeing to being in poor health, rather than reporting on experienced stigma. Consequently, this statement was excluded from the analysis of the 2006 data.

Second, similar percentages of respondents reported having lost a friend or being treated with less respect between the surveys compared to anytime prior to 2004/05. In addition, although percentages remained low, there was an increase in the percentage of respondents whose family and friends had treated them badly (Statement 2); who agreed that people felt uncomfortable in their presence (Statement 4); who thought people were concerned about catching HIV from the food they prepared or from touching them (Statement 5); and that many people avoided them because they are HIV positive (Statement 9). Third, by contrast with the increase in respondents who reported experienced stigma to the statements above, fewer respondents reported that they experienced subtle manifestations of stigma (Statements 6 and 8) between the surveys than anytime before the first survey.

Table 9.14. Experienced stigma between 2004/05 and 2006

	Pre 2004/05			Between 2004/05 & 2006		
To what extent do you agree or disagree with the following?	Disagree	Neither agree nor disagree	Agree	Disagree	Neither agree nor disagree	Agree
1. I have lost friends because I am HIV positive	85% (204)	5% (13)	10% (25)	88% (197)	3% (6)	9% (21)
2. Family members and friends have treated me badly because I am HIV positive	93% (226)	5% (12)	2% (4)	93% (208)	3% (6)	4% (10)
3. When HIV made me very sick my close family members were willing to take care of me	3% (6)	2% (4)	96% (230)	n/a	n/a	n/a
4. When people find out I am HIV positive, they feel uncomfortable in my presence	70% (169)	26% (65)	3% (8)	83% (186)	11% (25)	6% (13)
5. People are concerned that they could 'catch' HIV from the food I prepare or from touching me	80% (191)	15% (36)	5% (11)	86% (194)	6% (13)	8% (17)
6. People who have no reason to fear still worry that they will catch HIV from me	56% (130)	27% (66)	17% (41)	78% (175)	12% (27)	10% (22)
7. People treat me with less respect when they find out I am HIV positive	82% (198)	12% (29)	6% (15)	89% (199)	6% (14)	5% (11)
8. Because I am HIV positive, people say unkind things behind my back	33% (80)	31% (76)	36% (86)	66% (147)	19% (43)	15% (34)
9. Many people avoid me because I am HIV positive	73% (176)	23% (56)	4% (9)	83% (185)	10% (23)	7% (15)

Note: Numbers in parentheses indicate the number of respondents
Percentages do not always total 100% due to rounding effects

Experiences of stigma between 2004/05 and 2006 therefore appeared relatively uncommon as the majority of respondents reported no experienced stigma. However, as with experiences of stigma prior to 2004/05, a significant minority (25%) of respondents did report experiences of stigma between 2004/05 and 2006. This either suggested that a relatively small percentage of respondents remained in a stigmatising environment (i.e. they continue to report experiences of stigma), or that stigma was relevant for different people at different times. To assess which of these alternatives appeared most likely, a transition analysis was conducted. Table 9.15 shows that a significant proportion of individuals (45%) who reported experienced stigma prior to 2004/05 subsequently reported no stigma. This indicates that experienced stigma may not be an ongoing problem for many people. Conversely, the table also shows that 35% of respondents (i.e. 20 respondents) who reported experienced stigma between the 2004/05 and 2006 surveys had previously reported no experience of stigma. This suggests that new experiences of stigma may also occur as the social context for individuals changes, as, for example, when someone new is informed about the individual's HIV status.

However, the main point to be drawn from Table 9.15 is that the majority of respondents (65%, or 37 respondents out of the 57) who reported stigma between the 2004/05 and 2006 survey had also reported experienced stigma prior to the 2004/05 survey. This suggests that most of the stigma reported in this study was experienced by a small, but significant, minority (17%, or 37 respondents out of the 224) of the sample who live in a stigmatising environment, and have done so for a while. This finding was strengthened by the relatively high positive correlation (0.64, $p < 0.0001$) between stigma experienced between the surveys and stigma experienced when sick (see Part II of this chapter). In other words, respondents who experienced stigma when they were sick were also likely to experience ongoing stigmatisation. However, it is important to note, once again, that these questions say nothing about the intensity or severity of the stigma.

Table 9.15. Transition table for experienced stigma pre 2004/05 and between 2004/05 and 2006

		Experienced stigma between 2004/05 and 2006		
		No	Yes	Total
Experienced stigma pre 2004/05	No	55% (91)	35% (20)	111
	Yes	45% (76)	65% (37)	113
	Total	100% (167)	100% (57)	224

Note: Numbers in parentheses indicate the number of respondents

9.5 Discussion

This chapter provides the first quantitative analysis of experienced stigma amongst individuals on long-term HAART in a developing country context. It shows that the majority of respondents have experienced stigma at some stage of their lives. This is problematic as any experience of stigma could make people fearful of further HIV-status disclosure, thereby undermining efforts to combat the HIV/AIDS epidemic.

On the other hand, it appeared that most of the stigma reported was experienced by a small, but significant, minority of individuals who reported ongoing experiences of stigma.[124] This suggests that experienced stigma may be concentrated among

[124] This small group gains its significance when the proportion is generalised to the current population of PLWHA in South Africa. In this context, experiences of stigma among even 15% of respondents become present among roughly 900,000 people (15% of the roughly 6 million people in South Africa infected with HIV.

relatively few individuals who live in particularly stigmatising environments (as suggested by the fact that most gossip seemed to come from the immediate neighbourhood). This finding highlights another potential avenue for stigma reduction as it may be feasible, in some instances, to identify individuals living in such environments and intervene on a case-by-case basis.[125] Anyone intervening on this basis (as a counsellor) would need to identify the source of stigma and the reasons behind the stigmatising behaviours (whether they be informed by instrumental stigma, symbolic stigma, resource-based stigma or other factors).

Consistent with previous research from South Africa (Skhosana *et al.*, 2006), very few individuals reported experienced stigma from family members. This is also in line with findings from Chapter 5 and 6 that very few young individuals in Cape Town expressed negative behavioural intentions towards family members with HIV/AIDS. It thus appears that the perception among the general public that PLWHA are supported by their family (see Chapter 8) may well be an accurate reflection of reality. However, readers are cautioned that as the HAART sample is not necessarily representative, extrapolation should not be made to the general group of PLWHA. Furthermore, a few respondents did report stigma from family members (most notably that some had gossiped about them), which means that due consideration needs to be given to situational context. This need for caution is underscored by the findings of recent qualitative research in Khayelitsha and other nearby townships (Kahn, 2004; Mlobeli, 2007). Kahn describes a few cases of outright rejection from the family as a progression starting with initial acceptance, followed by social distancing and gossip, and culminating in being forced to leave home as the participant's family "didn't want to stay with people that have AIDS" (cited in Kahn, 2004, p. 14). Kahn also, however, cites cases of family acceptance, thus pointing to the complex and context-specific nature of stigma.

This chapter indicates that there may be a significant disconnect between relatively low levels of experienced stigma among PLWHA in Khayelitsha and the high degree of perceived stigma among the general population (see Chapter 8). Building upon the discussion in Chapter 8, where perceived stigmatisation of PLWHA among the

[125] This might, for example, be feasible for organisations working in small communities or through Home-Based Carers (see WHO (2002) for a description of Home-Based Care).

general public was greater than measured negative behavioural intentions toward PLWHA, we are now seeing these perceptions outweigh experiences of stigma as well. This corroborates Vanlandingham *et al.*'s 2005 finding which suggested that experiences of stigma are less common than they are perceived to be.

The analysis presented here showed that illness reported by respondents was a significant determinant of experienced stigma, i.e. people who reported more illness also reported more stigma. This, as noted earlier, is supported by qualitative research (Almeleh, 2006) in which the connection between HIV and visible illness is readily made, often resulting in stigmatisation by community members regardless of a person's status, as, for example in:

> Like they saw me walking on the streets, they will say, 'There is that bitch that has got AIDS.' So, all those things, they are not good to hear. Like before I know my status while I was very, very sick, so they were always saying that that lady has AIDS. But now that I am well, I am fine; they don't have those words again (cited in Almeleh, 2006, p. 9).

As mentioned in Chapter 2, when HIV status is so closely linked to illness, there is often a disbelief that people can be HIV positive if they look well, i.e. if they are visibly asymptomatic (Almeleh, 2006; Kahn, 2004; Mlobeli, 2007). Kahn, for example, cites an instance of this: "I told him twice [that] I am positive. But he didn't believe that; he said, 'you [don't] look sick!'" (Kahn, 2004, p. 25). It seems possible therefore, that people experience a greater degree of stigma when they are sick, because when they are healthy HIV is 'hidden'.

Finally, the analysis in this chapter shows that respondents who received HAART from the Site C clinic experienced significantly more stigma than respondents from other clinics. My supporting preliminary qualitative data suggests that this is perhaps because a Site C participant's HIV status can be surmised through clinic layout (i.e. if they are seen in specific clinic rooms) and via gossip his/her HIV-status becomes known in the community. This is consistent with other recent qualitative research in Khayelitsha:

> Other patients at the clinic can deduce that you are HIV-positive if you sit in certain sections of the clinic. This often leads to such patients telling others in the community that you are HIV-positive based on where they saw you (Mlobeli, 2007, p. 80).

Given that the majority of respondents reported the primary source of gossip to be neighbours and people on their street, i.e. members of their community, it seems possible that in this instance community-level factors, influenced by the structural design of the clinic, were shaping the stigma being experienced.[126]

However, as mentioned earlier there are also a number of other unobserved clinic characteristics that could create a stigmatising environment in, or around, Site C clinic. In addition, given that individuals choose which clinic they attend, another explanation (although less likely due to resource constraints) is that PLWHA who experience stigma travel to Site C clinic because it is perceived to be the most supportive and sensitive to issues around involuntary HIV-status disclosure. Further research is therefore needed to determine the underlying factors behind the relationship between stigma and clinics. Such research could lead to useful knowledge to inform stigma reduction policy.

[126] A qualitative study was, at the time of writing (June 2008) being designed to test this hypothesis. Results are expected in 2009.

Chapter 10. Perceived stigma among individuals on HAART

This chapter measures the nature and extent of perceived stigma (i.e perceptions of the nature and level of stigma in the social environment) among individuals on HAART. It provides examples of potential effects of perceived stigma; and explores potential determinants of perceived stigma (with a particular emphasis on the link between experienced stigma and perceived stigma). In so doing, it provides the first systematic research on perceived stigma among a sample of the growing cohort of people in developing countries who have had their health restored by HAART.

As mentioned previously, perceived stigma may result from personal experiences of stigma-related prejudice and discrimination, but is usually a product of social learning, which is exacerbated by reported incidents of stigmatising experiences (Scambler & Hopkins, 1986). Given the widespread perception in the general population that PLWHA are stigmatised (see Chapter 8), it is likely that PLWHA would have perceived there to be a high degree of stigma in the community around them before they were diagnosed HIV positive and would continue to hold such perceptions after diagnosis – even if they themselves experienced no stigma.

Chapter 9 showed that a significant disconnect exits between the comparatively low levels of stigma experienced by individuals and overall perceptions in the general population that PLWHA are stigmatised. It is also possible that a disconnect exists between actual personal experiences of stigma and perceptions among PLHWA of the extent to which other PLWHA are stigmatised. Qualitative research among HIV positive women in the United States has identified such a phenomenon, with pervasive reports of perceived stigma, even among women who reported no specific personal experiences of stigma (Sandelowski *et al.*, 2004). Subsequent quantitative research concurs with this finding. In the United States, 89% of young PLWHA reported perceived stigma but only 64% reported experiencing stigma (Swendeman *et al.*, 2006). A much wider gap was found in a study from South India with 97% of HIV-positive respondents reporting perceived stigma, but only 26% actually experiencing it (Thomas *et al.*, 2005).

This chapter explores whether perceived stigma among PLWHA is more consistent with their actual experiences or whether, as is the case among the general population, perceived stigma is common despite relatively few respondents reporting personal experiences of stigma. The second section highlights potential effects of perceived stigma. Perceived stigma among PLWHA can result in fear of being stigmatised, which can lead to depression and anxiety (Kang *et al.*, 2006). Perceived stigma can also discourage HIV status disclosure to friends and family (Derlega *et al.*, 2002) and to sexual partners (Skhosana *et al.*, 2006). Perceived stigma can thus be damaging to both individual quality of life and to efforts to combat the epidemic.

The case of Judge Edwin Cameron provides an example of someone who held back from disclosure and thereby denied himself much needed social support for fear of being stigmatised.[127] When poor health finally left him little choice but to disclose his status he, in fact, found that he received overwhelming support (Cameron, 2005). Similar fears of disclosure are expressed by a woman in Khayelitsha:

> I feel that I can't tell my parents about my status, and that my life will be shortened and that I will not be able to reach my goals because they will reject me (cited in Mlobeli, 2007, p. 63).

The final section in the chapter provides an initial exploration of factors that influence perceived stigma. Specifically, this analysis aims to assess the relationship between experienced stigma and perceived stigma. This will provide an indication of the degree to which perceived stigma is influenced by personal experiences of stigma.

10.1 The extent and nature of perceived stigma

The 2004/05 HAART Panel survey included four questions to measure perceived stigma. These questions (displayed in Table 10.1) are identical to the questions used to measure perceived stigma in the general population (Chapter 8). Three key findings emerge clearly from Table 10.1. First, the majority of respondents believed

[127] Edwin Cameron was a South African High Court Judge at the time when he published his story in his book: *Witness to AIDS*.

that PLWHA are supported by their family when they disclosure their HIV status. Given that few respondents reported any experience of stigma from family members (see Chapter 9), it thus appears that that these perceptions reflect the lived experienced of the PLWHA surveyed.

Second, most respondents believed that PLWHA are often treated unfairly or badly, and that people say unkind things about PLWHA. The number of respondents thinking other PLWHA experience such stigma was therefore significantly greater than the number of respondents that reported these experiences themselves. Unless the HAART Panel Study sample did comprise individuals living in significantly different social environments to PLWHA in general (which, as discussed earlier, is a possibility given the sampling technique), this suggests a disconnect between experienced stigma and perceived stigma. A similar conclusion is drawn from the responses to the last question in Table 10.1, which showed that 30% agreed that most people prefer to avoid PLWHA as much as possible. This contrasted strongly with the mere four percent of respondents who in the 2004/05 survey reported that many people avoided them because they were HIV positive (see Table 9.4).

Last, it is worth noting the significant number of respondents who answered "neither agree nor disagree" to these questions. This suggests that many of the respondents believed that some PLWHA experience stigma while others do not. This is especially the case with responses to Statement 4: 60% of respondents neither agreed nor disagreed that most people prefer to avoid PLWHA. Furthermore, it is worth noting that few respondents disagreed outright with these statements. This is important because any degree of perceived stigma may lead to fears of being stigmatised, and hence lead to behaviours that aim to reduce the risk of potentially stigmatising situations.

Table 10.1. Measures of perceived stigma among individuals on HAART

Please tell us how strongly you agree or disagree with the following statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know	Total
1. Most people with HIV are supported by their families when they disclose their HIV status	0% (0)	3% (6)	36% (86)	52% (126)	10% (24)	0% (0)	101%
2. People with HIV often get treated unfairly or badly by others	1% (2)	6% (13)	37% (90)	47% (112)	10% (25)	0% (0)	101%
3. People say unkind things about HIV positive people	0% (1)	6% (14)	28% (66)	56% (136)	11% (25)	0% (0)	101%
4. Most people prefer to avoid people with HIV as much as possible	1% (2)	9% (22)	60% (145)	24% (57)	6% (15)	1% (1)	101%

Note: Numbers in parentheses indicate the number of respondents
Percentages do not total 100% due to rounding effects

Table 10.2 displays a comparison between perceived stigma among the HAART sample and perceived stigma in the general population of Khayelitsha. For ease of comparison, "strongly disagree" answers are again combined with "disagree" answers, and "strongly agree" with "agree." Two main points of interest emerge from this comparison. First, compared to individuals on HAART, a greater percentage of adults in Khayelitsha perceived there to be general support from family members, but otherwise perceived that PLWHA are stigmatised. Second, a significantly greater percentage of the HAART Panel Study sample answered "neither agree nor disagree." The greater uncertainty in the sample of individuals on HAART may have resulted from this sample knowing more people who were living with HIV/AIDS (which is likely as many were recruited from HIV positive support groups) and hence knowing people who have had experiences different to their own.

Table 10.2. A comparison of perceived stigma among the HAART sample and among adults in Khayelitsha

	Individuals on HAART			**Adults in Khayelitsha**		
Please tell us how strongly you agree or disagree with the following statements	Disagree	Neither agree nor disagree	Agree	Disagree	Neither agree nor disagree	Agree
1. Most people with HIV are supported by their families when they disclose their HIV status	3% (6)	36% (86)	62% (150)	1% (8)	17% (96)	81% (450)
2. People with HIV often get treated unfairly or badly by others	6% (15)	37% (90)	57% (137)	14% (77)	18% (102)	68% (379)
3. People say unkind things about HIV positive people	6% (15)	28% (66)	67% (161)	11% (63)	17% (94)	72% (402)
4. Most people prefer to avoid people with HIV as much as possible	10% (24)	60% (145)	30% (72)	8% (43)	27% (149)	64% (349)

Note: Numbers in parentheses indicate the number of respondents
Percentages do not always total 100% due to rounding effects

10.2 Potential effects of perceived stigma

This section provides examples of the potential negative effect of perceived stigma by means of two analyses. First, the relationship between perceived stigma and both depression or anxiety, on the one hand, and self-efficacy or confidence, on the other, is explored. Second, data collected on reasons for non-disclosure were examined to infer potential effects of perceived stigma.

The first analysis used an index of perceived stigma created in a two-step process. First, the questions in Table 10.1 were coded from 0 (no perceived stigma) to 4 (maximum perceived stigma reported). Note that the scale for Question 1 was reversed, i.e. "strongly disagree" represented no perceived stigma. The single respondent who answered "don't know" to Question 4 was excluded from the analysis. Second, the perceived stigma index was then created by summing the scores to all four questions. The perceived stigma index thus comprised values ranging from 0 (no perceived stigma) to 16 (high perceived stigma for all question). Simple bi-variate regressions were then conducted to provide an indication of the relationship between perceived stigma and (1) depression/anxiety and (2) self-efficacy/confidence (see Chapter 9 for details about the construction of these indices).

Results showed a strongly significant, positive relationship between perceived stigma and depression/anxiety ($p < 0.0001$) and a strongly significant, negative relationship between perceived stigma and self-efficacy/confidence ($p < 0.0001$). This result is consistent with previous research findings (Berger *et al.*, 2001). Although the direction of causality between perceived stigma and these psychological outcomes is unclear, these findings provide an initial suggestion of the effect of perceived stigma. In addition, these findings provide evidence of construct validity of the perceived stigma index as the relationship between perceived stigma and these psychological variables was in the expected direction.

Now consider the questions displayed in Table 10.3 and Table 10.4 about the importance of various factors as reasons for non-disclosure of HIV status to others. When asked about the people they had not disclosed to, over half of the respondents

indicated that perceived stigma (Table 10.3: Question 6, i.e. belief that people would be less friendly) was an important factor in the decision not to disclose. When asked specifically about sexual partners they had not disclosed to, the perception that they might be rejected (Table 10.4: Question 1), lose financial support (Table 10.4: Question 2) and might be physically hurt (Table 10.4: Question 5) were also important factors for over half of respondents. This suggests that perceived stigma, in the rather broad sense of the term, was an issue in these cases. Note, however, that the answers to these questions do not tell us anything about the scale of the problem for PLWHA because we do not know how many people fall into the category of people or sexual partners they had decided not to disclose to.

Table 10.3. Reasons for non-disclosure of HIV-status to people in general

Think of the people you have **not** disclosed to. How important were the following reasons?	Not important	Slightly important	Important	Very important	Extremely important	Total
1. You thought they would tell other people without your permission	29% (71)	41% (100)	12% (28)	12% (29)	6% (14)	100%
2. You felt too ashamed to tell them	40% (97)	17% (42)	31% (75)	11% (25)	1% (3)	101%
3. You didn't know how to talk to them about it	33% (80)	13% (31)	42% (101)	11% (26)	2% (4)	101%
4. You thought they would not understand	25% (61)	15% (36)	43% (102)	14% (33)	3% (8)	100%
5. You thought they would worry too much about you	26% (63)	33% (80)	24% (57)	12% (29)	5% (13)	100%
6. You thought they would stop being friendly	44% (110)	21% (49)	25% (61)	7% (18)	3% (4)	100%

Note: Numbers in parentheses indicate the number of respondents
Percentages do not always total 100% due to rounding effects

Table 10.4. Reasons for non-disclosure of HIV-status to sexual partners

Think of sexual partners you have **not** disclosed to. How important were the following reasons?	Not important	Slightly important	Important	Very important	Very,very important	Total
1. You thought they would reject you	41% (76)	23% (42)	15% (29)	15% (29)	5% (9)	99%
2. You thought they would stop providing financial support	45% (81)	24% (45)	16% (30)	12% (22)	3% (6)	100%
3. You did not trust them not to tell other people	49% (90)	25% (47)	14% (26)	9% (17)	3% (5)	100%
4. You thought they would not believe you	35% (64)	13% (24)	38% (69)	13% (24)	2% (3)	101%
5. You thought they might get angry and hurt you	40% (73)	17% (31)	22% (42)	10% (19)	10% (19)	99%
6. They were not important enough in your life	47% (87)	26% (48)	22% (40)	4% (8)	1% (1)	100%

Note: Numbers in parentheses indicate the number of respondents
Percentages do not always total 100% due to rounding effects

In addition to highlighting the potential effect of perceived stigma on disclosure decisions, Table 10.3 indicated another aspect of stigma that needs to be considered. The fact that 60% of respondents cited feelings of shame as being an important, at least to some degree, reason for non-disclosure (Table 10.3: Question 2) suggested that internalised stigma was experienced by this sample of PLWHA. Chapter 11 will provide a more detailed analysis of internalised stigma.

10.3 Determinants of perceived stigma

The 2004/05 HAART survey was not designed specifically to assess factors that determine perceived stigma. It was not, therefore, possible to develop fully specified models. Consequently many factors that are likely to influence perceived stigma were not included in the analysis, which must therefore be read as an initial exploration of potential determinants of perceived stigma. The primary aim of this analysis was to assess whether experienced stigma was significantly related to perceived stigma. A significant positive relationship would indicate that even if individually experienced stigma was not common in people's lives, any experience of stigma could contribute to perceived stigma and its attendant problems. A secondary objective of this analysis was to assess whether perceived stigma varied according to the clinic where the respondents received their HAART. A significant clinic effect would re-emphasise the need for further research to assess the factors affecting stigma at the clinic level flagged in Chapter 9.

An OLS regression model was used, as the dependent variable (the perceived stigma index) described in the previous section comprised 16 values.[128] The independent (explanatory) variables used in the regression to explore potential determinants of perceived stigma are displayed in Table 10.5.

[128] Sensitivity analysis using ordered probit regression models showed the level of significance of the coefficients to be robust across technique. The results from this analysis are presented in Appendix G.

Table 10.5. Variables used to assess potential determinants of perceived stigma

Perceived stigma
Experienced stigma
Clinic where HAART was received
Gender
Education
Religious affiliation
Years HIV positive (time between diagnosis and interview dates)

Personal experience of stigma was probably the most obvious factor shaping whether PLWHA believe that they live in a stigmatising environment or not. Individuals who have experienced stigma are obviously more likely to view their social environment as stigmatising. The variable created in Chapter 9 to measure experienced stigma at any time before the 2004/05 HAART survey was therefore included in the model.

However, initial analysis of the relationship between experienced stigma and perceived stigma showed that 20% of respondents who expressed perceived stigma had reported no experienced stigma. This clearly showed that experienced stigma was far from being the only factor shaping perceptions about the stigmatising environment. It was thus necessary to control for other factors that could reasonably be hypothesised to influence the perceptions that PLWHA have of their social environment. One set of potential explanatory factors relates to the social environment itself. Including the variables for clinic was an obvious potential proxy for different localised social environments within Khayelitsha. As mentioned earlier, inclusion of the clinic variables would inform us as to whether individuals who received HAART from Site C (who were predicted to experience more stigma than anyone else) also reported more perceived stigma than individuals from other clinics.

Education might also be a proxy for social environment, if better educated respondents tended to mix with similarly educated people. However, given the contradictory relationships found between stigma and levels of education in Chapter 5 and 6 the nature of this relationship was on open question.[129]

[129] In Chapter 5, individuals with more years of completed education were associated with lower levels of instrumental stigma. By contrast, Chapter 6 found that individuals with more years of completed education were associated with more negative behavioural intentions towards PLWHA who were family/friends, and higher levels of symbolic stigma.

As discussed earlier in the context of experienced stigma, another variable that could proxy for the social environment is religious affiliation. If we assume that people who declare a religious affiliation live in a social environment populated by similarly religious individuals, then, given the negative moral connotations associated with HIV/AIDS (Aggleton & Chase, 2001; Deacon & Simbayi, 2006; Ogden & Nyblade, 2005), it follows that people affiliated to a religious organisation are more likely to perceive that they live in a stigmatising environment than people not affiliated to a religious organisation.

Another set of potential explanatory factors relates to the experiences of other PLWHA. Given previous research findings that women are more likely to be stigmatised than men (France, 2004; Leclerc-Madlala, 2001, 2002), and given that a greater percentage of women attend support groups[130] (where experiences are often shared), it seems reasonable to hypothesise that women are more likely to see themselves as living in a stigmatised environment than men. Similar hypotheses tested true in research conducted in the United States (Swendeman *et al.*, 2006).

Finally, it also seems likely that individuals who had been living longer with HIV would have encountered more stories about other people's experiences of stigma and discrimination, and thus would be more likely to perceive themselves as living in a stigmatising environment than people with a more recent HIV diagnosis.

10.3.1 Regression results

Table 10.6 displays the regression results for the exploration of determinants of perceived stigma among PLWHA. Results indicate that, as expected, individuals who reported more experienced stigma were predicted to express greater levels of perceived stigma. No significant difference was found in perceived stigma expressed by individuals who received HAART from Site C clinic and those who received HAART from Site B (the comparative group in the model displayed). However, a post-regression test revealed that compared to individuals who received HAART from

[130] Ninety-five percent of the women in the HAART Panel Study compared to 81% of men respondents had, at some stage, attended a support group.

Michael M clinic, those who received HAART from Site C clinic expressed significantly more perceived stigma ($p < 0.03$).[131] This indicates that in addition to reporting more experienced stigma, and after controlling for experienced stigma, individuals from Site C also perceived greater levels of stigma compared to individuals from Michael M clinic.

Religious affiliation was the only other significant predictor of perceived stigma. Respondents who reported an affiliation to a religious organisation were more likely to believe they were living in a stigmatising environment.

Table 10.6. Ordinary least squares regression model for perceived stigma

Model	**10.6.1**
Regression	**OLS**
Experienced stigma	**0.121*** [0.022]**
Michael M clinic (base = Site B)	0.400 [0.320]
Site C clinic (base = Site B)	-0.256 [0.248]
Other clinic (base = Site B)	0.029 [0.343]
Gender (base = women)	-0.073 [0.323]
Education	-0.015 [0.034]
Religious affiliation (base = no religious affiliation)	**0.645** [0.293]**
Years HIV positive	0.024 [0.038]
Constant	**7.23*** [0.462]**
n	225
R-squared	0.16
Prob > F	0.000

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
n/a: Not applicable

[131] The Wald test for simple linear hypotheses about the parameters of the most recently fitted model was used to compare perceived stigma among individuals who received HAART from Site C clinic and those who received HAART from Michael M clinic.

10.4 Discussion

This chapter provides the first quantitative analysis of perceived stigma amongst HAART patients in a developing country context. Although relatively few respondents reported that they had experienced a significant amount of stigma (see chapter 9), the majority reported perceived stigma (i.e. believed they lived in a stigmatising environment). This is consistent with the disjuncture between experienced and perceived stigma found in other contexts (e.g. Sandelowski *et al.*, 2004; Swendeman *et al.*, 2006; Thomas *et al.*, 2005).

As suggested by Scambler & Hopkins (1986), with high overall levels of perceived stigma in the general community (see Chapter 8) this disjuncture may be a product of social learning. In other words, the HIV-positive individuals in this study would probably have perceived HIV-related stigma in the social environment before they were diagnosed HIV positive. Once diagnosed, any experience of stigma, no matter how infrequent, and any stories heard about stigma experienced by others were likely to perpetuate the idea that PLWHA face a stigmatising environment.

The construct of perceived stigma therefore highlights the important role played by the social climate in defining the behavioural options available to individuals with a stigmatised disease. This is particularly the case as perceived stigma can impede HIV prevention, treatment and care efforts, even in a context in which there are, in fact, very low levels of HIV-related discrimination and stigmatisation. Although the survey on which the analysis presented in this chapter was based was not designed specifically to measure the impact of perceived stigma, it has nevertheless enabled the analysis to identify examples of such stigma that could have negative consequences for individuals and thereby impede efforts to combat the epidemic. One such example would be the extent to which perceived stigma was identified to have discouraged HIV status disclosure.

The identification of relatively high levels of perceived stigma in both the general population and among PLWHA is, therefore, an important finding of this study. It provides evidence for how stigma can be found to have such a negative impact despite there being evidence of relatively few expressions of negative behavioural intentions

towards PLWHA, and far less personal experience of stigma on the part of PLWHA, than is commonly perceived. Nevertheless, experienced stigma has a significant influence on perceived stigma, so we cannot conclude that perceived stigma is easily addressed simply by educating people about the lower levels of experienced stigma than commonly perceived in the social environment.

The analysis in this chapter suggests two avenues for future research that could yield important information for the design of interventions to reduce perceived stigma. First, it is important to understand the factors that determined the difference in experienced and perceived stigma between different communities, even those in relatively close geographical proximity to one another. More specifically, in the context of Khayelitsha, further research is needed to explain why Site C appears to be, and is perceived as, a significantly more stigmatising environment than other locations. Second, it would also be useful to an overall understanding of stigma and stigmatising processes for research to be undertaken into the underlying reasons why individuals affiliated to a religious organisation should have expressed significantly more perceived stigma than those with no such affiliation.

Chapter 11. Internalised stigma among individuals on HAART

This final empirical chapter measures the extent and nature of internalised stigma, and its potential determinants. Internalised stigma (self-devaluation based on HIV status) has been shown to manifest in PLWHA and to have a significant impact on their lives (Berger *et al*., 2001). A recent study in Cape Town found internalised stigma to be prevalent amongst the sample of 1,063 PLWHA (Simbayi *et al.*, 2007b). In Simbayi's study, which is the first to investigate the effects of internalised stigma in South Africa, internalised sigma was shown to be a significant predictor of cognitive-affective depression. In addition, internalised stigma has been associated with fear of HIV-status disclosure (Mak *et al.*, 2007 (Hong Kong)). A similar association was revealed in Chapter 10 with shame reported as an important reason for non-disclosure of HIV status. This was a manifestation of internalised stigma within the HAART Panel Study sample and pointed to the potential negative impact that internalised stigma might have on HIV prevention, treatment and care.

This chapter completes the comprehensive measurement of stigma in the dissertation. It measures the extent and nature of internalised stigma among individuals on HAART and explores whether internalised stigma remains an issue for individuals who have been on HAART for a relatively long period (at least 3 years). In addition this chapter provides an assessment of the potential determinants of internalised stigma. In particular, it explores the relationships between internalised stigma and both experienced stigma and perceived stigma.

11.1 Measures of internalised stigma

The analysis presented below uses data from the second wave of the HAART Panel Study conducted in 2006 (see Chapter 9 for full details of the survey sample). Internalised stigma was measured by means of responses to seven statements, measured along a 4-point Likert Scale (a "don't know" response was recorded where none of these options was applicable). Table 11.1 shows the response frequencies for

these statements. For each statement, except Statement 7, at least 15% of respondents reported internalised stigma. That is, a significant minority of respondents reported feelings of shame, guilt, being unclean, being 'a bad person' or being 'not as good as others'. Shame was the most frequently articulated aspect of internalised stigma measured, with 50% of respondents disagreeing with the statement that they never feel ashamed of having HIV.

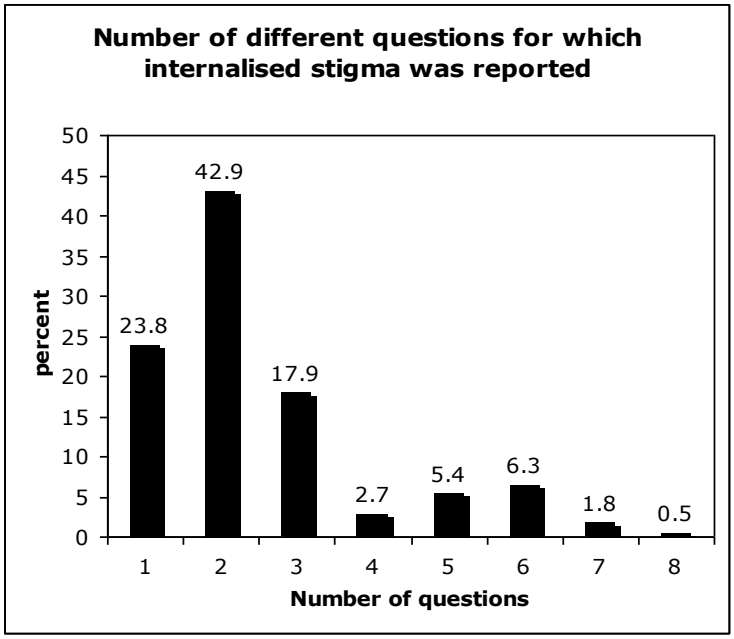
Table 11.1. Measures of internalised stigma among individuals on HAART

To what extent do you agree or disagree with the following?	Strongly disagree	Disagree	Agree	Strongly agree	Don't know	Total
1. I never feel ashamed of having HIV	17% (37)	33% (75)	34% (76)	15% (34)	1% (2)	100%
2. HIV makes me feel like a bad person	45% (100)	38% (84)	15% (34)	2% (5)	0% (1)	100%
3. I feel I am just as good as others who are HIV negative	3% (7)	12% (27)	25% (57)	59% (132)	0% (1)	99%
4. Having HIV makes me feel unclean	41% (92)	36% (80)	17% (37)	6% (14)	0% (1)	100%
5. People's attitudes about HIV make me feel worse about myself	29% (66)	54% (121)	11% (25)	5% (12)	0% (0)	99%
6. I feel guilty because I have HIV	30% (68)	48% (108)	18% (40)	4% (8)	0% (0)	100%
7. HIV/AIDS is punishment for bad behaviour	41% (91)	45% (100)	8% (18)	2% (4)	5% (11)	101%

Note: Numbers in parentheses indicate the number of respondents
Percentages do not always total 100% due to rounding effects

Figure 11.1 shows a histogram of the number of different statements for which each respondent reported internalised stigma. Conclusive statements about the impact of internalised stigma cannot be made from this information as the severity and nature of stigma may vary dramatically from item to item. Nevertheless, it is noteworthy that 87% of respondents reported some internalised stigma, and furthermore that about 14% of respondents reported internalised stigma on the majority of items. Consistent with research by Lee *et al.* (2002), it was found that PLWHA experience varying degrees of internalised stigma, including some who report none at all.

Figure 11.1. Number of internalised stigma dimensions reported per respondent



11.2 Determinants of internalised stigma

Research conducted to examine an attribution model of internalised stigma (that is, whether self-perceived blame in contracting HIV determines levels of internalised stigma) found that this model of stigma was not supported (Mak *et al.*, 2007).[132] The study concluded that other psychosocial and contextual factors might be more pivotal in affecting internalised stigma among PLWHA. This chapter uses OLS regression techniques to explore some of the factors that might influence internalised stigma.[133]

The seven questions listed in Table 11.1 were coded from 0 (no internalised stigma) to 4 (highest degree of internalised stigma) and then summed into an index to create the dependant variable for the analysis: internalised stigma. Explanatory factor analysis[134] to test construct validity indicated that the questions were indeed probing

[132] Mak *et al.* (2007) measured self-perceived blame with responses to the following statement: "It is my own fault that I am infected with the disease." They hypothesised that the greater degree of responsibility personally felt by PLWHA the greater would be the level of internalised stigma they reported.

[133] Sensitivity analysis using ordered probit regression models showed the significance of the coefficients to be robust across technique. The results for the sensitivity analysis are presented in Appendix H.

[134] The factor analysis used Varimax rotation and Eigen values greater than one.

one underlying dimension and the index displayed internal reliability (α=0.68). In addition, the construct validity of the internalised stigma index was tested by its correlation with a depression/anxiety index – internalised stigma scores should be positively correlated with depression/anxiety (Berger *et al.*, 2001; Mak *et al.*, 2007; Simbayi *et al.*, 2007b).[135] Construct validity was supported by the expected positive correlation (0.28) between internalised stigma and depression/anxiety.

Table 11.2 displays the independent (explanatory) variables used as potential determinants of internalised stigma. Link and Phelan (2006, p. 528) suggest that "an insidious form of discrimination occurs when stigmatised individuals realise that a negative label has been applied to them and that other people are likely to view them as less trustworthy and intelligent." Internalised stigma thus develops when PLWHA, being aware that PLWHA are stigmatised (perceived stigma) or having personally experienced discrimination based on their HIV status (experienced stigma), endorse and internalise these beliefs, feelings and actions (Kang *et al.*, 2005; Mak *et al.*, 2007). Accordingly, it was hypothesised that respondents who had experienced more stigma and those with higher levels of perceived stigma would be more likely to manifest internalised stigma.

Table 11.2. Potential determinants of internalised stigma

Internalised stigma
Experienced stigma (from HAART 2004/05 & HAART 2006)
Perceived stigma (from HAART 2004/05)
Gender
Age
Education
Religious affiliation
Years HIV positive (time between diagnosis and interview dates)
HIV/HAART knowledge
Health at time of interview (self-perceptions of health)
Experience of side-effects
Illness effect on household
Household income at the time of the interview
Personal income at the time of interview
Clinic where HAART was received

[135] As described in Chapter 9, the depression/anxiety index was created with five questions probing how often (never, hardly ever, sometimes, often, or all the time) the respondent experienced various emotions in the past year. These questions were: (1) "Felt that problems are piling up so high that you cannot overcome them?"; (2) "Felt that you cannot stop feeling very sad and depressed – even with help from your friends or family?"; (3) "Felt lonely?"; (4) "Felt nervous or stressed?"; and (5) "Been so worried or anxious that you have felt tired, worn out or exhausted?" All five questions were summed to create an index with a possible range from 0 ('never' on all questions) to 25 ('all of the time' for all questions). Factor analysis indicated construct validity and the index showed internal reliability (α = 0.80).

An experienced stigma index was created by summing two of the experienced stigma indices used in Chapter 9: experienced stigma prior to the 2004/05 HAART survey and experienced stigma between the 2004/05 and 2006 HAART surveys. In other words, the experienced stigma index used here accounted for experiences (as measured by the survey questions in this study) at anytime prior to the 2006 HAART survey. The perceived stigma index created in Chapter 10 was included in the model. It is noted that perceived stigma was measured in the HAART 2004/05 survey (i.e. about one year before internalised stigma was measured). The reader must therefore be aware that any significant changes in perceived stigma that might have occurred during that year may bias the results.

The inclusion of experienced stigma and perceived stigma in the regression models predicting internalised stigma seemed appropriate, given that this dissertation conceptualises, and measures, these constructs as three distinct dimensions of stigma. Simbayi *et al.* (2007b, p. 1827), on the other hand, indicate that experienced stigma and internalised stigma may equate to basically the same thing: "AIDS discrimination experiences were correlated with internalised stigma scores...and was [*sic*] not included in the regression model to avoid conceptual and statistical redundancy." In addition, some authors suggest that internalised stigma is likely to make an individual more sensitive to both actual and anticipated (perceived) stigmatisation and discrimination (Herek, 2002; Lee *et al*., 2002). Internalised stigma might also therefore be a determinant both of reported experienced stigma and of perceived stigma (i.e. the causal relationship might be in the opposite direction to the model proposed: rather than feeling ashamed of their HIV-positive status as a response to negative external attitudes – real or perceived – towards PLWHA, their feelings of shame about their status result in PLWHA being hyper-sensitive and perceiving stigmatising attitudes and behaviours towards them where they do not, in fact exist). Given these counter arguments to using experienced stigma and perceived stigma as determinants of internalised stigma, an additional model will be shown that evaluates the effect of excluding these factors.

Previous research conducted in Cape Town found that men were more likely to report internalised stigma than women (Simbayi *et al.*, 2007b). This finding was inconsistent with studies conducted in the United States (Holmes & Shea; 1997;

Swendeman *et al.*, 2006). Although no clear hypothesis could thus be drawn from previous research, the significant gender differences revealed in these research findings pointed to the importance of including gender as a control variable. Holmes and Shea (1997) also found that younger and less educated individuals manifested more internalised stigma. Similar hypotheses were drawn in this analysis.

The potential influence that moralistic explanations of HIV infection have on stigma has already been discussed. It was hypothesised that those affiliated to a religious organisation would have a greater awareness of the moral connotations associated with HIV/AIDS and the moral discourse surrounding HIV/AIDS. They would therefore feel more ashamed and 'bad' and internalise stigma to a greater extent.

It is clearly possible that internalised stigma might be influenced by the amount of time people live with HIV. Lee *et al.* (2002) found that the more recent the diagnosis the greater the extent of internalised stigma. This finding was repeated in Cape Town with internalised stigma showing a significant negative correlation with the number of years since an HIV positive diagnosis (Simbayi *et al.*, 2007b). This could indicate that people with a more recent diagnosis have had less time to come to terms with their diagnosis, and consequently still feel ashamed and guilty about their HIV-status. A similar hypothesis was drawn for this analysis.

In addition, poor knowledge of HIV/AIDS has been associated with increased internalised stigma (Lee *et al.*, 2002). This finding was linked to worries about spreading the disease and affecting friends and families. It was hypothesised that individuals who showed poorer knowledge about HIV/AIDS would be more uncertain about the disease (particularly about modes of transmission) and therefore internalise greater degrees of stigma. The HAART Panel Study respondents were asked a module of questions about HIV and HAART.[136] Responses to these questions were summed to create an index of HIV/HAART knowledge.

[136] Questions in 2006 HAART survey designed to measure knowledge about HIV and HAART treatment asked respondents to indicate to what extent they thought the following statements were true or false: (1) "People receiving ARV treatment can still transmit HIV to other people through unprotected sex"; (2) "Unprotected sex with withdrawal before ejaculation protects against HIV"; (3) "One should continue to take ARV treatment after gaining weight"; (4) "It is correct to stop ARV treatment when one no longer suffers from

Lee *et al.* (2002) also found that internalised stigma was influenced by health status. It was hypothesised that the appearance of illness might increase internalised stigma as a result of self-blame and feelings of shame for contracting a preventable disease. Two variables were included to test this hypothesis: self-perceptions of health at the time of the interview[137] and experiences of side-effects in the three months prior to the interview.[138]

As suggested in Chapter 9, illness experienced by the respondents may have interfered, to varying degrees, with the normal activities of household members who needed to take time off work, school or other activities to provide care for the respondent. Although these effects of illness on the household were not found to influence experienced stigma, which suggests that PLWHA were not stigmatised because others thought of them as a burden, this might nevertheless have resulted in feelings of shame and self-blame being experienced by the respondents, who viewed themselves as a burden on the household. Following the methods outlined in Chapter 9, a variable was formed to reflect the combined effect of illness on the households the respondents resided in at the time they started HAART and at the time of the 2004/05 HAART survey. Again the reader must be cognisant that this variable used data collected about a year before the measurement of internalised stigma, which might add bias.

Following the theory of resource-based stigma, PLWHA may feel ashamed and blame themselves for the financial predicament of their family or household. This was suggested in a study conducted by Holmes and Shea (1997), which found greater manifestations of internalised stigma among individuals with lower income.

opportunistic infections"; (5) "ARV medication completely removes HIV from my body"; (6) "After a couple of years, one can stop taking ARV medication"; and (7) "When both partners are HIV positive there is no need to use a condom."

[137] Self-perceptions of health were measured on a 10 point Likert Scale with the question: "If 10 is the healthiest you have been in your life, what score would you give for how you feel now?"

[138] As in Chapter 9, the respondents were asked whether they had experienced any of the following side-effects from the ARVs in the past three months: (1) nausea/stomach problems; (2) headaches; (3) fevers, chills, sweats; (4) felt sad or depressed; (5) unwanted loss of weight; (6) problems with having sex such as loss of interest or lack of satisfaction; (7) skin problems; (8) muscle-aches and joint pain; (9) pain, numbness or tingling in the hands and feet; (10) feeling dizzy and light-headed; (11) feeling very tired/exhausted; and (12) trouble remembering.

Household income and personal income were thus included to test whether economic context influences the manifestation of internalised stigma.[139] It was hypothesised that respondents from poorer households and with lower personal income would feel more of a burden on their families' financial resources, and hence would manifest more internalised stigma.

Last, Chapters 9 and 10 indicated that experienced stigma and perceived stigma varied according to the clinic where respondents received their HAART. This indicated that stigma can vary within different communities, even within a relatively small geographical area. As the mechanism behind these differences is not known, it seemed intuitive to control for potential 'clinic effects' which might also influence internalised stigma.

11.2.1 Regression results

Table 11.3 displays the OLS regression results. Model 11.3.1 includes experienced stigma and perceived stigma as potential determinants of internalised stigma, while these variables are excluded in model 11.3.2. Results in the first model show that, as expected, after controlling for the other variables in the model, respondents who had reported more experienced stigma were predicted to manifest internalised stigma to a greater degree than respondents who reported fewer experiences of stigma. Perceived stigma was not, however, significantly associated with internalised stigma. By contrast with the only other research on internalised stigma undertaken in connection with HIV/AIDS in Cape Town (Simbayi *et al.*, 2007b), men were associated with less internalised stigma than women. Consistent with Lee *et al.* (2002), internalised stigma appeared to be influenced by health status, as respondents who had experienced more side-effects in the three months prior to the 2006 HAART survey were predicted to manifest more internalised stigma.[140]

[139] The natural log of both the household income and personal income was taken to reduce the effect of outliers.

[140] Self-perceived health at the time of the 2006 HAART interview was not significantly associated with internalised stigma. This was not, however, unexpected as the majority of respondents reported perfect health; leaving little variation in the health status based on this variable.

The last significant result was a clinic effect. Respondents who received HAART from Michael M clinic or 'other clinics' were associated with less internalised stigma than respondents from Site B clinic.[141] A post regression test showed that respondents who received their HAART from Site C clinic were significantly ($p < 0.026$) more likely to report internalised stigma than respondents from Michael M clinic.[142] This is similar to the results of predictors of experienced stigma (Chapter 9) and perceived stigma (Chapter 10). It appears therefore that respondents who received their HAART from Site C clinic were more likely to report more experienced stigma, perceived stigma and internalised stigma than respondents from Michael M clinic.

The second model (11.3.2) shows that the exclusion of experienced stigma and perceived stigma resulted in a relatively small decrease in the amount of variance explained by the model (the R-squared dropped from 0.28 in the first model to 0.23 in the second). This indicates that although experienced stigma had some influence on internalised stigma it was not the most important factor influencing internalised stigma. Gender differences were not significant in the second model. On the other hand, the effect of education became significant: respondents who reported more years of completed education were associated with lower levels of internalised stigma. The predicted influence of side-effects being experienced became more significant thereby indicating the importance of health status as a predictor of internalised stigma. Last, consistent with the first model, compared to respondents from Site B clinic those from 'other clinics' were associated with less internalised stigma; whereas compared to respondents from Michael M clinic respondents from Site C clinic showed significantly (post regression test: $p < 0.026$) more internalised stigma.

[141] 'Other clinics' (n = 10) include Brooklyn Medical Clinic, KTC Day Hospital, Mitchell's Plain, Tygerberg and Vinigar Pharmacy.

[142] The Wald test for simple linear hypotheses about the parameters of the most recently fitted model was used to compare perceived stigma among individuals who received HAART from Site C clinic and those who received HAART from Michael M clinic.

Table 11.3. OLS regression models of determinants of internalised stigma

Model	11.3.1	11.3.2
Regression	**OLS**	**OLS**
Experienced stigma	**0.102*** [0.032]**	n/a n/a
Perceived stigma	0.007 [0.039]	n/a n/a
Gender (base = women)	**-0.940* [0.484]**	-0.766 [0.486]
Age	0.031 [0.033]	0.014 [0.072]
Years of education	-0.116 [0.079]	**-0.146** [0.072]**
Religion (base = no affiliation)	0.343 [0.456]	0.516 [0.425]
Years HIV-positive	-0.001 [0.081]	0.012 [0.080]
HIV/HAART knowledge	-0.464 [0.287]	-0.489 [0.298]
Experience of side-effects	**0.163* [0.088]**	**0.237*** [0.078]**
Self-perceived health	-0.304 [0.250]	-0.251 [0.241]
Illness effect on household	-0.031 [0.054]	0.002 [0.050]
Household income (natural log form)	-0.030 [0.149]	-0.054 [0.241]
Personal income (natural log form)	-0.105 [0.109]	-0.095 [0.099]
Michael M clinic	**-1.132* [0.594]**	-1.028 [0.644]
Site C clinic	0.220 [0.491]	0.398 [0.456]
Other clinic	**-2.028** [0.949]**	**-2.222** [0.883]**
Constant	**11.801*** [4.285]**	**12.654*** [4.014]**
n	181	197
R-squared	0.28	0.23
Prob > F	0.000	0.000

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors
n/a: Not applicable

11.3 Discussion

This chapter shows that internalised stigma is a problem for many PLWHA, even after they have been on HAART for an extended period and that internalised stigma is correlated with personal experience of stigma. However, experienced stigma was only one of many factors influencing internalised stigma. This indicates that minimising experiences of HIV-related discrimination will not in and of itself alleviate internalised stigma. These findings, then, highlight the importance of interventions to reduce internalised stigma being targeted specifically at PLWHA to assist individuals to cope psychologically with their HIV-status and adapt to living with the disease. Importantly, internalised stigma was evident despite the fact that the vast majority of respondents belonged to a support group (90%). This makes it clear that membership of a support group was not in itself sufficient to eliminate internalised stigma. The high percentage of respondents involved with support groups might, however, situate support groups as a potentially useful forum through which to introduce interventions to reduce internalised stigma.

The regression results indicate that intervention strategies to reduce internalised stigma may need to give special attention to women (who expressed more internalised stigma than men) and provide additional support when individuals experience side-effects resulting from their treatment. In addition, the variation in internalised stigma relative to the clinic where HAART is received adds to the emerging picture that stigma can vary significantly even within a relatively small geographical area. Research to determine what it is that makes respondents who received HAART from Site C especially susceptible to internalised stigma, in addition to experienced stigma and perceived stigma, may be of considerable value for efforts to reduce stigma.

Chapter 12. Conclusion

This study set out to provide a comprehensive account of HIV-related stigma in Cape Town, South Africa, by drawing on a range of datasets. This was achieved through the measurement of different dimensions of stigma; and through the measurement of both stigmatising attitudes and behavioural intentions among the general population, as well as the experiences of stigma among people living with HIV/AIDS (and on HAART). Several key findings provide important insights into HIV-related stigma and point towards recommendations both for policy aimed at stigma alleviation and for future research on HIV-related stigma.

First, a full understanding of HIV-related stigma requires a comprehensive evaluation. As shown in this dissertation, a wider set of measures captures aspects of stigma that are missed in studies that focus on single dimensions of stigma or behavioural intentions. The research reported on here reveals not only that individuals can simultaneously be susceptible to a range of different dimensions of stigma but also that some of the dimensions are interconnected (experiences of stigma, for example, influence both internalised stigma and perceived stigma).

The distinctions between the different dimensions of stigma exhibited by the general population are important for a number of reasons. They showed that the extent of stigma varies in relation to the specific dimension being measured. Instrumental stigma and symbolic stigma were identified as the most pervasive stigmatising attitudes. Furthermore, the significant increases detected in both instrumental stigma and symbolic stigma over the course of the relatively short period between the initial and final surveys on which this research has been based emphasise the urgency of the need for more creative and effective attempts to address these dimensions of stigma.

In addition, it was found that the category ‘behavioural intentions towards PLWHA’ should itself be divided into two different aspects: (1) behavioural intentions towards family/friends; and (2) behavioural intentions towards strangers. From a methodological viewpoint it is important, then, to note that measures of stigma need to be sensitive to the relationship between the respondent and the potentially

stigmatised subject. Intervention strategies can also be informed by this distinction as the generally positive intentions towards family and friends indicate the potential for support for PLWHA from family and friends; while considerably more negative behavioural intentions reported towards strangers indicate the need to develop more tolerant attitudes towards PLWHA in general.

It was important to make a distinction between stigmatising attitudes, on the one hand, and behavioural intentions, on the other, in order to explore whether, and ultimately demonstrate that, each stigmatising attitude (instrumental, symbolic and resource-based) could separately influence negative behavioural intentions towards PLWHA. This points to the need for interventions to reduce HIV-related discrimination to be multifaceted, i.e. they need to recognise the distinctions between instrumental stigma, symbolic stigma and resource-based stigma, and understand their different derivations and outcomes. Given the finding that each dimension of stigma is complex and influenced by many factors, such as, to give just one example, a general tendency to be prejudiced towards other groups, these interventions need in the first instance to continue to focus on the basics, such as the provision of HIV-related education. But to be fully effective they will then need to go on to address much more difficult and far-reaching problems such as general bigotry.

This research's measurement of experiences of stigma among PLWHA revealed that nuanced manifestations of stigma (such as gossip and "bad looks") were more prevalent than overt forms of discrimination (such as being shunned by friends and being avoided). This suggests that the low levels of negative behavioural intentions towards PLWHA in the general population identified by this study might not have measured the full extent of such intentions because survey questionnaires did not probe the more subtle manifestations of stigma. This highlights the importance of measuring actual experiences of stigma and points to the need for tools to measure the much more nuanced manifestations of stigma in the general population that are at the core of the perception of stigma among PLWHA and may well have a significant determining influence on internalised stigma. This will clearly pose significant methodological problems for future research, as the more subtle forms of discrimination are by definition much more difficult to detect. In this regard, survey questionnaire designers should work closely with anthropologists, psychologists and

other qualitative researchers to ensure that quantitative instruments are fine-tuned enough to pick up subtle but important psycho-social realities.

In addition, most of the stigma reported in the survey responses was experienced by a small, but significant, minority who generally reported that their experience of stigma was ongoing. This suggests that a case study approach might be another potential avenue for interventions to reduce HIV-related stigma. In other words, in some instances large gains might be achieved through a direct approach to alleviating stigma that would involve: (1) identifying individuals living in particularly stigmatising environments; (2) determining the perpetrators and the underlying attitudes behind their stigmatising behaviours; and (3) intervening to assist people to change their attitudes.

Finally, with respect to experiences of stigma, there was a strong association between experienced stigma and illness, as well as an indication that when HIV-positive individuals appear to be healthy, people do not believe that they have HIV. This underlines the importance of a more extensive knowledge about HIV that goes beyond simple information about how HIV is, or is not, transmitted. It also highlights the need to recast HIV as a chronic manageable disease. Methodologically, this finding demonstrates that efforts to measure experiences of stigma need to take cognisance of the fact that levels of stigma may vary at different times in people's lives – the measurement of low levels of stigma among healthy individuals may not result from the absence of stigma but from the fact that when people are healthy stigma is 'hidden'.

The extent of internalised stigma (especially feelings of shame) measured by the analysis of questionnaire responses points to the important need to develop strategies that are targeted specifically at helping PLWHA cope with their HIV status and adapt to living with the disease. Stigma experienced by PLWHA clearly influenced the degree to which stigma became internalised, and part of the solution must accordingly involve finding ways to reduce all forms of discrimination manifested towards PLWHA. However, the research has identified that other factors (such as gender and health) also influenced internalised stigma and this suggests that specific tools need to be developed to help PLWHA cope psychologically with the disease.

The measurement of perceived stigma, both from the perspective of the general population and among those who have to live with the disease, demonstrated that there is a widespread belief that PLWHA are generally stigmatised. This has important implications. It may help explain the anecdotal evidence that, even in the absence of high degrees of HIV-related discrimination, stigma has a significant negative impact on HIV prevention, treatment and care efforts. It also suggests that if the general public is harbouring unrealistically high perceptions about the extent to which PLWHA experience stigma (as is indicated by this research) then a strategy to change these perceptions might, in and of itself, achieve a significant reduction in the negative impact of stigma.

In summary, then, this study shows that HIV-related stigma is a problem that has serious implications for HIV prevention, treatment and care; but perhaps in a way different from that commonly perceived. Instead of extreme forms of discrimination based on HIV status in all spheres of people's lives, and here one is obviously particularly concerned about the life-experience of people living with HIV/AIDS, it would appear that much more nuanced forms of stigma are more commonly experienced, and that these usually originate from sources outside the household, as family members are generally supportive.

12.1 Recommendations for further research

Although experiences of stigma in this study were measured among a relatively large sample of individuals on long-term HAART treatment, it is possible that these findings might not fully reflect the lived experiences of PLWHA elsewhere, even in other regions of South Africa and other communities in the Western Cape. For us to be entirely confident of the wider applicability of these research findings it would be necessary to measure experiences of stigma among a more widely representative sample of PLWHA. It would be important for this research, and research on stigma in general, to include a qualitative component. Without such a qualitative component it will not be possible to determine whether measured levels of stigma accurately reflect

reality, or whether some key unidentified aspect of stigma has been missed in the survey measurements.

A more comprehensive measurement of experiences of stigma is needed to confirm, or provide evidence against, what appears to be a disconnect between the relatively few direct experiences of stigma and the comparatively widespread perception that PLWHA are stigmatised. To complement the further research for which a need has been identified above it would be important to ascertain why people believe that PLWHA live in a stigmatising environment. This would be especially pertinent for PLWHA who report few experiences of stigma themselves. Is it because they personally witness other PLWHA experiencing stigma, or because they hear second-hand accounts of how other people are experiencing stigma? If it is the latter, then is it the case that high levels of perceived stigma are being generated by a social discourse that builds around just a few instances? And if so what media, if it is a case of media involvement, can be held responsible for creating and perpetuating this discourse?

This study has provided the first attempt to measure resource-based stigma by means of survey questions. Although resource-based stigma was reported by relatively few individuals it was clearly found to influence behavioural intentions towards PLWHA in those instances where it was identified. This provides a pointer to the potential importance of this dimension of stigma. Further research is needed to develop and test new methods to measure stigma that is attributable directly to the response of family members to the drain on resources occasioned by the onset of illness in PLWHA.

This study has highlighted some factors that are important determinants of stigma and clearly point to ways of developing strategies for targeted interventions. There are, however, other significant determinants of stigma that appear to be acting as proxies for underlying factors that need to be the subject of further research. Specifically, it will be important to examine the significance of race variables as determinants of stigma within the general population. In the case of the particular geographical area which has been the locus for this research, it would also be informative to explore why individuals who received antiretroviral treatment from Site C clinic reported

significantly more experiences of stigma, perceived stigma and internalised stigma than those whose HAART treatment took them to other clinics. To determine the underlying factors behind findings such as these it will be necessary to elicit community level variables that influence stigma. Qualitative research techniques would probably be most effective for such research.

This study has come up with the somewhat unexpected finding that stigma actually increased among the surveyed population between 2003 and 2006. This runs wholly counter to many current theories that would suggest that stigma should have decreased over this period given the increase in number of people on HAART. This underlines the importance of future research to monitor changes in stigma and determine what factors are influencing such changes. This is especially the case as this study has found that stigma (even instrumental stigma) increased significantly among individuals who reported good knowledge about HIV transmission. Identifying the factors that appear to have undermined rational thinking, even among those with a good understanding of HIV-transmission, can only prove helpful to future interventions to reduce stigma. This finding clearly has considerable potential significance for national policy on HIV/AIDS education and the dissemination of information about a disease that needs to be perceived not as a highly infectious and inevitably fatal illness, an obvious occasion for stigma, but rather as a chronic but manageable disease.

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Appendices

Appendix A. Westbrook & Bauman Scales

Stigma of HIV/AIDS: Personal View

Here are some statements that people with HIV have made about themselves. For each statement, circle the answer that comes closest to the way you feel about yourself. [Response options: strongly agree, agree, disagree and strongly disagree.]

1. When people know I have HIV I feel uncomfortable around them.
2. I feel ashamed that I have HIV.
3. Because I have HIV, I should not take care of other people's children.
4. I have been brave in handling my HIV.
5. I must have done something to deserve getting HIV.
6. I should not share dishes or glasses just in case someone might catch HIV from me.
7. If I applied for a job, and someone else also applied who did not have HIV, the employer should hire the other person.
8. Although I have HIV, I am a person who deserves as much respect as anyone else.
9. I feel that it was my fault that I got HIV.
10. People are right to be afraid of me because I have HIV.
11. Because of my HIV, I feel I am less attractive to those who might want to date me.
12. I have a lot to teach people about life through having HIV.
13. I am embarrassed about having HIV.
14. I feel it is completely safe for me to care for other people's children even though I have HIV.
15. I deserve a lot of credit for how well I have coped with HIV.
16. I feel guilty about having HIV.
17. I agree with mothers who do not want their children to play with my children because of my HIV.
18. I understand why people would reject my friendship because I have HIV.
19. I think I am a person of good moral character.
20. I feel ashamed about the way I got HIV.
21. Because of my HIV, I should not hold a new infant.
22. My neighbors would be right to be upset if they learned I had HIV.
23. I think less of myself because I have HIV.
24. I think that my getting HIV was just a matter of bad luck.

Perceived Stigma of HIV/AIDS: Public View

The general public has a wide range of beliefs about people who have AIDS or HIV. Here is a list of some examples of these beliefs and attitudes. For each statement, circle the answer that best describes what you think other people's beliefs and attitudes are about HIV. [Response options: strongly agree, agree, disagree and strongly disagree.]

1. Most people believe that if you have HIV, you must have done something to deserve it.
2. Most people are afraid to be around a person with HIV.
3. Most people are uncomfortable around people who have HIV.
4. Most people think less of a person who has HIV.
5. Most people think that people with HIV are of good moral character.
6. Most people think that someone with HIV should not take care of other people's children.
7. Most people think that people with HIV deserve respect as much as anyone else.
8. Most people feel that if you have HIV, it is your own fault.
9. Most mothers would allow their children to play with a child whose mother has HIV.
10. Most people would reject the friendship of a person with HIV.
11. Most people think that if you have HIV you are not as good as everyone else.
12. Most people think you should be embarrassed about having HIV.
13. Most people would not share dishes or glasses with someone who has HIV because they are afraid they will catch it.
14. Most people would be upset if someone with HIV moved in next door.
15. Most people believe that having HIV is something to be ashamed about.
16. Most people think that people with HIV should be admired for their bravery in the face of the illness.
17. Most people think that people with HIV should feel guilty about it.
18. Most mothers would not want someone with HIV to hold their new infant.
19. Most people feel less attracted (as a date) to someone with HIV.
20. Most people believe that people with HIV deserve a lot of credit for how well they cope with the disease.
21. Most people feel that how you get HIV is something to be ashamed about.
22. Most people think that getting HIV is just a matter of bad luck.
23. Most employers would hire someone with HIV to work for them.
24. Most people think that people with HIV can teach us a lot about life.

Appendix B. Consent form for the HAART Panel Study

Last year you generously agreed to be a part of this panel study. A panel study is one in which we re-interview people regularly. This panel study explores the lives of people using anti-retroviral treatment. It is run by researchers at the University of Cape Town. We would like to re-interview you now.
You are kindly invited to participate in the 2006 survey. Before you decide whether to take part, we want to make sure that you understand the following information about the study.

What is the purpose of the study?

The University of Cape Town is doing research to assess the experiences of people using antiretrovirals. The questionnaire again asks about work, living arrangements, health and sexual relationships. It is our expectation that the results from this study will improve our understanding of the health and work experience of many South Africans today.

What are the possible benefits of participating?

There will be no direct benefit to you; however the information we obtain from this study will give policy makers a better understanding of the lives of people living with HIV who are taking antiretrovirals. What you have to say could play an important role in improving the lives of people living with HIV, those who need antiretroviral treatment and those who are currently taking treatment- including yourselves.

What are the possible drawbacks or discomforts in participating?

This is only a survey; however, the issue of HIV/AIDS is very personal and sensitive. Some people may find it painful to recall and discuss their own experience.

Do I have to participate?

Your participation in this study is voluntary. Should you agree to participate, you are required to sign this form. You are free to withdraw from the study at any stage and this will in no way affect your ARV treatment.

What will happen to me if I participate?

Information regarding your experience with antiretrovirals will be recorded and treated confidentially.

Will the information be treated confidentially?

Yes, should you agree to participate in the study, all information collected for this study will be kept strictly confidential. Individual responses to our questions will never be made public, and no information which could identify you or your household will ever be released.

Contact details

If you have questions about this interview contact Nondumiso Hlwele (Tel 021-650-5117 fax 021-650-4657 or Email: nhlwele@commerce.uct.ac.za).
This study has been reviewed and approved by the Centre for Social Science Research Ethics Committee.

I, ... (name of respondent in block letters) have read and understood all the information given to me about my participation in this study and I was given the opportunity to discuss it and ask questions. I volunteer to take part in this study. I have received a copy of this consent form.

Signature of respondent **Date**

Interviewer/fieldworker: I have:

Explained the nature and purpose of the study to the respondent	N	Y
Handed over a copy of the consent form	N	Y

Signature of interviewer/fieldworker **Date**

Appendix C. Chapter 5 Sensitivity analysis using ordered probit (o-probit) instead of OLS, and logit instead of probit regressions

Table A.1. Sensitivity analysis for Chapter 5 regression models

	Behavioural intentions	Instrumental stigma	Symbolic stigma	Resource-based stigma
Model tested	**5.8.1**	**5.8.2**	**5.8.3**	**5.8.4**
Regression for sensitivity analysis	**O-probit**	**O-probit**	**O-probit**	**Logit**
Coloured (base = black)	**0.495*** **	**0.967*** **	**1.413*** **	**1.100*** **
	[0.115]	**[0.104]**	**[0.091]**	**[0.280]**
White (base = black)	**0.825*** **	**0.777*** **	**1.124*** **	**1.253***
	[0.210]	**[0.194]**	**[0.149]**	**[0.655]**
Gender (base = women)	-0.033	0.108	**0.244*** **	**0.474***
	[0.082]	[0.071]	**[0.061]**	**[0.279]**
Age	-0.008	-0.017	0.001	0.035
	[0.018]	[0.016]	[0.018]	[0.060]
Years of education	0.009	**-0.068*** **	-0.029	-0.101
	[0.021]	**[0.018]**	[0.021]	[0.074]
HIV knowledge	**-0.148*** **	**-0.232*** **	**-0.132*** **	-0.118
	[0.024]	**[0.024]**	**[0.020]**	[0.076]
Religion (base = no affiliation)	-0.105	-0.075	0.071	0.342
	[0.122]	[0.115]	[0.091]	[0.397]
Know someone with HIV (base = no)	**-0.242** **	**0.200** **	**0.279** **	-0.243
	[0.117]	**[0.087]**	**[0.109]**	[0.359]
Know someone who died of AIDS (base = no)	0.023	0.011	0.038	-0.178
	[0.093]	[0.077]	[0.092]	[0.290]
Bigotry	**0.161*** **	n/a	**0.050*** **	**0.331*** **
	[0.025]	n/a	**[0.019]**	**[0.060]**
Log *per capita* household income	0.018	**-0.101***	-0.011	-0.034
	[0.053]	**[0.053]**	[0.043]	[0.170]
Instrumental stigma	**0.120*** **	n/a	n/a	n/a
	[0.014]	n/a	n/a	n/a
Symbolic stigma	**0.057*** **	n/a	n/a	n/a
	[0.020]	n/a	n/a	n/a
Resource-based stigma	**0.406*** **	n/a	n/a	n/a
	[0.122]	n/a	n/a	n/a
Constant	n/a	n/a	n/a	**-3.120***
	n/a	n/a	n/a	**[1.781]**
n	1142	1256	1252	1305
F	35.95	26.18	38.16	7.03
Prob > F	0.000	0.000	0.000	0.000

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors
n/a: Not applicable

Appendix D. Chapter 6 sensitivity analysis using ordered probit instead of OLS, ordered logit instead of ordered probit, and logit instead of probit regressions

Table A.2. Sensitivity analysis for Chapter 6 regression models

	Behavioural intentions family/friends	Behavioural intentions strangers	Instrumental stigma	Symbolic stigma	Resource-based stigma
Model tested	**6.9.1**	**6.9.2**	**6.9.3**	**6.9.4**	**6.9.5**
Regression for sensitivity analysis	**O-probit**	**O-probit**	**O-logit**	**O-logit**	**Logit**
Coloured (base = black)	0.022	**-0.707*** **	**1.441*** **	**0.750*** **	0.529
	[0.203]	**[0.249]**	**[0.310]**	**[0.262]**	[0.362]
White (base = black)	-0.436	**-0.696*** **	**1.059*** **	**0.625***	**1.270*** **
	[0.269]	**[0.262]**	**[0.377]**	**[0.357]**	**[0.458]**
Gender (base = women)	**0.377*** **	0.075	-0.045	0.074	-0.028
	[0.124]	[0.104]	[0.193]	[0.181]	[0.264]
Age	0.006	-0.003	0.009	0.005	0.006
	[0.005]	[0.005]	[0.007]	[0.007]	[0.009]
Years of education	**0.048** **	-0.017	-0.007	**0.048***	0.014
	[0.021]	[0.028]	[0.039]	**[0.028]**	[0.040]
Importance of religion (base = not important)	**0.438** **	0.251	n/a	0.157	**0.501***
	[0.185]	[0.174]	n/a	[0.282]	**[0.301]**
Religion (base = no affiliation)	n/a	n/a	0.288	n/a	n/a
	n/a	n/a	[0.205]	n/a	n/a
Employment (base = unemployed)	**-0.182***	-0.002	-0.040	0.032	0.125
	[0.106]	[0.116]	[0.211]	[0.182]	[0.255]
Neighbourhood problems	0.011	0.001	0.012	**0.020***	**0.026** **
	[0.007]	[0.011]	[0.011]	**[0.011]**	**[0.012]**
General trust	**0.100***	**-0.151** **	**-0.241** **	0.040	-0.056
	[0.058]	**[0.070]**	**[0.097]**	[0.080]	[0.094]
Social-conservative	**-0.128*** **	**0.110** **	n/a	-0.010	-0.032
	[0.031]	**[0.043]**	n/a	[0.059]	[0.049]
Bigotry	**0.170*** **	**0.289*** **	n/a	0.044	0.108
	[0.048]	**[0.054]**	n/a	[0.076]	[0.087]
Instrumental stigma	**0.542*** **	0.061	n/a	n/a	n/a
	[0.065]	[0.069]	n/a	n/a	n/a
Symbolic stigma	-0.004	-0.020	n/a	n/a	n/a
	[0.057]	[0.066]	n/a	n/a	n/a
Resource-based stigma	0.237	**0.348** **	n/a	n/a	n/a
	[0.145]	**[0.133]**	n/a	n/a	n/a
n	438	426	474	488	506
Prob > F	0.000	0.000	0.000	0.090	0.035

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors n/a: Not applicable

Appendix E. HAART Panel Study attrition test

Table A.3. Attrition test for the HAART Panel Study

Model	**A.3.1**	**A.3.2**
Regression	**Probit**	**Logit**
Gender (base = women)	0.374	0.834
	[0.294]	[0.595]
Age	**0.040*** **	**0.072*** **
	[0.014]	**[0.023]**
Years of education	-0.034	-0.073
	[0.038]	[0.070]
Religion (base = no affiliation)	-0.114	-0.097
	[0.302]	[0.628]
Years HIV-positive	-0.001	0.021
	[0.056]	[0.118]
Employed	-0.201	-0.587
	[0.551]	[1.356]
Personal income	-0.001	-0.001
	[0.002]	[0.001]
Constant	**-2.300*** **	**-4.208**
	[0.810]	**[1.586]**
n	242	242
Pseudo R-squared	0.13	0.13

Note: The binary dependent variable separates the attritors (base) from the non-attritors
* Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors

Appendix F. Chapter 9 sensitivity analysis using ordered probit (o-probit) instead of OLS regressions

Table A.4. Sensitivity analysis for Chapter 9 regression models

Model tested	9.11.1	9.11.2
Regression for sensitivity analysis	O-probit	O-probit
Gender (base = women)	0.038	0.069
	[0.159]	[0.169]
Age	0.008	0.003
	[0.010]	[0.011]
Years of education	-0.010	-0.010
	[0.028]	[0.030]
Religion (base = no affiliation)	0.142	0.215
	[0.152]	[0.162]
Years HIV-positive	0.034	0.040
	[0.030]	[0.034]
Illness index	**0.103*** **	**0.098*** **
	[0.018]	**[0.020]**
Average household income	0.040	0.078
	[0.049]	[0.063]
Percentage contribution to household income	-0.002	-0.002
	[0.002]	[0.002]
Illness effect on household	-0.072	-0.043
	[0.080]	[0.090]
Michael M clinic	-0.004	0.033
	[0.225]	[0.250]
Site C clinic	**0.661*** **	**0.726*** **
	[0.178]	**[0.199]**
Other clinic	0.322	0.407
	[0.329]	[0.364]
Percentage disclosure to household members	n/a	0.418
	n/a	[0.270]
n	229	206
Pseudo R-squared	0.07	0.08

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors n/a: Not applicable

Appendix G. Chapter 10 sensitivity analysis using ordered probit (o-probit) instead of OLS regression

Table A.5. Sensitivity analysis for Chapter 10 regression models

Model tested	**10.6.1**
Regression for sensitivity analysis	**O-probit**
Experienced stigma	**0.092*** [0.017]**
Michael M clinic (base = Site B)	0.253 [0.222]
Site C clinic (base = Site B)	-0.202 [0.169]
Other clinic (base = Site B)	0.026 [0.265]
Gender (base = women)	0.030 [0.193]
Education	-0.005 [0.022]
Religious affiliation (base = no religious affiliation)	**0.394** [0.192]**
Years HIV positive	0.018 [0.026]
n	225
Pseudo R-squared	0.05

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors
n/a: Not applicable

Appendix H. Chapter 11 sensitivity analysis using ordered probit (O-probit) instead of OLS regressions

Table A.6. Sensitivity analysis for Chapter 11 regression models

Model tested	11.3.1	11.3.2
Regression for sensitivity analysis	O-probit	O-probit
Experienced stigma	**0.042*** [0.012]**	n/a n/a
Perceived stigma	-0.018 [0.045]	n/a n/a
Gender (base = women)	**-0.328* [0.202]**	-0.252 [0.196]
Age	0.013 [0.012]	0.006 [0.012]
Years of education	-0.040 [0.030]	**-0.049* [0.027]**
Religion (base = no affiliation)	0.027 [0.176]	0.115 [0.161]
Years HIV-positive	0.002 [0.030]	0.008 [0.028]
HIV/HAART knowledge	-0.169 [0.108]	-0.168 [0.111]
Experience of side-effects	**0.060* [0.031]**	**0.088*** [0.027]**
Self-perceived health	-0.097 [0.085]	-0.064 [0.082]
Illness effect on household	-0.010 [0.019]	0.003 [0.018]
Household income (natural log form)	-0.021 [0.052]	-0.029 [0.051]
Personal income (natural log form)	-0.037 [0.038]	-0.030 [0.034]
Michael M clinic	**-0.404* [0.233]**	-0.358 [0.248]
Site C clinic	0.104 [0.181]	0.145 [0.165]
Other clinic	**-0.923** [0.459]**	**-0.981** [0.416]**
n	181	197
Pseudo R-squared	0.06	0.05

Note: * Significant at the 10% level ** Significant at the 5% level *** Significant at the 1% level
Numbers in [ ] indicate standard errors
n/a: not applicable