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EXPERIENCES AND PERCEPTIONS OF HIV/AIDS-RELATED STIGMA AMONGST PEOPLE ON ANTIRETROVIRAL TREATMENT IN KHAYELITSHA, SOUTH AFRICA

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Experiences And Perceptions Of HIV/AIDS-Related Stigma Amongst People On Antiretroviral Treatment In Khayelitsha, South Africa

Abstract

HIV/AIDS-related stigma is a recognised problem for people living with HIV/AIDS (PLWHA) yet little research on experiences of stigma has been conducted in sub-Saharan Africa, the epicentre of the disease. This paper employs quantitative analysis to measure the extent and nature of stigma experienced by 242 people on antiretroviral treatment in Khayelitsha (an urban African community in Cape Town, South Africa). This research draws an important distinction between experienced stigma and perceived stigma (i.e. perceptions of stigma in the community). The results show that while relatively few respondents (17%) reported experiencing a lot of stigma, the majority (75%) had experienced some stigma. Experiences of stigma within households were found to be rare (thus adding to the emerging evidence of general support for PLWHA from family members). Although some reported no experiences of stigma, almost all individuals reported perceived stigma (i.e. believed they lived in a stigmatising environment). Both experienced stigma and perceived stigma were related to inconsistent condom use, fear of disclosure, depression/anxiety and lack of self-efficacy/confidence. As expected, experienced stigma influenced perceived stigma and those affiliated to a religious organisation were shown to manifest more perceived stigma. Health-related problems and the clinic where treatment was obtained (which could be a proxy for different social contexts) were significant determinants of experienced stigma. This indicates the importance of the biophysical manifestations of HIV/AIDS and community-level variables in shaping PLWHA's experiences and fears of stigma.

Introduction

This paper examines the experiences and perceptions of HIV/AIDS-related stigma amongst people on highly active antiretroviral treatment (HAART) in Khayelitsha, South Africa. Data is drawn from a 2004/5 survey of people living with HIV/AIDS (PLWHA) who had been on HAART for more than a year. The paper analyses their experiences of stigma (experienced stigma) as well as their perceptions about the broader stigmatising social environment (perceived stigma).

AIDS is a stigmatised disease because it is a transmissible lethal and incurable condition that is typically assumed to be the responsibility of the infected person (Herek, 2002: 596-7). It is often overlaid with other stigmas associated with, *inter alia*, homosexuality, drug use, race, gender, prostitution, poverty and homelessness, substance abuse and witchcraft (Herek *et al.*, 2003; Sandelowski *et al.*, 2004; *Castro* & Farmer, 2005; Swendeman *et al.*, 2006; Aggleton & Chase, 2001). This has created stigmatizing social environments the world over in which PLWHA have been treated badly within their homes, communities, religious organizations, work places and places of health care (e.g. Malcolm *et al.*, 1998; Holzemer & Uys, 2004; WHO, 2004). Examples from East and Southern Africa include verbal abuse and gossip (Kohi *et al.*, 2006; Almeleh, 2006; Mills, 2004); denial of health care (Sherr *et al.*, 2003); termination of employment, expulsion from homes (Kohi *et al.*, 2006); and exclusion from schooling and the military (Skinner & Mfecane, 2004). In extreme cases PLWHA have been physically assaulted and murdered after disclosing their status. In South Africa cases include the murders of Gugu Dlamini[1] (1998), Mpho Motloung[2] (2000) and in 2004, the rape and murder of Lorna Mlofana[3] (Almeleh, 2006; Skinner & Mfecane, 2004).

Holding prejudicial views and engaging in discriminatory behaviour is not stigmatizing *per se* – such attitudes and behaviours are stigmatizing only when they also reflect society's negative judgement of the target (Herek, 2002: 595). Stigma is at heart a social construct in which understandings about the

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

[2] 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".

[3] 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.

stigmatised condition are developed as part of socialisation (Link and Phelan, 2001). Both 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: 595), it is experienced and processed at the individual level. The psychological processes involved in accepting the stigmatised social role results in ‘internalised stigma’ whereby HIV-positive people devalue themselves in their own eyes (Herek, 2002; Scambler, 2004; Deacon *et al.*, 2005; Cameron, 2005). Such self-stigma can result in low quality of life, depression, anxiety, social withdrawal and even suicide (Farina *et al*, 1968; Muyinda *et al*, 1997; Arkell *et al.*, 2006; Link *et al*, 1997; Wright *et al*, 2000; Thomas *et al*, 2005).

One way of avoiding the stigmatised social role is to keep one’s HIV status a secret. This is most likely where PLWHA believe that they are living in a very stigmatising environment. This ‘perceived stigma’ – otherwise known as ‘stigma consciousness’ (Pinel, 1999) or ‘stereotype threat’ (Steele & Aronson, 1995) 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). This can lead to a wide disjuncture between experienced stigma and perceived stigma. For example, in the USA, 89% of young PLWHA reported perceived stigma but only 64% reported experiencing it (Swendeman *et al.*, 2006). A study from South India reported a much wider gap with 97% of HIV-positive respondents reporting perceived stigma, but only 26% actually experiencing it (Thomas *et al*, 2005).

PLWHA may respond positively to stigma by joining HIV/AIDS support groups and activist organisations, but the more typical reaction is social withdrawal (Link et al, 1997). As Goffman (1963) pointed out in his classic contribution, the stigmatised person’s central concern during interactions with people is the management of information. They are constantly wary of preventing their condition from being ‘discovered’ and intend, as Goffman 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’ (Goffman, 1963: 4). The vigilance required to remember what was told to whom and to hide one’s status can result in psychological stress for PLWHA (Herek, 2002; Sandelowski, 2004; Alonzo & Reynolds, 1995). Qualitative research in 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' (Almeleh, 2004: 24).

HIV/AIDS-related stigma is a problem not only for those who experience it, but also for managing the epidemic. Stigma discourages people from testing for HIV, and if they test positive, from disclosing to sexual partners and care-givers (Aggleton & Chase, 2001; Brown *et al*., 2001; Chesney & Smith, 1999; Wolf *et al.*, 2006; Kalichman & Simbayi, 2006; Hutchinson & Mahlalela, 2006, Nachega *et al.*, 2005; Skhosana *et al*., 2006). Fear of being labelled HIV positive can also result in mothers breast-feeding their babies rather than using formula feeding to reduce the risk of maternal transmission (Muko *et al*., 2004: 136; Skinner & Mfecane, 2004: 161), and may affect sexual decision making when condom-use is seen as a signifier of HIV/AIDS (Leclerc-Madlala, 1997).

Herek (2002: 600) observes that as a disease is better understood, and as treatment becomes available, stigma normally declines. Unfortunately this appears not to be the case with regard to AIDS where misconceptions abound and where a cure has still proved elusive (*ibid*). Thus even those PLWHA who have had their health restored through HAART, still have to confront the problem of AIDS related stigma. This is particularly the case in Sub-Saharan Africa (SSA), the epicentre of the AIDS epidemic, where enhanced access to HAART is a relatively recent phenomenon (Nattrass, 2006).

Research on stigma in SSA has three major limitations. Firstly, it tends to be qualitative and based on anecdotal evidence (Holzmer & Uys, 2004; Nyblade, 2006). As Lorentzen and Morris put it, 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: 33). Secondly, it is typically focused on social attitudes towards PLWHA; there is relatively limited research from the perspective of the stigmatised (Holzemer & Uys, 2004; Thomas *et al*., 2005). Thirdly, 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. 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 rollout itself. This paper contributes to addressing these gaps in the literature by exploring data on experienced and perceived stigma from a cohort of HAART patients in Khayelitsha, South Africa

Measuring Experienced And Perceived Stigma

In 2004, the AIDS and Society Research Unit (ASRU) at the University of Cape Town interviewed 242 people who had been HAART patients for at least a year. Although this was not a random sample (respondents were recruited through social networks and word of mouth) over two thirds of the starting (2001) cohort was recruited into the study and 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. It thus provides an adequate base for supplementing the existing qualitative studies related to stigma (Kahn, 2004; Almeleh, 2004, 2006; Mills, 2006) with statistical analysis.

Experienced Stigma

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 this 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.[4] This indicates that most experienced stigma occurs beyond the confines of the household.

Experienced stigma was measured using responses to nine statements (ranked on a 5-point Likert scale) about experiences of stigma since HIV diagnosis (see Table 1). This, of course, tells us something about whether stigma has 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

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[4] However, it must be noted that this result could be driven by selection bias in the survey. Given that respondents were recruited through HIV support-groups and social networks, it is possible that those who attend support groups also live in more supportive immediate social contexts. One must therefore avoid the temptation to conclude that the survey results indicate that this survey of HAART patients can be generalised to the experience of PLWHA in all households

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' is best interpreted with regard to these questions as meaning: 'both agree and disagree'/'some people do while others do not'. It is thus understood to represent *some* experience of stigma.

Four key findings are evident from Table 1. Firstly, the percentage of respondents reporting experienced stigma from family members is low (as expected). This concurs with previous research findings of few negative behavioural intentions in the general Cape Town population towards family or friends with HIV (Maughan-Brown, 2006a). However, it is noteworthy that 11% agreed and a further 5% neither agreed nor disagreed with the statement that they had lost a friend because of HIV. Thirdly, 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, perhaps based on a lack of knowledge around HIV transmission or lack of trust in this knowledge, may be a significant aspect of the stigmatising environment. This concurs with previous research which measured fairly high levels of instrumental stigma in Cape Town (Maughan-Brown, 2006a; Maughan-Brown, 2006b). Finally, 'unkind things said behind the respondents back' was the most common experience of stigma. This is consistent with qualitative research in Khayelitsha indicating that gossip is the most common and hurtful form of stigmatising behaviour (Almeleh, 2006; Mills, 2006).

Figure 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.

The nine questions listed in Table 1 were recoded so that a response of 'strongly agree'/'strongly disagree' to a particular question was scored as zero when it represented no experience of that dimension of stigma and four when it indicated some experience of stigma. The response options ‘agree’, ‘neither agree nor disagree’, and ‘disagree’ were then scored one, two or three respectively. The values ascribed to each answer were then summed and divided by nine[5] to form the index called ‘experienced stigma’. The experienced stigma index thus had a potential range of zero (no experienced stigma) to four (experience of stigma reported for every question). Actual values ranged from 0.3 to 2.9[6].

Explanatory factor analysis to test construct validity indicated that the questions were indeed probing one underlying dimension (experienced stigma). Both construct validity and internal reliability (α=0.82) indicate similar responses from groups of respondents. This suggests that some respondents were in good (relatively non-stigmatising) social situations, while others were in bad ones. This finding emphasizes the importance of context-specific analysis.

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[5] Questions were summed and divided by eight for four observations with missing data on one question and divided by seven for one observation with missing data on two questions.

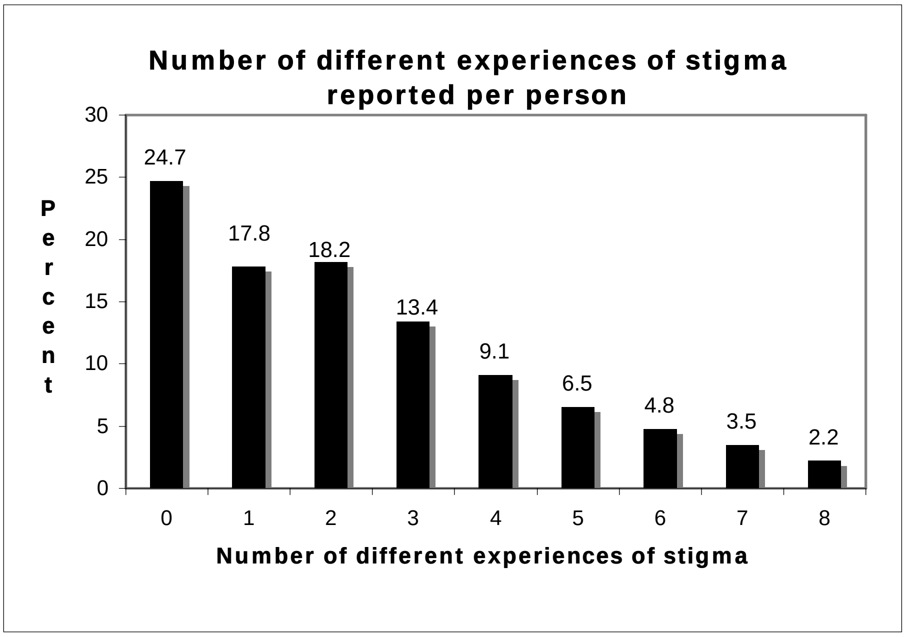
[6] The index comprised 32 unique values from 0.3 to 2.9 and is thus considered to be a continuous variable.

Table 1: 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
Q1 [A.36.1]	*I have lost friends because I am HIV positive*	15% (36)	70% (168)	5% (13)	10% (24)	0% (1)
Q2 [A.36.2]	*Family members and friends have treated me badly because I am HIV positive*	23% (57)	70% (169)	5% (12)	1% (2)	1% (2)
Q3 [A.36.3]	*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)
Q4 [A.36.4]	*When people find out I am HIV positive, they feel uncomfortable in my presence*	6% (15)	64% (154)	26% (65)	3% (7)	0% (1)
Q5 [A.36.5]	*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)
Q6 [A.36.6]	*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)
Q7 [A.36.7]	*People treat me with less respect when they find out I am HIV positive*	23% (56)	59% (142)	12% (29)	6% (15)	0% (0)
Q8 [A.36.8]	*Because I am HIV positive, people say unkind things behind my back*	10% (24)	23% (56)	31% (76)	34% (82)	2% (4)
Q9 [A.36.9]	*Many people avoid me because I am HIV positive*	14% (35)	59% (141)	23% (56)	4% (9)	0% (0)

Note: Numbers in parentheses indicate the number of respondents.
References to the question numbers used in the KSPS 2004/05 survey instrument are given in [ ].
Percentages might not total 100% due to rounding effects.

Figure 1: Histogram of the number of different experiences of stigma reported per person.



Perceived Stigma

Three items were used to measure perceived stigma (see Table 2). Two findings emerge clearly from Table 2. Firstly, the majority of respondents believed that PLWHA in general were supported by their families. This provides further evidence to the emerging picture of limited stigma towards family members. Note, however, that a third of the sample neither agreed nor disagreed with Q1: ‘Most people with HIV are supported by their families when they disclose their HIV status’. As discussed earlier, this is interpreted to mean that some family members are supportive, while others are not.

The second key finding from Table 2 is that most respondents believed that PLWHA are stigmatised by other people. The high percentage agreement with the statement (Q3) that people say unkind things about HIV people is consistent with the majority experiencing unkind things said behind their backs (Q8, Table 1). Again note the significant proportion answering neither agree nor disagree to these two items.

Table 2: Perceptions of stigma

	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
Q1 [C.54.1]	*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)
Q2 [C.54.2]	*People with HIV often get treated unfairly or badly by others*	1% (2)	6% (13)	37% (90)	47% (112)	10% (25)	0% (0)
Q3 [C.54.5]	*People say unkind things about HIV positive people*	0% (1)	6% (14)	28% (66)	56% (136)	11% (25)	0% (0)

Note: Numbers in parentheses indicate the number of respondents.
References to the question numbers used in the KSPS 2004/05 survey instrument are given in [ ].
Percentages might not total 100% due to rounding effects.

As Q1 in Table 2 has little variation, it is not used in further analysis. The remaining two items factor together and show internal reliability ($\alpha = 0.63$). These questions are summed and divided by two to create a 'perceived stigma' index. The perceived stigma index comprises eight unique values ranging from 0 (strongly disagree to both questions) to 4 (strongly agree to both questions).

Construct Validity Of The Stigma Indices

The 'construct validity' of the stigma indices can be tested by exploring their correlation with variables expected to be related to stigma. For example, stigma scores should be positively correlated with depression or anxiety and negatively related to self-esteem (Goffman, 1963; Laryea & Gien, 1993; Berger *et al.*, 2001). Table 3 shows that correlations between the stigma indices and indices created from the data set proxying for depression/anxiety[7] and self

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[7] 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 [KSPS 2004/05: A33_1 – A33_5] 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? (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

efficacy/confidence[8], despite being relatively weak, were in the expected direction. Furthermore, as expected, depression/anxiety was more highly correlated with experienced stigma than perceived stigma. Lastly, evidence of construct validity is strengthened by the fairly strong positive correlation between the two stigma indices.

Table 3: Correlations of stigma indices with related constructs

	Experienced stigma	Perceived stigma
Depression or anxiety	0.44	0.28
Self-efficacy or confidence	-0.18	-0.18
Perceived stigma	0.50	1

Correlation analyses and Ordinary Least Squares (OLS) regression (employed later in this paper) are optimal under the assumption that the experienced stigma and perceived stigma indices are continuous variables. This is not strictly speaking the case as neither variable can take on any value and intervals between the response options used to create the indices cannot 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’. However, both indices have a fairly normal distribution and sensitivity analysis (using techniques that assume the stigma indices are ordered, but not continuous variables) – show robust results across methods. Correlation analyses and OLS regression is thus used for ease of interpretation.

Impacts Of Stigma

As discussed earlier, stigma has had a negative influence on behavioural and psychological outcomes for PLWHA all over the world. This section explores

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questions) to 25 (‘all of the time’ for all questions). Factor analysis indicated construct validity and the index showed internal reliability ($\alpha = 0.80$).

[8] 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 [KSPS 2004/05: C53_1 – C53_4] 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 ($\alpha = 0.82$).

the self-reported impact of stigma on the lives of HIV-positive people on HAART in Khayelitsha (the KSPS respondents).

Table 4 and Table 5 display 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 KSPS respondents indicated that fear of stigma (Table 4: Q6, i.e. fear that people would be less friendly) was not an unimportant factor in the decision not to disclose. When asked specifically about sexual partners, they had not disclosed to, fear of rejection (Table 5: Q1), loss of financial support (Table 5: Q2) and fears of being physically hurt (Table 5: Q5) were also not unimportant factors for over half of respondents. This suggests that fear of 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. The fact that 60% of respondents cited feelings of shame as being an important, at least to some degree, reason for non-disclosure (Table 5: Q2) is suggestive of the importance of internalised stigma.

Table 4: Reasons for non-disclosure 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
Q1 [A.38.1]	*You thought they would tell other people without your permission*	29% (71)	41% (100)	12% (28)	12% (29)	6% (14)
Q2 [A.38.2]	*You felt too ashamed to tell them*	40% (97)	17% (42)	31% (75)	11% (25)	1% (3)
Q3 [A.38.3]	*You didn't know how to talk to them about it*	33% (80)	13% (31)	42% (101)	11% (26)	2% (4)
Q4 [A.38.4]	*You thought they would not understand*	25% (61)	15% (36)	43% (102)	14% (33)	3% (8)
Q5 [A.38.5]	*You thought they would worry too much about you*	26% (63)	33% (80)	24% (57)	12% (29)	5% (13)
Q6 [A.38.6]	*You thought they would stop being friendly*	44% (110)	21% (49)	25% (61)	7% (18)	3% (4)

Note: Numbers in parentheses indicate the number of respondents.
References to the question numbers used in the KSPS 2004/05 survey instrument are given in [ ].
Percentages might not total 100% due to rounding effects.

Table 5: Reasons for non-disclosure to sexual partners

	*Think of the sexual partners you have **not** disclosed to. How important were the following reasons?*	Not important	Slightly important	Important	Very important	Very, very important
Q1 [A.41.1]	*You thought they would reject you*	41% (76)	23% (42)	15% (29)	15% (29)	5% (9)
Q2 [A.41.2]	*You thought they would stop providing financial support*	45% (81)	24% (45)	16% (30)	12% (22)	3% (6)
Q3 [A.41.3]	*You did not trust them not to tell other people*	49% (90)	25% (47)	14% (26)	9% (17)	3% (5)
Q4 [A.41.4]	*You thought they would not believe you*	35% (64)	13% (24)	38% (69)	13% (24)	2% (3)
Q5 [A.41.5]	*You thought they might get angry and hurt you*	40% (73)	17% (31)	22% (42)	10% (19)	10% (19)
Q6 [A.41.6]	*They were not important enough in your life*	47% (87)	26% (48)	22% (40)	4% (8)	1% (1)

Note: Numbers in parentheses indicate the number of respondents.
References to the question numbers used in the KSPS 2004/05 survey instrument are given in [ ].
Percentages might not total 100% due to rounding effects.

Table 6 displays the relationships between both the experienced stigma and perceived stigma indices and behavioural and psychological correlates[9]. A significant positive relationship existed between experienced stigma and both the use of izangoma (i.e. traditional healers who call on ancestors to divine and cure illness) prior to starting HAART[10] and whether the respondent has ever been to an isangoma/spiritual healer[11]. A positive, but weakly significant, relationship existed between perceived stigma and the use of izangoma/spiritual

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[9] Logistic regression was used to assess relationships between stigma and binary variables. Ordinary Least Squared regression was used to assess relationships between stigma and continuous variables.

[10] Respondents were asked: Think back to the last time when you were very sick (before you went on ARVs). Did you visit an isangoma to see if he or she could help you? [KSPS 2004/05: A15] Thirty-five respondents had visited an isangoma and 207 had not.

[11] A binary variable separated all respondents who had either visited an isangoma before the start of HAART (35), visited an isangoma since starting HAART (2) or had ever been to a spiritual healer (27) [KSPS 2004/05: A15, A20a and A25a respectively]. Fifty-four respondents had visited either an isangoma or spiritual healer.

healers. This is consistent with the hypothesis that AIDS patients seek out izangoma and other traditional healers[12] in order to deal with possible bewitchment and the negative social consequences of being deemed to be cursed and thereby 'polluted' (Ashforth, 2005).[13] Thus, a PLWHA who goes to a traditional healer is more likely to believe that others are causing him or her harm – or, put differently, sees an added spiritual dimension to the stigmatising social environment.

Both experienced and perceived stigma were positively correlated with fear of disclosure[14] and negatively correlated with condom use[15]. A significant positive association was also found between depression/anxiety and both stigma indices; and a significant negative association between self-efficacy/confidence and both stigma indices. However, the direction of causality between stigma and psychological outcomes is unclear. Someone could lack confidence because they perceive stigma, or perceive stigma because they lack confidence. Similarly, people may be depressed and anxious because they are stigmatised, or be stigmatised because they are depressed and anxious people.

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[12] Two main categories of traditional healers (indigenous African healers) are generally recognised. iziNyanga who are usually male and use herbal and other medicinal preparations for treating diseases, but have no clairvoyance. And izangoma (diviners) who are usually female and, in addition to the use of African medicines, are trained to communicate with and use the power of ancestors in diagnosing and treating a mishap or disease (Ashforth, 2005).

[13] The strong associations found between stigma and health in the determinants of stigma section raises the question of whether it was health that was influencing visits to izangoma rather than stigma. After controlling for health the same relationships are found between stigma and visits to izangoma or spiritual healers.

[14] Fears of disclosure were assessed with the statement: I am afraid to tell people that I am HIV positive [KSPS 2004/05: A36_10]. Answers were recorded using a 5-point Likert scale from 'strongly disagree' to 'strongly agree'. A binary variable separated respondents who were afraid to disclose (n = 39) from those who indicated no fear of disclosure (n = 203).

[15] A binary variable separated respondents who reported using a condom every time they had sexual intercourse since HIV diagnosis (n = 144) from those reporting inconsistent condom use (n = 57). [KSPS 2004/05: A44]

Table 6: Experienced and perceived stigma and selected behavioural and psychological correlates

	Visited a sangoma pre-HAART	Ever visited either a sangoma or spiritual healer	Condom used everytime while HIV +	Fear of Disclosure	Depression or Anxiety	Self-efficacy or confidence
Model^	logit	logit	logit	logit	OLS	OLS
Experiences of stigma	POS ***	POS ***	NEG ***	POS ***	POS ***	NEG ***
Perceived-general	Non-sig	POS *	NEG **	POS ***	POS ***	NEG ***

Notes:

* Significant at the 10% level.	Non-Sig = non-significant relationship
** Significant at the 5% level.	POS = positive relationship
*** Significant at the 1% level.	NEG = negative relationship

^Logistic regression (logit) was used to assess the direction and significance of the relationship between the stigma indices and binary dependent variables. Sensitivity analysis, using probit regression, indicated robust results. Ordinary least squares regression (OLS) was used to test the direction and significance of the relationship between the stigma indices and continuous dependent variables.

Finally, there are indications that stigma may be undermining the effectiveness of HAART. Questions probing reasons for incomplete HAART adherence revealed that 14% of respondents did not fully adhere to their treatment regimen during the previous month because they did not want others to see them taking their medication. Fear of stigma may well have been an issue here. However, it is also possible that these respondents were motivated by other factors, such as more altruistic concerns like not wanting to worry loved ones by alerting them to the presence of a life-threatening disease. Qualitative research amongst HIV-positive people in Khayelitsha suggests that non-disclosure may well result from a concern not to cause anxiety – rather than from fear of stigmatising behaviour (Almeleh, 2006).

Determinants Of Experienced Stigma And Perceived Stigma

Understanding the specific factors that drive, or at least are associated with, stigma is crucial to the design of appropriate interventions to combat stigma. This section describes the hypotheses and variables used to explore potential correlates and determinants of stigma using Ordinary Least Squares (OLS)[16] regression models. Experienced and perceived stigma are analysed separately.

Independent Variables: Potential Determinants Of Experienced Stigma

The following independent (explanatory) variables are used in the OLS regression models to assess potential determinants of experienced stigma[17]:

- gender
- age
- education
- religious affiliation
- years HIV positive (time between diagnosis and interview dates)
- general state of health during the first six months on HAART (self perceptions of health)
- health at time of interview (self-perceptions of health)
- side-effects (side-effects in the 3 months prior to the interview)
- illness effect on household at start of HAART *or* in the 3 months prior to the interview
- labour-market status (working or not)
- personal income at the time of interview
- clinic where HAART is received

As noted earlier, disease stigma often attaches itself to existing stigmatising frameworks (Sontag, 1988; Herek & Capitanio, 1997). Gender-related stigma is one such framework 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

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[16] As noted earlier, the dependent variables (experienced stigma and perceived stigma) are not strictly continuous variables. Sensitivity analysis was, therefore, conducted with ordered logistic regression models. Results were consistent between the regression techniques. Ordinary least squares modelling is used due to ease of interpretation.

[17] For a summary of the independent variables and related survey questions refer to appendix A.

> an unfortunate stroke of luck – he is given sympathy and not blamed'. (France 2004:2)

France's findings concur with previous research from South Africa (Leclerc-Madlala, 1997, 2002). It was accordingly 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 circles where there is less stigma and (2) making better decisions about 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).

Beliefs in supernatural and moralistic explanations of HIV infection are widespread in Southern Africa (Deacon & Simbayi, 2006; Ashforth, 2005). Both Christian and traditional (African) religious discourse has been used to express the idea that HIV infection is a punishment for transgressing social norms (Ogden & Nyblade, 2005). It was accordingly hypothesized that those affiliated to a religious organization would have a greater awareness of the moral discourse surrounding HIV/AIDS. Assuming that they live in a social context surrounded by like-minded people, it was hypothesized that they would probably also experience more stigma than more secular-oriented people. Experiences of stigma will probably have some temporal dimension. 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 are therefore likely to increase with time. It was thus hypothesised that a positive relationship would be found between the length of time since HIV diagnosis and experience of stigma.

Alonzo & Reynolds (1995) 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 appearances and everyday activities. Alonzo & Reynolds describe this changing experience as a 'stigma trajectory'. It was accordingly hypothesised that the visible appearance of illness would increase experienced stigma. Three variables were created to test this hypothesis.

Table 7 displays the questions used to assess self-perceptions of health at the start of HAART and then three and six months later. Adding the scores for the three different time periods and taking the average created a variable representing the respondents' general state of health during the first six months on HAART. Self-perceptions of health were also reported for the time of the interview, but in this case using a 5-point Likert Scale with the response options: poor, fair, good, very good or excellent.

Table 7: Self-perceptions of health at the start of HAART, three months after the start of HAART and six months after the start of HAART

A9. *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

Respondents were asked about the side effects they had experienced in the three months prior to the interview (see Table 8). Some side-effects probably had relatively obscure symptoms (headaches, felt sad or depressed, and 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 (visible) impressions of poor health and were thus all included in the index[18]. A score of one was added to the variable 'side effects' for each additional side effect they reported. Thus,

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[18] It is noted that experiences of side-effects in the three months prior to the interview and self-perceptions of health at the time of the interview could be highly correlated and therefore be measuring the same thing. The correlation between these variables was relatively weak (-0.33) and thus they are both included in the analysis. Note also that the correlation was in the expected direction.

the ‘side-effects’ variable ranged from 0 (no side-effects) to 12 (every side-effect).

Table 8: Experience of side effects in the three months prior to KSPS 2004/05

A.13a	*Have you experienced any of the following side-effects from the ARV’s in the past three months?*	13.1 *Nausea/stomach problems*	Yes	1
			No	0
		13.2. *Headaches*	Yes	1
			No	0
		13.3 *Fevers, chills, sweats*	Yes	1
			No	0
		13.4 *Felt sad or depressed*	Yes	1
			No	0
		13.5 *Unwanted loss of weight*	Yes	1
			No	0
		13.6 *Problems with having sex such as loss of interest or lack of satisfaction*	Yes	1
			No	0
		13.7 *Skin problems*	Yes	1
			No	0
		13.8 *Muscle-aches and joint pain*	Yes	1
			No	0
		13.9 *Pain, numbness or tingling in the hands and feet*	Yes	1
			No	0
		13.10 *Feeling dizzy and light-headed*	Yes	1
			No	0
		13.11 *Feeling very tired/exhausted*	Yes	1
			No	0
		13.12 *Trouble remembering*	Yes	1
			No	0

A further set of variables were included based on the premise that experienced stigma might be linked to the negative impact on households – e.g. if care-givers have to take off time from work or school to look after the sick individual. This could arise within the household of the care-givers themselves resent the burden, or it might make the respondent vulnerable to gossip and stigma from neighbours and others associated with the household. This effect was measured with five questions (see Table 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 assess the combined effect that illness had on the respondents' households at the time they started HAART and on the households in the three months prior to the interview. It was hypothesised that the greater the negative effect of illness on households, the greater the resentment would be towards the respondent, and hence the greater the stigma likely to be experienced.

Table 9: Illness effect on the household at the time the respondent start HAART.

Interviewer: *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
C.49.1	*How often did anyone miss work to look after you or help you?*	1	2	3	4	5	6
C.49.2	*How often did a child have to stay home from school to look after you or help you?*	1	2	3	4	5	6
C.49.3	*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
C.49.4	*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
C.49.5	*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

Anecdotal evidence indicates resentment toward PLWHA in sub-Saharan Africa due to the resources expended on them (Moon, Mitchell & Sukati, 2002: cited in Stein, 2003). AIDS not only exacerbates resource-poor conditions through the expenditure needed to care for PLWHA, but also because the economic contribution previously made by PLWHA often diminishes or ceases completely. This results in a simultaneous double blow to the family, which could result in the PLWHA being blamed for their financial predicament. Labour-market status and income[19] were included to test whether economic context influences experienced stigma. It was hypothesised that respondents who were working and those with higher income would be less of a burden on their families' financial resources and hence would experience less stigma.

Most HAART patients in Khayelitsha obtain their medication from three clinics (Site B, Site C and Michael M) – see Table 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, HAART policies and visibility of the clinic 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 10: Clinics where HAART is 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

Table 11 displays three OLS regression models of potential determinants of experienced stigma. The first model indicated that controlling for age, gender, education, religious affiliation, income and clinic most of the health indicators showed a strong and negative relationship with experienced stigma. The respondents' health during the first 6 months of HAART showed the most statistical significance. Excluding this variable (model 11.2) reduced the strength of the model considerably (the adjusted R-squared). Experienced stigma was influenced by health at the time of the interview, experience of side-

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[19] Income included the following sources: disability grants, child support grants, wage income, self-employment profits, payment 'inkind' for work (food, clothing or other non-monetary items for which an estimated monetary value was given) and remittances.

effects, the clinic where HAART was received and income. Model 11.3 then excluded all health-related variables to assess other potential factors that influenced experienced stigma. Religious affiliation showed statistical significance, and the influence of both income and variation in clinics increased in significance.

Overall, health appeared to be the most statistically significant determinant of experienced stigma: respondents with poorer health, particularly at the start of HAART, were predicted to have experienced more stigma. These findings suggest that health problems play a major role in the experience of stigma. Respondents that receive HAART from the Site C clinic reported significantly more experienced stigma than respondents from any other clinic[20]. This suggests that context at a very localised level can effect experiences of stigma. It cannot be ascertained whether such an effect was driven by characteristics of the clinic itself (intolerant staff or structural layout, for example) or by characteristics of the community around the clinic[21] (individuals with less HIV/AIDS knowledge or a religious organisation giving certain messages, for example).

Greater levels of experienced stigma were predicted for respondents with lower levels of personal income. This was suggestive of the possibility of resource-based stigma (i.e. PLWHA who contribute less to the resources of the family are viewed as a financial burden and thus the stigma they experience is rooted in their being a financial burden). But, personal income *per se* tells us nothing about the relative contribution made within the household. The models were therefore adjusted to include a binary variable separating those whose personal income contributed less than fifty percent to household income (n =108) from those contributing more than fifty percent (n = 134). Those who contributed less than fifty percent to total household income experienced significantly more stigma than the others. This provides the first empirical evidence (to the best of my knowledge) indicating the possibility of resource-based stigma. However, as very little experienced stigma is reported as emanating from household

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[20] The regression models indicate that respondents from Site C reported more experienced stigma than respondents from Site B. In addition, post regression tests indicated that respondents from Site C clinic also reported more stigma than respondents from Michael M clinic ($p < 0.001$) and other clinics ($p < 0.001$). Respondents from other clinics were found to experience more stigma than respondents from Michael M clinic ($p < 0.001$).

[21] Different class structure between communities was one obvious factor that had the potential to explain variation in experienced stigma between communities. Four different household income measures (the respondents’ estimation of total household income, a summation of the income contribution from each household member in the household roster, and per capita household income based on both these measures) were added as controls in separate models. None of the household income variables had any effect on the models.

members, resource-based stigma would appear to involve assumptions about contributions within the household being made by external observers, such as neighbours, which are generally not shared by members of the household themselves.

Model 11.3 shows that conditional on the exclusion of the health-related variables, respondents affiliated to a religious organisation were shown to have experienced more stigma. This suggests that moral connotations associated with HIV/AIDS may play some role in the manifestations and experiences of stigma.
It is noteworthy that 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 lead to experienced stigma. This further strengthens the finding that households were supportive.

Table 11. Regression models for experienced stigma

	11.1	**11.2**	**11.3**
Gender (0=female)	0.001	0.002	0.042
	[.062]	[0.068]	[0.076]
Age	-0.003	-0.001	-0.001
	[0.004]	[0.004]	[0.005]
Education	-0.0002	-0.001	-0.004
	[0.011]	[0.011]	[0.011]
Religious affiliation (0=no religious affiliation)	0.004	0.075	0.150**
	[0.062]	[0.065]	[0.067]
Years HIV positive	0.009	0.011	0.010
	[0.013]	[0.014]	[0.014]
Self-reported general state of health during the first 6 months on HAART	-0.104***		
	[0.023]		
Self-reported health status at time of interview	-0.065**	-0.121***	
	[0.032]	[0.030]	
Self-reported side-effects in 3 months prior to KSPS 2004/05	0.286**	-0.314**	
	[0.141]	[0.137]	
Illness effect on household at start of HAART or in the 3 months prior to KSPS 2004/05	0.005	-0.007	
	[0.031]	[0.034]	
Working (0=not working)	0.099	0.136	0.118
	[0.106]	[0.102]	[0.109]
Personal income at the time of the interview	-0.0001*	-0.0001**	-0.0001***
	[0.00004]	[0.00004]	[0.00006]
Michael M clinic (base = Site B)	-0.025	-0.010	0.058
	[0.083]	[0.091]	[0.097]
Site C clinic (base = Site B)	0.173**	0.316***	0.437***
	[0.075]	[0.075]	[0.066]
Other clinic (base = Site B)	0.069	0.168	0.288***
	[0.172]	[0.144]	[0.101]
Constant	2.085***	1.429***	0.967***
	[0.285]	[0.266]	[0.261]
N	237	237	241
adj. R-squared	0.41	0.34	0.23
Prob>F	0.000	0.000	0.000

Notes: * Significant at the 10% level. ** Significant at the 5% level. *** Significant at the 1% level

Independent Variables: Potential Determinants Of Perceived Stigma

The following independent (explanatory) variables were used in OLS regression models to explore potential determinants of perceived stigma:

- experienced stigma
- gender
- education
- religious affiliation
- years HIV positive (time between diagnosis and interview dates)
- clinic where HAART is received

The personal experience of stigma is an important factor shaping whether PLWHA believe that they live in a stigmatising environment or not. The relatively high positive correlation (0.50) between experienced stigma and perceived stigma (see Table 4) provides empirical evidence of this. Hence any modelling of the potential determinants of perceived stigma ought to include a variable capturing experienced stigma. However, personal experience of stigma is clearly not the only factor shaping perceptions about the stigmatizing environment (after all 20% of respondents reported some degree of perceived stigma despite reporting no experiences of stigma). What other factors 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 is an obvious potential proxy for different localised social environments within Khayelitsha.

Education may also be a proxy for social environment. If better educated respondents tend to mix with similarly educated people, and given that better educated people are less likely to be stigmatising in Cape Town (Maughan-Brown, 2006b) – one could hypothesise that better educated people would perceive themselves as living in a less stigmatizing environment than those with fewer years of education.

As discussed earlier in the context of experienced stigma, another variable which can 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 (Deacon, 2006; Ogden & Nyblade, 2005; Aggleton & Chase, 2001), it follows that religions people are more likely to perceive they live in a stigmatising environment than non-religious people. Another set of potential explanatory factors relates to the experiences of other PLWHA. Given that women are likely to be stigmatised more than men (France, 2004; Leclerc-Madlala, 1997, 2002) and given that a greater percentage of women attend support groups[22] (where experiences are often shared), it seems reasonable to hypothesize that women are more likely to see themselves as living in a stigmatised environment than men. It also seems likely that individuals who had been living longer with HIV would have encountered more stories about other peoples' 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.

Table 12 shows that experienced stigma, religious affiliation and 'other clinic' were significant predicators of perceived stigma. Respondents who reported more experienced stigma and those affiliated to a religious organisation were more likely to believe they were living in a stigmatising environment. In addition, respondents who received their HAART from a clinic other than Michael M or Site C ('other clinic') had greater perceptions of a stigmatising social environment than respondents from Site B[23].

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[22] Ninety-five percent of the female KSPS respondents compared to 81% of male respondents had, at some stage, attended a support group.

[23] Note that only six respondents received HAART from 'other clinics' (see Table 9).

Table 12. Ordinary least squares regression model for perceived stigma

	11.4
experienced stigma	0.603***
	[0.080]
gender (0 = female)	-0.079
	[0.104]
education	-0.001
	[0.011]
religious affiliation (0 = no religious affiliation)	0.331***
	[0.094]
years HIV positive	0.011
	[0.014]
Michael M clinic (base = Site B)	0.072
	[0.120]
Site C clinic (base = Site B)	-0.021
	[0.090]
other clinic (base = Site B)	0.234**
	[0.092]
Constant	1.665***
	[0.155]
N	242
adj. R-squared	0.31
Prob>F	0.000

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

Conclusion

This paper provides the first quantitative analysis of experienced and perceived stigma amongst HAART patients in a developing country context. Although relatively few respondents (17%) reported experiencing a significant amount of stigma, the majority (75%) had experienced some stigma – and most individuals reported perceived stigma (i.e. believed they lived in a stigmatising environment). This disjuncture between experienced and perceived stigma has been reported in other contexts too (Sandelowski *et al.*, 2004; Swendeman *et al.*, 2006; Thomas *et al*, 2005). This either suggests that experienced stigma is low because PLWHA know they live in a stigmatizing environment and hence keep their HIV status secret – or it suggests that fears about the stigmatizing environment are excessive.

Experiences of stigma within households and perceptions that family members are engaged in stigmatising behaviours were found to be rare. This is consistent with previous research from South Africa (Skhosana *et al.*, 2006; Maughan-Brown, 2006b) and thus adds to the emerging evidence of general support for PLWHA from family members. Further research is needed to assess the various contexts, beyond the confines of the household, in which stigma is experienced.

Health-related problems appeared to be the most significant determinant of experienced stigma: respondents with poorer health, particularly at the start of HAART, reported more experienced stigma. This supports Alonzo and Reynold's (1995) stigma trajectory theory that stigma is dependent on the biophysical stages of HIV and AIDS, with greater degrees of stigma associated with increased physical manifestations of disease. This result is consistent with qualitative work conducted in Cape Town which found that some participants experienced stigma as a result of visible signs of illness, even before they were diagnosed HIV-positive, and once HAART restored their health, people stopped believing they were HIV-positive (Almeleh, 2006). This highlights the dynamic nature of stigma and that people are 'confronted by different social and individual circumstances as the disease progresses' (Almeleh, 2006: 32). Importantly, if periods of ill-health intersect with both disclosure (as Almeleh discovered) and stigma then the popular view of HIV/AIDS will continue to be one of a stigmatised debilitating and fatal disease (rather than one in which a person may live in good health).

The findings suggest that respondents that received HAART from the Site C clinic experienced and perceived significantly more stigma than respondents from any other clinic. This indicates the importance of community-level variables in shaping PLWHA's experiences and fears of stigma. Future identification of the factors contributing to a more highly stigmatised environment in Site C (clinic staff, levels of HIV/AIDS knowledge or religious organisations giving certain messages, for example) could well contribute to the design of appropriate interventions to combat stigma.

Evidence of resource-based stigma was indicated by the significant negative relationship between the percentage contribution of individual income to household income and experienced stigma. Given that irrational fears of infection and moralistic judgements also appear to influence the stigma experienced by PLWHA, this finding emphasises the complexity of HIV/AIDS-related stigma and indicates that methods to measure stigma need to be multi-dimensional.

Perceived stigma was influenced by experienced stigma and religious affiliation. Thus, moral associations made with HIV/AIDS may influence the development of perceived stigma and is suggestive of the role that religious organisations could play in reducing stigma.

HIV/AIDS-related stigma is a complex phenomenon. There is a great deal we still do not know and many avenues still to be explored. The findings of this paper suggest that the most productive of these are likely to be more detailed investigation into precisely what it is that differentiates some sites from others in terms of experiences and perceptions of stigma; examination of the dynamics behind the disjuncture between experienced and perceived stigma; and further research into the social context beyond the confines of the household, in which stigma is experienced.

Appendix A: A Summary Of The Independent Variables And Related Survey Questions

Variable Name	*Description*	*Value Range*	*n*	*Source question(s) from KSPS 2004/05*
Gender	Binary variable with female as the base	0/1	242	z8
Age	Age	16-64	242	a18_year & a2_year
Education	Highest completed grade of education	0-12	242	a5
Religious affiliation	Binary variable indicating affiliation to any religious group with no affiliation as the base	0/1	241	c60
Years HIV positive	Number of years since HIV diagnosis	0.8-15	242	a18 & a6
General state of health during the first six months on HAART	Average of health perceptions at the start of HAART, 3 month into HAART and 6 months into HAART	1-10	242	a9_start, a9_3mnth & a9_6mnth
Health at time of interview	Perception of health at the time of interview	1-5	239	d1
Side-effects in the 3 months prior to the interview	Experience of side-effects due to HAART in the 3 months prior to KSPS 2004/05.	0-12	239	a13a_5 & a13a_7
Illness effect on households at the start of HAART *or* in the 3 months prior to the interview	Degree to which illness affected households at the start of HAART and the current household in the past 3 months	0-3.9	242	c49_1-c49_5 & c51_1-c51_5
Working	Currently working	0/1	241	f12
Personal income at the time of interview	Personal income at the time of the interview from grants (disability, child support or pension), wage income and self-employment profits.	0-5300	242	a26b; a30b; a31b; a32b; f20; f52; g9
SiteB	HAART received from Site B clinic	0/1	240	a10
MichaelM	HAART received from Michael M clinic	0/1	240	a10
SiteC	HAART received from Site C clinic	0/1	240	a10

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