

Change in HIV-related stigma in South Africa between 2004 and 2016: a cross-sectional community study

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Abstract

A critical component of an AIDS-free generation is to reduce HIV-related stigma. Previous research predicted that stigma would decline over time with increased contact with PLWH, understanding of the disease and availability of treatment. The aim of the research was to explore change in stigma over a 12-year period, by comparing data collected from two large cross-sectional samples from South African communities in 2004 (before the roll-out of antiretroviral treatment (ART)) and in 2016. Students recruited respondents according to criteria related to age, gender, race and area of living. A survey assessing moral judgement and interpersonal distance was used to assess personal and perceived community stigma. Responses to ten identical items used in the 2004 and 2016 data collection were compared. Personal stigma attached to HIV decreased significantly over time, except in respect of having close contact with PLWH, such as dating and befriending. Perceived community stigma remained high in all subgroups. It is argued that perceived community stigma contributes to high levels of internalised stigma among PLWH. Interventions should focus on helping PLWH to cope with perceived stigma and strategies to address stereotyping, which contributes to perceived community stigma.

Keywords: HIV-related stigma, community sample, change over time, South Africa

Introduction

Since HIV/AIDS first appeared, it has been associated with fear, stigmatisation and discrimination (Parker & Aggleton, 2003). Stigma is described as a social construction reflecting deviance from an expectation, contributing to a discrediting social label that changes individuals' status in society (Goffman, 1963). Stigma becomes a social process of power that distinguishes, controls or excludes the actions of some groups along the lines of inequalities in society (Gilbert, 2016; Link & Phelan, 2014).

A critical component of an AIDS-free generation is to reduce HIV-related stigma (Grossman & Stangl, 2013; UNAIDS, 2010), because stigma is reported to have pervasive effects on all aspects of HIV-prevention and treatment (Katz et al., 2013; Mall et al., 2013; Stangl et al., 2013; Tsai et al., 2013) and the lives of people living with HIV (PLWH) (Lowther et al., 2014; SANAC, 2015; UNAIDS, 2014). Existing research predicted that HIV-related stigma would decline over time with increased contact with PLWH, understanding of the disease and availability of treatment (Brown, Macintyre, & Trujillo, 2003; Genberg et al., 2009; Mahajah, Sayles, & Patel, 2008; Visser et al., 2009). Apparently, no research has investigated the validity of these expectations and the effects of various interventions the past 12 years guided by two national strategic plans (SANAC, 2006; 2011) on HIV-related stigma. This research explores change in community HIV-related stigma the past 12 years since ART was introduced in the public health sector.

Forsyth and colleagues (2008) found a decrease in personal stigma and an increase in perceived community stigma over a one-year period (2004–2005), using cross-sectional samples from Tshwane. Similarly, Mall et al. (2013) who compared data from two community-based cross-sectional surveys performed four years apart (2004 and 2008) in a Western Cape semi-rural area, found that levels of HIV-knowledge had increased and HIV-related stigma had decreased over time. These changes were related to knowing

PLWH and having been tested for HIV. In contrast, Maughan-Brown (2010) found an increase in HIV-related stigma in data collected in 2003 (before ART roll-out) and 2006 (after ART roll-out) among young people (14 to 22 years) in Cape Town. The availability of ART and increased contact with PLWH was not associated with stigma scores.

There is thus contradictory results of change in stigma over the course of time. These studies did not compare changes over a long term. The aim of the current research was to explore change in stigma over a 12-year period by comparing data collected in 2016 with findings of research conducted in 2004 (Visser, Makin, & Lehobye, 2005).

Methodology

Two community-based cross-sectional surveys performed 12 years apart were compared to explore changes in HIV-related stigma over time.

Respondents

Third-year psychology students recruited respondents representing different gender, race and age groups in their neighbourhoods around Tshwane to complete a questionnaire as part of a course assignment. A convenience sample of 901 respondents were recruited in 2004 (Visser et al., 2005) and 1431 in 2016. Students received training in interviewing skills, data collection and research ethics. The data quality was controlled.

Measuring instrument

The survey consisted of two parallel stigma scales (Visser et al., 2008) to assess 1) personal stigma (perceptions of and reactions towards PLWH) and 2) perceived community stigma (stigma respondents attribute to *most people* in their community). These scales assess two core components of HIV-stigma in an African context: moral judgement and interpersonal distancing (Maman et al., 2009; Mbonu, Van den Borne, & De Vries, 2009; Nyblade, 2006).

A four-point response scale was used. In 2004 a pilot version of these two scales were used, where ten items were exactly the same and could be used as comparison. In the 2016-survey three stigma indicators used in the Demographic and Health Surveys were added to assess subtle discrimination (Table 3). All scales showed acceptable Cronbach's internal consistency scores (Table 1) (DeVellis, 2012). Cronbach's alpha scores were lower for 2004-subcales because less items were used.

Table 1 Reliability of scales

Scale and subscales	2016	2016	2004	2004
	Number of	Cronbach's	Number of	Cronbach's
	items*	alpha	items**	alpha
Personal stigma scale	14 items	0.88	10 items	0.80
Moral judgement subscale	7 items	0.79	4 items	0.66
Interpersonal distance subscale	7 items	0.85	6 items	0.75
Perceived community stigma	16 items	0.91	10 items	0.78
Moral judgement subscale	9 items	0.85	4 items	0.67
Interpersonal distance subscale	7 items	0.87	6 items	0.69

* All items of the 2016 scales were used.

** Only the corresponding items of the 2004 data collection were used.

Data analysis

In calculating scale scores, records with more than two missing values were deleted. Scales scores of the 2004 and 2016 data were compared using t-tests for independent samples.

Factors associated with each scale were identified for the 2016 data using ANOVA in the GLM procedure.

Ethics approval

Ethical approval was obtained from the Faculty of Humanities, University of Pretoria. All participants signed informed consent forms and participated voluntarily. No identifying data of respondents was captured.

Results

The 2004-sample had slightly more females and respondents older than 25 years and fewer black respondents than the 2016-sample (Table 2). Although it was expected that more people in the 2016-sample would know PLWH because of the development of the disease, the increase was small.

Table 2 Socio-demographic characteristics of the two samples

		2016 (n=1431)	2004 (n=901)
Gender	Male	705 (49.3%)	380 (42.2%)
	Female	706 (49.3%)	517 (57.4%)
	Unspecified	20 (1.4%)	4 (0.4%)
Age	18–19	254 (17.7%)	
	20–21	474 (33.1%)	578 (64.1%)
	22–23	373 (26.1%)	
	24–25	317 (22.2%)	
	25+		317 (35.2%)
	Unspecified	13 (0.9%)	6 (0.7%)
Race	Black	548 (38.3%)	265 (29.4%)
	White	617 (43.1%)	525 (58.3%)
	Coloured	129 (9.0%)	63 (7%)
	Indian	132 (9.2%)	45 (5%)
	Unspecified	5 (0.4%)	3 (0.3%)
Living area	Urban	1 208 (84.4%)	745 (83%)
	Rural	213 (14.9%)	135 (15%)
	Unspecified	10 (0.7%)	21 (2%)
Know someone with HIV	Yes	565 (39.5%)	283 (31.4%)
	No	860 (60.1%)	606 (67.3%)
	Unspecified	6 (0.4%)	12 (1.3%)

The two samples were compared in respect of responses per item (see Table 3) and the scale scores using corresponding items (see Table 4). The personal stigma scores of

respondents in the 2016-sample were significantly lower than those in the 2004-sample ($p < 0.0001$) on both subscales. The 2016-respondents showed less moral judgement of and distancing from PLWH, except in respect of dating and befriending PLWH (Table 3) – referring to close personal contact. One in four respondents would be ashamed if a family member had HIV and would be hesitant to test for HIV.

Table 3 Comparison of the responses of the 2004 and 2016 samples

Moral judgement	Personal stigma		Perception of community stigma	
	2016 (%) N=1431	2004 (%) N=862	2016 (%) N=1431	2004 (%) N=862
Getting HIV is a punishment for bad behaviour.	12.7	22.5	63.2	55.2
People with HIV have only themselves to blame.	16.4	27.0	67.3	67.2
People with HIV deserve as much respect as anyone else.	92.2	85.4	55.6	55.3
People with HIV should feel ashamed about having HIV.	9.7	21.9	52.4	57.0
People with HIV must have done something wrong to get it.	19.2		67.2	
I/People would think less of someone if I/people find out the person has HIV.	12.2		73.2	
I/People would be ashamed if someone in my/their family has HIV.	23.9		76.3	
People talk badly about people living with /thought to be living with HIV.			70.2	
People living with/thought to be living with HIV lose respect or standing in my community.			72.5	
Interpersonal distance				
I/People feel uncomfortable around someone with HIV.	29.4	43.2	77.0	79.9
I/People would employ a person even if it is known that he/she has HIV.	74.8	45.6	39.1	24.8
I am/People are afraid to be around a person with HIV.	19.6	35.5	63.9	80.4
I/People will not date a person if I/they know the person has HIV.	76.9	72.0	86.6	88.5
I/People would not like to be friends with someone with HIV.	13.48	10.8	56.0	45.7
I/People would be upset if someone with HIV moved in next door.	5.8	13.2	36.8	48.2
I/People would not like to sit in public transport next to someone with HIV.	14.0		51.9	
Other items				
I/People would be hesitant to take an HIV test due to fear of people's reaction if the result is positive.	25.1		77.4	
I take care to protect myself from HIV.	97.1		67.2	

Note: Strongly agree and agree responses were combined to form a positive response.

Perceived community stigma scores remained similar over time. Perceived moral judgement even increased significantly from 2004 to 2016. Respondents perceived that PLWH loose respect and standing in the community (72%). The perception was that people were less afraid of contact with PLWH (64% vs 80%) but would not like personal contact with them (56% vs 46%) (Table 4).

Table 4 Comparison of 2016 and 2004 stigma scores

Scale and subscales	2016 mean	2004 mean	T	p
Personal stigma scale	2.14	1.93	-9.77	<0.0001
Personal: Moral judgement subscale	2.29	2.10	-8.01	<0.0001
Personal: Interpersonal distance scale	2.03	1.83	-8.00	<0.0001
Perceived community stigma	1.29	1.31	0.96	NS
Community: Moral judgement subscale	1.34	1.42	3.07	<0.01
Community: Interpersonal distance subscale	1.26	1.25	-0.21	NS

Note: Low score indicates high stigma level
NS: not significant

Stigma in different subgroups

The 2016-results showed that high levels of personal stigma among respondents were related to being male ($p<0.0001$), being white ($p<0.001$) and living in a rural area ($p<0.0001$), similar to the 2004-data (Visser et al., 2005). Knowing PLWH did not predict less stigma in the 2016-data. Respondents who were hesitant to test for HIV because they feared people's reaction, showed significantly more personal stigma ($p<0.001$) than those who did not fear being tested.

Perceived community stigma was high among respondents irrespective of demographic characteristics, similar to the 2004-results (Visser et al., 2005). The only difference was that white respondents, more than other race groups ($p<0.001$), perceived others to distance themselves from PLWH.

Discussion

The findings of this study show that 2016-respondents showed significantly less moral judgement and social distancing towards PLWH than 2004-respondents. The 2016-respondents did not associate HIV with morality issues similar to previous research (Mbonu et al., 2009; Ogden & Nyblade, 2005; Visser et al., 2009). Some respondents still seemed to regard close personal contact, such as being friends with and dating PLWH and having family who lived with HIV as threatening. A quarter of the respondents were hesitant to test because they feared community reaction. They thus presented with low personal stigma but attributed stigma to others.

It is concerning though that perceived community stigma has remained high or even increased over the past 12 years and is prominent among respondents irrespective of demographic characteristics – like in previous research (Forsyth et al., 2008; Visser et al., 2005; 2009). Perceived community stigma reflects the general perception of HIV/AIDS in a community (how they feel about and respond to it) (Green, 1995). It develops over time due to misconceptions, fear, community observations and negative media reporting. PLWH are aware of these general perceptions. As a result they fear being judged, isolated and discriminated against - reflected in high internalised stigma (SANAC, 2015; UNAIDS, 2014).

The question arises which stigma score gives a true reflection of the level of stigma in the community? Social behaviour is influenced by personal attitudes and perceptions of community beliefs (Ajzen, 1991; Parker & Aggleton, 2003), therefore both these stigmas can influence behaviour, depending on the social situation. Community

stigma may be over-estimated though as individuals perceive themselves more positively than others (Miller, 2005).

Both studies found that personal stigma was higher among males, white respondents and in rural areas. Less exposure to the epidemic could influence stigma among white participants. Although, in contrast with previous research (Mall et al., 2013), knowing PLWH did not influence personal stigma in the 2016-sample. All respondents' stigma scores had declined, whether they had contact with PLWH or not. The finding that respondents who were hesitant to test, showed more personal stigma, corroborated the findings of Mall et al. (2013).

It should be kept in mind that the two large convenience cross-sectional samples recruited by students might not have been representative of the population. Despite that, data patterns were similar to those of other research (Forsyth et al., 2008; Mall et al., 2013).

Conclusion

The research provides evidence of decreasing personal stigma, specifically moral judgement and interpersonal distance in communities the past 12 years. In contrast, perceived community stigma has remained high. Focused community interventions are needed to assist PLWH to cope with the perceived stigma (SANAC, 2015). It is believed that evidence-based community interventions (Nyblade et al., 2009; Pretorius et al., 2016; Sengupta, et al., 2011; Stangl et al., 2013) could effectively reduce perceived community stigma in South Africa.

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