

Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

International Journal of Africa Nursing Sciences

journal homepage: www.elsevier.com/locate/ijans

Exploring intersectionality and HIV stigma in persons receiving HIV care in nurse-led public clinics in Durban, South Africa

Dudu G. Sokhela^{a,*}, Penelope M. Orton^{b,c}, Kathleen M. Nokes^{c,d}, William E. Samuels^e^a Department of Nursing, Durban University of Technology, PO Box 1334, Durban 4000, South Africa^b Durban University of Technology, South Africa^c Durban University of Technology, South Africa^d Durban University of Technology and International Nursing Network for HIV Research, South Africa^e Hunter College, City University of New York, United States

ARTICLE INFO

Keywords:

HIV
 Enacted HIV stigma
 Anticipated HIV stigma
 Internalizing HIV stigma
 Intersectionality

ABSTRACT

Background: Although stigma associated with South African people living with HIV has declined since the 1980s when HIV/AIDS was first identified, it still persists. Stigma is associated with poor health outcomes and avoidance of interactions with healthcare systems. The HIV stigma framework distinguishes three HIV-related self-stigma mechanisms.

Aims: The aims of this study were to explore intersectionality between HIV-stigma mechanisms and selected sociodemographic as well as HIV factors, and interrelationships between three HIV-related self-stigma mechanisms.

Setting and method: This study was a secondary analysis of data collected from a cross-sectional sample of people receiving HIV-related primary health care at different municipal clinics in Durban, South Africa ($N = 100$).

Results: The average participant was Black African, female, unemployed, with a monthly income below R2 500, most had completed primary school. No sociodemographic or HIV-related factors were significantly related to total or subscale HIV stigma scores. Respondents reported experiencing (enacted) no stigmatization, did not expect to experience (anticipated) much stigmatization from their social interactions with family, community, healthcareworkers, and reported no strong stigmatizing beliefs about themselves (internalized).

Conclusion: Intersectionality did not identify any particular socio-demographic or HIV-related factor associated with greater HIV stigma. Participants reported low HIV stigma arising from interactions with healthcare and social service providers or families. Although no socio-demographic or HIV-related factors were significantly associated with HIV stigma mechanisms in this relatively homogeneous sample, being marginalized can nevertheless result from living with other differences compared to societal norms and result in particular vulnerability when living with HIV/AIDS.

1. Introduction

Throughout history, fear of infection and being associated with affected people has resulted in stigmatization (Relf, Holzemer, Holt, Nyblade, & Caiola, 2021). Stigma affects those targeted by it psychologically and restricts social participation, often resulting in marginalization of a vulnerable population (van Brakel et al., 2019). Although stigma associated with South African people living with HIV (PLWH) has declined since the 1980s when HIV/AIDS was first identified, it still persists. HIV stigmatization occurs when people are seen in a negative light because of their HIV positive status (Abiri, Oakley, Hitchcock, &

Hall, 2016). Stigma is often associated with poor health outcomes and health utilization patterns. These factors may, in turn, make HIV-infected individuals hesitant to seek care if they fear that doing so will be stigmatizing and lead to prejudice and discrimination (Kane et al., 2019).

Intersectionality recognizes the impact of multiple social statuses such as gender and socioeconomic level. Intersectional stigma recognizes the convergence and impact of multiple stigmatized statuses (Relf et al., 2021). Intersectional stigma can result from multiple socio-demographic factors such as gender, age and employment status, along with being HIV infected. Thus, PLWH may be affected by multiple

* Corresponding author.

E-mail address: dudus@dut.ac.za (D.G. Sokhela).<https://doi.org/10.1016/j.ijans.2023.100596>

Received 9 November 2021; Received in revised form 15 June 2023; Accepted 11 August 2023

Available online 17 August 2023

2214-1391/© 2023 Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

sources of stigmatization. Significantly fewer men compared to women living in sub-Saharan countries have been tested for HIV and, unlike women, men who expressed anticipated HIV stigma had a 35% lower rate of HIV testing (Ha et al., 2019). A study of pregnant women in rural Kenya in 2011 found that 45% of the sample anticipated that they would lose their friends if they disclosed their HIV status to them, and, because of this fear, 6% in the overall study refused to be tested (Turan et al., 2011).

In a 2021 study in Kenya of women with unintended pregnancies and living with HIV, 52.6% of the sample did not report experiencing HIV-related discrimination. However, some reported that people's attitudes made them feel worse about themselves, felt that their bodies were disgusting, and experienced guilt due to their HIV status (Dwyer, Jain, Liambila, & Warren, 2021). HIV-infected married women reported that when disclosure to their spouses resulted in conflicts and fear of stigma/discrimination, they delayed disclosing their HIV status to others (Okareh, Akpa, Okunlola, & Okoror, 2015). In general, women have been found to be more likely to perceive HIV stigma, including internalized stigma, and feel less valued socially, more marginalized, or lacking in a valued social identity (Cuca et al., 2017).

The relationship between age and HIV stigma is complex. In general, older adults report less stigma (Emlet et al., 2015). A meta-analysis of 24 studies found a negative relationship between age and stigma, with younger people reporting greater levels of stigma (Lee, Kochman, & Sikkema, 2002; Vanable, Carey, Blair, & Littlewood, 2006; Wagner et al., 2010; Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2009). Younger South African women (aged 15 to 25 years) who were, employed, married or cohabiting with a partner, temporarily not living in the same house, had only completed secondary school education, reported more stigma than those from other demographic strata (Simbayi et al., 2017).

HIV-related stigma and discrimination in workplaces may be prevalent in most affected societies. In Tanzania, divorced respondents and those who had family members with HIV and who had been in the workplace for five years or more reported more frequent and severe HIV related discrimination than other workers, while female workers reported more discrimination than males (Kassile, Anicetus, & Kukula, 2015). A Ugandan study indicated that those who were stigmatized were perceived as immoral by fellow employees and those who perpetuated the stigma on others tended to be less educated and unaware of the effects of stigma and were viewed by fellow employees as backward (Twinomugisha & Marguerite, 2011).

Stigma is not a unidimensional concept, since it is also a fundamental cause of health inequities (Relf et al., 2021), it is important to understand its complexity. Stigma can arise from sociodemographic factors such as gender along with health-related issues, especially those with infectious aetiologies. Intersectionality theory has advanced understanding of the role of social context by highlighting the way individuals' multiple identities such as gender, sexuality, race, ethnicity, ability, socio-economic status, age and others interact with social systems of power in diverse and changing contexts (Heard, Fitzgerald, Wigginton, & Mutch, 2020). While, individuals and groups may share apparent and commonly acknowledged membership in certain groups or identities, they simultaneously are connected to members of other groups and identities that can be equally influential (Millburn, Beatty, & Lopez, 2019). The mechanisms of action of HIV-related stigma interact with multiple co-occurring statuses or positions of the person with HIV to generate some variation of intersectional stigma (Relf et al., 2021). We were interested in whether sociodemographic and HIV-related factors would interact with different types of HIV-related stigma.

2. Conceptual framework

Stigmatization originates in the cognitive representations that people hold regarding those who possess the stigmatized condition (Bos, Pryor, Reeder, & Stutterheim, 2013). Each society has its own approach

to categorizing people and identifying attributes that they consider to be ordinary and natural (Goffman, 2009). When people present themselves, they may have an attribute deemed by their society as being different and less desirable, resulting in the perception that the person is not "whole" and usual, but tainted and discounted; this attribute is a stigma. Attributes can either be obvious resulting in the stigmatized person being discredited or hidden resulting in the stigmatized person becoming discreditable. Discreditable individuals have a stigma that is predominantly concealable such as HIV infection (Chaudoir, Earnshaw, & Aniel, 2013). Stigma adversely affect the behaviours, physical and psychological health outcomes, and social functioning of PLWH (Ma, Chan, & Loke, 2019).

Most stigma research has focused on the individual level or self-stigma, which refers to how individuals respond to possessing a stigma. In comparison, public stigma is manifested via stigma mechanisms that occur at individual, inter-personal, and sociocultural levels. Stigma mechanisms are psychological responses by people who believe they have one or more characteristic that is socially devalued. The HIV stigma framework (Earnshaw & Chaudoir, 2009) identifies three HIV-related self-stigma mechanisms consistent with the three responses of how public stigma affects an individual (Bos et al., 2013). These three stigma mechanisms are: anticipated stigma which is an expectation of experiencing discrimination from others at some point in the future; enacted stigma which is having experienced discrimination from others in the past or present; and internalized stigma which is endorsement and application of negative beliefs and feelings that PLWH apply to themselves (Earnshaw & Chaudoir, 2009).

3. Aims and objectives

The aims of this study were to explore the intersectionality between HIV-stigma mechanisms and selected sociodemographic (age, gender, education, employment, monthly income, marital status, children living with them, and recent sexual activity) and HIV-related (years living with HIV/AIDS, CD4 cell count, viral load, and adherence to HIV medications) factors and the interactions between the three HIV-related self-stigma mechanisms.

The objectives of the study were to:

- Describe the intersectionality between HIV-stigma mechanisms and selected sociodemographic (age, gender, education, employment, monthly income, marital status, children living with them, and recent sexual activity) and HIV-related (years living with HIV/AIDS, CD4 cell count, viral load, and adherence to HIV medications) factors.
- Describe the interrelationships between the three HIV-related self-stigma mechanisms as reported by PLWH.

4. Methods

4.1. Study design

This study was a secondary analysis of data collected from a cross-sectional sample of PLWH who were receiving primary health care at different municipal clinics in Durban, South Africa. As members of the International Nursing Network for HIV Research (Holzemer, 2007), we developed the protocol for the primary study.

4.2. Setting

Respondents were recruited at six nurse-led public eThekweni municipal primary care clinics in Durban, South Africa. The eThekweni district is situated in KwaZulu-Natal (KZN), one of South Africa's nine provinces, and faces various social, economic, and health challenges (eThekweni Municipality, 2011). The total population of eThekweni district is 3 442 361 and makes up a third of the population of KZN;

Blacks constitute 73.8% of this population (KwaZulu-Natal Department of Health, 2018). According to the *South African National HIV Prevalence, Incidence, Behaviour, and Communication Survey*, KZN has the highest prevalence of HIV in South Africa (18.1%) (Simbayi et al., 2017).

4.3. Study population and sampling strategy

The sample and its recruitment are described in detail by Orton, Sokhela, Nokes, Perazzo and Webel (2021). Briefly, we recruited a convenience sample of 100 respondents who were 18 years old or older, confirmed HIV positive (according to their medical records), taking ART, and accessing HIV-related care at least every six months. Potential respondents were informed about the purpose of the study and how they were expected to participate. Those who agreed to participate gave written informed consent.

We estimated the sample size required to find what may be considered a “medium” effect, namely, $f^2 = 0.15$ (Cohen, 1988) for multiple regression analyses, (which subsumes generalized linear regressions such as these) (Hutcheon, Chioloro, & Hanley, 2010). We estimated that we would need 125 respondents to detect such a medium effect in the overall model (i.e., for each of the stigmatization outcomes) with the set of predictors used ($df_{\text{numerator}} = 16$) and when setting $\alpha = 0.05$ and $1 - \beta = 0.8$. We were able to collect data from 100 individuals, so our analyses are slightly underpowered. Although it is tenuous to rely on postdictive power (Yuan & Maxwell, 2005), we estimate that the power for our tests was 0.68, assuming $f^2 = 0.15$. The overall model effect sizes we obtained using the recommended adjusted likelihood-ratio-based (Nagelkerke, 1991) were 0.65 for Anticipated, 0.65 for Enacted, and 0.72 for Internalized. These high post hoc values suggest both that we would need fewer respondents ($n \approx 29$) and that the results we obtained model our data well.

4.4. Data collection tools

Respondents completed the study instruments with the help of the isiZulu-speaking research team members when respondents requested this assistance. Instruments were collected by the researchers and research assistant as soon as they were completed and placed in sealed envelopes. HIV related data was accessed through the medical record. Data were collected between September and November 2018.

The study packet consisted of instruments that asked about socio-demographic and HIV related factors, and the HIV Stigma Mechanism Measure. HIV viral load was divided into two categories: “undetectable” which, according to the South African Department of Health, is 50c/mL or less, and “detectable” which is greater than 50c/mL (Department of Health, 2019). The HIV Stigma Mechanism Measure measures three types of stigmatization: anticipated $f^2 = 0.15$ stigma, 9 items, e.g., “family members will treat me differently”; enacted stigma, 9 items, e.g., “community/social workers have discriminated against me”; and internalized stigma, 6 items e.g., “I think less of myself because I have HIV.”

A 5-point Likert type scale was used where higher scores indicated greater stigma (Earnshaw, Smith, Chaudoir, Amico, & Copenhagen, 2013). Items were averaged to create composite subscale scores (Earnshaw, Rosenthal, & Lang, 2016). Total HIV stigmatization scores were then computed by summing a respondent’s scores on each of the three subscales; each subscale score could then range from 1 to 5 while the total score could therefore range from 3 to 15. Cronbach’s α for this sample were 0.88, 0.81, and 0.93 for the anticipated, enacted, and internalized subscales, respectively.

4.5. Data preparation and analysis

Responses were collected via Redcap, a secure web application used to build and manage online research surveys and the resultant data. Data were regularly checked for quality. Data were cleaned and evaluated for

their adherence to assumptions of normality through Q-Q and density plots as well as through investigations of potential heteroskedasticity in the models’ residuals (visually and with Breusch-Pagan tests). There were no discernible patterns of heteroskedasticity (largest $\chi^2_{\text{Breusch-Pagan}} = 22.21$, $df = 13$, $p = .052$). Nonetheless, we employed generalized linear regressions which are more robust to degrees of heteroskedasticity than, for example, ANOVAs (Greene, 2012).

Although Q-Q and density plots suggested that the data for all ordinal and continuous variables were monotonic, the data’s distributions deviated from normality. These plots, as well as a review of the descriptive statistics in Table 3, note that this heteroskedasticity is largely because of restrictions to the data’s ranges and because many of the respondents did not report much perceived or internalized stigma. Generalized linear models can model these data more flexibly than ANOVAs since the former can test non-normal distributions of the data by design.

Pair-wise differences between levels and groups were analysed via Welch’s t -, χ^2 -, or Fisher’s exact tests where appropriate, and based on the assumptions possible for the given variables. Relationships between multiple variables and particular outcomes were investigated through generalized linear models using identity link functions. As noted above, these allowed analyses to better accommodate the distributions of these data.

Before being added to these models, variables were either standardized (with means = 0 and SDs = 1) or included as dummy variables both to eliminate the need for an intercept term and, more importantly, to facilitate analyses and interpretations. Dummy variables were all coded so that the presence of a given trait (e.g., being employed, being married/cohabitating, etc.) was coded as 1 and the absence thereof (e.g., being unemployed, single/widowed, etc.) was coded as 0. Data were analysed using R version 3.6.3 (R Core Team, 2020) interfaced via RStudio version 1.3.1008. R packages used included lmer (version 0.9–37) (R Core Team, 2020), psych (version 1.9.12.31) (Greene, 2012), and pwr (version 1.3–0) (Champely, 2020).

4.6. Ethical considerations

Ethics clearance was obtained from the Institutional Research Ethics Committee of the University in Durban (REC 87/16). Permission to conduct the study was obtained from the eThekweni Municipality Health Unit Research Committee. Respondents were informed about the purpose of the study, handed information letters and those who were willing to participate signed a consent form.

5. Results

5.1. Description of the respondents

Table 1 includes summaries of the respondents’ sociodemographic characteristics. In summary, most of the sample identified as Black African (99%) women (82%) who were not currently employed (67%) with monthly incomes that were either less than R2 500 (31%) or who had no monthly income (44%). Most (69%) had completed either some or all primary school grades, although 18% reported receiving no formal schooling and 13% had completed some or all of the secondary school grades. Although most (77%) of the respondents were currently single and had not been sexually active in the last 3 months (73%), most had at least one child (mean = 1.6, $SD = 1.4$) living with them. The proportions of these characteristics did not differ between the genders.

Men tended to be older ($t = 2.39$, $df = 21.4$, $p = .026$) and diagnosed as living with HIV for 3.67 years compared to 5.85 years for women ($t = 2.11$, $df = 30.1$, $p = .044$). Males also tended to have lower CD4 cell counts ($t = -2.75$, $df = 34.6$, $p = .001$) which might be a result of poor viral control or starting treatment later in the course of infection. Although 72% of the women had an undetectable viral load compared to 61% of the men, this difference was not significant ($p = .498$, Fisher’s

Table 1
Sample characteristics (N = 100).

	Overall (N = 100)	Men (N = 18)	Women (N = 82)	p- value
Age¹ Mean (SD)	38.46	44.67	37 (9.33)	<<0.001
Range	(10.45)	(12.82)	21 to 62	
Missing	21 to 77 05%	29 to 77 0%	years 6%	
Race/ethnicity				
Black African	99 % ²	100%	99%	≈ 1
Colored	01%		01%	
Missing	0%	0%	0%	
Employment				
Working	33%	44%	30%	≈ 1
Not working	67%	56%	70%	
Missing	0%	0%	0%	
Monthly income				0.318
No monthly income	44%	50%	43%	
R2500 or less	31%	17%	35%	
R 2500 or greater	24%	33%	22%	
Missing	01%	0%	01%	
Education				0.224
No schooling	18%	22%	17%	
Some primary schooling	39%	50%	37%	
Completed primary school	30%	11%	34%	
Some or completed secondary or higher	13%	17%	12%	
Missing	0%	0%	0%	
Marital status				>0.339
Married or partnered	19%	28%	17%	
Widowed	04%	06%	04%	
Single	76%	61%	80%	
Missing	01%	05%	0%	
Have children				0.344
Yes	92%	100%	90%	
No	08%	0%	10%	
Missing	0%	0%	0%	
Average (SD) number living with you	1.59 (1.35)	1.29 (1.4)	1.65 (1.34)	
N Missing	2	1	1	
Sexual activity in last three months				0.245
Yes	27%	39%	24%	
No	73%	61%	76%	
Missing	0%	0%	0%	
30-Day adherence				0.250
Mean (SD) adherence	88.53	91.11	87.95	
Range	(17.25)	(7.44)	(18.73)	
N Missing	0 – 100	75 – 100	0 – 100	
	1	0	1	
30-Day rating				0.215
Mean (SD) adherence	4.29 (1.00)	4.50 (0.71)	4.24 (1.05)	
Range	0 – 5	0 – 3	0 – 5	
N Missing	0	0	0	
Years diagnosed with HIV				<<0.001
Mean (SD) number of years	5.5 (4.61)	3.67 (3.79)	5.85 (4.70)	
Range	1997 – 2018	1997 – 2018	2002 – 2018	
Mean calendar year	2012	2014	2012	
Missing	2	0	2	
Most recent CD4 or T cell count				<<0.001
Mean (SD)	511 (312.07)	366 (217.05)	544 (322.27)	
N Missing	10	1	9	
HIV Viral load				0.498
Undetectable (50c/mL or less)	70%	61%	72%	
Detectable (greater than 50c/mL)	18%	22%	17%	
Missing	12%	17%	11%	

¹ n = 95.

² Percents have been rounded off; there are missing data for some variables.

exact test) likely due to the sample size; most (70%) of the participant's HIV viral loads were undetectable.

Since HIV-related stigma has been associated with health utilization, we measured medication adherence. Respondents reported that their ability to take the medications exactly as prescribed using a 100-point scale, and the mean 30-day rate was 88%. The respondents also rated their ability to reliably take their medications over the last 30 days on a 0- to 5-point scale where higher scores indicated better adherence. On this scale, they reported very good adherence (prior 30-day rating was 4.3); neither of these measures of medication adherence differed significantly between the genders (*ts* = 1.16 & 1.26, *dfs* = 69.34 & 35.64, *ps* = 0.250 & 0.215, respectively).

5.2. Levels of HIV-related stigmatization

Table 2 summarizes the respondents' total and subscale scores on the HIV Stigma Mechanism Measure. The mean total score (4.17) was not far above the minimally-possible value (3), which is consistent with low levels of stigma. Similarly, the scores for each of the three subscales—which could each range from 1 to 5—were all also close to their minima. This was true for both the male and female respondents. Respondents reported experiencing (enacted) no stigmatization, and did not expect to experience (anticipated) much stigmatization from their social interactions. They also did not appear to have stigmatizing beliefs about themselves (internalized). Table 3 breaks these scores down further by presenting the proportion of response options chosen for each item on the HIV Stigma Mechanism Scale and providing the mean (and SD) score for each item. Responses to all of the items tended towards the respondents reporting that stigmatization was “very unlikely” and that they tended to “never” feel that others were treating them differently based on their HIV status. They also tended to “strongly disagree” with all possible ways of measuring internalized stigma.

5.3. Relationships between HIV stigma mechanisms

Table 4 presents the correlations between the total HIV stigma scores and the three subscale scores that comprise it. We can see in this table that all three subscale scores correlate well with the total score (which they comprise), but that internalized stigma subscale scores correlate poorly with anticipated (*r* = 0.24) and especially enacted (*r* = 0.06) stigma sub-scores; anticipated and enacted sub-scores were rather highly correlated (*r* = 0.61).

5.4. Relationships between HIV-stigma mechanisms, sociodemographic, and HIV-related factors

Although the respondents did not report feeling strongly affected by stigma due to their HIV status, it was still possible that any stigmatization they did feel was related to either sociodemographic or HIV-related factors. We investigated this possibility through a series of linear regression models, with a different stigmatization mechanism (from the HIV Stigma Mechanism Scale) as the outcome in each model. We attempted to include all three subscales as outcomes in a multivariate generalized linear model, but did not have enough data for this multivariate model to resolve. We included in each model the sociodemographic and HIV-related factors described in Table 1 except for ethnicity, since all but one participant identified as a member of the same ethnicity (Black African).

Table 5 presents the parameters for each of the variables included as possible predictors of HIV Stigma Mechanism Scale Total scores. As can be seen in this table, none of the predictors were significantly related to total HIV stigma scores. Similarly—as can be seen in Table 6—this set of sociodemographic and HIV-related factors were not significantly related to any of the HIV Stigma Mechanism subscale scores.

The β-weights (i.e., effect sizes) for the terms in the models predicting anticipated and enacted stigma tended to be larger in magnitude

Table 2
HIV Stigma.

	Mean (SD) (n = 100)	Range (n = 100)	Mean (SD) (Men n = 18)	Range	Mean (SD) (Women n = 82)	Range
Total Scale scores	4.166 (1.58)	3.00–10.67	4.101 (1.52)	3.00–7.00	4.180 (1.61)	3.00–10.67
Anticipated subscale	1.378 (0.64)	1.00–3.67	1.203 (0.52)	1.00–3.00	1.417(0.66)	1.00–3.67
Enacted subscale	1.145 (0.41)	1.00–3.67	1.000 (0.00)	1.00–1.00	1.177 (0.45)	1.00–3.67
Internalized subscale	1.641 (1.09)	1.00–5.00	1.898 (1.50)	1.00–5.00	1.585 (0.98)	1.00–5.00

than those predicting internalized stigma (respective mean \pm 95% Cis, mean β s for anticipated and enacted = 0.054 ± 0.27 and 0.045 ± 0.15 ; mean β for Internalized = -0.0011 ± 0.11). The Akaike Information Criteria for the three subscale models were not very different (anticipated = 234.9, enacted = 234.2, and internalized = 217.4), so these general differences in β -weights were not from the model predicting internalized subscale scores being a worse fit to the data—if anything, the internalized model fit the data better than the other two. Internalized stigma may be less related to sociodemographic and HIV-related factors than are anticipated and enacted stigma which merits further exploration since the relationships are too weak here for us to detect with sufficient certainty.

6. Discussion

The first objective of this study was to explore if HIV-stigma mechanisms were affected by selected socio-demographic and HIV-related factors. The finding was that very few socio-demographic factors were related to HIV-stigma. It is not surprising that men reported being diagnosed more recently than women since South Africa's HIV prevention program initially targeted women of child-bearing years. Although women were found to be more influenced than men by community beliefs when deciding whether to be tested for HIV (Treves-Kagan et al., 2017), in the current study no differences were found on socio-demographic or HIV related factors based on gender. The potential of being stigmatized is socially communicated by others who are part of the same community (Treves-Kagan et al., 2017). Stigma is inherently a social construct and as living with HIV becomes more common, and societal norms change and evolve, there can also be a “decline in the capacity of the attribute to serve as a stigma” (Wagner et al., 2010). The province where the research was conducted has the highest prevalence of HIV in South Africa (18.1%) (Simbayi et al., 2017). The setting where data were collected served many HIV infected people and, as the number of infected people in the community has increased, perhaps negative societal norms related to living with HIV have declined.

The second objective of this research was to describe individual HIV-related self-stigma mechanisms as reported by PLWH. Levels of HIV stigma was considered to be low within the sample of people receiving health care in New York City (Earnshaw et al., 2013) but stigma was even lower in this Durban sample (1.93 in New York compared to 1.37 in Durban for anticipated; 1.31 compared to 1.14 for enacted; and 2.15 compared to 1.64 for internalized respectively). A scoping review of stigma in low- and middle-income countries found that stigma was associated with poor health outcomes, including less help-seeking (Abiri et al., 2016). Although the low incidence of HIV stigma was a welcome finding, it was somewhat unexpected since other researchers had found continued prevalence of HIV stigma in a South African population. A different instrument was used to measure HIV stigma in 2015 in a similar sample in Johannesburg with findings indicating that perceived HIV stigma was highly prevalent (88% of respondents) (Revelle, 2017).

6.1. Anticipated stigma

The individual level of public stigma is composed of anticipated, enacted, and internalized self-stigma mechanisms. Anticipated stigma

occurs when one expects to be stigmatized by others at some point in the future, and the anticipated HIV Stigma Mechanism subscale asks about whether the person is anticipating that s/he will be stigmatized by family members, community members, or healthcare workers. Anticipating stigmatization by healthcare workers could result in decreased engagement with the healthcare system and less adherence to treatment. As seen on Table 3 items 7 through 9, less than 3% of the respondents thought that it was likely that they would be stigmatized by healthcare workers. There was no statistical relationship between any of the socio-demographic or HIV-related factors and anticipated stigma (Table 6), although being employed and anticipating less stigma approached statistical significance. There was a weak relationship between internalized and anticipated stigma (Table 4, $r = 0.24$).

6.2. Enacted stigma

Enacted stigma results from having had experienced discrimination from others in the past or present and the enacted HIV Stigma Mechanism subscale asked about whether the person experienced being stigmatized by family members, community members, or healthcare workers. Less than 1% reported having experienced HIV-related stigma through the behaviour of healthcare workers (items 7 through 9 on the enacted subscale). Being older ($p = .08$) and more educated ($p = .06$) and a detectable viral load, which would indicate poor HIV clinical management, ($p = .07$), were associated with enacted stigma, although not significantly so. Research conducted in 2004 with teachers in the same area where this research was conducted found that teachers held HIV-related stigmatizing beliefs towards students (Wadley, Pincus, & Evangelii, 2019), which may explain the association between enacted stigma and more education. There was a strong relationship between enacted and anticipated stigma (Table 4, $r = 0.61$) which would be expected since having experienced stigma could lead to anticipating experiencing it again in a different social situation. Wadley et al. (2019) also reported that a number of respondents in their research (with a similar sample) frequently reported that enacted stigma was not relevant because they had not disclosed their HIV status to people outside of their close social networks because they feared being stigmatized.

6.3. Internalized stigma

When people endorse and apply negative beliefs and feelings about people living with HIV to themselves, they experience internalized stigma and the internalized HIV Stigma Mechanism subscale asks about how they feel about themselves. Nineteen percent agreed with the statement, *Having HIV makes me feel like I'm a bad person (item 1)* and 15% agreed with the statement *Having HIV is disgusting to me (item 6)*. Internalized stigma is weakly related to anticipated stigma ($r = 0.24$) and there is virtually no relationship with enacted stigma ($r = 0.06$), which suggests that people with internalized stigma have not experienced being stigmatized by family, community, or healthcare workers (Table 4). Internalized stigma was not related to any socio-demographic or HIV-related factors indicating that there is no particular at-risk group for internalized stigma. Internalized stigma has been associated with poorer mental health outcomes in a number of studies.

It is possible that respondents had low stigma because they have

Table 3
HIV Stigma Mechanism Scale (n = 100).

How likely is it that people will treat you in the following ways in the future because of your HIV status? (Anticipated stigma subscale)						
	Very Unlikely (1)	Unlikely (2)	Neither Unlikely or likely (3)	Likely (4)	Very Likely (5)	Mean (SD)
1. Family members will avoid me	76%	6%	3%	8%	7%	1.64
2. Family members will look down on me	77%	8%	2%	5%	8%	(1.27) 1.59
3. Family members will treat me differently	78%	8%	3%	3%	8%	(1.24) 1.55
4. Community/social workers won't take my needs seriously	79%	12%	4%	2%	3%	(1.20) 1.38
5. Community/social workers will discriminate against me	83%	9%	5%	0	3%	(0.89) 1.31
6. Community/social workers will deny me services	82%	13%	3%	0	2%	(0.82) 1.27
7. Healthcare workers will not listen to my concerns	85%	8%	5%	1%	1%	(0.70) 1.25
8. Healthcare workers will avoid touching me	86%	10%	2%	2%	0	(0.68) 1.20
9. Healthcare workers will treat me with less respect	86%	9%	2%	3%	0	(0.56) 1.22
How often have people treated you this way in the past because of your HIV status? (Enacted stigma subscale)						
	Never (1)	Not often (2)	Somewhat often (3)	Often (4)	Very often (5)	Mean (SD)
1. Family members have avoided me	89%	4%	0	0	7%	1.32
2. Family members have looked down on me	91%	5%	0	0	4%	(1.03) 1.21
3. Family members have treated me differently	89%	5%	1	0	5%	(0.80) 1.27
4. Community/social workers have not taken my needs seriously	95%	3%	0	1%	1%	(0.90) 1.10
5. Community/social workers have discriminated against me	95%	3%	0	1%	1%	(0.52) 1.10
6. Community/social workers have denied me services	94%	3%	1%	1%	1%	(0.52) 1.12
7. Healthcare workers have not listened to my concerns	94%	5%	0	0	1%	(0.55) 1.09
8. Healthcare workers have avoided touching me	98%	1%	0	0	1%	(0.45) 1.05
9. Healthcare workers have treated me with less respect	97%	2%	0	1%	0	(0.41) 1.05
How do you feel about being HIV-positive? (Internalized stigma subscale)						
	Strongly Strongly Disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly Strongly Agree (5)	Mean (SD)
1. Having HIV makes me feel like I'm a bad person	73%	6%	2%	9%	10%	1.77
2. I feel I'm not as good as others because I have HIV	75%	8%	1%	9%	7%	(1.40) 1.65
3. I feel ashamed of having HIV	74%	9%	2%	9%	6%	(1.28) 1.64
						(1.24)

(continued on next page)

Table 3 (continued)

How likely is it that people will treat you in the following ways in the future because of your HIV status? (Anticipated stigma subscale)	Very Unlikely (1)	Unlikely (2)	Neither Unlikely or likely (3)	Likely (4)	Very Likely (5)	Mean (SD)
4. I think less of myself because I have HIV	77%	8%	3%	7%	5%	1.55 (1.15)
5. Having HIV makes me feel unclean	75%	8%	2%	9%	6%	1.63 (1.24)
6. Having HIV is disgusting to me	78%	5%	2%	8%	7%	1.61 (1.27)

Table 4
Correlations between stigma types measured by the HIV Stigma Mechanism Scale.

	Total Stigma	Anticipated	Enacted	Internalized
Total Stigma Score	1	0.73	0.55	0.81
Anticipated	0.73	1	0.61	0.24
Enacted	0.55	0.61	1	0.06
Internalized	0.81	0.24	0.06	1

Table 5
Variable Parameters for a Linear Regression Model Predicting Total HIV Stigma.

Predictor	β	<i>t</i>	<i>p</i>
Age	0.20	1.18	0.243
Gender	-0.02	-0.07	0.948
Employment	-0.64	-1.80	0.077
Monthly Income \leq R2500 ¹	-0.10	-0.31	0.759
Monthly Income $>$ R2500 ¹	0.44	1.02	0.310
Education	0.17	1.09	0.280
Marital Status ²	0.16	0.50	0.617
Has Children?	0.07	0.23	0.821
Sexually Active (last 3 mos.)	-0.16	-0.59	0.556
Years Diagnosed with AIDS	0.07	0.59	0.556
CD4 Count	0.00	0.03	0.978
Detectable Viral Load	0.24	0.76	0.451
30-Day Adherence	0.04	0.15	0.878
30-Day Rating	-0.01	-0.04	0.969

1. Referent level is no monthly income.
2. Levels are single / widowed = 0; married / living with partner = 1.

lived with HIV for a long time; more than a year. In addition, they attended health facilities quite often to collect medication and were familiar with health care workers, who might have worked with HIV

Table 6
Variable Parameters for a Linear Regression Model Predicting HIV Stigma Mechanisms.

Predictor	Anticipated Stigma			Enacted Stigma			Internalized Stigma		
	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>
Age	0.08	0.45	0.655	0.29	1.74	0.088	0.13	0.86	0.390
Gender	-0.03	-0.10	0.921	0.31	1.14	0.259	-0.13	-0.53	0.600
Employment	-0.70	-1.97	0.053	-0.31	-0.89	0.379	-0.39	-1.22	0.230
Monthly Income \leq R2500 ¹	0.15	0.48	0.633	-0.11	-0.34	0.733	-0.19	-0.67	0.510
Monthly Income $>$ R2500 ¹	0.45	1.04	0.301	-0.02	-0.05	0.961	0.38	0.98	0.330
Education	0.29	1.85	0.070	0.29	1.90	0.063	-0.04	-0.27	0.790
Marital Status ²	0.11	0.33	0.740	-0.33	-1.03	0.305	0.30	1.03	0.310
Has Children?	0.09	0.28	0.780	-0.01	-0.02	0.983	0.05	0.19	0.850
Sexually Active (last 3 months)	-0.21	-0.76	0.447	-0.26	-0.92	0.363	-0.01	-0.06	0.960
Years Diagnosed with AIDS	-0.05	-0.40	0.693	0.11	0.86	0.394	0.09	0.85	0.400
CD4 Count	0.09	0.71	0.479	0.14	1.18	0.244	-0.10	-0.93	0.360
Detectable Viral Load?	0.32	1.02	0.313	0.58	1.84	0.070	-0.07	-0.24	0.810
30-Day Adherence	0.00	0.00	~1	-0.34	-1.40	0.168	0.19	0.84	0.400
30-Day Rating	0.19	1.04	0.301	0.29	1.65	0.105	-0.23	-1.45	0.150

1. Referent level is no monthly income.
2. Levels are single / widowed = 0; married / living with partner = 1.

positive people for long enough not to stigmatize them.

7. Strengths and limitations

By using an HIV-specific measure that examined the three individual stigma mechanisms, we found significant differences and those differences can generate different intervention strategies. While there were very low levels of either anticipated or enacted stigma by the behaviour of healthcare providers, respondents continued to report much higher levels of internalized stigma. Although this study did not examine the relationship between mental health issues and internalized stigma, other studies have found a relationship between depression and stigma. Limitations always arise from a cross-sectional approach with a convenience sample of moderate size. Despite those limitations, this research illuminated that people with HIV experience different levels of HIV-related stigma mechanisms.

8. Implications and recommendations

Stigma is multifactorial and can occur in a number of social contexts; it is essential to clearly identify which stigma mechanism is being experienced. Using instruments to specifically measure those mechanisms leads to a more precise understanding which, in turn, leads to more effective interventions. An extensive search of the literature identified that a broad range of intervention types has been used to decrease stigma in PLWH, specifically psycho-educational intervention, support group interventions for treatment adherence (ART), psychotherapy intervention, narrative intervention, and community participation intervention (Kassile, Anicetus, & Kukula, 2015). Healthcare providers for this HIV infected community in Durban, South Africa, can acknowledge that few respondents reported either anticipated or enacted stigma in a healthcare setting. Many respondents did report at least

some internalized stigma, which has been associated with depression and poor engagement with the healthcare setting. Although HIV-related stigma may be low in this community, intersectionality theory identifies that some HIV infected people may be stigmatized due to their sexual preference or drug using behaviours. Sexual and gender minority groups are visible and legally protected in South Africa, unlike other sub-Saharan African countries, but discrimination and stigma, high levels of crime and violence persists (SANAC, 2017). Different stigma instruments assess anticipatory, enacted, and internalized in different social contexts and the intersectionality between a number of potentially stigmatizing attributes should be considered when an instrument is being chosen.

South Africa's National Strategic Plan for HIV, TB and STI's 2017–2022 (SANAC, 2017) aimed to reduce new infections, as well as improve treatment, care and support amongst key and vulnerable populations, explicitly including transgender people. One of the aims of Goal 5 of the Strategic Plan is to reduce externalized and internalized stigma among people living with HIV and TB by at least 50%. In order to reach this aim, the strategies to reduce different stigma mechanisms will need to be tailored. According to the *South African National HIV Prevalence, Incidence, Behaviour and Communication Survey* (Simbayi et al., 2017), the overall national HIV prevalence estimate for people of all ages living in South Africa was 14.0%, or 7.9 million people, which is significantly higher than the 2012 estimate of 12.2%. This increase can be attributed both to decreased mortality and new cases which indicates that people are engaging in behaviours that spread the virus. Undetectable = Untransmittable (U = U) means that people with HIV who achieve and maintain an undetectable viral load by taking antiretroviral therapy (ART) as prescribed cannot sexually transmit the virus to others (National Institute of Allergy and Infectious Diseases, nd). However, if HIV infected people are reluctant to interact with healthcare settings, they will not receive treatment and the virus will continue to spread. Although none of the socio-demographic or HIV-related factors were significantly associated with HIV stigma mechanisms in this relatively homogeneous sample, being marginalized and stigmatized can result in other differences from the cultural norms and those populations are particularly vulnerable when living with HIV/AIDS. While respondents reported low levels of HIV-related stigma, other factors could result in marginalization and stigmatization. Newer models recognize the complexity of intersectionality and stigma.

CRedit authorship contribution statement

Dudu G. Sokhela: Conceptualization, Methodology, Investigation, Writing – review & editing. **Penelope M. Orton:** Investigation, Project administration, Resources, Writing – review & editing. **Kathleen M. Nokes:** Investigation, Project administration, Resources, Formal analysis, Writing – review & editing. **William E. Samuels:** Formal analysis, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We appreciate the ongoing collegiality generated through our involvement in the International Nursing Network for HIV Research.

References

Abiri, S., Oakley, L. D., Hitchcock, M. E., & Hall, A. (2016). Stigma related avoidance in people living with severe mental illness (SMI): Findings of an integrative review. *Community Mental Health Journal*, 52(3), 251–261.

- Bos, A. E., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and Applied Social Psychology*, 35(1), 1–9.
- Champly, S. (2020). *pwr: Basic functions for power analysis*. R package version 1.3-0. Retrieved from <https://CRAN.R-project.org/package=pwr>.
- Chaudoir, S. R., Earnshaw, V. A., & Anel, S. (2013). “Discredited” versus “discreditable”: Understanding how shared and unique stigma mechanisms affect psychological and physical health disparities. *Basic and Applied Social Psychology*, 35(1), 75–87. <https://doi.org/10.1080/01973533.2012.746612>
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Mahwah, NJ: Lawrence Erlbaum Associates.
- Cuca, Y. P., Asher, A., Okonsky, J., Kaihura, A., Dawson-Rose, C., & Webel, A. (2017). HIV stigma and social capital in women living with HIV. *Journal of the Association of Nurses in AIDS Care*, 28(1), 45–54.
- Dwyer, S. C., Jain, A., Liambila, W., & Warren, C. E. (2021). The role of unintended pregnancy in internalized stigma among women living with HIV in Kenya. *BMC Women's Health*, 21(1), 1–11.
- Emlert, C. A., Brennan, D. J., Brennenstuhl, S., Rueda, S., Hart, T. A., & Rourke, S. B. (2015). The impact of HIV-related stigma on older and younger adults living with HIV disease: Does age matter? *AIDS Care*, 27(4), 520–528.
- Earnshaw, V. A., & Chaudoir, S. R. (2009). From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. *AIDS and Behavior*, 13(6), 1160–1177. <https://doi.org/10.1007/s10461-009-9593-3>
- Earnshaw, V. A., Rosenthal, L., & Lang, S. M. (2016). Stigma, activism, and well-being among people living with HIV. *AIDS Care*, 28(6), 717–721. <https://doi.org/10.1080/09540121.2015.1124978>
- Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV stigma mechanisms and well-being among PLWH: A test of the HIV stigma framework. *AIDS and Behavior*, 17(5), 1785–1795. <https://doi.org/10.1007/s10461-013-0437-9>
- eThekweni Municipality.. (2011). *Integrated development plan: 5-year plan 2011–2016*. Durban: eThekweni Municipality.
- Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon and Schuster.
- Greene, W. H. (2012). *Ecometric analysis* (7th ed.). London: Pearson Higher Education.
- Ha, J. H., Van Lith, L. M., Mallalieu, E. C., Chidassica, J., Pinho, M. D., Devos, P., & Wirtz, A. L. (2019). Gendered relationship between HIV stigma and HIV testing among men and women in Mozambique: A cross-sectional study to inform a stigma reduction and male-targeted HIV testing intervention. *BMJ Open*, 9(10), e029748.
- Heard, E., Fitzgerald, L., Wigginton, B., & Mutch, A. (2020). Applying intersectionality theory in health promotion research and practice. *Health Promotion International*, 35(4), 866–876.
- Holzemer, W. L. (2007). University of California, San Francisco International Nursing Network for HIV/AIDS research. *International Nursing Review*, 54(3), 234–242.
- Hutcheon, J. A., Chiolerio, A., & Hanley, J. A. (2010). Random measurement error and regression dilution bias. *BMJ*, 340.
- Kane, J. C., Elafros, M. A., Murray, S. M., Mitchell, E. M., Augustinavicius, J. L., Causevic, S., & Baral, S. D. (2019). A scoping review of health-related stigma outcomes for high-burden diseases in low-and middle-income countries. *BMC Medicine*, 17(1), 1–40.
- Kassile, T., Anicetus, H., & Kukula, R. (2015). HIV/AIDS-related stigma and discrimination in workplaces in Tanzania. *Rwanda Journal*, 2(1), 31–41.
- KwaZulu-Natal Department of Health. (2018). *District Health Plan 2018/2019, eThekweni Health District*. Pietermaritzburg: KZDnOH.
- Lee, R. S., Kochman, A., & Sikkema, K. J. (2002). Internalized stigma among people living with HIV/AIDS. *AIDS and Behavior*, 6(4), 309–319.
- Ma, P. H., Chan, Z. C., & Loke, A. Y. (2019). Self-stigma reduction interventions for people living with HIV/AIDS and their families: A systematic review. *AIDS and Behavior*, 23(3), 707–741. <https://doi.org/10.1007/s10461-018-2304-1>
- Milburn, N. G., Beatty, L., & Lopez, S. A. (2019). Understanding, unpacking, and eliminating health disparities: A prescription for health equity promotion through behavioral and psychological research—An introduction. *Cultural Diversity and Ethnic Minority Psychology*, 25(1), 1. <https://doi.org/10.1037/cdp0000266>. Retrieved from.
- Nagelkerke, N. J. (1991). A note on a general definition of the coefficient of determination. *Biometrika*, 78(3), 691–692.
- National Institute of Allergy and Infectious Diseases. (n.d). HIV Undetectable = Untransmittable (U=U), or Treatment as Prevention. Retrieved from <https://www.niaid.nih.gov/diseasesconditions/treatment-prevention>. Accessed January 30,2021.
- Okareh, O. T., Akpa, O. M., Okunlola, J. O., & Okoror, T. A. (2015). Management of conflicts arising from disclosure of HIV status among married women in southwest Nigeria. *Health Care for Women International*, 36(2), 149–160.
- Orton, P. M., Sokhela, D. G., Nokes, K. M., Perazzo, J. D., & Webel, A. R. (2021). Factors related to functional exercise capacity amongst people with HIV in Durban, South Africa. *Health SA Gesondheid*, 26, 1–7.
- R Core Team, 2020. *R: A language and environment for statistical computing*. R Foundation for Statistical Computing, Vienna, Austria. Retrieved from <https://www.R-project.org/>.
- Relf, M. V., Holzemer, W. L., Holt, L., Nyblade, L., & Caiola, C. E. (2021). A review of the state of the science of HIV and stigma: Context, conceptualization, measurement, interventions, gaps, and future priorities. *Journal of the Association of Nurses in AIDS Care*, 32(3), 392–407.
- Republic of South Africa. Department of Health. (2019). *ART clinical guidelines for the management of HIV in adults, pregnancy, adolescents, children, infants and neonates*. Pretoria: Government Printer.
- Revelle, W. (2017). *psych: Procedures for personality and psychological research*, Northwestern University, Evanston, Illinois, USA. <https://www.scholars>.

- northwestern.edu/en/publications/psych-procedures-for-personality-and-psychological-research.
- SANAC. (2017). Let our actions count: South Africa's National Strategic Plan for HIV, TB and STIs 2017–2022. Retrieved from http://sanac.org.za/wp-content/uploads/2017/06/NSP_FullDocument_FINAL.pdf.
- Simbayi, L., Zuma, K., Zungu, N., Moyo, S., Marinda, E., Jooste, S., ... Naidoo, I. (2019). *South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2017: Towards achieving the UNAIDS 90–90–90 targets*. Cape Town: HSRC Press.
- Treves-Kagan, S., El Ayadi, A. M., Pettifor, A., MacPhail, C., Twine, R., Maman, S., ... Lippman, S. A. (2017). Gender, HIV testing and stigma: The association of HIV testing behaviors and community-level and individual-level stigma in rural South Africa differ for men and women. *AIDS and Behavior*, *21*(9), 2579–2588. <https://doi.org/10.1007/s10461-016-1671-8>
- Turan, J. M., Bukusi, E. A., Onono, M., Holzemer, W. L., Miller, S., & Cohen, C. R. (2011). HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: Results from the MAMAS Study. *AIDS and Behavior*, *15*(6), 1111–1120.
- Twinomugisha, B., & Marguerite, D. (2011). "We also have cases of the disease that you are researching about". Small-scale enterprises and the challenges of HIV/AIDS related stigma and discrimination in Kabale, Uganda. *Health Policy and Development*, *9*(1), 37–45.
- Vanable, P. A., Carey, M. P., Blair, D. C., & Littlewood, R. A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS and Behavior*, *10*(5), 473–482.
- Van Brakel, W. H., Cataldo, J., Grover, S., Kohrt, B. A., Nyblade, L., Stockton, M., ... Yang, L. H. (2019). Out of the silos: Identifying cross-cutting features of health-related stigma to advance measurement and intervention. *BMC Medicine*, *17*(1), 1–17.
- Wadley, A. L., Pincus, T., & Evangeli, M. (2019). A preliminary analysis of the association between perceived stigma and HIV-related pain in South Africans living with HIV. *African Journal of Primary Health Care & Family Medicine*, *11*(1), 1–5. <https://doi.org/10.4102/phcfm.v11i1.1647>
- Wagner, A. C., Hart, T. A., Mohammed, S., Ivanova, E., Wong, J., & Loutfy, M. R. (2010). Correlates of HIV stigma in HIV-positive women. *Archives of Women's Mental Health*, *13*(3), 207–214.
- Wolitski, R. J., Pals, S. L., Kidder, D. P., Courtenay-Quirk, C., & Holtgrave, D. R. (2009). The effects of HIV stigma on health, disclosure of HIV status, and risk behavior of homeless and unstably housed persons living with HIV. *AIDS and Behavior*, *13*(6), 1222–1232.
- Yuan, K. H., & Maxwell, S. (2005). On the post hoc power in testing mean differences. *Journal of Educational and Behavioral Statistics*, *30*(2), 141–167.