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Factors associated with external HIV-related stigma and psychological distress among people living with HIV in South Africa

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ABSTRACT

Background: HIV-related stigma and psychological distress among people living with HIV (PLHIV) pose a public health challenge in most African countries. This study aims to investigate the association between HIV-related stigmatizing attitudes and psychological distress amongst PLHIV in South Africa using the 2012 nationally representative population-based household survey.

Methods: The data used in the analysis were collected using a multi-stage stratified cluster sampling design. Bivariate and multivariate logistic regression models were used to identify factors associated with stigma among PLHIV with psychological distress. A total of 2521 HIV positive individuals that responded to the question on psychological distress, 34.3% had psychological distress and 37.9% experienced high levels of HIV related stigmatizing attitudes. Stigmatizing attitudes among PLHIV with psychological distress were significantly less likely among those with secondary level education [aOR = 0.67 (95% CI: 0.44-1.01), p = 0.050], those with correct knowledge about HIV and rejection of myths about HIV [aOR = 0.58 (95% CI: 0.38-0.89), p = 0.013], and those who ever tested for HIV [aOR = 0.65 (95% CI: 0.42-1.01), p = 0.054].

Conclusion: The findings suggest a need to reinvigorate stigma-reduction interventions in the national HIV response with emphasis on HIV awareness and education campaigns. In addition, HIV testing services should be reinforced through communication strategies targeted against HIV stigmatization, discrimination and fear. There is also a need to continuously engage PLHIV in programs through counselling and support interventions for acceptance of HIV positive status and to help them cope with HIV-related stigma.

1. Background

HIV-related stigma is one of the biggest challenges facing people living with HIV (PLHIV) and has been associated with poor mental health (Rueda et al., 2016). Stigma has been shown to have a negative impact on quality of life for people living with HIV (Ebrahimi Kalan et al., 2019; Rasoolinajad et al., 2018). Evidence suggests that psychosocial distress and general substance use increase amongst stigmatized PLHIV (Zhang et al., 2016). In addition, individuals with substance use disorders may engage in reckless behaviours or be exposed to heightened risks and likelihood of victimization (Zhang et al., 2016). PLHIV are more likely to be the victims of abuse, assault, and other violent crimes relative to seronegative individuals (Campbell et al., 2008).

Stigma has also been linked with health-related risk factors including

poor seeking healthcare and non-adherence to antiretroviral therapy (Kinsler et al., 2007; Dlamini et al., 2009; Rubens et al., 2018). Furthermore, experiences of social rejection, disapproval, and discrimination related to HIV may heighten a person's sense of shame regarding their illness and serve to lessen their motivation to maintain optimal health (Clum et al., 2009). Evidence shows that stigma is associated with concealment of HIV status and avoidance of health care for fear of being identified and stigmatized (Parker et al., 2007). Therefore, HIV-related stigma poses as a significant obstacle to the treatment and prevention of HIV/AIDS (Sambisa et al., 2010). In addition, HIV-related stigma can result in negative self-image that may in turn exert subtle negative influences on social interactions and affect behavioural outcomes such as engagement in risk behaviour (Clum et al., 2009). Consequently, PLHIV experiencing higher levels of HIV-related stigma are at increased risk of

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transmitting the infection to others (Rubens et al., 2018).

HIV-related stigma has been consistently associated with poor mental health outcomes (Rueda et al., 2016; Parcesepe et al., 2018). Evidence shows that PLHIV are two to three times likely to develop mental disorders than HIV negative people (Huang et al., 2018; Remien et al., 2019; Yi et al., 2015). Psychological problems such as depression and anxiety are among the most common comorbidities among PLHIV across the world (Obadeji et al., 2014; Pappin et al., 2012; Ngum et al., 2017). Research studies in different countries across the sub-Saharan Africa have reported high prevalence rates of mental disorders among PLHIV (Lawler et al., 2011; Minya et al., 2013; Siakwa et al., 2015). The presence of mental disorders among PLHIV is also associated with numerous health and healthcare seeking behaviours such as poor adherence to medications and low rates of retention in HIV care (Joska et al., 2014; Nel & Kagee, 2011; Springer et al., 2012).

While HIV-related stigma and psychological distress are each independent barriers to health seeking behaviour, HIV prevention and ART initiation, the interrelationship between these two remains poorly understood. Several studies have examined constructs of stigma and psychological distress, however, the role of HIV-related stigma mechanisms on the effect of psychological mechanisms on health outcomes remains complex due to a number of mediating pathways (Mitzel et al., 2015 Turan et al., 2016; Helms et al., 2016). The mediating pathways involved are important in designing interventions aimed at reducing the effects of HIV-related stigma and induced psychological distress (Turan et al., 2017).

Since HIV-positive serostatus is often not evident, managing social relationships and serostatus disclosure to avoid stigma and discrimination has been suggested as an added source of stigma induced stress among PLHIV (Swendeman et al., 2006). Different intervention strategies have been proposed, one that targets stigma (both externalized and internalized) and another that treats depression and addresses other mediating psychosocial factors (Turan et al., 2017). However, these are complex constructs that cannot be seen as a simple single notion. Programs with adequate resources may even target all these mechanisms in a comprehensive intervention strategy to maximize the probability of success in reducing the effects of HIV-related stigma on the well-being of PLHIV (Turan et al., 2017). However, more nuanced and deeper understanding of how different mechanisms affect health outcomes among PLHIV is important in designing interventions aimed at reducing the effects of HIV-related stigma.

Evidence shows that the mechanisms of how stigma affects psychological distress among PLHIV may be explained by several biological, environmental, social, economic and demographic factors (Tran et al., 2019). Therefore, the understanding of mechanisms between HIV-related stigma and psychological distress may be influenced by mediating contextual factors. Characterizing contexts of the populations of interest is important and should be incorporated in designing interventions to reduce stigma (Tran et al., 2019). This paper examines factors associated with HIV related stigmatizing attitudes among HIV-positive people in South Africa who are psychologically distressed using the 2012 nationally representative population-based HIV household survey.

2. Methods

2.1. Data source

This study used data from the 2012 South African National HIV Prevalence, Incidence and Behaviour Survey, a nationally representative population-based household survey, described in detail elsewhere (Shisana et al., 2014). Briefly, participants were selected using multi-stage cluster sampling design. A systematic probability sample of 15 households was drawn from each of 1000 enumeration areas (EAs) selected randomly from strata defined by locality type and province from the updated 2007 master sample of census EAs. All members belonging to selected household were asked to participate in the survey.

2.2. Study procedure

The survey administered age-appropriate questionnaires to consenting participants, soliciting information on demographic factors, and HIV-related knowledge, attitudes, practice, sexual history and behaviours including questions on HIV-related stigma (Shisana et al., 2014). Dried blood spots (DBS) specimens were also collected from participants who consented for HIV testing. Samples were tested for HIV antibodies using a testing algorithm with three different immunoassays (Vironostika HIV Uni-Form II plus O, Biomeriux, Boxtel, The Netherlands; Advia Centaur XP, Siemens Medical Solutions Diagnostics, Tarrytown, NJ, USA; (Roche Elecys 2010 HIV Combi, Roche Diagnostics, Mannheim, Germany).

The current study is based on a sub-sample of youth and adult individuals 15 years and older who tested positive for HIV who responded to questions which measured both HIV-related stigma and psychological distress during the interviews.

2.3. Measures

2.3.1. Primary outcome

The primary outcome measure of the HIV stigma scale was based on a question relating to attitudes and beliefs against PLHIV with 7 items measuring various aspects of HIV-related stigma (Shisana et al., 2005): (1) Would you buy food if you knew that a shopkeeper or food seller had HIV? (2) Would you be willing to care for a family member with AIDS? (3) If a teacher has HIV but is not sick, he or she should be allowed to continue teaching? (4) Is it a waste of money to train or give a promotion to someone with HIV/AIDS? (5) Would you want to keep the HIV positive status of a family member a secret? (6) Are you comfortable talking to at least one member of your family about HIV/AIDS? (7) A person would be foolish to marry a person who is living with HIV/AIDS?

Exploratory factors analysis was used to analyse responses to these questions (yes = 1, no = 2, not sure = 3). A varimax orthogonal rotation was used to assess the underlying domains of stigma and reduce the number of items needed (Fabrigar et al., 1999). Eigenvalues were used to identify factors that account for most variance within the items, and Cronbach's Alpha was used to assess the reliability of factor loadings. Variables with a factor loading of at least 0.4 and factors with an eigenvalue of at least 1 were retained for the final analysis (DeVellis, 1991). A simple HIV stigma index score was then calculated by summing the scores across all the items. Scores below the mean were classified as low levels of stigma and those above as high levels of stigma. The index variable was dichotomized into a binary outcome measure of low stigma = 0 and high stigma = 1. A Cronbach's Alpha of 0.60 or greater was considered sufficient to determine reliability.

The HIV stigma index scale was stratified by the presence and absence of psychological distress using respondent's experience of anxiety and depressive disorders measured using the Kessler 10 scale (Kessler et al., 2003), which consists of 10 items that describe how they felt during the previous 30 days. How often did you feel: Tired out for no good reason? So nervous that nothing could calm you down? Hopeless; Restless or fidgety: So restless that you could not sit still; Depressed? That everything was an effort? So sad that nothing could cheer you up? Worthless?' Responses to these items were recorded using a 5-point Likert scale (1 = never, 2 = rarely, 3 = some of the time, 4 = most ofthe time, 5 =all of the time). This scale has been validated among lowand middle-income countries including South Africa (Andrews & Slade, 2001; Spies et al., 2009). The scores from these responses were then summed to calculate a total score indicating whether the respondents were likely to experience psychological distress. Raw scores were then summed to calculate a total score indicating whether the respondents were likely to be well (score below 20), experiencing mild (score 20–24), moderate (score 25-29) or severe (score 30 and above) psychological

distress (Andrews & Slade, 2001). The scores were then dichotomized into those who scored <19 absence of psychological distress = 1) and those who scored ≥ 20 (presence of psychological distress = 2).

2.3.2. Explanatory variables

Explanatory variables included socio-demographic factors such as age in years (15–24, 25–34, 35–49, 50 years and older), sex (male and female), race groups (black African and other races), educational level (primary/no education, secondary, tertiary), employment status (unemployed and employed), asset-based SES (low and high) and locality type (urban formal, urban informal, rural informal/tribal areas, rural formal/farm areas). This also included HIV-related knowledge and awareness factors such as correct knowledge and rejection of myths about HIV (no and yes), ever test for HIV (no and yes), know HIV results (no and yes), self-perceived risk of HIV infection (no and yes), exposure to ARVs (no and yes), self-rated health (fair/poor and good/excellent).

2.4. Statistical analysis

Descriptive statistics were used to summarize characteristics of the study sample. Bivariate logistic regression was used to assess the factors associated with high levels of stigmatizing attitudes among HIV positive individuals with psychological distress. Statistically significant variables were entered into multivariate logistic regression analysis. All models accounted for the complex survey design. Crude and adjusted odds ratios (aOR) with 95% confidence intervals (CI) and a p-value ≤ 0.05 were considered statistically significant. All statistical analyses were conducted using the Stata software package All statistical analysis was done in Stata version 15.0 software using "svy" commands to introduce command to take into account complex survey design (Stata Corp, College Station, Texas, USA).

3. Results

3.1. Sample characteristics and HIV-related stigma

Table 1 presents sample characteristics of the study sample and the prevalence of high levels of stigmatizing attitudes among HIV positive individuals with psychological distress. The sample consisted mainly of those 25–34 years, was predominantly female and Black African. The majority were married, had secondary level education, unemployed, were from low SES households and resided in urban and rural informal areas. Most respondents did not have correct knowledge and rejection of myths about HIV, never tested for HIV, and did not know their HIV status. About half perceived themselves as being at risk of HIV infection. The majority were not on ARVs and reported excellent/good self-rated health.

The sample comprised 2521 HIV positive individuals that responded to the question on psychological distress, and 34.3% (95%CI: 30.5–38.3) had psychological distress. Of these, 37.9% (95% CI: 32.7–43.4) had high levels of stigmatizing attitudes for HIV. Table 1 shows that the prevalence of HIV related stigmatizing attitudes among HIV positive individuals with psychological distress was higher among those 50 years and older, other race groups, the married, those with no education or with primary level education, the unemployed, those from low SES households and those residing rural informal areas. The stigma levels were also higher among those who had no correct knowledge and rejection of myths about HIV, those who never tested for HIV, those who perceived themselves as being at risk of HIV, those not on ARTs and those who reported fair/poor self-rated health.

3.1. Factors associated with HIV related stigmatizing attitudes

3.1.1. Bivariate models

Table 2 presents results of the bivariate logistic regression models of the association between high levels stigmatizing attitudes among PLHIV

Table 1

Socio-demographic characteristics and prevalence of high levels of stigmatizing attitudes among HIV positive individuals with psychological distress.

Variables	Study sample		High levels of stigmatizing attitudes				
	Total	%	n	%	CI		
Age in years							
15 to 24	384	11.9	101	27.5	17.2-40.8		
25 to 34	890	40.3	274	37.5	28.7-47.2		
35 to 49	879	38.4	320	40.2	32.0-49.0		
50 years and older	368	9.4	126	41.8	30.3-54.3		
Sex							
Male	784	38.4	209	45.1	34.9-55.8		
Female	1737	61.6	612	34.7	28.8-41.1		
Race groups							
Black African	2293	97.3	758	38.1	32.8-43.6		
Other races	228	2.7	63	31.6	15.8-53.2		
Marital status							
Not married	2029	80.9	676	37.9	32.3-43.8		
Married	456	19.1	123	38.4	24.7-54.3		
Educational level							
Primary/no education	555	21.3	194	56.1	45.4-66.3		
Secondary	1493	74.4	473	31.9	25.4-39.2		
Tertiary	81	4.3	19	32.8	11.7-64.4		
Employment status							
Unemployed	1510	63	534	35.5	29.6-41.7		
Employed	885	37	248	40.9	30.6-52.0		
Asset based SES							
Low	2016	80.3	648	40.2	34.5-46.2		
High	479	19.7	159	29.2	17.9-43.6		
Locality type							
Urban formal	871	40.4	279	35.7	26.1-46.5		
Urban informal	500	13.4	164	17.5	11.3-26.3		
Rural informal/tribal areas	818	41.5	283	45.6	38.4-53.0		
Rural formal/farm areas	332	4.6	95	56.5	43.7-68.4		
Correct knowledge and myth rejection about HIV							
No	2013	81.3	666	39	33.1-45.3		
Yes	508	18.7	155	32.5	23.1-43.6		
Ever test for HIV							
No	474	19.4	128	42.6	29.6-56.6		
Yes	2041	80.6	693	36.9	31.3-42.9		
Know HIV results							
No	1895	94.7	647	36.4	30.5-42.7		
Yes	97	5.3	29	37.6	19.0-60.8		
Self-perceived risk of HIV							
No	1239	48.6	454	38.2	31.0-45.9		
Yes	1221	51.4	340	38.3	30.7-46.5		
Exposure to ARVs							
No	1738	69.7	529	39.7	32.9-46.9		
Yes	781	30.3	291	34.3	27.1-42.3		
Self-rated health							
Fair/poor	700	28.4	356	36.6	29.0-44.9		
Good/excellent	1811	71.6	465	38.9	32.0-46.3		

CI-confidence interval, SES = socio-economic status.

with psychological distress. Increase in levels stigmatizing attitudes for HIV was significantly associated with other race groups, those residing in rural informal/tribal areas and rural formal/farm areas, and those who perceived themselves as being at risk of HIV infection. Decrease in levels stigmatizing attitudes for HIV was significantly associated with secondary and tertiary level education, high SES households, correct knowledge and rejection of myths about HIV, ever tested for HIV, and exposure to ARTs.

3.1.2. Multivariate model

Fig. 1 multivariate logistic regression model of factors associated with high levels stigmatizing attitudes among PLHIV with psychological distress. HIV related stigmatizing attitudes among PLHIV with psychological distress was significantly less likely among those with secondary level education [aOR = 0.67 (95% CI: 0.44-1.01), p = 0.050] compared to no education/primary level education, those with correct knowledge and rejection of myths about HIV [aOR = 0.58 (95% CI: 0.38-0.89), p = 0.013] compared to their counterparts, and those who ever tested for HIV [aOR = 0.65 (95% CI: 0.42-1.01), p = 0.054].

Table 2

Bivariate regression models of factors associated with HIV related stigmatizing attitudes among PLHIV with psychological distress.

Variables	High levels of stigmatizing attitudes					
Age in years	OR	95% CI		p-value		
15 to 24	1					
25 to 34	1.26	0.82	1.93	0.29		
35 to 49	1.51	0.98	2.35	0.06		
50 years and older	1.62	0.95	2.75	0.08		
Sex						
Male	1					
Female	0.73	0.53	1.00	0.05		
Race groups						
Black African	1					
Other races	1.69	1.00	2.88	0.05		
Marital status						
Not married	1					
Married	0.88	0.59	1.32	0.543		
Educational level						
Primary/no education	1					
Secondary	0.60	0.41	0.88	0.01		
Tertiary	0.43	0.14	1.30	0.14		
Employment status						
Unemployed	1					
Employed	1.17	0.85	1.61	0.35		
Asset based SES						
Low	1					
High	0.69	0.50	0.96	0.03		
Locality type						
Urban formal	1					
Urban informal	0.67	0.42	1.06	0.09		
Rural informal/tribal areas	1.22	0.83	1.79	0.30		
Rural formal/farm areas	2.07	1.25	3.41	0.00		
Correct knowledge and myth re	eiection abo	out HIV				
No	1					
Yes	0.54	0.37	0.80	0.00		
Ever test for HIV						
No	1					
Yes	0.56	0.38	0.82	0.00		
Know HIV results						
No	1					
Yes	0.68	0.33	1.43	0.31		
Self-perceived risk of HIV						
No	1					
Yes	1.36	1.03	1.78	0.03		
Exposure to ARVs						
No	1					
Yes	0.75	0.56	1.00	0.05		
Self-rated health						
Fair/poor	1					
Good/excellent	0.95	0.74	1.21	0.66		

CI-confidence interval, SES = socio-economic status.

4. Discussion

This study used a nationally representative sample and shows that the prevalence of high levels of HIV related stigmatizing attitudes was higher among people with psychological distress compared to their counterparts. Despite many millions of rands spent on HIV education in South Africa, the results of the 2012 national survey indicated poor HIV knowledge (Shisana et al., 2014). In this sub-sample of HIV positive individuals, three quarters of the study sample had secondary level education but only 18.7% of the total sample knew the correct answers to the questions about HIV. Furthermore, although the majority of respondents indicated that they had tested for HIV, most did not know their HIV status, and about half perceived themselves at risk of HIV, and a third reported exposure to ARVs. These findings suggest a need for the involvement of the Department of Basic Education (DBE) in the response to the HIV epidemic through a life skills programme to improve HIV knowledge levels, especially because the majority of respondents reported secondary level education. This has been the case since year 2000 with little or success, and in 2017 DBE developed a new national policy which mandated it to provide curriculum-based Sexuality Education and

access to Sexual Reproductive Health Services. The current observations suggest that the implementation of the new policy need to be monitored and regularly evaluated to improve HIV education, teach learners skills to reduce their risk of infection and reduce the associated stigma.

The findings revealed that HIV related stigmatizing attitudes were higher among those with psychological distress and varied by sociodemographic variables. HIV related stigmatizing attitudes were higher among older age group, males, those with lower education, those from low SES household, and those residing in urban and rural informal areas. The prevalence of HIV related stigmatizing attitudes was also higher among those who had no correct knowledge and rejection of myths about HIV, those who never tested for HIV, and those not on ART among PLHIV experiencing psychological distress.

Other studies also found that the prevalence of HIV related stigmatizing attitudes varies with socio-demographic and health-related factors and context (Bagchi et al., 2019; Emlet et al., 2015; Subedi et al., 2019). This probably reflects the complex nature of HIV-related stigma and the social process that interacts with socio-demographic factors, HIV-knowledge, HIV testing and exposure to ART to reinforce stigma and discrimination (Visse et al., 2009; Hargreaves et al., 2018).

In this study the results of the final model revealed that the odds of HIV related stigmatizing attitudes among PLHIV with psychological distress were low among those with higher levels of education. Evidence shows that people with low or no educational attainment are likely to have misconceptions about HIV and may not have appropriate information regarding HIV mode of transmission and treatment (Carlos et al., 2015; Letamo, 2019; Mondal et al., 2015; Sano et al., 2016). Furthermore, the findings showed that HIV related stigmatizing attitudes among PLHIV with psychological distress was less likely among those with correct knowledge and rejection of myths about HIV. HIV-related stigma has been associated with a lack of proper information regarding the spread of the disease and fear (Boushab et al., 2017). It has been demonstrated that increased education reduced stigma (Pulerwitz et al., 2010; Jacobi et al., 2020). Hence, the need to have more HIV education and skill building strategies.

Furthermore, HIV related stigmatizing attitudes among PLHIV with psychological distress was low among people who ever tested for HIV. There is considerable evidence showing an inverse relationship between HIV-related stigma and HIV testing (Mall et al., 2013; Okumu et al., 2017; Rubens et al., 2018). Studies show that voluntary counselling contributes to reducing HIV-related stigma because it provides information that may reduce misconceptions about HIV and minimise mental stress (James & Ryan, 2018; Jürgensen et al., 2013). These findings highlight the fact that one's initial prognosis, access to accurate information regarding HIV, and access to care and supportive services are important in dealing with HIV stigma and psychological induced distress.

This study has some limitations. It is based on a cross-sectional design, which is appropriate for identifying associations, and not suitable for exploring causal pathways. Although item nonresponse can never be totally prevented, gaps in the data matrix or missingness can pose serious problems in the analysis, because restricting the analysis to complete cases results in loss of information, and therefore estimates may be less efficient (De Leeuw, 2001). The data on both psychological distress and HIV-related stigma were collected through a self-reported questionnaire, therefore recall bias and social desirability bias may exist. In addition, others have also suggested that self-reports of stigma and discrimination are not reliable for measuring discrimination at the structural or social level (Meyer, 2003). There is a need for more evidence that the construct of HIV stigma scale and the Kessler psychological distress scale are relatively consistent across different settings or cross-cultural populations. Nonetheless, given the widespread stigma experienced by people with HIV and its fairly consistent manifestations, we hypothesize that the validated HIV Stigma 7-item scale will have relevance in a variety of settings in South Africa. Furthermore, the K10 scale has been validated and can be used to detect HIV related mood and



Fig. 1. Multivariate regression models of factors associated with HIV related stigmatizing attitudes among PLHIV with psychological distress.

anxiety disorders among HIV positive individuals (Spies et al., 2009).

Another limitation is that the focus of this study was on stigmatizing attitudes but the many studies that have explored stigma, including a multi-country African study, have noted that the stigma associated with people living with HIV, is both internal and external, and it is this combination that has such disastrous effects (Parcesepe et al., 2018). However, this study was unable to investigate internal stigma since it was not measured in the national survey. Nevertheless, the major strength of this study is the fact that it utilised data from a large nationally representative survey, which can be generalised to other PLHIV in the country.

5. Conclusion

The findings identified little or no education, insufficient HIV knowledge and myth rejection, and never testing for HIV, as factors associated with HIV-related stigmatizing attitudes among PLHIV experiencing psychological distress. The findings suggest a need to reinvigorate stigma-reduction interventions in the national HIV response with emphasis on HIV awareness and education campaigns. In addition, HIV testing services should be reinforced through communication strategies targeted against HIV stigmatization, discrimination and fear. These interventions should be targeted at multiple levels including the interpersonal institutions such as schools, and workplaces. There is also a need to continuously engage PLHIV in programs through counselling, social support, appropriate coping strategies (resilience and self-efficacy) for acceptance of HIV positive status and to help them adapt to any encountered difficulties due to HIV-related stigma and psychological distress.

Author statement

I am the lead author of this manuscript.

Ethical statement

The survey protocol was approved by the HSRC's Research Ethics Committee (REC: 5/17/11/10) and the Associate Director of Science of the National Center for HIV and AIDS, Viral Hepatitis, STD and TB Prevention at the Centers for Disease Control and Prevention (CDC) in Atlanta, GA, USA.

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