HIV stigma and mental health status among women living with HIV in the Western Cape, South Africa

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Since the beginning of the epidemic, people living with HIV and the social groups to which they belong have been stigmatized worldwide. This cross-sectional study, conducted between July and November 2003, investigated the association between HIV stigma and mental health status among black women living with HIV in the Western Cape province of South Africa. Eligible participants completed a questionnaire that assessed HIV stigma, socio-demographic, and mental health status measures. Participants were recruited from one of five primary health care clinics in the rural Western Cape. Recruiters screened 177 women to assess their eligibility. Of those screened, 68% (n = 120) were eligible because they were black South Africans, between the ages of 18 and 45, were living with HIV/AIDS, sought primary health care from one of the five study clinics, spoke Xhosa, and provided written informed consent. *A priori* hypotheses postulated that women reporting more HIV stigma would experience more consequences for mental health sequelae. The main outcome measures were mental health status variables, including depressive symptomatology, stress of HIV discrimination, quality of life, post-traumatic stress, suicidal ideation and fear of HIV disclosure. In linear regression models, more reports of HIV stigma were associated with significantly more depressive symptomatology ($P = 0.03$) and a lower quality of life ($P = 0.00$). The findings from this study indicate that HIV stigma is associated with adverse mental health sequelae among black Xhosa women living with HIV. Educational and legal efforts are required to reduce HIV stigma. Moreover, a public health infrastructure that integrates HIV/AIDS treatment and mental health services may be a promising strategy for reducing the adverse mental health consequences of HIV stigma.

Introduction

Since the beginning of the epidemic, people living with HIV and the social groups to which they belong have been stigmatized worldwide.[1–3] Tackling the global epidemic of HIV requires an understanding of HIV stigma directed at persons perceived to be living with the virus, and people who are living with AIDS. While the 1990s witnessed declines in the overt expression of HIV stigma in the U.S.,[2] similar declines have not been observed internationally. Epidemiological surveillance studies continue to document the high prevalence of HIV infection in developing countries. In those poor countries most severely affected by the HIV epidemic, there are widespread misconceptions regarding HIV transmission.[4] Ignorance about HIV transmission, fear of those living with HIV, and lack of access to and understanding of treatment is at the very core of HIV stigma.

Several conceptual frameworks for understanding HIV stigma and its effects have been proposed. These frameworks posit that the fear of being identified with HIV prevents people from learning their serostatus, changing unsafe behaviours, and caring for people living with HIV.[5–8] Qualitative studies among at-risk ethnic minority women in the U.S. suggest that fear of stigma can deter women from seeking medical care,[9] discourage women from disclosing their HIV serostatus to others,[10,11] and adds further stress to their lives. At its most extreme, stigma may manifest itself as violence perpetrated against people living with HIV. Indeed, violence victimization after HIV infection has been documented among men and women in the U.S.[12,13] While this research is crucial for understanding the impact of stigma on the lives of people at risk or living with HIV in America, quantitative research that examines the impact of HIV stigma on women's mental health in developing countries is urgently needed.

The few studies that have examined the effects of HIV stigma in South Africa report it to be associated with decreased voluntary HIV antibody counselling and testing,[14] poor palliative care,[15] and reduced utilization of local health-care services among

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persons living with HIV.[16] These studies suggest that the effect of HIV stigma is as deleterious to health-care use and delivery behaviours in South Africa as has been reported in the U.S. These studies do not, however, specifically examine the impact of HIV stigma on a population that has been particularly traumatized by the HIV epidemic, namely black women living with HIV in South Africa.

The aim of the current study was to investigate the association between HIV stigma and mental health status among black women living with HIV in the Western Cape.

Methods

Study population

Participants were 120 black Xhosa-speaking women between the ages of 18 and 45 seeking medical care at one of five primary health-care clinics in the rural Western Cape province, located in the districts of Strand, Stellenbosch, Paarl and Hermanus. While the Western Cape has had the lowest prevalence of HIV of the nine provinces in South Africa since the start of the epidemic in 1990, from 1999–2000, HIV prevalence increased 44% (from 8.6% to 12.4%) in this province among women aged 15–49 attending antenatal clinics, the largest increase in any South African province.[17]

From July to November 2003, black South African, Xhosa-speaking female recruiters screened 177 women to assess their eligibility. Of the women screened, 68% met eligibility criteria for participation in the study. Women were eligible to participate if they were black South Africans, between the ages of 18 and 45 at the time of enrollment, were living with HIV or AIDS, sought their primary health care from one of the five study clinics in the Western Cape, spoke Xhosa (the most common language among black South Africans in the province), and provided written informed consent. Of the eligible women, all were enrolled and subsequently completed baseline assessments. Participants were compensated $5 (R40) for their time and effort for completing the baseline assessment. The study protocol received ethical approval from the Ethics Committee of the South African Medical Association prior to the start.

Designing the study questionnaire

In this cross-sectional study, participants completed a questionnaire administered by trained Xhosa-speaking women interviewers. Several steps were taken to enhance the cultural equivalence and reliability of the study measures. First, the English-speaking principal investigators and the bilingual study researchers who were fluent in both Xhosa and English reviewed the interview schedule to ascertain that each measure on the interview represented information that was germane to Xhosa-speaking women.[18] Subsequently, the questionnaire was translated from English into Xhosa by the bilingual researchers. This questionnaire was then reviewed by Xhosa women living with HIV, who evaluated the questionnaire in terms of linguistic appropriateness, comprehension, cultural and gender relevance, and sensitivity for face and construct validity. The questionnaire was then translated back from Xhosa into English to ensure accuracy and meaning of constructs. Study measures were selected for inclusion in the questionnaire because they were theoretically associated with HIV-related stigma, had acceptable measures of internal consistency, and had been used previously among ethnic minority women in the U.S.

Data collection and measurements

Prior to obtaining written informed consent, interviewers reassured participants that code numbers rather than names would be used on questionnaires to protect participants' confidentiality. Trained black Xhosa-speaking female interviewers administered the 1-hour questionnaire, which assessed socio-demographic factors such as age, education, income, marital status, and employment status. Health factors assessed included the women's pregnancy history, and time since HIV diagnosis, which was determineded by asking the interviewees the year they were clinically diagnosed with HIV.

HIV stigma, the primary predictor variable, was assessed using the 20-item Public Attitude subscale, derived from the larger HIV Stigma Scale.[19] This subscale assesses HIV-positive individuals' perception of HIV stigma, and their feelings of actual (or potential) public reactions towards them. Construct validity for this scale is supported by relationships with related constructs such as social conflict. Examples of scale items include 'People with HIV are treated like outcasts', 'Some people avoid touching me once they know I have HIV', 'When people learn you have HIV, they look for flaws in your character'. The scale uses a 4-point response format ranging from (1) strongly disagree to (4) strongly agree, with higher scale scores indicative of more HIV stigma.

Several mental health status variables were assessed. Depressive symptomatology was evaluated using the 20-item Center for Epidemiologic Studies–Depression Scale (CES-D), which assesses the presence of depressive symptomatology during the past seven days. The CES-D has been widely used with diverse populations.[20,21] Higher CES-D scores are indicative of greater depressive symptomatology. Quality of life was determined using the 8-item physical functioning subscale of the Medical Outcomes Study (MOS) General Health Survey. This scale assesses participants' perception of whether having HIV has limited their ability to engage in certain physical activities for three or more months. Higher scale scores represent experiencing fewer physical limitations and a better quality of life. [22] Post-traumatic stress was assessed using a well-validated 17-item scale[23] that investigates DSM-IV symptom criteria for post-traumatic stress among civilian populations. This scale has been used previously among people living with HIV,[24] and has acceptable convergent validity with the Mississippi scale for combat-related post-traumatic stress.[25] Higher scale scores are indicative of more severe post-traumatic stress. Suicidal ideation was evaluated using a 4-item index with higher scores indicative of greater suicidal ideation. Stress associated with HIV discrimination was assessed using a single item: 'In the past three months, how much stress has been caused by HIV discrimination?' Participants responded on a 4-point Likert scale of 0 (no stress) to 3 (a great deal of stress). A 10-item scale that examined participants' perceived threat of the adverse social consequences associated with disclosure of their HIV serostatus assessed fear of disclosure. Higher scores are indicative of the greater 'social risk' or fear of disclosure.

Statistical methods

The statistical analysis comprised several sequential steps. First, statistics described socio-demographic characteristics, HIV stigma, and mental health status variables. Next, univariate analyses examined significant associations ($P < 0.05$) between HIV stigma and the mental health status variables. Variables observed to be significant were entered into a linear regression model. To identify potential covariates, a second set of univariate analyses was estimated to examine significant associations between HIV stigma and the socio-demographic variables and time since their HIV diagnosis. Finally, a second linear regression model was derived to examine the relationship between HIV stigma and mental health status variables, while controlling for observed covariates.

Results

The study enrolled 120 black South African Xhosa-speaking women between the ages of 18 and 45 years (mean = 29.0, s.d. = 6.5). The majority of women were single (70.6%), unemployed (75.8%), reported a current household monthly income of less than US$150 (97.5%), and had at least one child (96%). Only 5% of the women reported having no formal education. Descriptive statistics characterizing women's HIV stigma and mental health status are presented in Table 1. Additionally, Cronbach's alpha, a measure of internal consistency, was calculated for each scale (Table 1).

In univariate analyses, HIV stigma was associated with several mental health status variables including depressive symptomatology ($P = 0.003$), quality of life ($P = 0.000$), fear of disclosure ($P = 0.027$), and post-traumatic stress ($P = 0.023$). HIV stigma was also associated with employment ($P = 0.03$), but was not linked with any other socio-demographic or health variables.

In the first regression model [F (4, 65) = 7.55, $P = 0.000$], women reporting more HIV stigma experienced significantly more depressive symptomatology ($P = 0.03$) and reported a lower quality of life ($P = 0.000$). Post-traumatic stress and fear of disclosure were not independently associated with HIV stigma beyond the other contributing variables (Table 2). In the second regression model, which included potential covariates, employment was not independently associated with HIV stigma.

Table 1. Descriptive statistics characterizing HIV stigma and mental health status ($n = 120$).

	Mean (s.e.)	Median	Range	α*
HIV stigma	84.6 (2.3)	83.0	44–145	0.91
Stress of HIV discrimination	1.3 (0.1)	1.0	0–3	0.92
Depressive symptomatology	22.7 (1.6)	19.0	0–57	0.92
Quality of life	12.6 (0.42)	14.5	0–16	0.90
Post-traumatic stress	41.6 (2.0)	37.0	17–85	0.95
Fear of disclosure	6.9 (0.98)	5.0	0–20	0.92
Suicidal ideation	0.8 (0.10)	0.0	0–4	0.70

*α = Cronbach's alpha is a measure of internal consistency of the scale.

Table 2. HIV stigma and its association with mental health status.

	β	r^2	adj r^2	d.f.	P
Mental health measures					
Model 1		0.331	0.287	61	0.000
Depressive symptomatology	0.323**				
Quality of life	–0.436*				
Post-traumatic stress	0.018				
Fear of disclosure	–0.029				
Socio-demographic covariate					
Model 2		0.331	0.275	60	0.000
Employment	–0.003				

*$P < 0.05$.
**$P < 0.01$.

Comment

This is one of the first articles to examine quantitatively HIV stigma and its mental health consequences among women living with HIV in South Africa. Our findings indicate that HIV stigma is associated with adverse mental health sequelae among women living with HIV. Women experiencing more HIV stigma reported significantly greater depressive symptomatology and a lower quality of life. And when examined independently, women relating greater experiences of HIV stigma also reported more severe post-traumatic stress and a greater fear of disclosure. The relationship of HIV stigma with any one of these mental health consequences is a cause for concern; however, it is the consistency of findings, across a spectrum of mental health status indicators, which is particularly disturbing. Collectively, the findings suggest that HIV stigma has a significant, profound, and deleterious effect on mental health status. Several considerations may help explain the observed relationship between this stigma and mental health.

It has long been recognized that having HIV, or even being regarded as at-risk of HIV, can lead to stigmatization and discrimination.[1–3] HIV is a stigmatizing condition. Women living with HIV are often marginalized and encounter significant social hostility.[26,27] With regard to the study population, this hostility may arise from pre-existing stigmas associated with their gender,[28] their race,[29] their being viewed as vectors for HIV transmission, or their lower socio-economic status.[29] Indeed, the persisting and miasmic influence of apartheid on black women's esteem[30] may also enhance their sensitivity and vulnerability to the adverse consequences of HIV stigma. Moreover, limited protections for the privacy and confidentiality of people living with HIV in South Africa[31] may also fuel concerns related to HIV stigma. Thus, the social construction of HIV for women in South Africa, and the social climate for black women living in the country, may interact and contribute to the negative mental health conditions among black women living with HIV experiencing HIV stigma.

It is highly conceivable that black women in South Africa living with HIV are distressed about the potential consequences of HIV stigma should their diagnosis become known to others. The stress of HIV stigma and discrimination alone may have deleterious effects on women's mental health. Furthermore, in an attempt to avoid the social hostility associated with HIV stigma, women living with HIV in South Africa may be more fearful of disclosing their HIV status. Fear of disclosure may impede women's access to medical care, social support and mental health services.[11,32] This was particularly prominent when this study was conducted, as no treatment was available in the public sector for people living with HIV in South Africa at that time. Limited access to care may be manifested in the range of mental health conditions observed among women in this study. Ironically, women living with HIV must bear the burden of HIV stigma at a time when they are most in need of medical care, social support and mental health services. The findings indicate an urgent need for interventions designed to reduce HIV stigma, and improve the clinical and mental health services to enhance women's ability to cope effectively with the consequences of stigma.

A number of individual-level and societal strategies are required to eradicate HIV stigma. These should include public HIV/AIDS education, programmes designed to address pre-existing stigmas, community-level interventions intended to enhance norms intolerant of HIV stigma, and legal sanctions prohibiting HIV discrimination. Unfortunately, HIV stigma is an attribute with deep roots and eradication may take decades.[2] In addition, strides should be made to improve the quality of life for people living with HIV. In 2004, South Africa was set to witness the advent of comprehensive care, including antiretroviral (ARV) treatment, in the public sector for people living with HIV.[33] Creating a public health infrastructure designed to integrate HIV/AIDS treatment efficiently with a range of social and mental health services may be a promising strategy for reducing the mental health consequences associated with HIV stigma.

As the study design is cross-sectional, a causal relationship between HIV stigma and the mental health sequelae cannot be demonstrated. Thus, poor mental health may exacerbate perceptions of HIV stigma. Moreover, caution must be exercised when generalizing these results to other populations. The consequences of HIV stigma may be more or less profound for different genders, in other African communities, in other countries, and among people of different sexual orientations. Additionally, the study involved a small sample size. This may limit the precision of effect estimates. Further research with larger sample sizes is needed to corroborate and extend these findings across diverse populations.

The HIV epidemic is a global public health tragedy. The toll of the epidemic can be measured in premature loss of lives and the concomitant economic burden on resource-constrained countries. It can also be measured in terms of the adverse mental health status of people living with HIV.

HIV stigma not only has detrimental effects on the mental health of people living with the virus, but also adversely affects those people at risk of HIV.[33,29] HIV stigma may be a significant threat to the success of educational efforts to prevent HIV infection and legislation designed to enhance HIV testing, treatment seeking, and the adoption of preventative strategies. Worldwide, eradication of HIV stigma remains an important public health goal for effectively combating the HIV epidemic.

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