Measuring HIV stigma for PLHAs and nurses over time in five African countries

William L Holzemer, Lucy N Makoae, Minrie Greeff, Priscilla S Dlamini, Thecla W Kohi, Maureen L Chirwa, Joanne R Naidoo, Kevin Durrheim, Yvette Cuca, Leana R Uvs

Abstract

The aim of this article is to document the levels of HIV stigma reported by persons living with HIV infections and nurses in Lesotho, Malawi, South Africa, Swaziland and Tanzania over a 1-year period. HIV stigma has been shown to negatively affect the quality of life for people living with HIV infection, their adherence to medication, and their access to care. Few studies have documented HIV stigma by association as experienced by nurses or other health care workers who care for people living with HIV infection. This study used standardised scales to measure the level of HIV stigma over time. A repeated measures cohort design was used to follow persons living with HIV infection and nurses involved in their care from five countries over a 1-year period in a three-wave longitudinal design. The average age of people living with HIV/AIDS (PLHAs) (*N*=948) was 36.15 years (SD=8.69), and 67.1% (*N*=617) were female. The average age of nurses (*N*=887) was 38.44 years (SD=9.63), and 88.6% (*N*=784) were females. Eighty-four per cent of all PLHAs reported one or more HIV-stigma events at baseline. This declined, but was still significant 1 year later, when 64.9% reported experiencing at least one HIV-stigma event. At baseline, 80.3% of the nurses reported experiencing one or more HIV-stigma events and this increased to 83.7% 1 year later. The study documented high levels of HIV stigma as reported by both PLHAs and nurses in all five of these African countries. These results have implications for stigma reduction interventions, particularly focused at health care providers who experience HIV stigma by association.

Keywords: HIV/AIDS, stigma, Africa, nurses, people living with HIV/AIDS (PLHAs).

William L Holzemer is Professor and Associate Dean for International Programs at the University of California, San Francisco, School of Nursing. He is an internationally recognised expert in academic nursing and HIV/AIDS care providing global leadership to the World Health Organization, the International Council of Nurses, and many universities around the world. Dr Holzemer is a member of the Institute of Medicine, and an elected member of the International Council of Nurses Board of Directors. For the last 20 years his research has focused on symptom management, adherence, stigma and quality of life for people living with the HIV infection.

Lucy N Makoae is a Lecturer at the National University of Lesotho Faculty of Health Sciences, in the Department of Nursing. She teaches and supervises research projects and also teaches various courses in public health such as epidemiology, surveillance of infectious diseases and control of communicable diseases. She has published papers in the areas of reproductive health, HIV and AIDS and in human resources for health.

Minrie Greeff is Professor in research in the Africa Unit for Trans-disciplinary Health Research of the Faculty of Health Science at North-West University, Potchefstroom campus. She has served as Head of the Department of Nursing as well as Director of the School of Nursing Science, where her research focused on HIV and AIDS and indigenous knowledge. She is elected director of the research committee of the Tau Lambda Chapter-at-Large of the Sigma Theta Tau International Honor Society for Nurses since 2006. In 2008 she became one of the few rated researchers of the National Research

Priscilla S Dlamini is Senior Lecturer at the University of Swaziland, Faculty of Health Sciences. She has served as Dean of the Faculty of Health Sciences for a 5-year period. She is involved in many country-level research studies on HIV/AIDS with a special interest in the role of traditional medicine and HIV/AIDS.

Thecla W Kohi is a Senior Lecturer in Nursing at the Muhimbili University of Health and Allied Sciences. She is research collaborator in a consortium of Higher Education Nursing and Midwifery Schools in Africa aimed at introducing or strengthening higher education in SADC countries. She is also working in collaboration with UCSF on an AIHA Twinning Center project.

Maureen L Chirwa is a Senior Lecturer, University of Malawi, specialising in health management and health systems. She has extensive research degree supervision and other postgraduate teaching experience. She also leads three studies for the Ministry of Health on documenting and evaluating relief, income and expenditure; and locum systems. Dr Chirwa is currently working on a performance management study for the Ministry of Health, commissioned by GTZ.

Joanne R Naidoo is a Lecturer at the School of Nursing, University of KwaZulu-Natal. She is core team member of the Joanna Briggs Institute for Evidence Based Nursing and Midwifery, completing a systematic review on the relationship of disclosure of HIV status and adherence to antiretroviral therapy among adults in Africa. She has participated in numerous HIV related studies as co-investigator or collaborator.

Kevin Durrheim is professor of psychology at the University of KwaZulu-Natal, where he teaches social psychology and research methods. He has published more than 80 peer-reviewed articles and book chapters on topics related to racism, segregation and social change.

Yvette Cuca is Project Director at the University of California, San Francisco, School of Nursing. She holds Master's degrees in Public Health and International Affairs, and her research focus is reproductive health and HIV/AIDS.

Leana R Uys is a Professor in Nursing and Deputy Vice Chancellor of the Faculty of Health Sciences at the University of KwaZulu-Natal. She has served as President of the South African Nursing Council and the Tau Lambda Chapter-at-Large of the Sigma Theta Tau International Honor Society for Nurses. Correspondence to: bill.holzemer@nursing.ucsf.edu

Résumé

Le but de cet article est de documenter les niveaux de la stigmatisation autour du VIH rapportés par les personnes vivant avec le VIH et les infirmières au Lesotho, au Malawi, en Afrique du Sud, au Swaziland et en Tanzanie pendant une période d'un an. Il a été démontré que la stigmatisation du VIH a un effet négatif sur la qualité de vie des personnes vivant avec le VIH, leur adhérence au traitement et leur accès à l'aide. Peu d'études ont documenté la stigmatisation du VIH par association comme elle est vécue par les infirmières et d'autres personnes travaillant dans le secteur de la santé qui soignent les personnes vivant avec le VIH. Cette étude a utilisé des échelles standardisées pour mesurer le taux de stigmatisation autour du VIH au cours d'une période de temps.

Une conception de cohorte en mesures répétées a été utilisée pour suivre les personnes vivant avec le VIH et les infirmières impliquées dans leur aide dans cinq pays pendant une période d'un an selon une conception longitudinale en trois vagues. L'âge moyen des PVVIH (N=948) était de 36.15 ans (SD=8.69), et 67.1% (N=617) étaient des femmes. L'âge moyen des infirmières (N=887) était de 38.44 ans (SD=9.63), et 88.6% (N=784) étaient des femmes. Quatre-vingt-quatre pour cent de toutes les PVVHI ont rapporté un ou plusieurs événements de stigmatisation autour du VIH à la base. Ce taux a baissé, mais était toujours considérable un an plus tard quand 64.9% ont rapporté avoir vécu au moins une instance de stigmatisation autour du VIH. A la base, 80.3% des infirmières ont rapporté avoir vécu un ou plusieurs événements de stigmatisation liés au VIH et cela a augmenté jusqu'à 83.7% une année plus tard. Cette étude a documenté de hauts taux de stigmatisations rapportés autant par les PVVIH que les infirmières dans ces cinq pays africains.

Ces résultats ont des implications pour les interventions de réduction de la stigmatisation, en particulier celles qui visent les prestataires de services de santé qui vivent la stigmatisation du VIH par association.

Mots clés: VIH/SIDA, stigmatisation, Afrique, infirmières, PVVIH.

Introduction

The Africa-UCSF HIV/AIDS Stigma Project has been studying the presentation of HIV-related stigma in Lesotho, Malawi, South Africa, Swaziland and Tanzania for the last 6 years. Over this period we have published qualitative descriptions of this form of illness-related stigma (Dlamini et al., 2007; Greeff et al., 2008; Kohi et al., 2006; Makoae et al., 2008; Naidoo et al., 2007; Uys et al., 2005), developed a conceptual model of HIV stigma (Holzemer et al., 2007), developed two instruments to measure the phenomenon as experienced by persons living with HIV infection (PLHAs) (Holzemer et al., 2007) and by nurses (Uys et al., 2009), and measured the interactions between stigma and quality of life over time (Greeff et al., in press). The current paper describes the level of stigma over time in the five African countries.

There is general recognition of the fact that in some cases, and some places, HIV stigma is a serious problem (Parker & Aggleton, 2003). However, since quantitative measures of stigma have not been available in the African context until quite recently (Visser *et al.*, 2008), it has not been possible to describe the prevalence of such problems, and therefore the public health importance of the issue. As we have talked about our study, presented results at conferences and interacted with PLHAs and health service providers, the questions 'So, how high is

the level of stigma in our country?' or 'How many people are experiencing HIV-related stigma?' were asked repeatedly. In some debates, the argument has been raised that other issues in HIV care should take precedence over stigma reduction. Some activists see arguments about HIV stigma as an excuse by health service providers and policy makers to explain poor service delivery. It is important not only to acknowledge that stigma exists, but also to describe the prevalence of HIV stigma in the lives of PLHAs in specific settings.

In our studies we have consistently worked with both PLHAs and nurses, exploring the experiences of HIV stigma of both groups, and developing instruments to measure HIV stigma in both groups. From our clinical experiences we know that PLHAs experience significant HIV stigma and we also have observed that nurses and other health care workers not only experience stigma themselves, but also stigmatise patients. This was supported when we interviewed PLHAs and heard many stories of their experiences of being stigmatised by health care workers. Since nurses are the largest number of health care workers (World Health Organization, 2006) and most of the authors are nurses, we focused this work on both PLHAs and nurses. This article describes HIV stigma experienced and reported by nurses and PLHAs over time in five countries in Africa.

Literature review

Most quantitative studies reporting on the level of HIV-related stigma have focused on community-level stigma (Berger et al., 2001; Mak et al., 2006). The first quantitative instrument of this kind developed for the African setting was published by Kalichman and colleagues (2005) and focuses on the level of stigma as manifested by communities about HIV or AIDS. Their research was done in South Africa, and they reported only on the qualities of their scale and not on the levels of stigma they found in the communities sampled. This strategy was previously criticised by Parker and Aggleton (2003) who were concerned with studies that focused so heavily 'on the beliefs and attitudes of those who are perceived to stigmatize others' (p.15) on the basis that it leads to interventions that aim at 'increasing tolerance' of PLHAs or 'increasing empathy' with PLHAs, and results in inadequate attention being given to the social character of the stigma phenomenon itself.

Very few studies have addressed the issue of the prevalence or level of HIV stigma in a quantitative manner in the African context, from the perspective of those experiencing HIV stigma. These are mainly from our own study and address relationships between HIV stigma and other variables, such as missing ARVs (Dlamini *et al.*, 2009), quality of life (Greeff *et al.*, in press), and taking of ARVs (Makoae *et al.*, in press).

In reviewing the literature, we found no studies that addressed the issue of measuring HIV stigma by association among nurses or other health care workers, although this form of stigma has been described by many researchers in the African setting. In our study, we have found a robust relationship between the level of stigma experienced by nurses and their job satisfaction (Chirwa *et al.*, 2009), as well as their intent to migrate (Kohi *et al.*, in review). Mahendra *et al.*, (2007) evaluated an HIV-stigma reduction strategy in three Indian hospitals, but their instrument does not measure stigma by association, focusing on the attitudes of the general public.

Study aim

The focus of this article is to report the level of stigma reported by a sample of PLHAs and nurses in five African countries over time. A major limitation of this data is that the sample was not drawn randomly, but represents a convenience sample.

The research questions were:

- 1. How much HIV stigma is being experienced by PLHAs and nurses?
- 2. Does the amount of HIV stigma being experienced by these two groups change over time?
- 3. Is there a difference between how the two types of nurse HIV stigma change over time?

4. Are there country differences in the amount of HIV stigma being experienced by these two groups?

Methodology

Research design

A repeated measures cohort design was used to follow persons living with HIV infection and nurses involved in their care in Lesotho, Malawi, South Africa, Swaziland and Tanzania over a 1-year period in a three-wave longitudinal design.

Setting and sample

Data were collected three times, from January 2006 to March 2007. Each site sought to gather data from 300 persons living with HIV infection and 300 nurses involved in their care, chosen using a purposive voluntary sampling approach. The PLHAs were recruited from HIV clinics, support groups, flyers in the community, and word-of-mouth referrals, and were invited to join the study. If they were interested in the study, appointments were made for them to meet with field workers in a convenient setting. Participants completed the instruments independently or were assisted in completing instruments by researchers or field workers. Respondents were reimbursed for transport and lunch was provided. For nurses, managers of the various health settings were approached to identify potential participants. Nurses received a small gift of appreciation for their willingness to participate. The available sample of PLHAs and nurses who completed the instruments over all three points in time was approximately one-third less that the initial desired sample.

Instruments

Three instruments were used:

- 1. Demographic questionnaire: The multi-item demographic questionnaire was used to obtain demographic, job, and illness-related information from the nurses and PLHAs.
- 2. HASI-N (HIV/AIDS Stigma Instrument Nurses) (Uys et al., 2009) is a 19-item instrument comprised of two factors. Factor 1 (Nurses Stigmatising Patients) included items such as 'A nurse provided poorer quality care to an HIV patient than to other patients' and 'A nurse shouted at or scolded an HIV patient.' Factor 2 (Nurses Being Stigmatised) includes items such as 'People said nurses who provide HIV/AIDS care are HIV-positive' and 'Someone called a nurse names because she takes care of HIV/AIDS patients.' Nurses responded to the question: 'Please mark how often you observed the event during the past three months.' A four-point Likert scale was used to capture their responses, including 'never', 'once or twice', 'several times', 'most of the time'. The Cronbach alpha for the total instrument of 19 items was 0.90. Concurrent validity was tested by comparing

the level of stigma with job satisfaction and quality of life. A significant negative correlation was found between stigma and job satisfaction. The HASI-N was inductively derived and measures the stigma experienced and enacted by nurses (Uys *et al.*, 2009).

3. HASI-P (HIV/AIDS Stigma Instrument - People Living With HIV/AIDS) (Holzemer et al., 2007) is a 33-item instrument that measures six dimensions of HIV-related stigma. PLHAs respond to the question, 'In the past three months, how often did the following event happen because of your HIV status?' A four-level Likert response format was used that included 'never', 'once or twice', 'several times', or 'most of the time'. The six factors include: (i) verbal abuse - verbal behaviour intended to harm the PLHA (e.g. ridicule, insults, blame), 8 items, alpha = 0.886; (ii) negative self-perception - negative evaluation of self based on HIV status, 5 items, alpha = 0.906; (iii) health care neglect - in a health care setting (e.g. hospital, clinic), offering a patient less care than is expected in the situation or than is given by others, or disallowing access to services, based on one's HIV status, 7 items, alpha = 0.832; (iv) social isolation deliberately limiting social contact with PLHA and/or breaking off relationships, based on one's HIV status, 5 items, alpha = 0.890; (v) fear of contagion – any behaviour which shows fear of close or direct contact with the PLHA or things they have used, for fear of being infected (e.g. not wanting close proximity; not wanting to touch; not wanting to touch or share an object; not wanting to eat together), 6 items, alpha = 0.795; and (vi) workplace stigma - disallowing access to employment or work opportunities based on one's status, 2 items, alpha = 0.758.

Protection of human subjects

The research protocol was approved by all of the seven universities involved (see author list). Permission to conduct the study was also obtained from the appropriate local and central government authorities. People who were interested in the study were given information about its background, and were told that participation was voluntary and that they could withdraw at any time. They were also assured of confidentiality of information obtained. Following this explanation, those who agreed to participate each signed a written consent form. The consent process and the survey were conducted in either English or the local language of the country. In South Africa participants used English and Tswana; in Malawi they used Chichewa; in Lesotho Sesotho; in Swaziland SiSwazi; and in Tanzania Kiswahili.

Data management and analysis

Survey data were entered into Statistical Package for the Social Sciences (SPSS) for Windows Version 15.0 software (2007).

Data entry accuracy was assessed by having 10% of the surveys double-entered and the two files were compared. We also ran descriptive statistics examining ranges to ensure the accuracy of the data. Discrepancies were resolved by examining the original surveys.

Stigma was measured by counting the number of times a stigma event was reported, with a potential maximum of 33 stigma events for PLHAs and 19 stigma events for nurses. For instance, the HASI-P scale has an item 'People cut down on visiting me'. If a respondent ticked that this had happened during the last 3 months, it counted as one event, even though it might have happened more than once.

Results

The purpose of this article is to explore and estimate the amount of HIV stigma around persons living with HIV infection and nurses in five African countries.

Sample description

The average age of the PLHAs (N=948) was 36.15 years (SD=8.69) and 67.1% (N=617) were female. The average age of the nurses (N=887) was 38.44 years (SD=9.63) and 88.6% (N=784) were female. Thirty-nine per cent of the PLHAs had no post-school qualification, while 67% of the nurses had diplomas or advanced qualifications post-school. The majority of the PLHAs (34.9%) had never been married, while the majority of the nurses (62.5%) were married (see Table 1 for more details).

Stigma experienced by PLHAs and nurses

There is tremendous variation in self-reported stigma among both the PLHAs and nurses. The maximum possible stigma events for PLHAs was 33, and for nurses 19. The results show that many PLHAs reported no experiences of HIV stigma during the past 3 months at each point in time. Further, the frequency of HIV stigma events declined over time for PLHAs. At baseline, 16.4% (N=239) PLHAs reported having experienced no stigma events over the last 3 months. By 12 months this has increased to 35.8% (N=368). The corresponding data for nurses do not indicate such an improvement in the stigma experience over time. Approximately 20% (N=272) of nurses reported experiencing no stigma events during the last 3 months at baseline, and this decreased to 16.3% (N=163) at Time 3. Nurses reported experiencing more stigma events over time whereas PLHAs reported less stigma events over time.

The results also indicated that fewer PLHAs report high levels of stigma events (25 events or more) as compared with the nurses (15 events of more). This is particularly evident at 6 (Time 2) and 12 (Time 3) months. In summary, 83.6% of all PLHAs reported

Variable	PLHAs (N=948)	Nurses (N=887)	
Gender			
Female	617 (67.1%)	784 (88.6%)	
Male	302 (32.9%)	101 (11.4%)	
Age	36.15	38.44 years	
	SD=8.69	SD=9.63	
Post-school education			
No post-school	151 (39.8%)	-	
Certificate	194 (51.2%)	279 (32.2%)	
Diploma/advanced	34 (9%)	587 (67.8%)	
Marital status			
Never married	328 (34.9%)	194 (23.3%)	
Married	259 (27.6%)	519 (62.5%)	
Widowed	212 (22.6%)	63 (7.6%)	
Divorced	86 (9.1%)	42 (5.1%)	
Cohabiting	52 (5.5%)	13 (1.6%)	

Table 2. Two repeated measures ANOVA for the two nurse stigma factors										
Country		Time I		Time	Time 2		Time 3			
	Ν	M	SD	M	SD	M	SD	F	df	Þ
Factor I:										
Nurses Stigmatising Patients	887	2.23	2.85	2.25	2.90	2.13	2.85	0.882	2,1772	0.41
(10 items; range: 0-10)										
Factor 2:										
Nurses Being Stigmatised	884	2.99	2.90	3.69	2.92	3.73	3.02	30.41	2,1766	0.000
(9 items; range 0-9)										η²=0.03

one or more HIV-stigma events at baseline and this decreased, but was still significant 1 year later when 64.9% reported experiencing at least one HIV-stigma event. At baseline, 80.3% of the nurses reported experiencing one or more HIV-stigma events and this increased to 83.7% 1 year later.

To explore the nurse data further, we standardised the frequency of reporting HIV-stigma events for nurses for each of the two sub-scales. We divided the number of events selected for each scale by the number of items in that scale and multiplied the proportion by 100. The results demonstrate that nurses are reporting fewer episodes of Nurses Stigmatising Patients, but an increase in events in Nurses Being Stigmatised.

To explore the change in mean number of nurse stigma events over time, we conducted two separate ANOVAs for each of the nurse stigma factor scores (Table 2). There was no significant difference over time for Factor 1, Nurses Stigmatising Patients. There was a significant difference over time for Factor 2, Nurses Being Stigmatised (F=30.41; df=2, 1766; p=<0.000). Nurses reported experiencing more Factor 2 HIV-stigma events at Times 2 and 3 than at Time 1.

PLHAs stigma events over time by country

PLHAs reported a significant decrease in stigma events over the three points in time (Table 3) (F=154.97, df=2, 1886, p=<0.000; η^2 =0.14). While the PLHAs reported an average of 8.69 stigma events at baseline, the events decreased to an average of 4.42 at Time 3.

We explored potential country differences to see whether the decrease in experience of HIV-stigma events was similar across the 5 countries. There is a significant difference between countries (F=41.18, df=4, 943, p=<0.000; η^2 =0.15). Bonferroni *post-hoc* comparisons showed that Lesotho and Tanzania reported higher stigma scores than Malawi, South Africa and Swaziland at the 0.05 level. While PLHAs in all countries reported significantly less stigma over time, Tanzania reported significantly less stigma at Time 3 (10.5 at baseline to 8.35 at Time 3). The interaction between country and time was also significant (F=21.60, df=8, 1886, p=<0.000; η^2 =0.08).

Reports by PLHAs of HIV-stigma events decreased in all countries, although the countries demonstrated different patterns of change over time. These patterns cannot be interpreted easily given that the samples in each country were convenience samples.

Table 3. Country (5 levels) by time (3 levels) repeated measures ANOVA comparing PLHAs' total stigma score

Country	Time I			Tim	e 2	Time 3		Totals		
	N	Mean	SD	Mean	SD	Mean	SD	Mean	SE	
Lesotho	174	13.40	5.92	10.50	5.40	3.58	4.02	9.16	0.33	
Malawi	189	6.94	7.21	3.19	5.73	3.75	5.75	4.64	0.31	
South Africa	281	6.61	5.75	5.19	5.45	3.41	4.61	5.07	0.26	
Swaziland	130	7.15	7.01	6.78	6.14	5.47	5.03	6.47	0.38	
Tanzania	174	10.50	5.40	6.47	6.76	6.80	6.17	8.35	0.33	
Totals	948	8.69	7.42	6.47	6.33	4.42	5.28			

Time main effects: F=154.97; df =2, 1866; p=<0.000Country main effects: F=41.18; df =4,943; p=<0.000.

Table 4. Country (5 levels) by time (3 levels) repeated measures ANOVA comparing nurses total stigma scores

Country		Time I		Time 2		Time 3		Totals	
	N	Mean	SD	Mean	SD	Mean	SD	Mean	SE
Lesotho	168	6.67	5.16	6.95	4.39	6.84	4.71	6.82	0.29
Malawi	171	5.99	4.42	5.38	4.12	5.67	4.84	5.68	0.29
South Africa	185	4.92	4.95	5.99	5.08	5.65	4.80	5.52	0.28
Swaziland	137	5.80	4.70	5.90	5.36	5.97	4.91	5.58	0.32
Tanzania	226	3.43	4.31	5.64	4.87	5.36	4.91	4.81	0.25
Totals	887	5.21	4.83	5.95	4.80	5.86	4.85		

Country main effects: F=7.03; df =4, 882; p=<0.000. Time main effects: F=7.47; df=2, 1764; p=<0.001

Nurse stigma events reported over time by country

A country (5 levels) by time (3 levels) repeated measures ANOVA for total nurse stigma scale was calculated (Table 4). Reports of HIV-stigma events increased significantly between baseline and Times 2 and 3 (F=7.47, df=2, 1764, p=<0.001; η^2 =0.01) and there were significant differences between countries (F=7.03, df=4,882, p=<0.000; η^2 =0.03). The Bonferroni *post-hoc* comparisons showed that Lesotho scored higher than South Africa and Tanzania. The interaction between country and time was also significant (F=5.10, df=8, 1764, p=<0.000; η^2 =0.02). Overall, the effect sizes were very small, so that one can conclude that there were few meaningful differences among the nurses by countries over time.

Discussion

This study documents that PLHAs and nurses reported high levels of HIV-stigma events in all five African countries. One year after our study began, 64.2% of all PLHAs and 83.7% of nurses reported experiencing one or more HIV stigma events over the last 3 months. Because the scoring of these stigma scales in this analyses ignores the frequency with which these events

happened, these can be considered conservative estimates of the percentage of individuals experiencing HIV stigma events.

The findings represent both encouraging and discouraging evidence of the amount of stigma being experienced by PLHAs and nurses. The significant reduction in reporting of HIV-stigma events over time among PLHAs is an important finding, and it was true for all five countries. However, the number of HIV-stigma events experienced by PLHAs remained high over time. There is a need to remain vigilant in the search for effective HIV-stigma reduction interventions, and in providing assistance to PLHAs to manage the HIV stigma that they experience. Nurses reported high levels of experiencing HIV-stigma events over time and, unlike the PLHAs, this experience of HIV-stigma events did not reduce over time, but rather increased. At the last measurement point, 83% of nurses reported experiencing one or more HIV-stigma events over the last 3 months.

Most of the published measures of stigma have focused upon HIV stigma in the general population or as experienced only by PLHAs. No studies have documented stigma experienced by nurses or health care workers, or HIV stigma by association. These results indicate that stigma by association requires more

attention, especially since our work indicates a link between job dissatisfaction and intentions to migrate among nurses, and HIV-stigma experience (Chirwa *et al.*, 2009; Kohi *et al.*, in press).

Country differences are difficult to interpret due to the convenience sampling strategy adopted in this study. Nevertheless, the results indicate that it is important to do regional surveys of HIV stigma and not assume similarity across countries and regions.

This study reports data on a large sample of PLHAs and nurses, providing the first normative data using standardised instruments giving us a glimpse of what the level of HIV-stigma events experienced by PLHAs and nurses is in five African countries. The limitations of the study included the convenient sampling of both PLHAs and nurses, and the fact that in larger countries only one geographical area was used. No normative data are currently available with which to compare the findings. We recommend that HIV-stigma reduction strategies target health workers who experience HIV stigma by association, as well as continued attention to the stigma experienced by PLHAs.

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