



PSYSOC 2013

Stigma among HIV/AIDS Patients in Africa: A critical Review

Joyceline Ntoh Yuh ^{a*}, Karen Ellwanger ^a, Lydia Potts ^a & Joseph Ssenyonga ^{a, b}

^a Carl von Ossietzky University, Faculty of Linguistics and Cultural Studies, Working Group Migration - Gender – Politics, Ammerländer Heerstr. 114-118, D-26111 Oldenburg.

^b Mbarara University of Science and Technology, Faculty of Science, Department of Educational Foundations and Psychology, P. O. Box 1410, Mbarara, Uganda

Abstract

By the end of 2011 Africa had 23.5 million HIV infected people and 72% of the new HIV cases globally (UNAIDS, 2012). The mainly sexual transmission of HIV in the African context is associated with stigma especially among women (Rankin et al., 2005). HIV/AIDS stigma includes negative behaviors, denial, secrecy, fear and self-blame related to the disease (Deacon, Stephney & Proslendis, 2005). HIV/AIDS stigma is associated with sexual promiscuity, hinders disclosure of serostatus, and affects uptake of preventive programs (Zungu-Dirwayi, 2004). Though there is an acknowledgement of the negative effects of HIV/AIDS stigma, there is little research that has been conducted on this pertinent issue on the African continent with the largest number of HIV infected and affected people globally. Prevention of new HIV infections require the acknowledgement of the fact that stigma is attached to disclosure of status yet seropositive people still engage in risky behaviors (Prince et al., 2006). Therefore there is need to design strategies to counteract the negative effects associated to HIV/AIDS stigma at all levels.

© 2014 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/3.0/>).

Selection and peer-review under responsibility of the Organizing Committee of PSYSOC 2013.

Keywords: HIV/AIDS stigma, Sexual transmission, Disclosure, Risky behavior

1. Introduction

Disease stigma is a well-documented social aspect of disease in medical literature. Disease stigma consequently is the social link between a disease and negative behaviours toward a person or group with that particular disease within the social sphere (Deacon, Stephney, & Proslendis, 2005). By 2011, 23.5 million African people were living with HIV/AIDS and 1.8 million had acquired the infection (UNAIDS, 2012). Most HIV infections are through

*Corresponding author: Joyceline Ntoh Yuh. Tel.: +49-15214877041
E-mail address: joyceline.ntoh.yuh@uni-oldenburg.de or n_joyce192002@yahoo.com

heterosexual transmission, a mode of transmission closely linked to sexual promiscuity and the resultant HIV-related stigma. The consequences of HIV-related stigma include failure to disclose one's infection status, isolation, discrimination and interference with access to health care services among others (Block, 2009; Zungu-Dirwayi, Shisana, Udjo, Mosala, & Seager, 2004). Therefore, HIV prevention on the African continent where HIV/AIDS is endemic necessitates a critical focus on HIV-related stigma at all levels of society (UNAIDS, 2012).

2. Nature, Content and Process of Stigma

2.1. Nature and content of stigma

Stigma is defined in many ways including real or imagined felt stigma associated with individuals of a particular group, with an undesirable behaviour or disease, and enacted stigma, which is a real-life experience of discrimination. Felt stigma is a subjective personal awareness of stigma while enacted stigma is overly expressed in acts of discrimination and hostility towards the stigmatized person. Felt stigma can be a feeling, described as fear or as a pattern of thinking (Block, 2009; Brown, Macintyre & Trujillo, 2003). Instrumental stigma arises from the fear of HIV transmission while symbolic stigma is based on prior attitudes toward people affected by HIV (Herek, 2002). Earnshaw, Bogart, Dovidio and Williams (2013) in their stigma and HIV disparity model explicated three types of stigma including internalised stigma or self-stigma defined as the devaluing and discrediting of a person or a group because of stigma. Perceived stigma refers to the appraisal of experiences of prejudice, stereotypes, and discrimination from others in the past and anticipated stigma is the expectation of such bias to occur in the future. Hence, there are perpetrators and targets (passive victim) of stigma, with stigma existing at individual, family, health care setting and community levels.

Stigma as a concept is defined and applied in different ways based on the researcher discipline. Stigma involves labelling a person or group and connecting the label to undesirable behaviour. Labelled people are clearly distinct from other people in society, face stereotyping, experience status loss and discrimination (Link & Phelan, 2001). HIV stigma is a social construct that devalues individuals with HIV and it is noticeable negative behaviours of prejudice, discounting, discrediting, and discrimination toward people perceived to have HIV and any individuals, groups and communities with which they are associated (Herek, 2002). Mawar, Sahay, Pandit and Mahajan (2005) noted that HIV stigma could also arise from participation in HIV/AIDS research studies that are often conducted in least developing countries. This implies that stigma exists in the research health care setting in the least developed countries where HIV/AIDS is endemic.

AIDS stigma results in silence and denial, self-blame, rejection, violence, self-isolation, failure to disclose one's HIV status, secondary stigma of HIV services providers and so forth. HIV/AIDS stigma is related to negative emotions including shame, guilt, fear, anxiety and self-blame (Deacon et al., 2005). AIDS stigma leads to discrimination at a personal level, structural discrimination in the social realm and self-stigmatization where stigmatized people accept the society dictates attached to the labels (Link & Phelan, 2001).

Men and women respectively perceive stigma differently. In Africa, women especially sex workers, are often blamed and personally held responsible for contracting and transmitting HIV to other through their risk behaviours. Women are categorised as a risky group engaging in risky behaviours associated with HIV transmission. This gendered perspective of stigma, with a moral dimension affects women more compared to men. Men engage themselves in risky behaviours with multiple concurrent sexual partners' behaviours that are acceptable in the African context (Duffy, 2005; Rankin, Brennan, Schell, Laviwa, & Rankin, 2005).

2.2. Stigma process

AIDS stigma as a process is linked to the nature of transmission, affects the person, social interactions, and seeking of preventive health care services. Heterosexual behaviour is the dominant mode of HIV transmission in Africa (UNAIDS, 2012). For this reason, how HIV is acquired that is who is infected and how, provides a fertile ground for AIDS stigma and blame. AIDS transmission attached to voluntary, avoidable and undesirable behaviour risky behaviour is considered one's sole personal responsibility, results into greater stigma compared to circumstances where HIV transmission is beyond a person's control. HIV is a disease perceived as a lifestyle

problem in the eyes of the African society. Risky behaviour linked to contraction of HIV for example concurrent partnerships are acceptable in the African context (Duffy, 2005; Green, Halperin, Nantulya & Hogle, 2006; Halperin & Epstein, 2004). In other situation, such risky behaviour for example sex work is unacceptable in society and raises question of morally acceptable behaviour in society. People with AIDS are therefore perceived to be responsible for their illness and blamed for the spreading the incurable and lethal HIV disease to others (Herek, 2004). Marginalise groups such as sex workers face stigma because of the nature of their unacceptable work in the African context. Stigma attached to HIV as an illness interacts with pre-existing stigma in various ways to result into dual stigma. This complicates the nature of stigma faced by such marginalised groups (Mawar et al., 2005; Reidpath & Chan, 2006).

AIDS stigma attached to the disease itself poses a risk to others. Stigma makes self-disclosure of serostatus difficult that puts the guiltless uninfected partner(s) at risk of contracting the disease. Because of AIDS stigma people who are aware of their status do not like to disclose it while at the same time still engage themselves in risky behaviours often with uninfected partners. Not disclosing sero-status disrupts relationships, get in the way of social support provision, and reinforces negative feeling of shame and guilt. Disclosure of infection status on the other hand leads to adverse effects including family disintegration, isolation of HIV infected and affected people, divorce and discrimination by the family and community alike (Prince et al., 2006; Zungu-Dirwayi, et al., 2004).

AIDS stigma affects the utilisation of preventive health care services. Fear of being associated with HIV, fear of disclosing their status and long waiting hours at health facilities hindered effective utilisation of available health services. Effective preventive measure for HIV positive individuals like the barrier methods may not be used because the perceive association of use to lack of trust and promiscuity (Prince et al., 2006).

Social stigma also results from officially sanctioned campaigns that deal with the HIV/AIDS epidemic (Gausset, Mogensen, Yameogo, Berthe, & Konte, 2012) because was associated with unacceptable behaviour in society. Consequently, the focus on exclusively sexual transmission of HIV was a factor that led to stigma.

3. Stigma Research in Africa

People living with HIV/AIDS and health care workers in Africa have reported experiences of high levels of AIDS related stigma (Duffy, 2005; Genberg et al., 2009; Holzemer et al., 2009). Community-level stigma studies among people living with HIV (Kalichman et al., 2009), and the general population (Ulası et al., 2009; Visser, Makin, Vandormael, Sikkema & Forsyth, 2009), and hospital based studies (Jacobi et al., 2013) suggest that stigmatizing attitudes were relatively high in Africa.

AIDS related stigma research in Africa has largely been descriptive in nature, health facility based, and adopting survey quantitative methods. The results of these studies provide individual general perceptions, knowledge and attitudes about AIDS related stigma, experiences of people living with HIV, focus on the stigmatised and the negative role of stigma in society. AIDS literature has diverse view of AIDS-related stigma definitions and the link between stigma and HIV prevention and care. Measurement of AIDS-related stigma presents a challenge to researcher especially enacted stigma. HIV stigma and prior existing stigma among marginalised groups like sex workers is complex to distinguish and measure. The complex nature of AIDS related stigma requires the use of diverse measure of stigma contrary to the exclusive reliance on only one measure of stigma. The positive outcome of stigma to the stigmatized populations for example specialized health care service is in essence ignored by most researchers (Gausset, et al., 2012; Nyblade, 2006; Reidpath & Chan, 2006).

4. Responding to AIDS-related stigma

Africa has high level of AIDS-related stigma with no corresponding structured interventions to reduce stigma. Recommendations of HIV stigma reduction strategies for various populations are consistently suggested but never translated into any tangible programs.

Jacobi and colleagues (2013) described a stigma reduction program in schools involving school-going children in Cameroon. This program adopted an educational strategies aimed at reducing stigma and facilitating acceptance of people living with HIV. Other interventions reflect the role of the faith-based organisations and religious leaders in dealing with AIDS related stigma (Hartwig, Kissioki & Hartwig, 2006, Fonchingong, Mbuagbo, & Abong, 2009;

Otolok-Tanga, Atuyambe, Murphy, Ringheim, & Woldehanna, 2007).

Herek (2002) asserts that interventions targeting reduction of AIDS related stigma need to provide updated information about HIV and how the disease is transmitted, while encouraging infection status disclosure at all levels. HIV prevention strategies need to increase personal decision-making, promote protecting oneself from AIDS without promoting blame for people who become infected. These strategies focus at the individual level of fighting stigma.

5. Conclusion

AIDS-related stigma in Africa results from many factors including the way HIV is transmitted, the incurable nature of HIV as a disease, and the risk HIV poses to others. AIDS-related stigma results into many negative emotions and behaviours directed toward HIV infected and affected people. Stigma is multidimensional in nature affect the individual, families and communities alike. Despite the acknowledgement of the negative effects of stigma in the African context, few structured interventions tackling the effects of stigma are noticeable. Therefore, HIV prevention strategies need to focus attention to reducing stigma at all levels.

References

- Block, R. G. (2009). Is it just me? Experiences of HIV-related stigma. *Journal of HIV/AIDS & Social Services*, 8, 1-19.
- Brown, L., Macintyre, K., & Trujillo, L. (2003). Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention*, 15, 49-69.
- Deacon, H., Stephney, I., & Proslendis, S. (2005). *Understanding HIV/AIDS stigma: A theoretical and methodological analysis*. Cape Town: HSRC Press.
- Duffy, L. (2005). Suffering, shame, and silence: The stigma of HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 16, 13-20.
- Earnshaw, V. A., Bogart, L. M., Dovidio, J. F., & Williams, D. R. (2013). Stigma and racial/ethnic HIV disparities: Moving toward resilience. *American Psychologist*, 68, 225-236.
- Fonchingong, C. C., Mbuagbo, T. O., & Abong, J. T. (2009). Barriers to counselling support for HIV/AIDS patients in southwestern Cameroon. *African Journal of AIDS Research*, 3, 157-165.
- Gausset, Q., Mogensen, H. O., Yameogo, W. M. E., Berthe, A., & Konte, B. (2012). The ambivalence of stigma and the double-edged sword of HIV/AIDS interventions in Burkina Faso. *Social Science & Medicine*, 74, 1037-1044.
- Genberg, B. L., Hlavka, Z., Konda, K., A., Maman, S., Chariyalertsak, S., Chingono, A., Mbwambo, J., Modiba, P., Van Rooyen, H., & Celentano, D. D. (2009). A comparison of HIV/AIDS-related stigma in four countries: Negative attitudes and perceived acts of discrimination towards people living with HIV/AIDS. *Social Science & Medicine*, 68, 2279-2287.
- Green, E. C., Halperin, D. T., Nantulya, V., & Hogle, J. A. (2006). Uganda's HIV prevention success: The role of sexual behaviour change and the national response. *AIDS and Behaviour*, 10, 335-346.
- Halperin, D. T., & Epstein, H. (2004). Concurrent sexual partnerships help to explain Africa's high HIV prevalence: Implications for prevention. *Lancet*, 364, 4-6.
- Hartwig, K. A., Kissioki, S., & Hartwig, C. D. (2006). Church leaders confronting HIV/AIDS and stigma: A case study from Tanzania. *Journal of Community & Applied Social Psychology*, 16, 492-497.
- Herek, G. (2002). Thinking about AIDS and stigma: A psychologist's perspective. *Journal of Law, Medicine, and Ethics*, 30, 594-607.
- Holzemer, W. L., Makoae, L. N., Greeff, M., Dlamini, P. S., Kohi, T. W., Chirwa, M. L., Naidoo, J. R., Durrheim, K., Cuca, Y., & Uys, L. R. (2009). Measuring HIV stigma for PLHAS and nurses over time in five African countries. *SAHARA-J: Journal of Social Aspect of HIV/AIDS*, 6, 76-82.
- Jacobi, C. A., Atanga, P. N. J. I., Bin, L. K., Mbome, V. N., Akam, W., Bogner, J. R., Kropf, S., & Malfertheiner, P. (2013). HIV/AIDS-related stigma felt by people living with HIV from Buea, Cameroon. *AIDS Care: Psychological and Social-medical Aspects of AIDS/HIV*, 25, 173-180.
- Kalichman, S. C., Simbayi, L. C., Cloete, A., Mthembu, P. P., Mkhonta, R. N., & Ginindza, T. (2009). Measuring

- AIDS stigmas in people living with HIV/AIDS: The Internalised AIDS-Related Stigma Scale. *AIDS Care: Psychological and Social-medical Aspects of AIDS/HIV*, 21, 87-93.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-385.
- Mawar, N., Sahay, S., Pandit, P., & Mahajan, U. (2005). The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma, discrimination and future needs. *Indian Journal of Medical Research*, 122, 471-484.
- Nyblade, L. C. (2006). Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health & Medicine*, 11, 335-345.
- Otolok-Tanga, E., Atuyambe, L., Murphy, C. K., Ringheim, K. E., & Woldehanna, S. (2007). Examining the actions of faith-based organisations and their influence on HIV/AIDS-related stigma: A case study of Uganda. *African Health Sciences*, 7, 55-60.
- Prince, B., Louw, J., Roe, K., & Adams, R. (Eds.). (2006). *Exploring the challenges of HIV/AIDS. Seminar proceedings from the SAHARA International AIDS conference*. Cape Town: HSRC Press.
- Rankin, W. W., Brennan, S., Schell, E., Laviwa, J., & Rankin, S. H. (2005). *The stigma of being HIV-positive in Africa. PLoS Medicine*, 2, 702-704. doi: 10.1371/journal.pmed.0020247
- Reidpath, D. D., & Chan, K. Y. (2006). HIV, stigma, and rates of infection: A rumour without evidence. *PLoS Medicine*, 3, 1708-1710. doi: 10.1371/journal.pmed.0030435.
- Ulasi, C. I., Preko, P. O., Baidoo, J. A., Ehiri, J. E., Jolly, C. M., & Jolly, P. E. (2009). HIV/AIDS-related stigma in Kumasi, Ghana. *Health & Place*, 15, 255-262.
- UNAIDS. (2012). *UNAIDS world AIDS day report 2012*. Geneva: UNAIDS.
- Visser, M. J., Makin, J. D., Vandormael, A., Sikkema, K. J., & Forsyth, B. W. C. (2009). HIV/AIDS stigma in a South African community. *AIDS Care: Psychological and Social-medical Aspects of AIDS/HIV*, 21, 197-206.
- Zungu-Dirwayi, N., Shisana, O., Udjo, E., Mosala, T., & Seager, J. (Eds.). (2004). *An audit of HIV/AIDS policies in Botswana, Lesotho, Mozambique, South Africa and Zimbabwe*. Cape Town: HSRC Press.