Rewriting the narrative of the epidemiology of HIV in sub-Saharan Africa

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Abstract

The fight against HIV remains complicated with contracting donor resources and high burden of HIV among reproductive age adults still often limiting independent economic development. In the widespread HIV epidemics of sub-Saharan Africa (SSA), it is proposed that key populations with specific HIV acquisition and transmission risk factors, such as men who have sex with men (MSM), female sex workers (FSW), and people who use drugs (PUD), are less relevant because HIV transmission is sustained in the general population with average HIV acquisition and transmission risks. However, the understanding that key populations are less relevant in the epidemics of Africa is based on the surveillance system from which these populations are mostly excluded. Outside of SSA, the epidemics of HIV are generally concentrated in the same populations that are excluded from the primary HIV surveillance systems in SSA. The manuscripts included in this special issue present convincing data that FSW, MSM, and PUD carry disproportionate burdens of HIV wherever studied in SSA, are underrepresented in HIV programs and research, and require specific HIV prevention services. These manuscripts collectively suggest that the only effective path forward is one that transcends denial and stigma and focuses on systematically collecting data on all populations at risk for HIV. In addition, there is a need to move to a third generation of HIV surveillance as the current one inadvertently devalues HIV surveillance among key populations in the context of widespread HIV epidemics. Overall, the data reviewed here demonstrate that the dynamics of HIV in Africa are complex and achieving an AIDS-free generation necessitates acceptance of that complexity in all HIV surveillance, research, and prevention, treatment, and care programs.

Keywords: HIV, Africa, men who have sex with men, female sex workers, injecting drug use, epidemiology

Résumé

La lutte contre le VIH demeure compliquée avec les réductions des ressources des bailleurs de fonds et des charges élevées du VIH parmi les adultes en âge de reproduction limitant encore souvent un développement économique indépendant. Les épidémies de VIH généralisées du SSA, il est proposé que les populations clés avec HIV acquisition et transmission risque facteurs spécifiques, tels que les hommes ayant des rapports sexuels avec des hommes (HSH), travailleuses du sexe (FSW) et les personnes qui consomment des drogues (PUD) sont moins pertinentes parce que la transmission du VIH est soutenue dans la population générale avec moyennes risques de transmission et d'acquisition du VIH. Toutefois, étant entendu que les populations clés sont moins pertinentes dans les épidémies de l'Afrique repose sur le système de surveillance dont ces populations sont généralement exclues. â l'extérieur de l'Afrique subsaharienne, les épidémies de VIH se concentrent généralement dans les mêmes populations exclues par les systèmes de surveillance du VIH primaires en Afrique subsaharienne. Les manuscrits inclus dans ce numéro spécial présentes des données convaincantes que FSW, MSM, PUD portent un fardeau disproportionné du VIH partout où il est étudié en Afrique subsaharienne, sont sous-représentées dans la recherche et des programmes contre le VIH et ont besoin de services spécifiques de prévention du VIH. Collectivement, ces manuscrits suggèrent que les perspectives d'avenir seulement efficace est celui qui transcende le déni et la stigmatisation et met l'accent sur la collecte systématique de données sur toutes les populations à risque pour le VIH. En outre, il est nécessaire de passer à une troisième génération de la surveillance du VIH, comme l'actuel dévalue la surveillance du VIH parmi les populations clés dans le contexte des épidémies de VIH généralisées. Dans l'ensemble, les données examinées ici démontrent que la dynamique du VIH en Afrique est complexe et parvenir à une génération sans- SIDA nécessite l'acceptation de cette complexité dans toute surveillance du VIH et la recherche, prévention, traitement et les programmes de soins.

Mots clés: Travailleuses du sexe (TS), Homme ayant des rapports sexuels avec d'autres hommes (HSH), VIH, Afrique, utilisateurs de drogue (UD)

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Research and surveillance data suggest that incident HIV infections are declining in many countries across sub-Saharan Africa (SSA). However, SSA remains the continent most affected by HIV and AIDS with an estimated 22.9 million people living with HIV and accounting for more than two-thirds of new HIV infections globally (UNAIDS 2010). HIV remains functionally incurable. While antiretroviral therapy can facilitate people living with HIV/AIDS to have a complete and productive life, provision and uptake of treatment are still limited in most parts of SSA. Since HIV often affects adults when they have the most potential to contribute to society and lifelong treatment is expensive, the economic impacts of HIV are significant (Lachaud 2007; Piot, Bartos, Ghys, Walker & Schwartlander 2001; Piot, Bartos, Larson, Zewdie & Mane 2008). The direct medical and drug costs, as well as the indirect costs related to decreased productivity, have limited development in many settings (Badri et al. 2006; Hubben, Bishai, Pechlivanoglou, Cattelan, Grisetti, Facchin, et al. 2008; Krentz & Gill 2012). Further complicating the fight against HIV are contracting global resources related to global recessions, austerity measures in many donor countries, and donor fatigue (Avdeeva, Lazarus, Aziz & Atun 2011; Zumla 2012). Thus, the people fighting HIV are facing a future that forces them to do more with less. It is exactly this complicated reality that suggests that the people leading this fight against new HIV infections in Africa must now move beyond business as usual.

In the widespread HIV epidemics of SSA, it is often proposed that particular populations with specific HIV acquisition and transmission risk factors are less relevant because HIV transmission is sustained in the general population with average HIV acquisition and transmission risks. In 2000, a collaborative group convened by the World Health Organization defined generalized epidemics as being when the HIV prevalence is consistently higher than 1% in antenatal clinics in contrast to concentrated epidemics where HIV prevalence is consistently higher than 5% in at least one of the particular population subgroup but less than 1% in antenatal clinics (UNAIDS & WHO 2000). Finally, this group defined low-level epidemics where HIV prevalence is less than 5% any population subgroup and less than 1% in antenatal clinics (UNAIDS & WHO 2000). While some countries in Western and Northern Africa have concentrated epidemics, the continental countries in Southern and Eastern Africa all have generalized epidemics; a categorization independent of the burden of disease in population subgroups (UNAIDS 2010). Moreover, the epidemiology of HIV in SSA has traditionally been characterized using population-based surveillance informing mathematical models. While these surveillance systems are useful in understanding the epidemiology of HIV, they are focused on the general population with limited attention to the epidemiology of HIV among specific subpopulations. To the knowledge of the authors, there are no HIV surveillance systems in SSA that have effective and standardized mechanisms to collect data on particular subpopulations. Thus, the understanding that specific subpopulations are less relevant in the epidemics of Africa is based on a system from which these populations are mostly excluded.

Outside of SSA, the epidemics of HIV are mostly concentrated among the same population subgroups that are excluded from

the primary HIV surveillance systems in SSA (Baral, Beyrer, Muessig, Poteat, Wirtz, Decker, et al. 2012; Baral, Poteat, Wirtz, Stromdahl & Beyrer 2012; Baral, Sifakis, Cleghorn & Beyrer 2007; Beyrer, Baral, van Griensven, Goodreau, Chariyalertsak, Wirtz, et al. 2012; Beyrer, Baral, Kerrigan, El-Bassel, Bekker & Celentano 2011; Mathers, Degenhardt, Ali, Wiessing, Hickman & Mattick 2010). The population subgroups include female sex workers (FSW), men who have sex with men (MSM), male-tofemale transgender people (TG), and people who inject drugs (PID) and have been grouped using several terms including most at risk populations, vulnerable populations, and key populations. Each of these three populations has specific biological and behavioral risk factors that potentiate concentrated HIV epidemics among them. Among FSW, individual-level risks include high numbers of partners and high periodicity of sexual intercourse and genital ulcerative diseases that mediate HIV acquisition and transmission (Baral, Beyrer, et al. 2012). The elevated HIV acquisition risks associated with anal intercourse as well as the sexual role versatility have been shown to drive HIV epidemics among MSM (Beyrer et al. 2012). Lastly, the efficiency of HIV transmission from parenteral exposures has resulted in rapidly expanding HIV epidemics among PID (Degenhardt, Mathers, Vickerman, Rhodes, Latkin & Hickman 2010). These individual-level risks are contextualized by higher-order risks including stigma and discrimination that limit targeted HIV prevention, treatment, and care expenditures, services, and research (Trapence, Collins, Avrett, Carr, Sanchez, Ayala, et al. 2012). While the importance of key populations was recognized in the early phases of the HIV epidemics in many countries of SSA, their importance was devalued when the HIV epidemics became widespread in the general population. However, the prevalence of risk factors, including unprotected intercourse, sexually transmitted infections, and high numbers of sexual partners and consequent high HIV incidence, and prevalence did not decrease in line with the decreased attention to the needs of these populations.

This edition of the SAHARA Journal is explicitly focused on rewriting the narrative of the epidemiology of HIV in Africa using the most current epidemiology and prevention data available for FSW, MSM, TG, and PID. The papers in this special issue vary in structure with some using more traditional comprehensive reviews, some being analytic in assessing risk contexts, and some using a case-study approach. The majority of the papers are led by African scientists, Practical and sustained solutions on this continent can only come from African people speaking about African problems highlighting paths forward. International authors have only been engaged in instances where such expertise could not be found in the region. Each paper was peer-reviewed by leading global experts before final acceptance.

There are three papers with each focusing on characterizing the epidemiology of HIV in one of the three key populations of FSW, MSM, and PID (Mbwambo 2012; Muraguri 2012; Ngugi 2012). The paper focusing on FSW demonstrates clearly that where data are available on FSW, the burden of disease is disproportionately high in the context of epidemics that already predominantly affect women (Ngugi 2012). However, more than half of

African countries lack meaningful data on the size of FSW populations and thus lack an understanding of the fraction of the HIV epidemic attributable to these women. Where data are available, coverage of prevention, treatment, and care programs is low (Ngugi 2012). The review for MSM in Africa revealed that there is now HIV prevalence data for MSM with about a third of SSA countries surveyed to date highlighting the disproportionate burden of HIV among these men in the backdrop of female predominant epidemics (Muraguri 2012). The paper on PID suggests that injecting drug use is a growing problem across the continent with the best data available from East Africa and a prevalence of HIV that is multiple times higher than that of other reproductive age adults. The last paper characterizes the state of knowledge for transgender people in SSA (Jobson 2012). However, since there are only sparsely available data from Africa for the epidemiology and HIV prevention needs among TG populations across Africa, a commentary is included describing the levels of knowledge and highlighting future directions. Globally, TG are known to carry a very high burden of HIV in high- and middle-income countries around the world, and have been characterized in different settings across Africa, but are invisible in HIV surveillance across the continent (Baral, Beyrer, et al. 2012).

There is a common theme across the reviews of epidemiology suggesting a dearth of high-quality data. In addition, the data that are available are mostly prevalence data from convenience samples of mostly young men and women with comparisons to age-standardized data for the general population. As such, the increased relative burden of disease that has been estimated for each of these three populations appears to be consistently conservative. These comparisons are further conservative, as the prevalent infections in these populations are also included in the burden of disease in the general population. These two factors suggest that the actual relative burden of disease among these key populations compared to the general population is likely far higher than has been estimated.

There are two papers focused on the status of HIV prevention for MSM and FSW in SSA (Rebe 2012; Scheibe 2012). The messages of these papers are that there are existing biomedical and behavioral approaches with proven efficacy that should be scaled up to meet the current need, but also that there needs to be a serious investment to evaluate the efficacy of novel HIV prevention strategies. The papers highlight remarkable similarities between the themes of prevention needs for MSM and FSW including that prevention programs must be multi-modal and address all levels of HIV risk if they are to be effective (Rebe 2012; Scheibe 2012). Biomedical approaches to decrease acquisition and transmission risks will only be as effective as it is possible to implement them with a critical mass of coverage (Bekker, Beyrer & Quinn 2012). The latter is only possible when HIV prevention also addresses the structural realities of stigma and discrimination in which these men and women find themselves (Auerbach, Parkhurst & Cáceres 2011). The last set of papers aims to characterize these rights-constrained environments that represent the reality of today including increasingly punitive legislation criminalizing same-sex practices as well as active manifestations of homoprejudice and homophobia ranging from verbal assaults to murder of young men and women (Beyrer 2012; Semugoma 2012). The last paper provides further context to the limited research and low coverage of prevention programs for these populations across Africa by examining the large-scale funding mechanisms that support HIV work, including the president's emergency plan for AIDS relief and the Global Fund for AIDS, Tuberculosis and Malaria (Ryan 2012). This analysis highlights the underinvestment in these populations relative to the burden of disease. These results are congruent with earlier analyses by the Global HIV Prevention Working Group that estimated that in generalized epidemics, less than 1% of expenditures support these populations with 0.5% for SW, 0.1% for MSM, and $\sim\!\!0\%$ for PID (Global HIV Prevention Working Group 2009).

This series of manuscripts presents sufficient data to indicate that these populations play an integral role to the epidemiology of HIV of Africa. However, there are laws criminalizing at least one of these populations in every country on the continent and it is the enforcement of these laws that has limited the available data on the HIV epidemiology and prevention needs of these populations. Moreover, the enforcement of these laws has created a data paradox, where the absence of HIV surveillance or coverage data limits capacity for data-driven advocacy for targeted expenditures to support data collection characterizing the burden of disease among these populations (Grosso, Hoan Tram, Ryan & Baral 2012; Public Policy Office, amfAR & Center for Public Health and Human Rights 2011). The manuscripts presented here suggest that denying the existence of these populations exacerbates vulnerabilities rather than addressing them. Stigmatizing these populations will likely achieve the same with populations that are purposefully excluded from the existing services or exclude themselves for fear of adverse consequences including stigma and discrimination (Beyrer et al. 2011).

These manuscripts collectively suggest that the only effective path forward is one that transcends denial and stigma and focuses on systematically collecting data on all populations at risk for HIV. The data presented in this special issue of SAHARA Journal also highlight that the HIV epidemic classification system proposed in 2000 is outdated and has resulted in a scenario where there is a dearth of data on these populations in generalized epidemics. The term mixed epidemics has been proposed and we strongly recommend using this term to describe a country's epidemic where the HIV prevalence among FSW, MSM, or PID is greater than 15% with greater than 1% in antenatal clinics. The manuscripts in this special issue suggest that wherever studies among these populations in generalized epidemics have been conducted, the findings indicate that every generalized epidemic would be more appropriately defined as a mixed epidemic. Taken together, these manuscripts suggest that countries should be classified with this new HIV classification system only when data are available characterizing the epidemiology of HIV for at least one of these populations collected in a safe and rights-affirming way. It is time for all HIV epidemiologists to rewrite the narrative of the epidemiology of HIV in Africa to a narrative that appreciates the complexity of these epidemics including all atrisk for infection. The data presented here demonstrate that the the dynamics of HIV in Africa are complex and achieving an AIDS-free generation necessitates acceptance of that complexity in all HIV surveillance and prevention programs.

About SAHARA Journal

SAHARA Journal has been in operation since 1994; it is an internationally reputable open access journal which is published by a premier global AIDS Publisher, Routledge. SAHARA Journal has become one of the leading African voices on HIV and related issues in SSA. It is full text in PubMed, indexed in IBSS, ISI, sociological abstracts (Sociofile), African Index Medicus and Bibliographic Databases including EMBASE/EmNursing/compendex/GEOBASE/Mosby yearbooks and Scopus. The Journal is listed on SABINET and AJOL. It is also full text in South African E-Journals.

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References

Auerbach, J.D., Parkhurst, J.O., & Cáceres, C.F. (2011). Addressing social drivers of HIV/AIDS for the long-term response: conceptual and methodological considerations. Global Public Health, 6(suppl. 3), S293 – S309, doi: 10.1080/17441692.2011.594451.

Avdeeva, O., Lazarus, J.V., Aziz, M.A., & Atun, R. (2011). The global fund's resource allocation decisions for HIV programmes: addressing those in need. Journal of the International AIDS Society, 14, 51, doi: 10.1186/1758-2652-14-51, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3223126/pdf/1758-2652-14-51.pdf (Accessed 3 November 2012).

Badri, M., Maartens, G., Mandalia, S., Bekker, L.G., Penrod, J.R., Platt, R.W., et al. (2006). Cost-effectiveness of highly active antiretroviral therapy in South Africa. PLoS Medicine, 3(1), e4, doi: 05-PLME-RA-0296R1 [pii] 10.1371/journal.pmed.0030004.

Baral, S., Beyrer, C., Muessig, K., Poteat, T., Wirtz, A.L., Decker, M.R., et al. (2012). Burden of HIV among female sex workers in low-income and middle-income countries: a systematic review and meta-analysis. Lancet Infectious Diseases, 12(7), 538–549, doi: 10.1016/S1473-3099(12)70066-X.

Baral, S., Poteat, T., Wirtz, A., Stromdahl, S., & Beyrer, C. (2012). Global burden of HIV infection among transgender persons: a systematic review and meta-analysis (THPDC0202). Paper presented at the XIX International AIDS Conference, Washington, DC, July, 2012. http://pag.aids2012.org/Abstracts.aspx?SID=283&AID=19729 (Accessed 3 November 2012).

Baral, S., Sifakis, F., Cleghorn, F., & Beyrer, C. (2007). Elevated risk for HIV infection among men who have sex with men in low- and middle-income countries 2000–2006: a systematic review. PLoS Medicine, 4(12), e339.

Bekker, L.-G., Beyrer, C., & Quinn, T.C. (2012). Behavioral and biomedical combination strategies for HIV prevention. Cold Spring Harbor Perspectives in Medicine, 2(8), doi: 10.1101/cshperspect.a007435.

Beyrer, C. (2012). Lesbian, gay, bisexual, and transgender populations in Africa: a social justice movement emerges in the era of HIV. SAHARA Journal, In Press.

Beyrer, C., Baral, S., Kerrigan, D., El-Bassel, N., Bekker, L.G., & Celentano, D.D. (2011). Expanding the space: inclusion of most-at-risk populations in HIV prevention, treatment, and care services. Journal of Acquired Immune Deficiency Syndromes, 57(suppl. 2), S9699, doi: 10.1097/QAI.0b013e31821db944.

Beyrer, C., Baral, S.D., van Griensven, F., Goodreau, S.M., Chariyalertsak, S., Wirtz, A.L., et al. (2012). Global epidemiology of HIV infection in men who have sex with men. Lancet, 380(9839), 367–377, doi: 10.1016/S0140-6736(12)60821-6.

Degenhardt, L., Mathers, B., Vickerman, P., Rhodes, T., Latkin, C., & Hickman, M. (2010). Prevention of HIV infection for people who inject drugs: why individual, structural, and combination approaches are needed. Lancet, 376(9737), 285–301, doi: S0140-6736(10)60742-8 [pii] 10.1016/S0140-6736(10)60742-8.

Grosso, A.L., Hoan Tram, K., Ryan, O., & Baral, S. (2012). Countries where HIV is concentrated among most-at-risk populations get disproportionally lower funding from PEPFAR. Health Affairs, 31(7), 1519–1528, doi: 10.1377/hlthaff.2012.0216.

Global HIV Prevention Working Group. (2009). Global HIV Prevention: The Access, Funding, and Leadership Gaps. Washington, DC, http://www.globalhivprevention.org/pdfs/PWG_Access_Funding_and_Leadership_Gaps_Final.pdf (Accessed 3 November 2012).

Hubben, G.A., Bishai, D., Pechlivanoglou, P., Cattelan, A.M., Grisetti, R., Facchin, C., et al. (2008). The societal burden of HIV/AIDS in Northern Italy: an analysis of costs and quality of life. AIDS Care, 20(4), 449–455, doi: 10.1080/09540120701867107.

Jobson, G. (2012). Transgender in Africa: invisible, inaccessible, or ignored? SAHARA Journal, In Press.

Krentz, H.B. & Gill, M.J. (2012). The direct medical costs of late presentation (<350/mm) of HIV infection over a 15-year period. AIDS Research and Treatment, 2012, Article number 757135, doi: 10.1155/2012/757135 (Accessed 3 November 2012).

Lachaud, J.-P. (2007). HIV prevalence and poverty in Africa: micro- and macro-econometric evidences applied to Burkina Faso. Journal of Health Economics, 26(3), 483–504, doi: 10.1016/j.jhealeco.2006.10.007.

Mathers, B.M., Degenhardt, L., Ali, H., Wiessing, L., Hickman, M., & Mattick, R.P. (2010). HIV prevention, treatment, and care services for people who inject drugs: a systematic review of global, regional, and national coverage [Review]. Lancet, 375(9719), 1014–1028, doi: 10.1016/S0140-6736(10)60232-2.

Mbwambo, J. (2012). Drug trafficking, use and HIV risk: the need for comprehensive interventions. SAHARA Journal, In Press.

Muraguri, N. (2012). The first decade of scientific inquiry among men who have sex with men in sub-Saharan Africa: current knowledge and future directions. SAHARA Journal, In Press.

Ngugi, E. (2012). Female sex workers in Africa: epidemiology overview, data gaps, ways forward. SAHARA Journal, In Press.

Piot, P., Bartos, M., Ghys, P.D., Walker, N., & Schwartlander, B. (2001). The global impact of HIV/AIDS. Nature, 410(6831), 968–973, doi: 10.1038/35073639.

Piot, P., Bartos, M., Larson, H., Zewdie, D., & Mane, P. (2008). Coming to terms with complexity: a call to action for HIV prevention. Lancet, 372(9641), 845–859.

Public Policy Office, amfAR & Center for Public Health and Human Rights, JHSPH. (2011). Achieving an AIDS-Free Generation for Gay Men and Other MSM: Financing and Implementation of HIV Programs Targeting MSM (Vol. 1). Washington DC, The Foundation for AIDS Research (amfAR).

Rebe, K. (2012). New HIV prevention technologies and their relevance to key populations in African epidemics. SAHARA Journal, In Press.

Ryan, O. (2012). Demand for programs for key populations in Africa from countries receiving international donor assistance. SAHARA Journal, In Press. Scheibe, A. (2012). HIV prevention measures for female sex workers in Africa. SAHARA Journal, In Press.

Semugoma, P. (2012). Anti-homosexuality legislation in Uganda: assessing effects on HIV prevention, treatment, and care services. SAHARA Journal, In Press.

Trapence, G., Collins, C., Avrett, S., Carr, R., Sanchez, H., Ayala, G., et al. (2012). From personal survival to public health: community leadership by men who have sex with men in the response to HIV. Lancet, 380(9839), 400–410, doi: 10.1016/S0140-6736(12)60834-4.

UNAIDS (2010). Report on the Global AIDS Epidemic 2010. Geneva, United Nations.

UNAIDS & WHO (2000). Guidelines for Second Generation HIV Surveillance. Geneva, WHO.

Zumla, A. (2012). The Global Fund Round 11 cancellation fiasco: turning disaster into opportunity? [Editorial]. The International Journal of Tuberculosis and Lung Disease, 16(3), 285-286, doi: 10.5588/ijtld.12.0066.