PERSPECTIVES PAPER

Medicalization of HIV and the African Response

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Abstract

Since the discovery of HIV, the advent of anti-retrovirals in the late 80s heralded an era of medicalization of HIV and fostered major advancements in the management of the disease. Africa, despite its high HIV burden, lagged behind in the adoption of these advancements due to major resource and logistical constraints. Innovative responses such as family-centered models of care, community systems strengthening, integration of HIV care with existing health services, and economic and mobile phone-based approaches have been critical in the successful roll-out of evidence-based HIV/AIDS treatment even in the most resource-limited settings. (Afr J Reprod Health 2014; 18[3]: 25-33)

Keywords: medicalization, HIV, Africa

Résumé

Depuis la découverte du VIH, l'avènement des antirétroviraux à la fin des années 80 a marqué l'ère de la médicalisation du VIH et a favorisé des progres majeurs dans la gestion de la maladie. En dépit de son lourd fardeau du VIH, l'Afrique traîne dans l'adoption de ces progrès en raison des contraintes importants de ressources et des logistiques. Des réponses innovantes telles que les modèles centrés sur les soins dans la famille, le renforcement des systèmes communautaires, l'intégration des soins du VIH dans les services de santé existants, et les approches fondées sur l'économie et les téléphones portables ont joué un rôle c rucial dans le succès de la mise à disposition de traitements du VIH fondés sur des preuves, même dans la plupart des pays à ressources limitées. (Afr J Reprod Health 2014; 18[3]: 25-33)

Mots-clés: Médicalisation, VIH, Afrique

Introduction

Medicalization, a process of defining and treating non-medical problems as medical problems in terms of illness and disorder, has been in existence since the 19th century¹⁻³. Medicalization is based on a biomedical model of disease that sees behaviors, conditions or illnesses "as a direct result of malfunctions within the human body"^{1,4}. Commercial and market interests are currently the main drivers of medicalization due to recent advances in biotechnology, genomic medicine, consumer focus and managed care².

Recognizing a condition as a disease or disorder, and having it treated to improve the experience and quality of life of the affected individual, is a key benefit of medicalization. Numerous examples exist where medicalization of certain problems previously confined to socio-

cultural circles has helped in finding solutions. For example, Alzheimer's, a previously neglected disease often associated with senility, is now classified as a mental illness treatable using biomedical drugs^{5,6}. What was largely considered normal or aberrant child behavior in the past has been medicalized, resulting in rising numbers of children being diagnosed with attention deficit hyperactivity disorder (ADHD)⁷. Male sexual problems such as erectile dysfunction and perceived undersized penises have also been medicalized resulting in development of therapies such as Viagra and penile enlargement^{8,9}.

On the other hand, medicalization may connote negative aspects such as unnecessary focus on biomedical language, explanations, and solutions to address what are often cultural, psychological, relational, and social problems¹⁰. Opponents of medicalization argue that construing non-medical

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(human) problems as medical conditions fails to recognize the normal variations exhibited by human beings and instead promotes viewing human beings as objects that need fixing up¹¹. This, they argue, unnecessarily drives up the cost of treatment and obscures understanding or changing the very social structures that cause human suffering¹¹.

Medicalization of HIV in sub-Saharan Africa (SSA)

HIV is widely considered both a social and biomedical disease¹². It is considered a social disease because of its modes of acquisition and transmission (contact and exchange of body fluids especially heterosexually), implications connotations due to stigma and prejudice that often surround people living with it. Conversely, it is a biomedical disease because it is caused by a retrovirus, results in immune deficiency and opportunistic infections and responds well to antiretroviral medication¹³. HIV is thought to have originated from SSA based on the theory that the Simian Immunodeficiency virus (SIV) transferred from chimpanzees in central Africa to humans and that the virus mutated into HIV and spread among humans¹⁴. HIV synonymity with SSA still remains because SSA accounts for most cases of new infections and AIDS-related deaths¹⁵. For instance, of the estimated 35.4 million people living with HIV in 2012, about 69% were from SSA¹⁵. Within sub-Saharan Africa, southern Africa countries of Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe experience the most severe HIV epidemics in the world with their national prevalence varying between 10-25% ¹⁶.

Despite the high rates of HIV, most countries in SSA have made significant progress towards ending the epidemic including reductions in overall HIV prevalence, a reduction in AIDS-related deaths, reduced new infections and reduced mother to child transmission¹⁷. Arguably, these reductions have resulted from medicalizing various responses to the epidemic^{18,19}. The progress in management and prevention of HIV two or more individuals who identify themselves as partners or family members, and "family members at risk" are defined as partners and/or

across SSA has been commendable. Kenya, for instance, has one of the highest coverage of prevention of mother-to-child transmission (PMTCT) services, with 69% of HIV PMTCT positive pregnant women receiving antiretroviral prophylaxis in 2011. Additionally, the country is a global leader in the scaling up of voluntary medical male circumcision for adults, reaching a 60% coverage in areas where circumcision prevalence is much lower than the national average²⁰. Other countries have adopted policies and innovative programs to increase National HIV/AIDS service coverage. For instance, Malawi been a pioneer in offering lifelong antiretroviral therapy (ART) to all pregnant women infected with HIV (Option B+) regardless of their CD4 count or clinical stage. In 2010, South Africa's provision of free ART to all eligible people, coupled with mass HIV testing and counseling and tuberculosis screening, resulted in South Africa being the country with the largest ART program in the world, with more than 2.1 million people receiving therapy¹⁶. At the end of 2012, five countries with generalized epidemics namely: Botswana, Namibia, Rwanda, South Africa and Swaziland had already achieved universal access to ART. All these successes made by different countries might have immensely benefited from medicalization of different components of the HIV services. For instance, preexposure prophylaxis (PrEP), early treatment regardless of CD4 count and treatment as prevention (TaSP) are current aspects medicalization of HIV prevention that complement behavior change¹.

Medicalization of Family as a HIV Response

Although HIV initially infects individuals, it affects and exposes the entire family to HIV in the process. It is for this reason that a HIV care and treatment program in Kenya called Family AIDS Care and Education Services (FACES) embraced the concept of family as its model of care²¹. The family model of care is based on the linkage between index patients and their family members at risk. A "family", in this context, is defined as children less than 15 years of age of index patients. The family model of care is designed to identify, engage and care for all HIV-positive

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family members, prevent new infections among family members at risk, and raise family support and awareness within the HIV department at a health facility as shown in Figure 1 borrowed from Lewis $et \ al^{2l}$. Comprehensive family-centered services are built around this process.

Family model of care

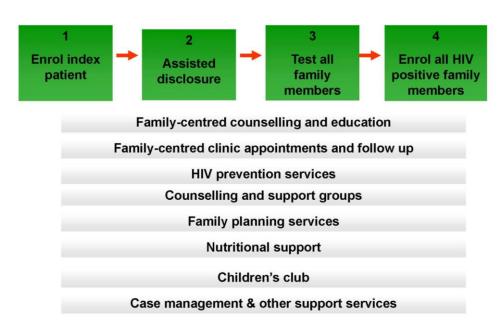


Fig 1: The Family Model of Care Approach

The FACES Program (visit: www.faceskenya.org/about/about-faces/), which uses this family model of care, is a CDC PEPFAR-funded program mitigating the impact of HIV in Kenya. This is done through close collaboration with the Kenyan Ministry of Health in the implementation of coordinated, compassionate and comprehensive, quality HIV services including HIV care and treatment, prevention of mother-to-child transmission, cervical cancer screening and prevention, voluntary medical male circumcision, and HIV testing and counseling services at public, private, and faith-based health facilities. Currently, FACES supports a total of 140 health facilities in the three counties (Kisumu, Migori, Homa Bay) in Nyanza. A cumulative total of 183,632 individuals have been enrolled in care to date, out of which 76 846 are currently on ART.

As a result of the program's resolve to 'medicalize the family' in response to HIV, FACES program data show that for each index

patient, approximately 2.5 family members at risk were identified and 1.6 family members tested. The approach was instrumental in reaching children with 61% of family members identified and tested being children. The approach also led to identifying 71% and enrolling 89% of those tested into care²¹.

Medicalization of Mobile Phone Technology in HIV Care and Treatment Service Provision

The use of mobile phone technology (m-Health) in HIV care and treatment services has increased exponentially over the years. In resource limited settings, individuals on HIV treatment face several challenges including economic and structural barriers which hinder their access to healthcare services²²⁻²⁴. Over time, this often results in poor drug adherence and likely treatment failure. Therefore, the use of mobile phone technology has come in as a useful strategy in the management of

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HIV/AIDS in developing countries, where the mobile phone penetration rate is 89% ²⁵.

Several studies in SSA have demonstrated that mobile phone technology can be used to promote high adherence to ART which ultimately translates to prolonged viral suppression^{26,27}. For example, in rural Kenya a randomized control trial found that medication adherence levels measured after 48 weeks were significantly higher among participants receiving weekly SMS reminders (53%) compared to participants in the control arm $(40\%)^{27}$. Similarly, the WelTel randomized trial found that 62% of patients in the intervention arm receiving text messages reported achieving adherence greater than 95% and virological suppression, compared to 50% in the control group²⁶. Put together, these results suggest that the use of SMS is an efficacious strategy for improving HIV medication adherence developing countries²⁸.

The m-Health platform has also been utilized in other health priorities such as voluntary medical male circumcision, where text messaging resulted in a modest but significant improvement in attendance at the 7-day post-operative clinic visit following adult male circumcision compared with the standard of care²⁹. Additionally, m-Health has been used to improve community health care workers (CHWs) access to health information, decision-making and logistical support. example, an SMS-based communication and professional networking platform enabled CHWs in rural Malawi to request specific technical information from district managers, report important events to the district level (e.g., stock outs, transportation breakdowns), or to coordinate referrals and care³⁰. This study demonstrated that m-Health not only fosters CHW efficiency and delivery of services through improved management of logistics, reporting events, and addressing emergencies³⁰.

Clinicians' HIV consultation hotlines have also been another area where mobile phones have shown promise³¹. *Uliza!* (Swahili for "ask") Clinicians' HIV Hotline, a platform for free telephone consultation services by experienced volunteer doctors to rural healthcare providers in Nyanza, Kenya, was overwhelmingly viewed as useful, and resulted in the implementation of the

advice given to providers in the majority (72%) of medical charts audited³¹. This suggests that *Uliza*! increased access to current information for the provision of quality HIV care in a rural resourcelimited setting with the potential for nationwide scale-up³¹. Thus, m-health provides a strategic opportunity to improve health care services to underserved populations. However, caution should observed be in implementing m-Health interventions as more research is needed to determine whether long-term effects such as behavior change decline with time.

Integration of HIV care Within Existing Health Care Systems in Sub-Saharan Africa

HIV care in SSA was initially managed within HIV care and treatment programs, primarily termed as vertical HIV programs. However, with HIV progressively becoming a chronic illness resulting in increased workload and strain on the limited health resources³², it was necessary to use a more diagonal approach aimed at strengthening health systems and incorporating vertical ART programs³³. With increased funding opportunities, most health facilities in SSA have moved towards management of HIV using a chronic health care model, by integrating HIV care in the existing health care systems in order not to stretch the already limited resources. Integration benefited immensely from the scale-up of HIV programs through national efforts and funding support from such agencies as the US President's Emergency Plan for AIDS Relief³².

Increased funding for HIV has led to improvement of services offered in primary health facilities³⁴ and promotion of a public health approach that emphasizes service decentralization, community mobilization and education, teambased approaches and task-shifting to trained nurses and health workers³³. As an example, the FACES program, in collaboration with the County Health Management Teams, has successfully integrated HIV services in most government-run facilities in the Western Region of Kenya. Additionally, Tuberculosis (TB) screening and treatment³⁵, cervical cancer screening³⁶, family planning provision³⁷ and PMTCT³⁸ have successfully been integrated into HIV care

programs within existing health care systems in Kenya. Promotion of linkages between TB and HIV care in resource limited settings has seen the improvement of management of HIV patients who are affected by both diseases³⁵.

Medicalization of Community Systems as a Response to HIV

Community-led structures and mechanisms play an important role in the response to community health challenges and achievement of health for all³⁶. These structures and mechanisms can be strengthened to enable communities, key affected populations and community-based groups to participate in the development, implementation and evaluation of services pertaining to major health challenges such as HIV/AIDS³⁶. This community systems strengthening is particularly important in low-resource countries where understaffed and ill-equipped health systems render delivery of conventional healthcare services unrealistic and inadequate for the increasing number of people living with HIV/AIDS (PLWHA)³⁹.

Thus, community based programs are an important response to the HIV/AIDS epidemic as they help decentralize conventional health services and establish a sustainable continuum of care for PLWHA at the community level⁴⁰. Community and lay healthcare workers in SSA have played a crucial role in the scale-up of HIV treatment and support services by increasingly taking up roles such as HIV counseling and testing, identification and tracking of non-adherent patients and treatment adherence counseling 41. This taskshifting has not only helped mitigate the chronic human resource crisis prevalent in many SSA health systems but also resulted in the delivery of quality healthcare, strengthened linkages to care and improvement of health outcomes among PLWHA⁴²⁻⁴⁴. Specifically, task-shifting to CHWs has led to positive perception of PLWHA, improved uptake of HIV testing and treatment, disclosure of results, improved increased virological suppression, enhanced quality of life and better survival rates of PLWHA 42,45. For instance, in a multisite study conducted in South Africa, patients receiving community-based

adherence support had significantly higher virological suppression, lower mortality and lower loss to follow-up⁴⁴. Several studies in SSA have also reported an increased adherence to ART and retention in care associated with use of CHWs in HIV care programs⁴⁶⁻⁴⁹. In some instances, care and support provided by CHWs has been shown to be comparable to, or sometimes better than, the care provided by trained healthcare providers⁵⁰.

Community-based initiatives are effective in tackling major challenges that plague HIV program scale-up in SSA such as chronic health worker shortages, integration of ART services into the general health system, defaulter tracing, adherence optimization and patient empowerment⁴⁵. Sustainability of such initiatives can be fostered through alignment with broader health systems, improvement of health evaluation systems, improved supervision, capacity-building and remuneration of CHWs^{41,42,45,51}.

Medicalization of Income-Generating Ventures

HIV has been described as a disease of the poor because of its concentration in developing countries of SSA and among women who are economically deprived. These countries are characterized by serious economic and structural challenges that make it difficult to reasonably deliver health services. While there have been efforts to take HIV care services closer to the people, many people in the expansive rural areas with poor road networks still find it challenging to enroll and remain in care^{52,53}. Because of poor road networks, it is often expensive and time consuming to travel to HIV care clinics. Many, especially women, opt to either not enroll in care at all or dropout of care when they cannot afford getting to their care clinics. Food insecurity is also a major issue related to poverty for people in care⁵⁴⁻⁵⁶. Weight loss and under-nutrition, which are both symptoms of food insecurity, have been associated with increased likelihood of mortality among HIV patients^{57,58}. For the majority of people who depend on one meal a day, taking antiretroviral drugs is a daunting task because some ARVs are taken more than once a day and need to be taken after food. To illustrate the gravity of this matter, a study by Anema and

colleagues showed that 90% of HIV service providers in nine SSA countries provide food support to their patients⁵⁷.

HIV care providers have attempted measures to ameliorate poverty in order to increase uptake and retention into HIV care and above all increase survival of patients. For instance, Food by prescription (FBP) program is a donor-funded initiative in Kenya established in 2006 in collaboration with its development partners. The program operates in all regions of Kenya and reached 27,913 patients by 2007⁵⁹. The program includes nutritional screening, assessment, education, counseling, and provision of fortified corn-soy flour supplements to malnourished adults living with HIV, HIV-positive pregnant and postpartum women, and malnourished orphans and vulnerable children. An evaluation paper using program data by Nagata and colleagues⁵⁵ show that FBP patients gained 2.01 kg in weight and 0.73 kg/m2 in BMI over follow-up of about 100 days. The greatest gains were among the most severely undernourished (BMI, 16) patients. Only 13.1% of clients attained a BMI≥20, though 44.5% achieved a BMI increase of more than 0.5. Greater BMI at baseline, younger age, male gender, and not requiring highly active antiretroviral therapy were associated with a higher rate of attainment of BMI\ge 20. There are numerous examples like this one throughout SSA^{54,56,60,61} that show that medicalizing food in the HIV response has beneficial effects on patients.

There is anecdotal evidence that engaging women in income generating projects prevents involvement in high risk sexual behaviors 62,63. Thus, other than food donations, sustainably empowering poor HIV affected households to initiate income generating projects may be a better option. With such projects patients can cater for their nutritional needs while being retained in care. Several economic interventions have been tried to enhance income through food security, some of which have been successful⁶⁴. Shamba maisha (farm is life), a small pilot project providing initial farm inputs to poor HIV affected households to increase their economic and nutritional status has shown that it is largely feasible. The study shows that even though CD4 counts did not change significantly, probably due to a short follow up

period of 12 months, mean annual family income increased by \$1,332 over baseline⁶⁴.

Conclusion

This paper demonstrates that medicalization of various aspects of HIV prevention and treatment has been the norm in Kenya, SSA and the world Successful medicalization of the social aspects of HIV/AIDS such as the family, communication, integration, community system strengthening and income-generating ventures complements medical solutions such as ART, microbicides. PrEP and the search for a HIV vaccine resulting in a formidable response to HIV/AIDS. Even in the most dire resource constraint settings, medicalization of the HIV response in SSA has enabled mobilization of hitherto under-utilized resources in healthcare thus enhancing access to evidence-based care for those living with HIV.

Acknowledgement

We would like to sincerely thank the Family AIDS Care and Education Services (FACES, KEMRI-UCSF) staff, patients and their families for allowing us to use their knowledge and experiences. We also wish to thank CDC for their funding support and KEMRI for facilitating the running of the FACES program. The authors also duly acknowledge the contribution of the BIARI programme of the Brown University, Rhonde Island, USA for their contribution to making this publication possible.

Contribution of Authors

SG and SN compiled the initial presentation that was presented in the 2013 Biomedical HIV prevention forum in Abuja, Nigeria. SG, SN, BN, ZK and EO each contributed a section in the first draft of this paper while EAB provided input.

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