# REVIEW ESSAY Sins of Omission: Public Health and HIV/AIDS in Africa

## ALEXANDER RÖDLACH

Gregory Barz and Judah M. Cohen (eds.). 2011. *The Culture of AIDS in Africa: Hope and Healing Through Music and the Arts*. Oxford: Oxford University Press. 500 pp.

Patricia C. Henderson. 2011. AIDS, Intimacy and Care in Rural KwaZulu-Natal: A Kinship of Bones. Amsterdam: Amsterdam University Press. 254 pp.

Aginam Obijiofor and Martin R. Rupiya (eds.). 2012. HIV/AIDS and the Security Sector in Africa. Tokyo: United Nations University Press. 281 pp.

Ross Parsons. 2012. Growing Up With HIV in Zimbabwe – One Day This Will All Be Over. Woodbridge: James Currey. 197 pp.

Jenny Trinitapoli and Alexander Weinreb. 2012. *Religion and AIDS in Africa*. Oxford: Oxford University Press. 279 pp.

#### Introduction

Several books and edited volumes exploring issues related to HIV and AIDS in Africa have recently been published. Some are distinguished from mainstream publications, which focus on themes considered important by the establishment, by their exploration of aspects of HIV and AIDS in Africa that have been insufficiently recognized and addressed by health care providers, policy makers, and funding organizations. The five publications – authored by anthropologists, artists, civil servants, political scientists, psychotherapists, and sociologists – reviewed in this article are particularly valuable in this regard. They discuss oversights that can be conceptualized as "sins of omission," referring to the failure to do something that can and ought to be done regarding the prevention of new infections, treatment, and care for those living with HIV and AIDS and their households. The choice of "sin" is deliberate to underscore the moral implications of our research, which can ameliorate or exacerbate human suffering. The books are reviewed in no particular order; however, the first book's ethnographic approach allows the reader a multifaceted glimpse at the experience of living with HIV and AIDS, introducing the topic.

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#### http://www.africa.ufl.edu/asg/v13/v13i4a4.pdf

#### Sin of Omission I – Lack of Support for Care Provided Outside Formal Health Care

During three years of ethnographic fieldwork, Henderson, an anthropologist, studied individuals' experiences of living in the context of HIV and AIDS in KwaZulu-Natal, South Africa. In particular, she records the suffering from HIV and AIDS prior to the rollout of antiretroviral treatment (ART), and highlights patterns of care outside of the formal health care sector within a context of limited resources. The subtitle of the book – *A Kinship of Bones* – refers to meanings "related to sociality, relationships and intimacy" (p. 18), which are essential for understanding caregiving. The body's flesh disappearing during the progression of AIDS mirrors a disintegration of social relations and intimacy. Yet, because of their durability, bones are also linked to strength and endurance. The author discusses aspects of care that are both provided and withheld in relations of intimacy, kinship, and neighborliness, particularly through reference to touch, support, and the use of language in the context of illness.

The author first explores the effects of HIV and AIDS on the human body and links them to local notions of the "proper" physical and social body. Henderson then raises the question of research and care ethics in relation to people who are dying or in mourning, emphasizing the unfolding nature of research and care. Subsequently, she argues that children who have lost one or both parents are not passive and powerless; they exercise a considerable amount of agency in soliciting support from others. What follows is a discussion about care from the point of view of healers, who understand HIV/AIDS through reference to past social dissonance and histories of discrimination, and integrate indigenous and biomedical frameworks when explaining and treating illnesses. The author then explores the tensions between the desire for procreation, intimacy, and care among couples living with HIV and AIDS. This is followed by a description of care undertaken by homebased caregivers. Throughout the book, Henderson emphasizes tenacity in seeking support and care, particularly outside the formal health care sector, and enables readers to identify possible avenues for interventions that have been insufficiently utilized by public health programs.

While I enjoy Henderson's skilled use of language, her interpretations appear at times to go beyond what the data suggest. Further, she sometimes seems unfamiliar with the science and medicine of HIV/AIDS, adding some naiveté to her thoughts. For example, she refers uncritically to the simultaneous use of herbal and biomedical treatment without discussing possible drug interactions (p. 76). In addition, while I appreciate the extensive use of the Zulu language, the English translations were not always correct. For instance, wangivusa was wrongly translated as "she raised him" (p. 157); it actually should be "she raised me." Furthermore, some of the translations from Zulu are too literal, e.g. when isibindi is translated as "liver," adding that this term is indicative of courage, which is the actual meaning of isibindi in this context.

#### Sin of Omission II - Ignoring Religion's Potential for HIV/AIDS Programs

Sociologists and demographers Trinitapoli and Weinreb conducted mixed-methods research in Malawi and Kenya. They recorded services and sermons, collected in-depth semi-structured interviews with ministers and lay members of congregations, and analyzed conversations at markets, bars, bus stops, and other venues. They expanded the scope of their analyses using secondary data from across sub-Saharan Africa. Their central argument is that, to understand the effects of religion on the AIDS epidemic, we need to account for

both the role of individual religiosity and the broader religious context in altering the behavior of individuals and the pool of risk. Their general conclusion is that religion has desirable effects on HIV/AIDS awareness, prevention, and care.

The authors investigated the efficacy of the widely known ABC prevention model (Abstain, Be faithful, use Condoms) and identified in their data strong evidence that religious involvement delays the onset of sexual activity and increases rates of abstinence and marital fidelity. They argue that these rates are associated with the degree of social control and vigilance of sexual conduct within congregations. This may explain why people who are more religious, as measured by involvement in their religious communities, are less likely to be HIV-positive. Their data further indicate that religious groups overall represent a balanced position about condoms - "a pragmatic, humane, but somewhat distasteful solution to the imperfections of the human character" (p. 107) – explaining why denominational differences in condom use are marginal.

Overall, religious congregations that combine moral messages about AIDS with openness to testing and condom use provide the best protection against HIV infection. Such evidence is frequently overlooked by public health experts, whose main emphasis tends to be condom use. This also holds true for other local African prevention strategies, e.g., encouraging divorcing an unfaithful spouse by providing a supportive network within congregations for divorcees and promoting religious messages discouraging materialism and consumption within the context of the commodification of sex; both local strategies are relevant for preventing HIV infections. Similarly, messages discouraging alcohol drinking are pertinent to AIDS prevention efforts; alcohol consumption is associated with extramarital sex and low and inconsistent use of condoms, and subsequently with HIV infection.

Beyond themes related to preventing infections, Tinitapoli and Weinreb find evidence that religious organizations do more to dampen stigma than to perpetuate it. The more a congregation is involved with the sick, the lower the degree of stigma. Exposure to or interaction with people living with HIV and AIDS erodes negative attitudes about them and, consequently, reduces stigma and discrimination. Religious groups also provide significant care and material and psychological support to individuals and households affected by the epidemic. Further, the authors argue that the epidemic is transforming religious expressions and the religious landscape. For example, references to sexual behavior and care for AIDS sufferers and orphans feature prominently in many congregations. Overall, it seems that religious groups are disproportionately winning converts. This book is a valuable assessment of the relationship between religion and HIV/AIDS in Africa, correcting biases about religion in the existing public health literature and awareness, treatment, and care programs that overlook the potential of religion to prevent and address human suffering due to the epidemic.

The publication has a few minor shortcomings. The main weakness is that the dearth of ethnographic data leaves some questions unanswered or poorly understood. Further, the authors seem unfamiliar with the literature on certain aspects of social life, such as language. For example, they argue that many African languages lack a word for abstinence, forcing abstinence campaigns to develop a new vocabulary. This is not quite true; in languages that are strongly context-dependent, multi-vocal terms gain specific meanings in specific contexts. Thus, a term used within the context of HIV and AIDS gains a meaning specific to the disease and behavior associated with it.

#### Sin of Omission III - Overlooking the Epidemic's Threat to Security in Africa

The volume edited by Obijofor and Rupiya provides a wide range of policy perspectives on the challenges of HIV/AIDS to the security sector, examining the impact of the epidemic on military, police, and prison services, including peacekeeping missions. The contributors to this volume focus on selected African countries and sub-regional organizations that are representative of other countries and organizations across the continent.

The first section of the book comprises six chapters that concentrate on sub-regional policy perspectives concerning HIV/AIDS and the military, describing the potential impact of HIV/AIDS on the military. The authors demonstrate that HIV/AIDS affects the recruitment process, deployment, and effectiveness of the military. They examine measures that should be taken by the military to mitigate the impact of HIV/AIDS, argue for the observance of human rights and individuals' sexual morals within the army, explore the importance of synchronizing public health and security policies, and address cultural factors related to HIV and AIDS. The second part focuses on the challenges posed by HIV/AIDS to peace-keeping in Africa. It examines the nexus between culture and HIV/AIDS in African peace-keeping operations, drawing a causal link between the hyper-masculine culture among peace-keeping forces and high-risk sexual behavior and highlighting the lack of data on the epidemic's impact and effects on peace-keeping operations. The third part focuses on the challenges of HIV/AIDS to the police force, highlighting attitudes and perceptions about HIV and AIDS among police that lead to stigma and discrimination. The contributing authors also discuss overcrowding, the established prison culture, and the paucity of data about HIV/AIDS in prisons. The fourth part focuses on gender-related factors that drive HIV transmission, arguing for the empowerment of women and the adoption of gender-sensitive approaches in addressing HIV/AIDS, and discussing the increasing use of rape as a weapon in some African conflicts. Overall, this publication fills a gap in the existing literature by highlighting the need for a closer collaboration of the security sector with the public health sector.

However, while based on valuable personal and professional experience, some of the chapters are overly descriptive and may not influence the academic and policy communities. Further, it would have been better if several authors had collaborated on single articles, integrating professional with academic expertise. This would have increased the strength of the arguments and the potential to influence both public health and the security sector.

### Sin of Omission IV - Trivializing the Arts' Potential in HIV/AIDS programs

The contributors to this volume, edited by Barz and Cohen, are physicians and social scientists, journalists and documentarians, and professional artists and educators who describe how music and other expressive art forms gained prominence in addressing HIV and AIDS.

The authors of the chapters in the first section describe the place of music in international HIV/AIDS initiatives, lay out some of the classic discussions of the arts' role in AIDS-related efforts, and explore the nature of cultural production in an environment in which artists' work must engage numerous layers of political and cultural discourses to succeed. In the second section of the volume, the contributing authors explore the use of music, dance, and drama to address HIV/AIDS in a variety of African contexts, describing the often hidden continuities in arts-based health interventions and providing accounts of HIV education through drama and forums. The third part of the volume explores how local

forms of expression are utilized in campaigns to prevent new HIV infections, reduce stigma, and provide further education on HIV/AIDS issues. The authors examine the ways in which public visual culture reorients images and cultural norms into anti-AIDS messages, describe how the musical arts and drama equip communities with skills and agency, and analyze how internationally funded health efforts layer onto existing local practices of identity, class, power, and gender. The fourth part of the volume shifts the focus toward specific artists whose creative drive often encourages cultural change. The fifth part of the volume highlights the role of amateur performing groups, particularly choirs and drama groups, in delivering HIV/AIDS-related messages, arguing that groups attempt to use their exposure to become famous, while instilling in their audiences a sense of community. The last section of the volume presents a set of case studies that interrogate how popular media mediate HIV/AIDS in a variety of African contexts, underscoring the importance of artistic forms for understanding the disease's social and cultural reach. The authors also note that representations of the epidemic often end up reinforcing colonialist, exotic images of Africa. Overall, this volume is indeed, as the editors write, a "launching pad for further work on the interdependence of medicine, culture, and creative expression" (p. 19). A stronger collaboration between the arts and public health will result in more effective programs.

However, the volume also has significant shortcomings. While the volume covers most artistic expressions, it strongly focuses on the musical arts and does not include other artistic expressions, such as wood and stone carving. Further, a large percentage of the contributions are overly descriptive and provide only superficial and preliminary analyses. The editors could have provided stronger leadership in editing individual chapters and excluded some chapters that provide nothing new or unique to the volume. The volume integrates several "interludes," but it is not always clear what distinguishes an "interlude" from a "chapter." It seems to me that at least one of the interludes is simply a weak chapter that was differently classified to justify its inclusion. Some of the chapters refer to ART, while others don't; this gives the impression that the latter date from a time before the massive rollout of ART and need to be updated. Disturbing also is the abundance of strong statements in many chapters without providing evidence or support from the literature. For example, Barz says that traditional healers "contribute significantly to the overall health and spiritual well-being of many" (p. 30) without providing evidence from the literature. Similarly, Eller-Isaacs writes that "[a]fter seeing these artists in action, it was clear to me that ..." (p. 66) without explaining why it became clear.

#### Sin of Omission V – Discounting the Lived Experience of Individuals Receiving ART

Parsons, a child psychotherapist and anthropologist, has created an ethnographic description of children living with HIV while growing up in a small Zimbabwe town under conditions of extreme adversity. His aim was to understand HIV prevention, treatment, and care from the viewpoint of these children and their caregivers. In order to present as full a picture as possible of the lives of children growing up with HIV, Parsons closely observed their lives within their families, at clinics, and in churches; interacted with the children's health care providers; interviewed traditional and faith healers; and closely followed local media. He developed close relationships with 13 children and their caregivers, which were transformed over time from being therapeutic associations with clients and ethnographic affiliations with informants to close social bonds of fictive kinship (p.173).

Parsons paid close attention to kinship and concludes that idealized structures of relatedness are negotiated considering various factors. When family elders discuss who should take care of children who have lost at least one of their biological parents, their decision is influenced by the dire economic and social conditions, as well as by the availability of potential caregivers. When the mother and maternal kin are selected as caregivers, it means that they are cared for by kin more distant to them than their paternal kin, which often translates into the experience of not receiving the same level of care as other children in the same household. This encourages the children to develop and maintain fictive kinship relations in churches, hospitals, and schools, which are an additional possible source of support and care. The ultimate form of fictive kin for the children, according to the author, is God the loving father and Jesus the ultimate caregiver. The children expect to be supported by them. Faith is a daily feature in the children's lives, though they struggle with theodicy, trying to remain faithful to a belief in the benevolent and all-powerful God in the face of extreme suffering. Their Christian faith and the fellowship experienced in churches are more important for the children than biomedical treatment.

ART is generally not viewed as positive; it is disliked and associated with negative meanings. The children are aware that medical treatment prevents, or at least delays, their physical death but only marginally addresses their social suffering, which sometimes is akin to social death. The latter is attributed to the strong stigmatization of the disease. Children are reluctant to admit their HIV status. They cautiously try to pass as "normal," but this a nearly impossible task, due to treatment regimens and the physical signs of HIV infection. The children in Parsons' study had low expectations for their futures. In the unpredictability of their lives, when death was ubiquitous and could come at any time, they felt dislocated and alone, identifying heaven as their home and longing to be there. Parsons experienced that these children chose, at some point, to withdraw from treatment, deciding to end their struggles.

The strength of this publication is that it provides a detailed and painfully engaging portrayal of the lives of HIV-positive children, with insights essential for assessing existing treatment and care programs for people living with HIV and AIDS, particularly children. Parsons also challenges the emotional remoteness and other characteristics of health care that are profoundly culturally alien to the African context and offer little to people living with HIV and AIDS.

As with other publications, this publication has certain shortcomings. At times, the author leaves questions unanswered. For example, the author mentions that most HIV-positive children in Zimbabwe die before the age of five, even when they are enrolled in ART (p. 1). As the children in his study are adolescents, they seem to be outliers and perhaps not representative of children living with HIV in Zimbabwe and elsewhere. Further, Parsons at times promises something without delivering it. For instance, he says that children profoundly challenge current ideas about child rights, child-rearing practices, and the mental well-being of the young (p. 53), but he fails to explicitly describe how these ideas are challenged.

#### **Conclusions**

Each of the five publications highlights one or more issues that are downplayed, overlooked, or misrepresented in the mainstream literature on HIV/AIDS and general public health practice: Henderson emphasizes aspects of AIDS care outside the formal health care sector,

Trinitapoli and Weinreb correct common misconceptions about the role of religion in HIV/AIDS in Africa, Obijofor and Rupiya's volume highlights the threat to security from the epidemic, Barz and Cohen describe the wide range and impact of arts-related responses to the disease, and Parsons portrays the lived experience of being HIV-positive. Each of these books includes findings and insights that have the potential to improve AIDS-related programs and policies and, subsequently, the lives of those affected by the epidemic and/or living with HIV and AIDS in Africa.

Despite the wide range of topics covered, there are several overlaps and shared insights in the books. For instance, Henderson and Parsons caution against quickly drawing conclusions from AIDS-related research and applying findings to develop or revise existing understandings, programs, and policies. Parsons aptly argues that the suffering and pain witnessed require an "ethic of constraint," implying that immediate recourse to theoretical analysis and policy formulation seems premature and inappropriate, and advocates an "interpretive pause," an idea borrowed from Marilyn Strathern, which is "a form of deliberate hesitation before the headlong rush to policy and practice" (p.15). Both authors also argue that the assumption of passivity and unmitigated vulnerability circulating in discourse concerning "AIDS orphans" is not appropriate. While we should not underestimate the devastating effects of HIV and AIDS on children's lives, they are capable of exercising their agency in spite of the harsh realities. Trinitapoli and Weinreb agree with Parsons in concluding that the creation of fictive kin is a strategy actively sought by people living with HIV and AIDS in order to solicit support and care.

It is difficult to identify the publication of the highest quality among the five reviewed, because of the diverse and wide range of themes and the differing approaches taken by the authors. However, two of these five publications are simply exceptional: Parsons' ethnography is an excellent example of an in-depth, complex, and intimate portrayal of children living with HIV, and how long-term research and personal involvement can yield insights that can hardly be gained otherwise. Trinitapoli and Weinreb's analysis of a wide range of qualitative and quantitative datasets provides findings that indicate the invaluable positive role of religion on AIDS awareness, prevention, and care in Africa, correcting the often shallow, negative perception in the mainstream public health literature. I am confident that both books will transform future approaches to HIV and AIDS in Africa by addressing several "sins of omission."