

The Consequences of Rationing Antiretroviral Treatment in Sub-Saharan Africa

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The most salient characteristic of technology in the modern (industrial/post-industrial) world is the degree to which most technology is not salient for most people, most of the time.¹

According to the World Health Organization, in 2004 only 1 percent of the nearly 4.1 million people living with HIV/AIDS in Africa received desperately needed antiretroviral (ARV) treatment.² Over the last six years, various aid organizations and international donors have responded by regarding antiretroviral therapy (ART) as an integral dimension of health spending on the continent. The President's Emergency Plan for AIDS Relief (PEPFAR) has been by far the most significant, allocating US\$ 39 billion to HIV/AIDS as of 2008. Through specific targeting of ART, such programs have been instrumental in mitigating the suffering of more than a million people, but they have done little to curb the overall seroprevalence of the disease, and scarcity of ARV drugs continues.³ It is, therefore, critical to examine how the allocation of treatment reinforces structural inequalities, or *structural violence*, against the poor.

Through this paper I will argue that the inequitable allocation of ART in sub-Saharan Africa enhances historical and contemporary patterns of

¹ Paul Edwards, "Infrastructure and Modernity: Force, Time and Social Organization in the History of Sociotechnical Systems," in *Modernity and Technology*, ed. Philip Brey, Andrew Feenberg, and Thomas J. Misa (Cambridge: MIT Press, 2003): 185-226.

² Peris S. Jones, "When 'Development' Devastates: Donor Discourses, Access to HIV/AIDS Treatment in Africa and Rethinking the Landscape of Development," *Third World Quarterly* 25, no. 2 (2004): 386.

³ Eran Bendavid and Jayanta Bhattacharya, "PEPFAR in Africa: An Evaluation of Outcomes," *Annals of Internal Medicine* 150, no. 10 (19 May 2009): 688-95.

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inequality, leading to negative outcomes for the already disadvantaged. First, I will utilize the framework of structural violence and the needs/capabilities approach of Sen and Nussbaum, to highlight how the unequal treatment of HIV/AIDS enhances historical patterns of inequality in post-colonial Africa. I then turn to three articulations of how inequitable ART distribution enhances structural violence. Poorly conceived antiretroviral allocation strategies worsen the condition of crumbling healthcare sectors, reinforce economic inequalities in Zambia, and restrict the agency of impoverished Ugandans at the family, local, and national levels.

On Structural Violence and the Restriction of Human Potential

Nay, take my life and all, pardon not that:
You take my house when you do take the prop
That doth sustain my house: you take my life
When you do take the means whereby I live.

Shylock – *The Merchant of Venice*⁴

According to standards set forth by Felipe MacGregor and Marcial Rubio,⁵ *structural violence is the indirect restriction of human potential by intermediary physical, social, economic, and political systems or institutions*. In order to better understand this definition it helps to examine its component parts. Peace and violence theorist Johan Galtung refers to *violence* in terms of realizing *human potential*. Violence, he says, is “that which increases the distance between the potential and the actual, and that which impedes the decrease of this distance.”⁶ In other words, violence is the act of restricting human potential. Galtung’s notion of violence is more conceptually expansive than the realm of agent-dependent, direct violence. It also includes the role of intermediary forces. However, to gain consensus on what should be meant by *human potential* is problematic. In fact, Galtung himself stops short of defining the full scope of what should be included in the discussion.⁷ Understandably, this debate is easily “saturated with moral judgments that invite anachronism,”⁸ so it is important for the purposes of this analysis to qualify human potential according to more widely accepted norms.

⁴ William Shakespeare, *The Merchant of Venice*, IV; i; 386–389.

⁵ Felipe E. MacGregor and Marcial Rubio C., “Rejoinder to the Theory of Structural Violence,” in *The Culture of Violence*, ed. Kumar Rupesinghe and Marcial Rubio C. (Tokyo: United Nations University Press, 1994), 49.

⁶ Johan Galtung, “Violence, Peace and Peace Research,” *Journal of Peace Research* 6 (1969): 168.

⁷ Galtung, 1969, 169.

⁸ Loïc Wacquant et al., “Sidney W. Mintz Lecture for 2001: An Anthropology of Structural Violence/Comments/Reply,” *Current Anthropology* 45, no. 3 (1 June 2004): 322.

Bioethicists and global health practitioners often cite the Universal Declaration of Human Rights⁹ as a standard by which the allocation of healthcare should be measured. Unfortunately, disagreements over cultural relativism and state sovereignty threaten to mire discussions of human potential and structural violence in an agent-dependent debate on morality.¹⁰ Instead, structural violence must be imagined separately from implied notions of the inherent rights of man. Thus, I will frame human potential by the needs/capabilities outlined by Martha Nussbaum and Amartya Sen in their pivotal book *The Quality of Life*. In development discourse Nussbaum and Sen's barometer of needs/capabilities can augment simple neoclassical indicators of developmental success (such as GNI and national savings rates) and will help to situate the discussion of structural violence in a more pragmatic and balanced realm.

The most pertinent of the potentialities laid out by Sen and Nussbaum include but are not limited to: **life** (length, quality); **bodily health** (nourishment, condition); **bodily integrity** (freedom of movement, exchange, access to information); **senses, imagination, and thought** (religion, political and artistic expression, adequate education); **practical reason** (the planning of one's life); **affiliation** (empathy, freedom of assembly, speech, information/cultural exchange, non-discrimination); and **control over one's environment** (political agency, material accumulation).¹¹ Nussbaum and Sen argue that these needs/capabilities are essential to the maintenance of life and the qualities that make life worth living. The restriction of these essential needs/capabilities should therefore be seen as an act of violence.

Now, let us shift our focus to three different forms of violence in order to better understand the meaning of *intermediary* forces. In their *Rejoinder to the Theory of Structural Violence*, MacGregor and Rubio highlight the importance of structural violence in its relationship to "direct" and "cultural" violence. They define these three kinds of violence – direct, structural, and cultural – as a causal network. *Direct violence* is seen as an event perpetrated by one agent against another. A husband beats his wife after she discovers she is HIV positive, for example. *Cultural violence* is a restrictive process of "invariant permanence" (or, slowly changing reality) exemplified by religious, ideological, linguistic (etc.) standards or customs. Oftentimes, social mores restrict the agency of women under the guise of various cultural and religious traditions. One form of violence can be seen not only as a consequence of the other two,

⁹ United Nations, "Universal Declaration of Human Rights," online, <<http://www.un.org/Overview/rights.html>>.

¹⁰ See Jack Donnelly, *Universal Human Rights: In Theory and Practice* (Ithaca, NY: Cornell University Press, 2003), and Michael Ignatieff, *Human Rights as Politics and Idolatry*, ed. Amy Gutmann (Princeton: Princeton University Press, 2001).

¹¹ Martha C. Nussbaum and Amartya Sen, eds., *The Quality of Life* (Oxford: Clarendon Press, 1993).

but also as a legitimating or justifying force of the others.¹² As a rule of thumb, it is all too often culturally and institutionally acceptable for men returning from a hard day's labor to take their frustrations out on their wives in the form of beating.

From this causality of violence, MacGregor and Rubio make an important distinction between societal structures and the concept of culture. The relationship between structure and culture is often muddy. Structure is best defined as the physical and institutional systems existing between various agents in society. Culture, more heavily dependent on human relationships, exists within and between the structures of society. Despite their interconnectedness, culture is not clearly addressed through short-term changes to physical and institutional structures. This will be elucidated in later examples of cultural and institutional reactions to limited ARV availability in sub-Saharan Africa. As this analysis proceeds, it is important to *attempt* to hold notions of *culture* apart from *structure* when engaging in analyses of structural violence.

Critics of Galtung's structural violence argue that the lack of direct agency softens the theory by removing culpability from instances of violence, and uniformly treats acts of violence (economic, political, physical, etc.) that should be differentiated. Loïc Waquant worries that structural violence will "conflate full-fledged domination with mere social disparity."¹³ Indeed, focusing solely on structural violence threatens to negate the often overt perpetration of direct physical harm against victims. It is for precisely this reason that the concept of structural violence is used to augment the notions of other, more agent-specific forms of violence, and to understand the greater forces in society that perpetuate and legitimate all kinds of violence. Moreover, differentiating economic, political, physical (etc.) realms of violence threatens to ignore the interconnectedness of modern society.

Skeptics like Kenneth Parsons argue that Galtung over-generalizes inequality into one meta-category, reducing all undesirable outcomes of societal interaction to structural violence.¹⁴ While Parsons' popular call to create subcategories of violence (oppression, discrimination, marginalization, etc.) does not go unappreciated as a significant critique of the general vagaries of structural violence, examining the social, political, and economic inequalities brought about by societal institutions, programs, and systems requires a more all-encompassing definition. Peter Prontzos defines structural violence broadly as "political and economic" and "lethal and non-lethal." He includes in his definition a myriad of consequences, including the "collateral damages" of structural violence: over-exhaustion from work; increased stress and heart

¹² MacGregor and Rubio 1994, 51–52.

¹³ Wacquant 2004, 322.

¹⁴ Kenneth A. Parsons, "Structural Violence and Power," *Peace Review* 19, no. 2 (April 2007): 176.

disease; homelessness; inadequate access to emergency services in the event of a natural disaster; etc.¹⁵ We must be careful not to equate structural violence with one kind of violence alone, but see it as an overarching concept that recognizes the interdependence of structural forces resulting in undesirable outcomes.

MacGregor and Rubio view the measurement of structural violence as a means of establishing preventative therapy for the organism of society in the same way that preventative medicine addresses disease.¹⁶ It is an objective means of measuring the structural forces of society on the reduction of a group or individual's effective performance. More subtly, structural violence focuses on the notion of "pressure" (physical, biological, spiritual/psychological, etc.), flowing in and out of economic, political, and social structures. These pressures affect human interactions until a certain threshold is exceeded, creating an avoidable reduction in the realization of human capabilities.¹⁷

MacGregor and Rubio's notion of pressures fits well with Paul Farmer's view of structural violence in the context of public health. Arguing that the primary victims of structural violence are the poor, Farmer maintains that structural violence is an essential tool that must be used to reintegrate inequality into the understanding of poverty.¹⁸ Farmer's focus on disparity highlights the consequences born of structural violence with an urgency not often found within development discourse. Ignoring disparity, he argues, . . . turns a blind eye to the pathologies of power that transcend all borders. Perpetuating such fictions requires dishonest, de-socialized analyses that mask – whether through naiveté or fecklessness or complicity – the origins and consequences of structural violence.¹⁹

In *Pathologies of Power*, Farmer illustrates his notion of structural violence as being inextricably linked to the condition of the poor. Using the notion of Liberation Theology, he highlights the suffering of the poor as "structured" by historic and economic processes and forces that conspire "through routine, ritual . . . or the hard surfaces of life, to constrain agency."²⁰ Farmer focuses acutely on the relationship between structural violence and the field of medicine, calling upon national and international institutions to adopt an

¹⁵ Peter G. Prontzos, "Collateral Damage: The Human Cost of Structural Violence," in *Genocide, War Crimes and the West: History and Complicity*, ed. Adam Jones (New York: St. Martin's Press, 2004), 304.

¹⁶ MacGregor and Rubio 1994, 42.

¹⁷ *Ibid.*, 46.

¹⁸ Amartya Sen, Foreword to *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, by Paul Farmer (Berkeley: University of California Press, 2005), xvi.

¹⁹ Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor* (Berkeley: University of California Press, 2005), 245.

²⁰ *Ibid.*, 40.

approach that emphasizes the equitable distribution of already abundant resources.²¹

We can now define structural violence according to MacGregor and Rubio as the indirect restriction of human potential; in terms of Sen and Nussbaum's needs/capabilities; and by intermediary physical, social, economic, and political systems or institutions.²² I will use this idea of structural violence, informed by Farmer's emphasis on the close relationship to inequality, to explore the allocation of antiretroviral therapy in sub-Saharan Africa. Though the provision of antiretroviral medications is widely accepted as a necessary tool for persons living with AIDS to achieve needs/capabilities essential to life, the mere presence of ART does not guarantee the realization of these needs. On the contrary, the following cases demonstrate how ART distribution strategies can be responsible for halting and even reducing human potential in situations of scarcity.

On Positioning Structural Violence: A Post-Colonial Articulation

"Our cursory examination . . . must be *geographically broad* . . .
[and] *historically deep*."²³

To understand the full impact of ART allocation and the subsequent negative externalities in sub-Saharan Africa, it is essential to bring the full scope of history and geography under consideration. The current circumstance of structural violence, highlighted by ARV scarcity, is a particular articulation of a longstanding history of structural inequality throughout the region. In his discussion of the negative impacts of HIV/AIDS treatment in Africa, Sean Peris points to "so-called 'postcolonial' and 'post-development' inquiries" as providing illuminating insight.²⁴ Treatment of HIV/AIDS can be seen as a part of Western geopolitical intrigue, and an expression of imperial sovereignty residing in the "capacity to dictate who may live and who may die."²⁵ Though arguable, this view of Western power points to a larger legacy of colonial control. European colonialism has shaped many of the structural inequalities responsible for the rapid spread of HIV/AIDS in Africa today, including the particular formation of the health sector.

Poverty and disempowerment are two of the most dire and long-lasting consequences of colonialism in Africa. Susan Craddock points to the framework of historical forces set in motion by colonial administration in the early twentieth century that resulted in ideal societal conditions for disease

²¹ *Ibid.*, 244.

²² MacGregor and Rubio 1994, 49.

²³ Farmer 2005, 42.

²⁴ Jones 2004, 386-387.

²⁵ *Ibid.*, 387.

transmission in Malawi. A combination of household taxes, land appropriation, and price controls led to impoverishment and a significant male labor migration in many British protectorates. As a result, tuberculosis (TB) and venereal disease, more deadly before the development of modern treatments and vaccines, were rampant throughout much of the region.²⁶ Colonial-era healthcare, however, only served to create structural inequalities in health outcomes:

Then, as now, health care was desperately short of resources. More importantly, though, public health broadly conceived was not the primary focus. Colonial health care seems to have been focused, first, on protecting the health of white administrators, corporate heads, and settlers and, second, on ensuring the labor force's capacity to work. The ill health of [Africans] was only a concern when it threatened someone else.²⁷

The current impact of migration (an economic necessity today) is similar to a century ago, with one major exception: venereal disease and TB have been overshadowed by HIV/AIDS.²⁸ Although the goal of healthcare distribution has arguably changed since those times, the legacy of inequitable allocation of many essential health resources remains etched in patterns of socioeconomic transaction as well as in the minds and imagined social and political spaces of ordinary Africans.

Walter Rodney, in his book *How Europe Underdeveloped Africa*, also points out the inequitable formation of the healthcare sector in colonial Kenya. Most social services went to whites, and were meant only to facilitate exploitation. "For the chosen few, the British . . . maintained a segregated hospital service . . . the 4000 Europeans in the country in the 1930's had 12 modern hospitals, while the African population of at least 40 million had 52."²⁹ Those Africans whose labor was not directly involved in surplus production for export were denied medical treatment altogether. These export extraction priorities can best be seen today in the geographical formations of transport infrastructure. Where exports weren't available, there was no need for roads and railways.³⁰ There are exceptions to this pattern in places like colonial Kenya, where relatively robust health systems have been left over. Emphases on education, immunization, and preventative services were the hallmarks of

²⁶ Susan Craddock, "Disease, Social Identity, and Risk: Rethinking the Geography of AIDS," *Transactions of the Institute of British Geographers*, 25, no. 2 (2000): 156.

²⁷ Carol A. Heimer, "Old Inequalities, New Disease: HIV/AIDS in Sub-Saharan Africa," *Annual Review of Sociology* 33 (2007): 564.

²⁸ Craddock 2000, 156.

²⁹ Walter Rodney, *How Europe Underdeveloped Africa* (Washington, DC: Howard University Press, 1982), 207.

³⁰ Rodney 1982, 208–209.

these decentralized systems. Though they have been largely effective in addressing the spread of disease,³¹ the majority of sub-Saharan African countries do not enjoy the advantages of Kenyan health infrastructure.

Now, the modern chimera of the international political economy has replaced the old system of European colonialism. Instead of one colonial overlord, African nations must face the scrutiny and oversight of a multiplicity of sovereign powers, aid agencies, and multilateral lenders. In this new geographic space, power relations between donors and recipients play a major role in the question of access to ART. Foreign aid contingent on structural adjustment cripples African governments and devastates healthcare systems through privatization.³² World Trade Organization (WTO) agreements make it harder for countries without their own pharmaceutical manufacturing sectors to import generic ARVs.³³ Furthermore, according to observations by Haakonsson and Richey, despite provisions in the TRIPS agreement (Trade Related aspects of Intellectual Property Rights) entitling every nation to compulsory licensing for the importation and production of generic ART drugs, fear of political reprisals from Western nations that would jeopardize continued aid and assistance has influenced every African nation (except Eritrea and Ghana) to forego such licenses.³⁴

Acknowledging these historical and contemporary patterns is imperative. The dynamics of disease need to be simultaneously understood in terms of the interactions between institutional, socioeconomic, and historical contingencies of place.³⁵ The historic precepts of colonialism have led to a socioeconomic environment, and a health sector, that embodies structural violence and propagates disease amongst its victims. In many cases, contemporary economic structures prevent the rehabilitation of these systems. It is for these reasons that I situate the discussion of structural violence in ART allocation, as a particular moment in the long history of inequality and European colonialism in Africa, and in the present day as a critique of resounding neoliberal logic.

On Rationing Antiretroviral Treatment: Explicit vs. Default-Implicit Priorities

In Sub-Saharan Africa rationing of ART is already occurring and will persist for many years to come. The question facing African

³¹ Miriam Chaiken, "Primary Health Care Initiatives in Colonial Kenya," *World Development* 26, no. 9 (1998): 1701-1717.

³² See Merideth Turshen, *Privatizing Health Services in Africa* (New Brunswick, NJ: Rutgers University Press, 1999).

³³ Susan Craddock, "Market Incentives, Human Lives, and AIDS Vaccines," *Social Science and Medicine* 64 (2007): 1046.

³⁴ S.J. Haakonsson and L.A. Richey, "TRIPS and Public Health: The Doha Declaration and Africa," *Development Policy Review* 25, no. 1 (2007): 79.

³⁵ Craddock (2000), 154.

governments and societies is not whether to ration ART, but how to do so in a way that maximizes social welfare, now and in the future.³⁶

In the language of economics, finite antiretroviral treatment is an excludable good (where consumption by one person limits its availability to others). Those who have poor access to ART are at a structural disadvantage compared to those with sufficient access, or those with no need for treatment. The applicability of structural violence is evident in this respect. Those least likely to have access are more likely to be in desperate need of treatment. In the same paradoxical language of economics as before, “rationing is a morally neutral concept,” not implying intent to deprive but rather emphasizing efficient allocation of a scarce resource.³⁷ However, such determinations are rarely made in the best interests of society. As in any triage situation, certain calculations are made in circumstances where demand overwhelms supply (or supply of *affordable* treatment). But as Sydney Rosen et al. point out, the disparity between supply and demand of ART is less important than the presence of debate over how to best allocate scarce resources.

Some African countries “explicitly” debate how best to allocate ART to needy populations (Botswana is a shining example). But in most African states, lack of debate leads to “default-implicit priorities” of allocation.³⁸ Rosen et al. point out that explicit rationing systems often include limiting treatment to a number of subpopulations: mothers of new infants, skilled workers, poor people, high-risk populations, residents of designated geographic areas, those with ability to co-pay, and those showing commitment to adherence. Meanwhile, “default-implicit” alternatives direct resources to far fewer groups. These groups include: persons with access to HIV testing; those again able to pay the primary and intermediate costs of treatment; treatment on a first-come, first-served basis; and those able to queue on waiting lists.³⁹

While explicit rationing systems have their share of negative externalities, default-implicit models in particular present the greatest structural threat to the poor. Africans with a priori access to a full range of medical services, money for treatment, means to be among the first in line for treatment, and those with the political and social “pull” to circumvent waiting lists are often the first to receive ART under implicit circumstances. The poor rarely, if ever, fall into these categories. African governments have two options:

. . . ration deliberately, on the basis of explicit criteria, or allow implicit rationing to prevail. Implicit rationing is not likely to

³⁶ Sydney Rosen, Ian Sanne, Alizanne Collier, and Jonathon L. Simon, “Rationing Antiretroviral Therapy for HIV/AIDS in Africa: Choices and Consequences,” *PLoS Med* 2, no. 11 (2005): 1098.

³⁷ *Ibid.*, 1098.

³⁸ *Ibid.*, 1099–1102.

³⁹ *Ibid.*, 1099–1102.

maximize social welfare, nor does it allow for transparency and accountability in policy making. . . . In the absence of [public debate], decisions about access to treatment will be made arbitrarily and will, most likely, result in inequity and inefficiency – the worst of both worlds.⁴⁰

While the wrong kinds of rationing may present enhanced structural violence, arguably the greatest structural threat to the poor is represented by lack of explicit policy. In the absence of responsible and open decision making intermediary social, political, and economic structures will likely determine flows of ART, and will almost certainly exclude the poorest populations. Adriana Petryna and Arthur Kleinman refer to this as the “selective visibility” of structural forces resulting in conflated forms of pharmaceutical triage where the desperately poor are routinely cut off from needed medical treatment.⁴¹ For most of the millions in desperate need of ART in Africa, exclusion from treatment is only reality.

On the Consequences of Cascading Costs to Crumbling Healthcare Sectors

While it is clear that inequitable treatment strategies disproportionately affect the disadvantaged, they also damage the already questionable effectiveness of the health sector, leading to even worse health outcomes for the poor. Insufficient access to treatment is inescapably intertwined with poverty. When miracle antiretroviral cocktails were introduced in the mid-1990s, promoting the possibility of improved living with the disease, the availability of treatment actually worsened inequality in health outcomes between the rich and poor:

The poor were systematically excluded from ART as the drugs were thought to be too expensive, too complicated and not sustainable to use in resource-poor settings. This combination of factors has led to a global pandemic in which the poor have excess risk of acquiring HIV and, once infected, have less access to lifesaving ART. As a result, the most heavily HIV-burdened countries have become further impoverished due to the epidemic.⁴²

⁴⁰ Ibid., 1103.

⁴¹ Adriana Petryna and Arthur Kleinman, “The Pharmaceutical Nexus,” in *Global Pharmaceuticals: Ethics, Markets, Practices*, ed. Adriana Petryna, Andrew Lakoff, and Arthur Kleinman (Durham, NC: Duke University Press, 2007), 20.

⁴² Joia S. Mukherjee, “Structural Violence, Poverty and the AIDS Pandemic,” *Development* 50, no. 2 (2007): 115–116.

The perception that HIV/AIDS treatments are too advanced and economically infeasible for the poor has led aid agencies to heavily favor prevention strategies over even the possibility of treatment.⁴³

At the outbreak of the AIDS epidemic in Africa, the British Department for International Development (DFID) declared ART to be too costly and complicated for major allocation to the poor. Instead, DFID's efforts were focused resoundingly on preventative measures. The overriding philosophy stated that even if medications were affordable, decrepit health systems in poor African countries were incapable of allocating the drugs safely and equitably.⁴⁴ One rationale for not funding treatment was that the rationing of scarce ART would actually contribute to institutional corruption, as more powerful elites might use their influence to corral available medications. Jones labels this, and other similar lines of thinking, as "imaginary red herrings." Supply is already scarce, he argues, and disallowing more ART drugs will do nothing to prevent *new* corruption.⁴⁵ Despite the propensity for corruption evidenced in Zambia (which I will touch upon in the next section), logical problems like these have prevailed for years, exacerbating issues of inequality and poor health in recipient communities.⁴⁶

As Erica Nelson argues, the degradation of the healthcare sector does not exist independent of suffering African economies. The repercussions of crippled healthcare systems "reverberate throughout sub-Saharan Africa." Both AIDS-related and unrelated deaths increase "as human capital plummets, public resources are decimated and access to [health] becomes even more limited."⁴⁷ Degrading and underfunded health sectors breed situations of implicit rationing and drain needed resources that could be directed towards the health and well-being of the rest of society.

Inversely, problems of increased attention towards HIV/AIDS have begun to cause greater burdens to the health sector. Vertically implemented international donor programs like PEPFAR have shifted health priorities in a number of African countries towards HIV/AIDS (though not enough to halt the spread of the disease) and placed increasing strains on already poor health infrastructure. In order for national governments to secure needed international health funding they must allocate the vast majority of that funding to HIV/AIDS. As Jeremy Shiffman argues, this shift in focus is causing a "crowding-out" effect of other potentially more exigent public health emergencies.

⁴³ Ibid., 119.

⁴⁴ Jones 2004, 396.

⁴⁵ Ibid., 398-399.

⁴⁶ Ibid., 400.

⁴⁷ Erica Nelson, "The Vicious Cycle of Underdevelopment and HIV/AIDS: How HIV/AIDS Is Decimating Sub-Saharan Africa's Health Sector" (M.Phil. dissertation, Trinity College Dublin, 2007), 43.

For instance, with an HIV prevalence of 3.1%, Rwanda has been allocated US\$ 187 million since 2003 exclusively for HIV/AIDS from three international programmes (the Global Fund, PEPFAR and the World Bank's Multi-Country AIDS Programme), compared to only US\$ 37 million annually in government expenditure on health. These funds threaten to overwhelm a weak health system.⁴⁸

International programs have made great strides in providing increased access to ART (as of 2008 1.7 million new recipients of ARV medications could be attributed to PEPFAR, ⁴⁹ decreasing the death rate by 10.5 percent⁵⁰). However, problems of ARV scarcity persist in most African countries and the overall rate of infected adults needing treatment has changed very little.⁵¹ In the worst possible scenarios these shifting priorities may have even contributed to worsening effects in non-targeted health areas and in terms of health in general.⁵²

It is clear that a crumbling health sector, overwhelmed both by input and output, has a devastating impact on the realization of the needs/capabilities of life and bodily health for ordinary people. As Joia Mukherjee points out, the AIDS virus thrives in the shadow of structural violence, "defined as the physical and psychological harm that results from exploitive and unjust social, political and economic systems."⁵³ Additionally, the good (yet poorly conceived)⁵⁴ intentions of international donors, coupled with reliance on insufficient national health systems, cause further structural violence through crowding-out effects.

On the Structurally Violent Economics of ART Allocation in Zambia

HIV/AIDS is making the world's poorest countries poorer. In sub-Saharan Africa indicators of family stability such as food security, education, and healthcare show the impact of the disease.⁵⁵ Joia Mukherjee estimates that in Zambia the AIDS-related loss of a household head results in an 80 percent drop

⁴⁸ Jeremy Shiffman, "HIV/AIDS and the Rest of the Global Health Agenda," *Bulletin of the World Health Organization* 84, no. 12 (December 2006): 923.

⁴⁹ Waffa M. El-Sadr and David Hoos, "The President's Emergency Plan for AIDS Relief – Is the Emergency Over?" *The New England Journal of Medicine* 359 (7 August 2008): 554.

⁵⁰ E. Bendavid and J. Bhattacharaya, "PEPFAR in Africa: An Evaluation of Outcomes," *Annals of Internal Medicine* 150, no. 10 (2009): 688–695.

⁵¹ *Ibid.*, 689.

⁵² Herbert Duber, Thomas Coates, Greg Szekeras, Amy Kaji, and Roger Lewis, "Is there an association between PEPFAR funding and improvement in national health indicators in Africa? A retrospective study," *Journal of the International AIDS Society* 13, no. 21 (2010).

⁵³ Mukherjee 2007, 116.

⁵⁴ For more on the problematic role of international institutions, see Daniel Esser, "More Money, Less Cure: Why Global Health Assistance Needs Restructuring," *Ethics & International Affairs* 23, no. 3 (September 2009).

⁵⁵ Mukherjee 2007, 118.

in monthly income. Across Africa agricultural productivity is in decline because farmers sick with AIDS spend nearly 20 fewer hours per week farming compared to healthy farmers.⁵⁶ Of course, lowered productivity for farmers not only results in a decrease in available funds for that family to pay for needed ART, but also causes national food shortages and negative impacts to GDP growth. In Zambia, default-implicit ART allocation strategies reflect continued structural inequalities among the disadvantaged, where more equitable distribution would surely improve the economic livelihood of farmers and poor households, and by extension, would be a boon to the whole of society. The needs/capabilities of life, bodily health, integrity, and control over one's environment are wrapped tightly in the potential economic outcomes of Zambia.

The inequitable criteria for delivery of ART are made clear in a survey conducted by Peris Jones in 2004. Respondents were identified as "key cross-sectoral actors" in the distribution of the drugs. All the survey participants consistently identified economic criteria as one of two predominant tools, alongside clinical, used to determine access to ART. "The financial contribution that [people living with HIV/AIDS] were required to make towards their [ART], as well as associated costs such as those for testing – was identified as the fundamental barrier to access and the greatest engine of inequity."⁵⁷

When interviewed, the same pool of respondents cited instances in which poor Zambians seeking consultation for HIV/AIDS treatment in Lusaka hospitals reported being asked whether they were employed prior to seeing a doctor. Jones also notes particular observations at an HIV/AIDS clinic in Lusaka, where a sign announced that patients needed to present a receipt of payment before consultation. Respondents also mention the debated application of "fast track" systems in which patients were guaranteed treatment only after providing proof of ability to pay more than the usual fee.⁵⁸ According to Jones, expensive treatments are systematically denied to those deemed too poor to pay. But what are the true costs of treatment?

Through extensive fieldwork, Jones established a broad range of economic impediments to ART access in Zambia. These costs not only include fees for monthly contribution to ARV medication (about US\$ 9), but also a host of other essential follow-up tests and intermediate expenses, none of which are a one-time expense: CD4 count (US\$ 21), liver tests (US\$ 15), other testing and counseling (US\$ 0.23), and transportation to and from clinics and hospitals (US\$ 1).⁵⁹ Depending upon how frequently patients need to make visits for these tests and treatments, monthly totals based upon Jones's estimates could

⁵⁶ Ibid., 118.

⁵⁷ Peris Jones, "On a Never-Ending Waiting List: Toward Equitable Access to Anti-Retroviral Treatment? Experiences from Zambia," *Health and Human Rights* 8, no. 2 (2005): 82-83.

⁵⁸ Ibid., 88-89.

⁵⁹ Ibid., 82-83.

range from \$46 to US\$ 140 per patient. These are exorbitant costs in a country where the per capita GNI in 2004, the year this survey was conducted, stood at US\$ 1.12 per day, and 68 percent of the population sat below the national poverty line.⁶⁰

The costs of treatment are put even further out of reach when high rates of queue jumping, associated with bribery and employment in the Zambian civil sector, are taken into account.⁶¹ Although it is not official public policy, many respondents interviewed suggested that the Zambian government allowed privileged access to ART for employees of the state.⁶² These instances further reduce the ability of the poor to access scarce ART, diminishing the productive agricultural base of society. Ultimately the inequitable distribution of ART, combined with waning GDPs, unsustainable debt, and a crumbling health sector, reinforces structural violence and maintains “the status quo of global socio-economic inequalities.”⁶³

Jones contends that the potential role of ART could be to ease the high levels of mortality and morbidity that place “devastating financial and social burdens upon states, NGOs and society more generally.” Food insecurity, worker absenteeism, and increasing rates of orphaned children could be mitigated by adequate treatment, saving three times the costs of treating opportunistic infections and caring for orphans.⁶⁴ Nevertheless, countless healthcare providers irrationally prescribe ART regimens to people living with AIDS solely on the basis of wealth, as patients are “advised to take the full combination, a reduced combination, or avoid antiretrovirals [altogether] depending on income.” Drug-resistant strains of HIV/AIDS are thus allowed to emerge, exponentially enhancing the costs of treating disease in general. As the World Bank points out, the high price of ART in concert with ballooning costs of other necessary treatments offers African governments little ability to adequately invest in health infrastructure.⁶⁵

HIV/AIDS generates poverty, contributes to famine by crippling the productive capacity of poor farmers, and consumes necessary national and private resources, ultimately rendering the needs/capabilities of life, bodily health, bodily integrity, and control over one’s environment (or what Jones points to as *social and economic rights*), beyond reach.⁶⁶ Inequitable treatment of

⁶⁰ World Bank, “World Development Indicators Online,” The World Bank Group (2009), <<http://databank.worldbank.org/ddp/home.do>>.

⁶¹ Jones 2005, 87.

⁶² *Ibid.*, 88–89.

⁶³ Nelson 2007, 43.

⁶⁴ Jones 2004, 401.

⁶⁵ David E. Bloom, “Something to Be Done: Treating HIV/AIDS,” *Science* 288, no. 5474 (23 June 2000): 2171.

⁶⁶ Jones 2004, 388.

the disease merely serves to *increase the distance between the potential and the actual*⁶⁷ realization of essential needs/capabilities.

On ART Allocation and Restricted Political Agency in Uganda

In her book *Contagious*, Priscilla Wald invokes the notion of Benedict Anderson's *Imagined Communities*⁶⁸ to explain the "epidemiology of belonging" in the context of disease. Wald compellingly utilizes the concept of the *outbreak narrative* to entwine the analysis of disease emergence with shifting social and political formations.⁶⁹ Indeed, patterns of AIDS treatment reveal a complex relationship between disease and society (especially in terms of specific disease-related advocacy groups that arise).⁷⁰ On the local level, ARV drugs represent the best hope for people living with AIDS to resume their productive roles in society. ART simultaneously represents power extensions that highlight the interplay between structure and agency – between powerful ruling elites and weak local recipients. When access to these essential drugs is diminished, so too is the sense of personal agency and national identity. In this way, unequal ART allocation in Uganda is especially significant to the maintenance of Sen and Nussbaum's needs/capabilities of bodily integrity, practical reason, affiliation, and control over one's environment.

Susan Reynolds Whyte et al. explore the social outcomes of access to treatment in Uganda, uncovering disturbing rifts in civil life that challenge the family, the community, and the national identity of Ugandans. At the center of the traditional Ugandan family unit, as throughout Africa, women face especially dire consequences when confronted with HIV/AIDS. Whyte cites one particular Ugandan woman torn between wanting to know her HIV status for the health of her child, and fearing the suffering she would inevitably face.⁷¹ Women encounter a multitude of negative outcomes from disclosure of infection, including accusations of infidelity, blame, abandonment, violence, anger, stigma, depression, and guilt over burdening the family.⁷² Although many of these consequences are often widely felt by both genders, patriarchal African societies do place a greater burden on women.

⁶⁷ Galtung 1969, 168.

⁶⁸ See Benedict Anderson, *Imagined Communities: Reflections on the Origin and Spread of Nationalism* (New York: Verso, 1991).

⁶⁹ Priscilla Wald, *Contagious: Cultures, Carriers, and the Outbreak Narrative* (Durham, NC: Duke University Press, 2008), 33.

⁷⁰ See Jeremy Shiffman and Stephanie Smith, "Generation of Political Priority for Global Health Initiatives: A Framework and Case Study of Maternal Mortality," *The Lancet* 370 (13 Oct 2007).

⁷¹ Susan Reynolds Whyte, Michael Whyte, Lotte Meinert, and Betty Kyaddondo, "Treating AIDS: Dilemmas of Unequal Access in Uganda," in *Global Pharmaceuticals: Ethics, Markets, Practices*, ed. Adriana Petryna, Andrew Lakoff, and Arthur Kleinman (Durham, NC: Duke University Press, 2007), 245.

⁷² Heimer 2007, 568.

Treatment alone does little to mitigate these consequences. In fact, treatment becomes a financial burden on the whole family unit. Paying the high cost of ART often means withdrawing support to other relatives and prioritizing social relations.⁷³ Spouses and close relatives hide their conditions from one another, risking the silent spread of the disease, while many commit suicide to spare the family of burden.⁷⁴ Because of scarcity and high cost, ART also moves poor people to conceptualize and weigh their relations to immediate relatives that would otherwise remain implicit.⁷⁵ The threat of infection puts stress on family cohesion. The potential cost of treatment suddenly places monetary value on the life of the mother, or the youngest son, and families are forced to redefine where human worth meets the threshold of cost.

Patients are also suddenly forced to “envision social relations and distinctions on national and even international scales.”⁷⁶ As Whyte et al. argue, medicinal knowledge is social knowledge that is linked to the political imagination of greater society. Sadly, the imagined national community⁷⁷ of Uganda is irreversibly damaged by perceptions of exclusion among the poor and HIV positive. Many are suspicious of the vicious disparity that exists between their destitution and the conviction that social elites secretly use ART.⁷⁸ The behavior of hiding one’s condition and keeping expensive treatments secret from family and neighbors is pervasive across all levels of Ugandan society. This crisis encourages the continuation of the pandemic.⁷⁹

Historical patterns of inequitable treatment stemming from colonialism have greatly affected the perception of Western medicine among marginalized Africans.⁸⁰ Many are understandably suspicious of the role of healthcare workers. Combine this age-old skepticism with the often overwhelming negative social outcomes that many Africans face when confronted with HIV/AIDS (fear of humiliation, “being treated differently by health care workers,” prosecution and imprisonment) and it is easy to understand why so few people living with AIDS seek either diagnosis or treatment.⁸¹

In addition to stigmas at the family and local level, in many parts of Uganda information about treatment and its availability is scarce. Though many have heard of ART, most have no idea where to find it. Healthcare workers often either do not know where ARVs can be obtained, or choose not

⁷³ Whyte 2007, 249-250.

⁷⁴ *Ibid.*, 252.

⁷⁵ *Ibid.*, 250-251.

⁷⁶ *Ibid.*, 260.

⁷⁷ See again Anderson 1991.

⁷⁸ Whyte 2007, 255.

⁷⁹ *Ibid.*, 258.

⁸⁰ Heimer 2007, 564.

⁸¹ UN AIDS, *Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes*, Geneva: Joint United Nations Programme on HIV/AIDS (December 2007): 10.

to tell many patients out of sensitivity for those they know cannot afford treatment. Indeed, many hospitals choose not to carry ART medications in order to lessen the heartbreaking spectacle of disparity.⁸² New rifts emerge in communities where counselors and providers have access to treatment and their clients do not.⁸³ The common belief among many Western healthcare providers, that poor African communities are simply too underdeveloped to cope with treatment, is reinforced.⁸⁴ Lack of public disclosure and new asymmetries of information that emerge allow the disease to quietly fester, unencumbered by healthcare intervention.

Just as ART scarcity negatively affects economic outcomes in Zambia, systems of structural violence damage political agency within the family and the larger imagined community in Uganda. Questions of bodily integrity, practical reason, affiliation, and control over one's environment play a distinct role in social behaviors that affect health. Shame, rifts in interpersonal relationships, and social asymmetries of information directly limit the health outcomes of poor Africans. As Whyte notes, dilemmas described by the situation of pharmaceutical triage and identity show the painful reality of structural violence in full force.⁸⁵

Conclusion

Structural violence is an essential concept in understanding the dynamic relationship between poverty and the mechanisms that foster and maintain it. The scarcity of medicines essential to life produces a compelling example of these mechanisms. Not all structural violence is manifested in poverty, but all poverty is derivative of structural violence. To understand the causes and consequences of structural violence requires, as Paul Farmer put it, an examination that is both geographically broad and historically deep.⁸⁶ Examining structural violence as a consequence of historical and geographic forces is essential to understanding the situation of ARV allocation in sub-Saharan Africa. The outcomes of "default-implicit" rationing enhance structural violence, widening the gap between rich and poor.

The consequences to the health of the poor and the health sector in general are linked to individual ability to pay for life-saving medications as well as the allocation of funds to prop up decrepit healthcare systems. In Uganda, inequitable ARV allocation enhances preexisting economic disparity by allowing HIV/AIDS to cripple the productive base of society, reducing the total time allocated to labor among poor households and eating away at the

⁸² Ibid., 247-248.

⁸³ Ibid., 246.

⁸⁴ Jones 2004, 397.

⁸⁵ Ibid., 261.

⁸⁶ Farmer 2005, 42.

productive capacity of the poor. Finally, diminished political agency completes the chain of causality, as people avoid seeking treatment because of the financial and social burdens it entails. The disease is left to fester within the degrading imagined communities of sub-Saharan Africa.

In the future, equitable distribution of ART will imply explicitly mapping the criteria for allocation with emphasis on “availability; financial, geographic, and cultural accessibility; quality; and equality.”⁸⁷ As Peris Jones points out, the structural violence resulting from allocating ART in under-resourced health systems is shaped by the imbalance of power between donor nations and African countries, as well as between the state and civil society within recipient countries. To change inequitable patterns of accessibility will require a complete reorientation of many institutional structures, both internationally and on a local level.⁸⁸ Indeed, just as we cannot hope to cure the symptoms of a disease without understanding its root cause, we cannot begin to address poverty and inequality without first addressing their origins in structural violence. This will require a concerted effort among health practitioners, donors, and aid agencies to establish a *comprehensive epidemiological approach to structural violence*.

⁸⁷ Jones 2005, 93.

⁸⁸ *Ibid.*, 97.