Exploring Disease in Africa:

AIDS
Sleeping Sickness
Small Pox

A curriculum for advanced high school +College students

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AIDS: THE MAKING OF AN EPIDEMIC
HEALTH, HUMAN RIGHTS AND ETHICS

AIDS TODAY

AIDS is the only disease in this curriculum that has emerged recently, in the past few decades rather than centuries or millennia ago. It is a disease that has captured a lot of peoples' attention, and although it is a pandemic, it is inextricably linked with Africa. As a continent, Africa has suffered the worst AIDS epidemic based on a number of different measures. The 2007 WHO/UNAIDS report stated that there were 22.5 million adults and children living with HIV in Africa (out of a total of 32.2 million globally). There were 1.6 million adult and child deaths due to AIDS, and nearly 2.2 million children under the age of 15 living with AIDS. On the continent as a whole, 5% of all adults aged 15-49 were infected with HIV or AIDS. While these statistics can only allude to the truly devastating toll AIDS has made in Africa, there have also been small successes. In this section, we will aim to correct some common misconceptions by exploring the epidemic through questions of health and human rights.

THE WORST EPIDEMIC?

One of the first questions many people have about AIDS in Africa is why the epidemic is so bad there. Asked in another way, why are there so many cases of AIDS in Africa or why is Africa's epidemic so much worse than that in Europe or the United States?

The simplest answer to this question, and possibly the most persuasive one, was put forth by the historian John Iliffe. He argues that Africa has experienced the worst AIDS epidemic because it had the first AIDS epidemic. By this he means that since AIDS originated in Africa, the disease had a head start there, infecting people long before the disease had even been recognized. Thus, from the very beginning, Africa was at a disadvantage since the disease had been spreading silently for a decade or more before anyone noticed—let alone could do anything about it.

There are other answers, however, to this question. Some people point to the lack of a strong health care system in many parts of Africa, the large scale movement of people, and the low status of women. Each of these factors has surely contributed. The lack of a strong, functioning health care system in many countries has meant that prevention efforts in addition to diagnostic testing and treatment have all been stymied. One way to slow the epidemic is through diagnosing HIV, but in places where testing facilities are few and people are wary of visiting hospitals, HIV testing is unlikely. Since the 1960s when the first cases of HIV emerged in Central Africa, there have been huge movements of people around the continent. Just in East and Central Africa, fighting in the Congo and Uganda caused thousands of troops from neighboring countries to stream in. The movement of people is important since it is people who transmit the disease sexually, picking it up in one places and potentially bringing it to another place thousands of miles away. Finally, the low status of women in many societies has contributed to the epidemic's growth. In many places, women—be they prostitutes or faithful wives—are unable to negotiate for the use of condoms. When men have unprotected sex with infected prostitutes in urban areas and then unprotected sex with their wives in rural areas, the disease jumps from one realm to another.

The impact of the epidemic on the continent has been tremendous, and felt economically, socially and politically. AIDS typically afflicts the most productive members of society—adults of working age. As people grow sicker, they may seek professional care. Hospitals are overwhelmed and even cursory efforts to provide treatment or care for those already infected put a huge drain on health care systems that usually spend only an average of $1-$2 per person per year. When working age adults eventually succumb to the disease, they often leave behind sick spouses and orphans that must be cared for. They also leave behind jobs that someone else may or may not be able to fill. In some African countries, there are severe shortages of teachers and other professionals because of the epidemic. These have trickle down effects on many other parts of the country.

DISEASE ECOLOGY

It is basically impossible to accurately identify the first case of HIV. General consensus now favors a theory that HIV emerged in Central Africa, and was a mutation of the animal disease Simian Immunodeficiency Virus, which affects monkeys. By studying both of these diseases, scientists have surmised that SIV began infecting humans due to human contact with infected monkeys. That contact may have come through the process of killing sick monkeys and coming in contact with contaminated blood, or through consumption of infected monkey meat.

As was discussed in the introduction, many potent human diseases were originally derived from animal diseases. But SIV's ability to infect humans was only the first step. At this stage, a person only became sick if they came in contact with an infected monkey. The more serious mutation occurred when SIV mutated into a purely human disease that could be transferred divertly from person to person, without the presence of a monkey. It was only at this stage that Human Immunodeficiency Virus emerged.

By combing through old hospital records and conducting interviews, scholars and journalists have found cases of HIV in Africa from the 1970s onward. Difficulties remain in determining how widespread it was, since records are often incomplete and many countries do not have centralized bodies for collecting health data. Furthermore, sporadic early cases in rural areas surely went unreported and even today; many people do not travel to hospitals in order to die. Deaths that occur in homes may or may not be reported.

Unlike sleeping sickness, AIDS is not an overtly environmental disease, in other words, there is no insect or plant vector needed to transmit the disease, nor does the virus need specific conditions to thrive. But if we consider the environment as what is all around us including landscapes that have been shaped by humans, we see that AIDS is affected by the environment. Since this is a disease of the modern era, we need to weigh how man-made changes have affected the course of the disease.

One of the most striking ways in which AIDS is clearly environmental is that while it can exist anywhere, the epidemic spread along very specific routes. The virus moved throughout the continent in the same way that an adventurous traveler would: by way of roads. Early research of prevalence rates showed that along major roads, the HIV rates were much higher than in nearby more remote areas. These roads connected different countries, weaving across the continent and allowing necessary goods

to be moved from place to place. Once the roads were built and there was regular traffic, towns grew up next to these roads to service the many diverse needs of travelers. Places to eat, drink and sleep were abundant, as were other locales that serviced more basic human needs. Prostitutes did a brisk business, and were exposed to diseases from across the continent. Once these women were infected, they became stationary hosts for the virus while visiting truck drivers served as mobile hosts, moving the virus around the continent. The truck drivers were nearly perfect vehicles to transport the disease since they were almost all men, frequently visited prostitutes in different towns and practiced unprotected sex. (Before you condemn their behavior as irresponsible remember there was little reason to use a condom prior to AIDS, and that condoms could be quite difficult to find.) As this example shows, if we recognize roads as part of the environment, we see how the presence of roads shaped the epidemic.

A second way that human impact on the land changed the epidemic was through the growth of urban areas. As millions of people across the continent made a transition from rural, primarily agricultural livelihoods to urban ones, the shape of the epidemic changed. Urban environments—cities—draw people from all over a country, maybe even from multiple countries. Part of what makes cities exciting and dynamic is this mixing of people from different backgrounds and with different experiences. This diversity is what makes cities such potent places for disease. In cities there is likely to be a larger pool of prostitutes and for sexual contact between people from different places. Prostitutes are again the static hosts. They may become infected after having sex with a man from another country. After infection, however, she is able to infect all the men she has sex with—who may come from a dozen different rural villages. Those infected men, in turn, become the mobile hosts. They carry the virus with them back to their rural homes. They may have a wife in the rural area that then becomes infected, or he may engage with a prostitute there. Either way, the growth of urban areas coupled with the greater contact between urban and rural areas allowed HIV to spread rapidly into rural areas.

PREVENTION AND TRANSMISSION

You may wonder why people don't just prevent AIDS since it isn't contagious in the way a disease like smallpox is. Although AIDS is not spread easily and is not contagious in the same way, there are strong cultural barriers to prevention. HIV is spread through bodily fluids such as breast milk, semen, vaginal fluid and blood. The most common routes of transmission in Africa are: 1º from an infected mother to child either in the process of emerging from the birth canal or during subsequent months of breast feeding and 2º from heterosexual intercourse. Other ways to become infected that are less common in Africa include through intravenous drug use or blood transfusions, through homosexual anal intercourse, and through injections given with contaminated needles. One of the sad advantages to having a weak health care system was that blood transfusions were relatively uncommon in Africa, and that many people did not have extensive contact with hospitals in order to receive contaminated injections**.**

The primary mode of transmission is through heterosexual intercourse, which means there are additional burdens to talking about AIDS. In most African societies, sex is a taboo subject. Although information is shared, it is done so only under particular circumstances. In some cases, it may not be discussed between parents and children, but only through grandparents and children. In other cases, children may not become privy to information until they have participated in coming of age ceremonies

and rituals that may not take place until the late teens. Despite this fact, though, there have been successful efforts to make sex—and thus AIDS—an appropriate subject for public conversation. Some countries, Uganda being a notable example, took very public approaches and had politicians and public officials talking about AIDS. This approach meant that knowledge of AIDS increased as public conversation increased and that incidence of the disease has fallen.

Condoms have emerged as one of the best preventative measures against HIV. They allow for people to continue having sex while remaining protected from the virus. While condoms appear to be an easy solution, there are also barriers to this method. Prior to the AIDS epidemic, condom use was extremely low in Africa. If condoms were available, they were expensive. Even when condoms were more widely available, people weren't comfortable with them. More specifically, many men weren't comfortable using condoms. One of the biggest drawbacks to condoms is that it is primarily a male-controlled preventative measure. While women may ask that their husbands, lovers, or clients use condoms, it is ultimately his decision.

AFRICAN ACTION AGAINST AIDS

One of the enduring myths of the AIDS epidemic is that the continent has been dependent on action by foreigners. Rarely have the actions of normal Africans citizens been recognized. People wonder what, if anything, Africans have done in response to the epidemic.

It's best to begin with a few facts. In the early years of the epidemic, African governments were incapable of responding to the AIDS epidemic. Initial lack of response could be attributed to lack of money and infrastructure. There was also apathy about talking about a sexually transmitted disease in public. From a financial perspective, there was not enough money in health budgets to pay for treatment at hospitals, or for prevention and education campaigns. In terms of infrastructure, there weren't enough clinics to provide testing and diagnosis. These were just some of the shortcomings. It took time for the devastating capacity of AIDS to be recognized, and its position as a truly global disease to emerge. Only after these things became apparent did many of the Western NGOs open up their doors, and did money from individual countries and global organizations flow in. In the time it took for all of this to happen, Africans already had devised coping mechanisms to deal with the fallout of the epidemic.

In the face of these realities, ordinary people were left to pick up the slack. The slack that remained was monumental. It meant providing care for the sick and dying, care for the spouses and children that remained, and some sort of education about how to prevent the disease. And amazingly, many ordinary people did rise to the challenge. Home-based care is a technique that is used across the continent, and is a direct response to the lack of available medical services. Home based care has semi-trained community members regularly visiting the homes of HIV and AIDS patients to provide basic care. This system allows for people to be helped who are living in areas without formal hospitals or clinics, and is a response to the lack of doctors and nurses. By training community members in basic health and hygiene practices, doctors and nurses remain free to deal with particularly difficult conditions. Home-based care workers have organized in countries across the continent, providing support to patients while also helping to lessen the stigma attached to the disease.

One of the tragic effects of the epidemic is the growing number of orphans left behind when AIDS-afflicted parents pass away. In many areas, these orphans are adopted into communities rather than being institutionalized. Community based care means that children remain in the communities they grew up in, often times being taken in by relatives. It is a system that leaves individual families bearing the cost of the epidemic rather than the state. More recently, some states and private organizations have begun compensating these families with small subsidies of food, clothing or materials to repair their houses. As the number of orphans grows and the number of healthy parents decreases, a greater burden is being placed on grandparents and the elderly. While these people have nobly stepped forward to assume their familial duties, this is an issue that will only grow more complicated.

Possibly the best known response of citizens to the AIDS epidemic is the existence of the Treatment Action Campaign (TAC: http://www.tac.org.za/community/about) in South Africa. The organization was started in 1998, in response to the lack of anti-retroviral drugs available to HIV positive people in South Africa. Since the group's inception, they have fought for greater access to HIV drugs by raising public awareness and understanding about the availability, affordability and use of HIV treatments. In one landmark case, TAC sued the South African government, claiming that the constitution assured all citizens a right to health, and that right implied a right to drugs to treat HIV. (You'll read part of the constitution a little later.) The courts sided with the TAC activists and agreed that the government did have a duty to provide treatment to all, although it recognized that financial constraints might prevent instantaneous coverage. Since then, it has become law that all South African citizens have access to anti-retroviral drugs. Despite the law, actual access has been erratic and TAC has continued to protest and sue the government in order to speed up the roll out of drugs.

GENERIC DRUGS & SOUTH AFRICA

Despite the initial reluctance of the South African government to provide anti-retroviral drugs, they eventually took a huge step and become one of the first countries in the world to produce generic ARVs. In the late 1990s, the South African government declared a public health emergency because of the AIDS epidemic. Coupled with their declaration, the government announced they would break international drug patents held by European and American pharmaceutical companies This meant that the South African government had decided to produce these medicines without paying the companies that developed them. Technically, it was illegal to break these patents, but international guidelines stated they could be broken in times of health emergencies. The South African government argued that AIDS was causing a catastrophe, and that they had the right to break patents to help save the lives of millions of their citizens. The generic drugs are identical in chemical composition to those sold by the pharmaceutical companies, but are far, far cheaper. While South Africa made the preparations to begin production of the drugs (a huge task that involved building factories and gathering qualified personnel to run them), they began importing generic drugs manufactured in India. It was the importation of these cheaper drugs that allowed the government to start providing ARVs to its citizens.

AVAILABILITY AND REGIONAL DIFFERENCES

What kind of treatment do Africans receive for AIDS? The treatment options in Africa are quite mixed, and are very dependent on which country you live in, whether you reside in a rural or urban area, and

possibly most important, how wealthy you are. As may be obvious, people who are wealthier, live in urban areas, and are citizens of richer nations have a much better chance of procuring drugs. Many factors hinder access to drugs, though poverty is probably the biggest. Other reasons limiting access include the inefficiency of many health care systems, inadequate systems in place to distribute the drugs and provide follow up, and the lack of education and training of health care workers.

As an example, let's compare Botswana with rural Tanzania. Botswana is one of the richest countries in sub-Saharan Africa due to a vast natural reservoir of diamonds. The country has no international debts, and since independence has invested wisely in health, education and transportation infrastructure. Much of the population is located in the southern part of the country, and there is a strong network of health clinics and hospitals staffed with qualified doctors and nurses. Botswana also has one of the highest adult prevalence rates of HIV on the continent, probably just under 30%. Although this is a frighteningly high prevalence rate, the country has used its relative strengths to help combat the epidemic through free access to anti-retroviral drugs. Once a person has been diagnosed with HIV (and there is mandatory testing at all clinics) the patient becomes eligible to receive free drugs. The drugs are paid for by the government, and are available throughout the country, dispensed at the already-presented hospitals and by already-trained staff. Botswana may be one of the best examples of a positive response to a very bad situation.

A quite different example comes from Tanzania. It is a much poorer nation, has a far larger population that is spread throughout the country, not just concentrated in one region. Although the adult prevalence rate is roughly half of that in Botswana, there are other disadvantages. There are fewer hospitals and health clinics, and severe shortages of both supplies f**or** the hospitals and doctors to staff them. In the past few years the Tanzanian government committed to purchasing anti-retroviral drugs, but the cost on the regular market was so expensive, very few could be procured. With help from the Clinton Foundation, a lower than normal price was negotiated for the drugs, which enabled the government to purchase a larger supply. But purchasing the drugs was only part of the problem. More than three years after the initial deal, access to drugs in rural areas is still low. Even today, those suffering from AIDS in rural areas are more likely to die without treatment than to receive access to these life-saving drugs.

HEALTH AND HUMAN RIGHTS

The WHO notes that, "no other disease has so dramatically highlighted the stark injustices and inequalities in access to health care, economic opportunity and the protection of basic human rights as HIV/AIDS."

AIDS has come about in the golden age of discussions about human rights. To understand what types of human rights questions AIDS raises, we first must understand what it is meant by human rights. It turns out that there are two types of rights. Positive rights are outlined in the Covenant on Economic, Social and Cultural Rights. Negative rights are encapsulated in the Covenant on Civil and Political Rights.

Positive rights are typically thought of as things that governments ought to do for their citizens. For

example, children have a 'right to education,' and governments must provide schools, teachers, and books to allow its citizens to fully appropriate that right. If there is a right to health, it is considered a positive right, since it requires governments to provide institutions and conditions so that can be achieved. Although this is not a hard and fast rule, these positive rights have been more fully embraced by formerly communist or socialist countries where provision of basic social services such as education and primary health care are provided, but where commitment to other rights (such as freedom of speech) is weaker.

The types of rights much more commonly discussed and embraced in the United States are negative rights, which serve as indicators of what governments should not do to citizens. Negative rights outline a sort of boundary around a space of activity that all citizens should be allowed to do. We often think of rights such as the ability to speak freely, practice religion or participate in politics as activities falling within this protected space. Freedom of political affiliation is a negative right since it means the government will not interfere with your right to be engaged with politics.

As you can see, depending on what document you read, and what covenants your country signs, what constitutes a “human right” can vary a lot from country to country. This is ironic since discussions about human rights began after World War II with the creation of the United Nations. The decades of ensuing treaties, declarations and covenants were meant to provide a global—universal—statement about what every person in the world was both entitled to (positive rights) and protected from (negative rights). This was a somewhat idealistic vision, however, since countries have chosen to adopt only those covenants that are appealing to them, and enforcement is virtually impossible. The reality of this situation has led many people to claim that rather than being truly attainable, human rights should be considered only as aspirational—describing what governments should strive to do, not what they actually can do. The AIDS epidemic has rendered these discussions more urgent, and as the TAC lawsuit demonstrates, courts around the world are now beginning to decide what a right to health truly means.

ETHICS OF SCARCITY

The AIDS epidemic is also raising a lot of difficult ethical and moral questions about how to use scarce resources. In African countries that are among the poorest in the world, and where the epidemic has hit hardest, governments and citizens have had to make tough decisions about how to spend money. Should it be spent trying to prevent new infections, caring for HIV+ people, schooling for the orphans of AIDS victims or something else?

In countries like the small southern African nation of Lesotho, dilemmas like this are not just hypothetical. They are questions of severe scarcity where the decisions made determine who lives and who dies. To date, many governments have shied away from being too open about exactly how bad the situation is, fearful of citizens' anger when faced with the desperate reality. In these cases, politicians make important decisions about how to divide scarce resources without adequately involving affected populations.

If we look closer at the small country of Lesotho, we can see some of the dramatic—and

difficult—decisions that must be made about how to use scarce resources. In Lesotho, there is a total population of 1.9 million people. Devastatingly, 30% of the adult population is HIV positive. The reality of the budget situation in Lesotho is that anti-retroviral drugs can only be purchased for somewhere between 1-20% of the people who are infected with HIV. In this situation, difficult choices must be made about who will get access to drugs. Someone—the government, citizens, funding agencies—must decide who will get access to the drugs. One possibility about how to decide include using a random lottery. From an ethical perspective, a lottery solution that every life is of equal worth, and thus there is no fairer way to distribute a scarce item than to do so randomly. An utilitarian approach on the other hand would try to figure out a method that would generate the most good for the largest number of people. Using this logic, drugs might be given preferentially based on education, job or social status. Another approach would be to follow the tenets of distributive justice—trying to equally share the benefits and burdens throughout society. In this way, the drugs might be distributed equally across world regions or equally amongst different age groups, cities or occupations. No matter what method is used all of the available options lead to a tragic outcome for those left out.

Discussion Questions

- Hillary Clinton recently said that if AIDS was a disease that primarily afflicted white women, much more would be done. Do you believe this is true? How do our stereotypes and Africa's history influence the response to AIDS in Africa?
- How has AIDS in Africa been an environmental disease? Explain AIDS in terms of disease ecology. How is it affected by geography, settlement patterns, and animal-human contact?

Activity Ideas

1. Scarcity Exercise. If you were in a position to decide, how would you decide how to spend limited money for AIDS? To buy drugs to treat infected people, to prevent new cases, to care for orphans and families affected by an AIDS-death, or something else? Explain your reasoning.

- First, brainstorm who could receive the money. Why would they need it? What claims would they make?
- Second, given the competing claims, how would your group decide? Describe your process in detail and the logic guiding it. What would be your criteria to determine who received the money? Are there exclusionary criteria? And, who should make the decision?
- Finally, using the method your group outlined above, who would receive the funds? Share your method and the outcome with the rest of the class.

Now try your method in another scenario. In this case, you are deciding which person should receive access to a life-saving kidney dialysis machine, the only one that is available in your hospital. The people you must decide among include: a six week old baby; the Pope; a mother of three young children; a poet; a bachelor; the inventor of the dialysis machine; a Nobel-prize winning author; a researcher on kidney disorders; Hitler; and a teenage dropout. Use the method you outlined above. Does the method still seem viable?

If all the groups have not explored the full range of possibilities, make sure to discuss the pros and cons of randomly choosing (based on the view that all humans are equal and no one has more or less right to the use of the machine); eliminating criteria (over a certain age, preexisting medical condition); inclusion criteria (must be within a particular age range, good health); and determination of social worth (what has, or will, a person contribute to society).

2. Read and consider the following human rights documents excerpted below. Do you think that these documents imply that there is a right to health? What kinds of actions on the part of the state are required to fulfill the obligations described in these documents? Do you consider these documents to be aspirational or practical? Finally, compare the three human rights documents with the South African constitution. Is the right to health in the human rights documents are clear as that expressed in the constitution?

International Covenant on Economic, Social and Cultural Rights, Article 12
“The right of everyone to the highest attainable standard of physical and mental health.” Requiring states to work on, “the prevention, treatment and control of epidemic, endemic, occupational and other diseases” and “the creation of conditions which would assure to all medical service and medical attention in the event of sickness.”

World Health Organization Constitution Preamble
“The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”

Universal Declaration of Human Rights, Article 25

"Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control."

South African Constitution, Section 27: Health care, food, water and social security
(1) Everyone has the right to have access to -
(a) Health care services, including reproductive health care;
(b) Sufficient food and water; and
(c) Social security , including, if they are unable to support themselves and their dependants, appropriate
(ci) Social assistance.
(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights.
(3) No one may be refused emergency medical treatment.