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Grinnell Peace Studies Student Conference Spring 2012

Neglected Tropical Diseases: The Ignored Pandemic

Neglected tropical diseases (NTDs) are infections that typically afflict the world’s poor. They are neglected because, despite their prevalence, they do not receive much humanitarian aid compared to other deadlier diseases. NTDs have been feared throughout history and people are often stigmatized for their infections. In determining the best way to fix this problem, one must understand the social issues at play in order to inform healthcare and general aid workers how best to proceed. Much more funding and medicine is needed to cure NTDs but knowing how to best allocate funds is a daunting task, requiring knowledge of the complex social implications of NTDs. NTDs infect the poor because they are too destitute to afford preventative measures, such as proper sanitation, and curative measures like medicine. Global development issues, such as obtaining education and clean water, are important like treating these diseases. Both are important but the emphasis should vary depending on factors in a region. Curing these diseases must be coupled with increased global development of poverty-stricken regions to properly eliminate these diseases.

NTDs are very sinister, because while they do not usually kill they almost always debilitate. Depending on the disease, the infections hurt the patients by causing a variety of conditions. According to Dr. Peter Hotez, a leading NTD doctor, include “severe anemia, malnutrition, delays in intellectual and cognitive development, … blindness, [as well as] horrific limb and genital disfigurement … skin deformities …[increasing] the

risk of acquiring HIV/AIDS and suffering complications during pregnancy" (Hotez: 2009). More specifically, in order to understand neglected diseases, one must understand their pathology. Schistosomiasis, a parasitic worm, infects approximately 207 million people worldwide (Hotez: 2008). The early symptoms include muscle pains, fatigue, and fever, and over time, the infection causes internal organ damage. In children, it can impair physical and cognitive growth. Hookworm, a parasitic nematode, infects approximately 576 million people worldwide (Hotez: 2008). The direct affects are anemia and iron deficiency, and in children these symptoms result in deficient cognitive and physical growth. Leprosy, a chronic bacterial infection, infects 0.4 million people (Hotez: 2008). It primarily infects the lining and nerves of the upper respiratory tract but it also creates disfiguring skin lesions. All of these conditions demonstrate how NTDs usually horribly debilitate the infected, rather than kill.

NTDs "not only result from poverty but also help to perpetuate it. Children cannot develop to their full potential, and adult workers are not as productive as they could be" because of physical and mental degradation (Hotez: 2009). They affect one in six people—over one billion; yet these diseases are chronically ignored by humanitarian groups and the general public (Global Health Initiative Fact Sheet: 2007). Since NTDs do not usually kill their hosts, they are not given priority in most humanitarian efforts. Funding for HIV/AIDS, malaria, and tuberculosis research and treatment is far higher, and all three kill people at high rates. An estimated 530,000 people die each year from neglected diseases, versus the one to three million people who die each year from HIV/AIDS and malaria. However, when comparing disability-adjusted life years (DALYs), which measure disease burden by adding years of life lost plus years of life

with disability, the numbers are more similar. The number of DALYs annually for HIV/AIDS, malaria, and tuberculosis are 84.5 million, 46.5 million, and 34.7 million, respectively. For neglected diseases, the number of DALYs annually is 56.6 million (Hotez et al.: 2006). Though their mortality rate is comparably low, NTDs are not a minor nuisance.

The full effect of NTDs stretches far beyond the direct health impacts. NTDs also foster poverty in traditionally poor areas. For example, hookworm causes severe anemia, which greatly reduces a child's ability to attend and perform well in school. This negative impact on attendance lessens the child's future wage-earning capability, possibly up to 43% lower (Hotez: 2008). Lowered pay stifles an economy already in trouble. Thus, NTDs prevent overall economic growth, not to mention the healthy physical growth of the child.

NTDs are out of sight, and therefore out of mind, because they for the most part only exist in the destitute rural areas of poverty-stricken countries (although some, such as dengue fever, exist in city slums). Between 1974 and 2004, the FDA approved only twenty-one drugs for neglected diseases—a mere one percent of all drugs approved in that time period (Committee on Appropriations: 2010). Pharmaceutical companies have very little incentive to create drugs for neglected diseases. Why pay, on average, $800 million per drug to create medicines for people who cannot afford to pay for them? There are incentive programs, such as priority review vouchers (PRVs), which give pharmaceutical companies a voucher for creating a drug for a neglected disease that allows the company to later speed up the normally slow FDA approval process for another drug. PRVs are a good incentive that could generate new drugs that are more

effective, less toxic, etc. However, simply more money is needed to provide the already existing drugs to people.

Unfortunately, relatively little money is spent curing these diseases. How does this happen when disease ravages so many people? Diseases are usually not thought of as a human rights violation, but treatable diseases left untreated are a significant violation of human rights. This violation is not active in the sense that someone is directly perpetrating it: genocide and suppression of free speech, for example, are obvious human rights violations that an individual or a specific group perpetrates. Neglecting diseases is not active. People and governments are involved just by not doing anything; rather than actively hurting people, they turn their heads as millions of diseased suffer. As written in the WHO constitution, "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (WHO Constitution: 2006). The violation of this right is caused by a failure to act. Thus, the only way to cure NTDs and stop this violation is to act.

Anthropologists should play a unique and vital role in the treatment of neglected diseases, because they can understand how to best help a group of people from a non-medical aspect. Because NTDs are inextricably linked to the social fabric of the infected community, understanding the situation is key. From an anthropological perspective, many social and cultural issues must be studied and taken into account, including the stigma surrounding disease and the social structures that surround the areas afflicted with these diseases.

Diseases have always been stigmatizing. Something causing lifelong disability and disfigurement easily inspires fear in the uninfected. It is only natural for uneducated

people to ostracize the sick: they are afraid of what they do not and cannot understand. Stigma is a powerful actor in the social structure and dynamics of a community. The shame of being sick is so strong it sometimes drives people to hide their disease and avoid much needed treatment. For example, an ethnography in northern India about discrimination practices toward people with leprosy demonstrates this strong desire to appear healthy but with a disregard for actual health. In the article, Barrett quotes a twenty-two year old man:

> The burden is worse than the bacteria. You see, the infection is easily treated, easily cured with [multidrug therapy]. . . . But even when the leprosy has been totally eliminated, many people will treat you as someone who is cursed for all time. That is the major problem (Barrett: 2005).

This commonly held belief amongst Indians about leprosy exemplifies an educational issue concerning NTDs that anthropologists are uniquely poised to study. While multidrug therapy for leprosy can make a patient noninfectious in thirty days and cured in six to nine months, the desire to not seem "cursed" is immense and lasting. Once afflicted with the disease, the physical effects are not concealable, so even if a "leper" moves to another area he or she is literally marked for life. For many, the only means of survival is begging because even when cured, they cannot ever get work. This ostracism forces some victims to reject treatment and ask doctors to actually increase the size of their ulcers (a painless procedure due to the nerve damage caused by the ulcer) to "enhance physical deformities for begging" (Barrett: 2005). As a result, powerful social stigmas disproportionately hurt the diseased.

Social structures in rural South African settlements also create harsh stigmatization (Ashforth: 2004). While not a neglected disease, AIDS is a prime example

of this effect. The syndrome and its symptoms resemble cultural conceptions of witchcraft. To people who strongly believe in the power of traditional healers, the concept of HIV/AIDS seems ludicrous. Consider this: a foreign doctor tells a patient she has something too small to see that will eventually wreck her immune system, which fights off other diseases that are also caused by things too small to see. Coupled with the fact the onset of AIDS is years after first contraction, it is no wonder why people have trouble believing the doctors. Witchcraft, a concept deeply embedded in their culture, is a much more plausible explanation to them than this mysterious, invisible thing described by outsiders. People in the communities that try to get nontraditional medicine, such as antiretroviral drugs face incredible stigmatization as a result.

A study in Tanzania reaffirms that a distrust and misunderstanding of Western medicine creates problems with the treatments that people are receiving. As one local male resident said:

> … people really think about it, before buying medicine as it costs so much money. If you don't feel sick then you don't take medicine. Medicine is for sick people. The health workers turn you away if you don't feel sick, so why take 'praziquantel' now if you feel well? (Mwanaga et. al.: 2004)

The issues he explains cannot be fixed easily; they are the manifestations of inadequate education. Misconceptions on how modern medicine works is a serious problem but it goes even beyond a cost-benefit analysis of buying medicine. The study also found that adults are increasingly refusing free treatment. The reasons range from feeling sick after taking the medicine and missing work because of it to not believing the medicine works at all. All of the reasons lead to the same thing: no medicine means no cure.

Lack of education on medical issues in India, South Africa, and Tanzania are forms of structural violence. Structural violence prevents people from reaching their full

potential, which requires basic needs such as health and safety to be fulfilled. Structural violence is also historically entrenched in inequality, which manifests itself in this situation as economic inequality. Economic inequality leads to poor education in impoverished areas. However, there is hope: in South Africa, tuberculosis-awareness programs have begun to change traditional healers' beliefs on curing the disease. The healers, through education, are beginning to realize what their limitations are as medical practitioners. Some are beginning to tell their patients to seek Western medicine if they are coughing up blood.

In the fight to eradicate diseases, society must not fall into, as the ethnographer Philippe Bourgouis calls it, a "pornography of violence" (Bourgois: 2001). A "'pornography of violence' … submerges the structural causes of urban destitution under lurid details of blood, … and gore" (Bourgouis: 2001). Looking at image after image of starving children, their condition made worse by parasites stealing the few nutrients and calories they consume; grotesque ulcers; and a doctor extracting guinea worm from a patient's foot are part of a pornography of violence. A barrage of graphic images allows the viewer to become desensitized to the devastating effects of the diseases. This "pornography of violence" then allows the viewer to watch dispassionately as people are permanently crippled and then ostracized for their conditions. Because the viewer is not personally connected to the graphic imagery through social or physical relationships, they are desensitized rather than moved to action. This effect accounts for people knowing about these diseases but not caring enough to act and help fight the injustice, a passive human rights violation.

Within the fight to cure NTDs there are two schools of thought on how best accomplish this goal. One theory is that the only way to cure NTDs is to fix broader global development issues first, by providing access to things like clean water, proper sanitation, and education. The other theory is that NTDs keep people in their economic class, so eradication of disease must precede the eradication of poverty. Given the extent to which NTDs disable people the correct conclusion is that the other global development issues cannot be fixed without simultaneously curing neglected diseases; however, the degree to which each is fixed should vary according to regional needs. Providing education is not viable if people cannot attend school. NTDs cannot be cured if the infected areas do not have access to clean water. Neither global development issues nor NTDs can be solved unless the people with power care enough to act. Therefore those who have power must act by both providing funds and means to cure NTDs and fix global development issues concurrently.

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