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Fighting Stigma: Lymphatic Filariasis

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Introduction

Mosquitoes are everywhere, and millions of people fall victim to mosquito bites daily. While mosquito bites are generally harmless, for those who live in underdeveloped countries, these bites carry diseases that result in severe socioeconomic and physical subordination (Wynd et al., 2007). People who contract Lymphatic Filariasis (LF), an infectious disease transmitted by mosquitoes, may experience grotesque enlargements of their affected body parts, which include the arms, the legs, and the genital areas. When such swelling occurs, the patient is said to have progressed to a stage of LF known as elephantiasis, a term designed for the elephant-like texture of the resulting skin (Evans, Gelband & Vlassot, 1993).

In 1997, the World Health Organization classified LF as a potentially rectifiable disease. Since then, the World Health Assembly has called upon its member states to initiate drug programs to eliminate LF as a health problem (Wynd, Melrose, Durrheim, Carron & Gyapong, 2009). LF has been effectively controlled in endemic areas in the Pacific, the Caribbean, and in China, but the disease still runs rampant in India, East Africa, and 80 tropical and sub-tropical countries. Approximately 120 million people are already infected with LF, and 40 million have advanced to elephantiasis (Evans et al., 1993; Sudomo, Chayabejara, Duong, Hernandez, Wu & Bergquist, 2010; Wynd et al., 2007). In these countries, medical access and hygiene measures do not adequately accommodate overpopulation (Wynd et al., 2007). Reforming the healthcare systems of these countries, contrary to popular belief, is not enough. Battling LF is an issue that requires a profound radicalization of human thought. However, before we can begin to examine what is implied by this "revolution of thought," it is important to understand how LF is contracted and spread.

A Peek into the Biology of LF

LF is caused by a nematode, a long thin parasitic worm, ranging from 7-10 cm in length, that resides in the lymph channels of the infected person. The adult form, known as macrofilaria, mates and releases millions of larva called microfilariae (mf) into the bloodstream (Ahorlu, Dunyo, Koram, Nkrumah, Aagaard-Hansen & Simonsen, 1999).

Now mosquitoes become relevant. Mosquitoes serve as transmitting agents for LF. Several mosquito genera can transmit LF, but the most common is *Wuchereria bancrofti*. Other genera include *Culex quinquefasciatus*, which breeds in dormant water in urban villages, and *Brugia malayi*, which is somewhat confined because it requires freshwater plants found in rural areas for growth of larvae (Evans et al., 1993).

A female mosquito takes a blood meal when it bites a person who has mf circulating in his/her bloodstream. As it sucks blood, the female mosquito also ingests the mf. For 12 days, the mf progressively mature in the mosquito and enter the "infective stage." At this point, when the mosquito takes another blood meal, the mosquito can now pass mf into another person's bloodstream, thereby infecting the person (Evans et al., 1993). The mf continue to grow in the host's bloodstream, and eventually migrate into the lymphatic system, where they block the flow of lymphatic fluid. The blockage causes the fluid to drain into the extremities of the body, usually the legs and feet, where phenotypic changes in the skin become apparent. These changes depend directly on the activity of the worms, and the consequential blockage in the lymph nodes (Burril, Loutan, Kumaraswami & Vijayasekaran, 1996).

The Physical & Socioeconomic Impacts

"As the severity of the disease becomes more apparent, social and economic stigma follow suit."

Most patients with LF tend to experience skin fold thickening and pigmentary changes to their skin. In these instances, the infected skin hardens and develops small bumps, such that even pressing cannot dent the skin. Furthermore, due to the dryness of the skin, soaking the patients' skin in water does not relieve the painful cracks that soon develop (Burril et al., 1996; Evans et al., 1993). Along with skin changes in the early stages of LF, infected persons also have to battle other infections. The lymphatic system is vital to the elimination of pathogens, and a blockage of the system causes an onset of secondary diseases that make it even more difficult for patients to live a normal lifestyle (Burril et al., 1996).

Swelling of body parts is a consequence of LF. Those who have swollen toes find it nearly impossible to wear shoes, which are vital for protection against the outside environment. An infected Haitian woman expressed her despair: "When I need to go to school for them [my children] I can't wear my shoes, and they wouldn't want

me to go out looking any old way" (Coreil, Mayard, Louis-Charles & Addiss, 1998). The lack of shoes increases the chances of the patient's suffering from a secondary infection. Specifically, the swelling of the toes is accompanied with the tightening of skin cells, which facilitates further growth of bacteria and fungi. Because the toes have been greatly enlarged at this point, it is difficult to pry individual toes apart for removal of bacteria. In this way, infected persons become breeding grounds for further diseases (Burril et al., 1996).

The trauma of LF patients does not end here. Those who continue to experience progressive swelling are declared to have elephantiasis and are in for a life of painful disability. As the severity of the disease becomes more apparent, social and economic stigma follow suit. Most females in India, East Africa, and Haiti, for example, are expected to nurture children (Wynd et al., 2007). However, young, unmarried women with LF are unable to abide by the standards set by society, due to limited marriage prospects (Wynd et al., 2009). In Thailand and West Africa, there is a common perception that children born to LF-infected women will also inherit the genes for the disease (Wynd et al., 2009). There are also significant economic implications that enforce the image of these infected LF women's being poor marriage prospects. In fact, a study on infected Haitian women by Coreil and colleagues found that many women were unable to "harvest the garden produce because [one] has to stand to do it." These women thus struggle to find a partner and an identity in Haiti and coastal Ghana, where financial contributions to the family are essential aspects of social culture (Coreil et al., 1998). It is this very fear of an economic burden and of increased attention to their infected state that render many women reluctant to seek treatment, even if they have desires for such treatment. Coreil and colleagues reported one family member's sentiment: "You've lived with it this long, why do you need this treatment so far away?" Another woman expressed her despair: "I ask for death because it makes me very sick. I've been suffering with this for 33 years."

Men with LF share similar sentiments, especially in regards to marriage and employment problems (Wynd et al., 2009). Male sexual disability has not been significantly studied, but even so, it is believed that young men with hydrocele, another form of LF, struggle to "establish their sexual identity and their capacity to be reliable economic providers" (Coreil et al., 1998). In South America, for example, researchers discovered that many marriages lacked sexual activity due to the painful intercourse resulting from LF (Wynd et al., 2009). In Tanzania and Haiti, for example, men in the advanced stages of LF are considered socially "unacceptable" to the rest of society due to their inability to produce a child (Evans et al., 1993). Infected men and women are thus unable to and sometimes prohibited from selling garden produce in the market by the rest of society, and therefore cannot contribute to the household economy (Coreil et al., 1998). This exclusion leaves these individuals seemingly helpless, with few options to alleviate their social and economic distress.

Treatment & Prevention

What can be done to ease and prevent cases of LF? Medically, diagnosis of the disease is the first important step. Regardless of whether the patient is asymptomatic or symptomatic, a LF patient will have functional abnormalities with the lymphatic vessels (Addiss & Dreyer, 2000). Infection can be confirmed by using a microscope to examine a slide of dried blood from the potential LF patient for microfilaria. A more sensitive method involves tracking the movement of the adult worm in an ultrasound examination (Addiss & Dreyer, 2000). If the worm is alive and traveling in the blood stream to the lymph nodes, the test is considered positive, and the person is declared to have LF. The same concepts hold true for the DNA test, where the test is deemed positive if there are genes from the active worm present in the bloodstream.

Since LF does not have a permanent cure, most medical officials believe that prevention and forms of temporary treatment are the best methods. Diethylcarbamazine (DEC) is a drug that is considered one of the top options (Addiss & Dreyer, 2000). DEC has not been shown to reverse existing lymphatic damage, but it prevents further worm-associated damage. to the lympatic system. In essence, the drug clears the patient's blood of microfilaria, thereby reducing the opportunity for mosquitoes to further transmit the infection to other people (Evans et al., 1993).

"More than 1.5 billion people in the world are suffering from parasitic infections such as LF, which can be controlled by improved hygiene."

Retesting the patient for microfilaria after the treatment helps assess the effectiveness of the drug. If the patient still exhibits microfilaria positive results, the DEC treatment is repeated every 6-12 months. If the patient does not exhibit signs of the live adult worm in the blood-stream, the patient may opt to proceed with surgery. Overall, DEC has proved to be quite effective according to reports from villages in Haiti, Brazil and India, and is therefore a likely foundation of the global effort to eliminate LF (Addiss & Dreyer, 2000; Global Alliance to Eliminate Lymphatic Filariasis, 2010; Sudomo et al., 2010).

Along with DEC, doctors usually recommend specific courses of action depending on the severity of LF. For example, acute dermatolymphangioadenitis (ADLA) patients experience recurrent bacterial infections in the lower limbs. Recurrent ADLA usually results in elephantiasis, and the prevention of ADLA is key to preventing the development of elephantiasis. Cold compresses, rest, and antibiotic therapy of the bacteria have served as ef-

fective methods of control. Lymphoedema, which also results in inflammation of the lower limbs, has been studied extensively in Brazil, Haiti, and India, and can be treated by careful practice of hygiene. The World Health Organization recommends that infected individuals wash their affected body part with soap and water twice daily, keep their nails clean, wear shoes if possible, and use local antibiotic creams to treat small wounds that may appear (Wynd et al., 2009).

Hygiene is the most endorsed method of treatment and prevention. In the case of lymphoedema, for example, the practice is so effective that the swelling can actually disappear completely. This is because the lymphatic channels have the ability to reestablish lymph flow if the lymphatic channels are kept free from secondary infection (Wynd et al., 2009). However, the difficulty lies in the fact that many of these underdeveloped communities do not even have sufficient water for drinking, let alone for hygiene purposes. In African countries, for example, two out of every five people lack safe drinking water (Burril et al., 1996; Sudomo et al., 2010; Wynd et al., 2009). In addition, more than 1.5 billion people in the world are suffering from parasitic infections such as LF, which can be controlled by improved hygiene. This lack of hygiene and infrastructure, combined with the spread of W. bancrofti mosquitoes in Haiti and other underdeveloped countries across the globe, puts LF patients in a critical position (Evans et al., 1993).

These modes of treatment and prevention are limited to the areas where the WHO has already established organized programs (Addiss & Dreyer, 2000). Consequently, most medical officials believe that education is a prerequisite for effective prevention methods (Evans et al., 1993; Wynd et al., 2007). Prevalent misconceptions of LF need to be tackled in order to control the spread of the disease. In studies conducted in the Philippines, Ghana, Haiti, and India, many communities believed incorrectly that LF is spread via excessive physical stress and work, overdrinking of palmwine, and a very active sexual life (Ahorlu et al., 1999).

In a study conducted by Haliza and colleagues, only nine of 108 respondents in Malaysia knew that LF is transmitted by mosquito bites (Evans et al., 1993). They attributed LF to walking barefoot on dirty ground and consuming contaminated food and drinks. In addition, Evans and colleagues reported that residents who were more knowledgeable about the cause and transmission of LF took greater precautions in personal hygiene, essential for the prevention of LF. Even though some countries such as the People's Republic of China are experiencing a rise in public awareness of LF, other developing countries have only recently located the foci of their endemic areas and have yet to begin raising public awareness of LF (Wynd et al., 2009). With greater health literacy and awareness of LF comes an increased understanding of how to prevent LF, a greater concern for one's chances of getting LF, and an increased likelihood of seeking preventative health care services. Where We Step In...

"Those who have LF are often excluded from society due to a dichotomy that exists between "us" (the uninfected) and "them" (the infected)."

It is essential that we embrace an open mind when we encounter disability, and relay tolerance to others. Those who have LF are often excluded from society due to a dichotomy that exists between "us" (the uninfected) and "them" (the infected). These labels cause those who suffer from LF to fall to the bottom rung of the social ladder, contributing to a sense of subjugation and subordination. When most people encounter a description of LF or meet an individual with LF, they may tend to cringe back in horror and feel a sense of relief for not being infected. Coreil and colleagues describe how LF patients "received glances" and were subjected to rude remarks about their infected arms. The disgust and alienation that these patients received contributes to a striking decrease in their self-esteem. In fact, one women reported that she "hopes to die" because she has been living with the disease for such a long period of time (Coreil et al., 1998). It is this general attitude that needs to be upturned in order to truly combat LF and its implications.

We have to realize that those who suffer from disabling and deforming diseases are humans too. They deserve to be integrated into the everyday activities of society. There is no reason why people experiencing inflammation due to LF should be shunned from the school and work community, or be considered useless and a burden on society. We need to talk and listen to organizations and individuals connected with LF, and decrease the schism that exists between these individuals and the rest of society. We unconsciously endorse "inclusive exclusion," a phrase that reveals the "dual nature" of combating LF. On one hand, we attempt to help LF patients by improving their physical health through medical preventions, but on the other hand, our mindset still remains somewhat dehumanizing as we see these people who live so differently from us.

According to the World Health Organization, more than 120 million people are presently infected by lymphatic filariasis, and approximately 40 million are "disfigured and incapacitated" by the disease (WHO, 2011). The more we educate ourselves and others about LF, the more we allow health providers to understand the importance of combating this disease (Wynd et al., 2009). We have the potential to increase public willingness to seek necessary preventative health measures against LF. Students, staff, and teachers can begin to form non-profit organizations and clubs centered on fundraising for LF treatment and research. The money, resources and time we spend on this particular cause can potentially allow WHO to expand LF treat-

ment programs in endemic areas, and give the 120 million people infected with LF a chance to be treated for their illness. In addition, attempts to raise awareness on LF give inhabitants of endemic areas a chance to better understand how LF can be prevented and treated. And once the misconceptions are corrected, as seen in Tanzania and the Philippines, the citizens of these countries may be empowered to take better care of their hygiene and well being (Evans et al., 1993).

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