

What Neglected Tropical Diseases Teach Us About Stigma

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Neglected tropical diseases (NTDs) are a group of 20 diseases that typically are chronic and cause long-term disability, which negatively impacts work productivity, child survival, and school performance and attendance with adverse effect on future earnings.¹ Data from the 2013 Global Burden of Disease study revealed that half of the world's NTDs occur in poor populations living in wealthy countries.² Neglected tropical diseases with skin manifestations include parasitic infections (eg, American trypanosomiasis, African trypanosomiasis, dracunculiasis, echinococcosis, foodborne trematodiasis, leishmaniasis, lymphatic filariasis, onchocerciasis, scabies and other ectoparasites, schistosomiasis, soil-transmitted helminths, taeniasis/cysticercosis), bacterial infections (eg, Buruli ulcer, leprosy, yaws), fungal infections (eg, mycetoma, chromoblastomycosis, deep mycoses), and viral infections (eg, dengue, chikungunya). Rabies and snakebite envenomization involve the skin through inoculation. Within the larger group of NTDs, the World Health Organization has identified "skin NTDs" as a subgroup of NTDs that present primarily with changes in the skin.³ In the absence of early diagnosis and treatment of these diseases, chronic and lifelong disfigurement, disability, stigma, and socioeconomic losses ensue.

The Department of Health of the Government of Western Australia stated:

Stigma is a mark of disgrace that sets a person apart from others. When a person is labeled by their illness they are no longer seen as an individual but as part of a stereotyped group. Negative attitudes and beliefs toward this group create prejudice which leads to negative actions and discrimination.⁴

Stigma associated with skin NTDs exemplifies how skin diseases can have enduring impact on individuals.⁵ For example, scarring from inactive cutaneous leishmaniasis carries heavy psychosocial burden. Young women

reported that facial scarring from cutaneous leishmaniasis led to marriage rejections.⁶ Some even reported extreme suicidal ideations.⁷ Recently, major depressive disorder associated with scarring from inactive cutaneous leishmaniasis has been recognized as a notable contributor to disease burden from cutaneous leishmaniasis.⁸

Lymphatic filariasis is a major cause of leg and scrotal lymphedema worldwide. Even when the condition is treated, lymphedema often persists due to chronic irreversible lymphatic damage. A systematic review of 18 stigma studies in lymphatic filariasis found common themes related to the deleterious consequences of stigma on social relationships; work and education opportunities; health outcomes from reduced treatment-seeking behavior; and mental health, including anxiety, depression, and suicidal tendencies.⁹ In one subdistrict in India, implementation of a community-based lymphedema management program that consisted of teaching hygiene and limb care for more than 20,000 lymphedema patients and performing community outreach activities (eg, street plays, radio programs, informational brochures) to teach people about lymphatic filariasis and lymphedema care was associated with community members being accepting of patients and an improvement in their understanding of disease etiology.¹⁰

Skin involvement from onchocerciasis infection (onchocercal skin disease) is another condition associated with notable stigma.⁹ Through the African Programme for Onchocerciasis Control, annual mass drug administration of ivermectin in onchocerciasis-endemic communities has reduced the rate of onchocercal skin disease in these communities. In looking at perception of stigma in onchocercal skin diseases before community-directed ivermectin therapy and 7 to 10 years after, avoidance of people with onchocercal skin disease decreased from 32.7% to 4.3%. There also was an improvement in relationships between healthy people and those with onchocercal skin disease.¹¹

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One of the most stigmatizing conditions is leprosy, often referred to as Hansen disease to give credit to the person who discovered that leprosy was caused by *Mycobacterium leprae* and not from sin, being cursed, or genetic inheritance. Even with this knowledge, stigma persists that can lead to family abandonment and social isolation, which further impacts afflicted individuals' willingness to seek care, thus leading to disease progression. More recently, there has been research looking at interventions to reduce the stigma that individuals afflicted with leprosy face. In a study from Indonesia where individuals with leprosy were randomized to counseling, socioeconomic development, or contact between community members and affected people, all interventions were associated with a reduction in stigma.¹² A rights-based counseling module integrated individual, family, and group forms of counseling and consisted of 5 sessions that focused on medical knowledge of leprosy and rights of individuals with leprosy, along with elements of cognitive behavioral therapy. Socioeconomic development involved opportunities for business training, creation of community groups through which microfinance services were administered, and other assistance to improve livelihood. Informed by evidence from the field of human immunodeficiency virus and mental health that contact with affected people reduces negative attitudes and behavior among those participating in the intervention, contact between community members and persons affected by leprosy occurred through dialogue and interaction at events held in schools, village halls, and mosques. Furthermore, early detection and subsequent early treatment of leprosy can prevent individuals from the disability and disfigurement that we commonly associate with the disease, which often is not the message that afflicted individuals and their communities are hearing and seeing. Targeting media portrayal, the New Face of Leprosy project seeks to shift the messaging around leprosy to one of hope and positivity by promoting positive images—not presenting severe disfigurement as the representative image of leprosy—and strong messaging that the disease is curable.¹³

Although steps are being taken to address the psychosocial burden of skin NTDs, there is still much work to be done. From the public health lens that largely governs the policies and approaches toward addressing NTDs, the focus often is on interrupting and eliminating disease transmission. Morbidity management, including reduction in stigma and functional impairment, is not always the priority. It is in this space that dermatologists are uniquely positioned to advocate for management approaches that address the morbidity associated with skin NTDs. We have an intimate understanding of how impactful skin diseases can be, even if they are not commonly fatal. Globally, skin diseases are the fourth leading cause of nonfatal disease burden,¹⁴ yet dermatology lacks effective evidence-based interventions for reducing stigma in our patients with visible chronic diseases.¹⁵

Every day, we see firsthand how skin diseases affect not only our patients but also their families, friends, and caregivers. Although we may not see skin NTDs on a regular basis in our clinics, we can understand almost intuitively how devastating skin NTDs could be on individuals, families, and communities. For patients with skin NTDs, receiving medical therapy is only one component of treatment. In addition to optimizing early diagnosis and treatment, interventions taken to educate families and communities affected by skin NTDs are vitally important. Stigma reduction is possible, as we have seen from the aforementioned interventions used in communities with lymphatic filariasis, onchocerciasis, and leprosy. We call upon our fellow dermatologists to take interest in creating, evaluating, and promoting interventions that address stigma in skin NTDs; it is critical in achieving and maintaining health and well-being for our patients.

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