

Tackling podoconiosis, a common but highly neglected tropical disease



The work of Professors Davey and Newport has had direct and influential impact on patient care, community-wide disease prevention, training of professionals in disease management, raising awareness of podoconiosis in scientific and policy fora, and mobilising the private sector to engage in disease prevention.

Podoconiosis is a widespread non-infectious disease of the lower legs that causes swelling, pain, disability and extreme social stigma for sufferers. Through world-class genetic, public-health and social-science research, a group at Brighton and Sussex Medical School (BSMS) has generated evidence for a simple programme of treatment and prevention that has reached an estimated 60,000 patients in endemic areas of Ethiopia, providing significant clinical, social and economic benefits.

Overview

Podoconiosis is a non-infectious geochemical disease caused by chronic exposure to red clay soils derived from volcanic rock. Irritant particles are absorbed through the feet and collect in the lymphatic vessels and nodes of the lower legs, causing swelling, pain, immobility and disfigurement. Long-term, podoconiosis can result in fusion of toes, ulceration and bacterial

superinfection. The disease is most frequent in the highland regions of Africa, India and Central America and affects an estimated four million people globally, reducing the quality of life of afflicted individuals and constraining economic development for affected communities.

Podoconiosis is endemic in Ethiopia and north-west Cameroon, where it affects five to eight per cent of the population and is more common than HIV, tuberculosis and malaria. In addition to debilitating clinical effects, the disease poses an immense economic burden, with estimated costs to Ethiopia's economy of US\$208 million per year. It also leads to severe social stigma. Individuals suffering from podoconiosis are often excluded from social and religious gatherings and from marriage. Despite this considerable healthcare and socioeconomic burden, very little research on disease aetiology or pathogenesis has been done. Yet such research is critical for the rational deployment of limited resources for prevention, treatment and, ultimately, elimination of the disease.

Gail Davey (Professor of Global Health Epidemiology at BSMS) established a research group to study the aetiology (genetic, mineral and biochemical), clinical management and economic, ethical and social consequences of this debilitating and stigmatising disease. The genetics arm of this research group, led by Melanie Newport (Professor and Honorary Consultant in Infectious Diseases and Global Health at BSMS), has provided evidence that an area of the human genome commonly involved in responses to infection and environmental challenges plays a key role in an individual's susceptibility to developing podoconiosis.

Their research has led to a number of outcomes relating to clinical and social care of patients with podoconiosis. They have supported nationwide mapping of podoconiosis in Ethiopia, developed and validated clinical and quality-of-life measures, and completed the first genome-wide association study on a non-communicable disease in an African population. In addition, they have quantified the severe economic impact

on poor communities, developed and tested educational and training materials that describe the social impact on, and coping strategies adopted by, people suffering from podoconiosis, and they have applied a novel rapid ethics assessment prior to obtaining consent for genetics research in a low-income setting.

Achieving impact

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Their research provides evidence that allows communities to initiate simple treatment programmes to improve physical and psychological health. It is thought that such programmes now reach an estimated 60,000 patients in three regions of Ethiopia. Wearing shoes provides a simple preventive measure against podoconiosis. In countries where shoes are a scarce resource, establishing the importance of genetic susceptibility provides a robust scientific rationale to target children with a family history of the disease, ie those who are most likely to benefit from such interventions. Behavioural research, in collaboration with the Social and Behavioral Research Branch at the National Institutes of Health, USA, is testing community interventions, including campaign materials and household-level training sessions, to improve the use of shoes that are distributed to prevent disease.

On the strength of their research, in June 2013, the Ministry of Health in Ethiopia agreed to deliver training for the trainers of community health workers, covering 10 disease-endemic locations in Ethiopia and Cameroon and reaching approximately 300 trainers. The Ethiopian Ministry of Health has also approved an in-service training module on podoconiosis, developed by Professor Davey on the basis of research results and previous training, which will be used for the refresher training of 30,000 Health Extension Workers.

This work has also encouraged private-sector involvement and influenced national and international policy.



The International Podoconiosis Initiative

TOMS is a US-registered company that has pledged to donate a pair of shoes to a child in need for every pair of shoes sold. Founder Blake Mycoskie and his team visited endemic sites in Ethiopia and consulted with Professor Davey's research team to optimise the design of shoes distributed to prevent disease. TOMS has also provided significant research and advocacy support, funding the preparations for a nationwide mapping of podoconiosis, and appointed epidemiologist Dr Shira Shafir as Director of Impact Assessment to ensure that the shoes being distributed were having the impact intended.

In October 2010, Professor Davey presented evidence to the Department for Control of Neglected Tropical Diseases at the World Health Organization, which led to podoconiosis being recognised for the first time as a Neglected Tropical Disease. Her research has also underpinned successful advocacy to include podoconiosis among eight priority Neglected Tropical Diseases in the Ethiopian National Plan for Integrated Control of Neglected Tropical Diseases, launched in June 2013.

Future impact

Professor Davey serves as Director of Footwork, the International Podoconiosis Initiative. In November 2012, Footwork initiated talks between key stakeholders in the prevention and treatment of lymphatic filariasis and podoconiosis, paving the way for joint mapping of both diseases in Ethiopia and a subgroup working on improved diagnostics to differentiate these diseases in tropical settings. The nationwide mapping of podoconiosis across Ethiopia is now complete and the results – presented to the Ethiopian Ministry of Health in March 2014 – should allow them to identify which districts to prioritise for prevention and treatment interventions.

BSMS has become the global hub for podoconiosis research from which international collaborations are coordinated (www.podo.org/research)

Funding and partnership

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