

Leveraging social science knowledge for action on neglected skin diseases: key messages from the 5S Foundation

TIME FOR ACTION!

FROM SHADOWS TO SPOTLIGHT:
TRANSFORMING PERCEPTIONS OF NEGLECT



Key messages

- The **psychological and social wellbeing of people affected** by skin-related neglected tropical diseases (skin-NTDs), including experiences of stigma and marginalisation, are often overlooked.
- **Social sciences can help understand and amplify the knowledge** that affected people have about the social and economic structures that impact their vulnerability to, and experiences of, these diseases as well as their ability to live well.
- To maximise their impact and sustainability, policies, strategies and programmes need to explicitly **incorporate the needs and circumstances of people affected**.
- Such **needs and circumstances should be built into more holistic and inclusive services**, including psychosocial support. These should be integrated into local health systems close to where affected people live.
- **Health education campaigns**, including those for health professionals, are important for reducing public stigma, improving understanding, and dispelling misconceptions.

Photos: Front cover image by Jelle Visser, Sodo, Ethiopia, 2020
Inner cover image by Alex Kumar, West Gojjam, Ethiopia, 2019

The Social Sciences for Severe Stigmatising Skin Conditions (5S) Foundation

The 5S Foundation has developed an interdisciplinary approach to inform, evaluate and support the design and delivery of effective and contextually appropriate interventions to address three stigmatising skin-NTDs: mycetoma, podoconiosis, and scabies.

Primarily through qualitative approaches in community, refugee and policy settings, we have sought to understand problems and solutions concerning skin-NTDs by listening to and learning from the perspectives and experiences of people affected, as well as healthcare providers and policymakers. Here we share some of our current findings and the implications they may have for policy and practice.

Misunderstood and forgotten: a challenge for human development and social justice

Despite debilitating, disabling, and disfiguring hundreds of millions of the most marginalised and vulnerable communities around the world, skin-related neglected tropical diseases (skin-NTDs) are low priorities for governments, donors, public health initiatives, and research funders.

On top of the physical harm these diseases cause, they also damage people's psychosocial wellbeing and that of their families and communities. Those affected can experience stigma and discrimination – even within their own households – which can lead to isolation, mental illness and deepening poverty.

In the absence of the necessary commitment and action to deliver appropriate care, and of interventions to address the multiple contexts and experiences associated with these diseases, affected people are left to suffer in silence and are unable to live well.





The social dimensions of **scabies** and their implications for prevention and care

The impact of scabies on people's lives and wellbeing is commonly overlooked, even by health professionals. In the worst case, without understanding experiences of the condition amongst affected people, top-down narrow biomedical interventions can even contribute to the persistence of scabies incidence.

Scabies is viewed as a trivial and transient disease. Yet, if proper treatment is not provided and the underlying social and structural transmission causes are not addressed, it can, in effect, turn into a chronic condition.

Stigma associated with scabies is not fixed, but changes over time and across contexts. It can fall particularly heavily on vulnerable people such as women who may already lack power and agency to influence their circumstances.

Whilst scabies can affect anyone regardless of their socio-economic status, it is a visible indicator of social injustice and inequality. Scabies can be wrongly understood as being synonymous with poverty and is associated with people living in poor conditions regardless of whether they do or do not have scabies. Identifying social and structural dynamics is essential to determining the emergence, persistence, and re-emergence of scabies, and to unravelling how individual contexts affect scabies infection and treatment.

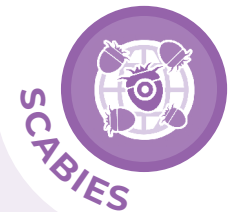
Our research reinforces the case for control strategies that understand and act upon both the intersecting socio-contextual dimensions of scabies risk and its consequences, and subsequent the care-seeking behaviour that these dimensions shape – including those that go beyond the health and water, sanitation and hygiene (WASH) sectors.

Research with refugee populations in Gambella Region, Ethiopia, identified the importance of not addressing scabies in isolation, and the need to understand and

“Scabies is painful and forced me to continuously scratch my body. The pain becomes worse at night and makes me restless. This has negatively affected my education. People get shocked, and they don't feel comfortable when they see the wounds on my body.”

Research Participant, Debre Elias region, Ethiopia

Photo: A woman seeks diagnosis for the itching of her child at an Internally Displaced People's camp in El-Gezeria State, Wad-Madani locality in Sudan. Millions of Sudanese people have been displaced by conflict and resettled in crowded camps which provide a conducive environment for the transmission of scabies. *Image by Ahmed Elfaig, 2023*



A parasitic infestation caused by tiny mites that burrow into the skin and lay eggs, causing intense itching and a rash. Despite being curable, scabies can lead to skin sores and serious complications like septicaemia, heart disease and kidney problems. It is contagious and spreads through skin-to-skin contact.

Although officially designated as a tropical disease, scabies is found in practically every country in the world, with at least 200 million people suffering from scabies at any one time. It is estimated that Ethiopia has nearly 15% scabies prevalence.

act on the contributing issues of deprivation, dependence and precarity in such settings.

People living in refugee camps understand how a range of factors can contribute to the emergence of scabies, including access to water, personal hygiene, immunity, and environmental factors. We must do more, including using research, to leverage their knowledge to inform health and humanitarian professionals and policymakers.

The underlying causes of these factors relate to larger-scale issues such as the neglect of refugee health in the national health system, and the lack of socio-economic and political considerations embedded within the refugee protection system. Inadequate healthcare services affect people's health-seeking behaviour to the extent that the disease is normalised as an inescapable aspect of refugee camp life.

The social dimensions of **podoconiosis** and their implications for prevention and care



Podoconiosis is commonly misunderstood, causes great ostracism and distress, and ruins the lives and livelihoods of people that suffer from it. It is so deeply neglected that it does not even feature as one of the 21 diseases included in the WHO NTDs roadmap.

Actions to address health disparities due to podoconiosis should not only focus on podoconiosis as a disease, but also on how social and economic structures and circumstances, including people's economic status, gender, age, where they live, and their social relations, affect their vulnerability to and experiences associated with the condition. People experience stigma for multiple reasons, not only from podoconiosis, and the pathways they do or do not take to seek treatment and care are shaped by these multiple, intersecting dimensions, which may contribute to disease progression and may increase suffering.

Such considerations need to be built into more holistic and inclusive services, including psychosocial support, that can be integrated into local health systems. These must be accompanied by socioeconomic empowerment interventions and health education campaigns to reduce public stigma, improve understanding, and dispel misconceptions, including in partnership with local traditional leaders and organisations.

Health practitioners must be trained and supported to better understand and respond to the psychosocial social dimensions of podoconiosis.



A progressive, debilitating form of leg swelling caused by many years of barefoot contact with irritant soil in highland tropical areas. Podoconiosis affects some of the most disadvantaged people in 27 countries across three continents.

Ethiopia bears 25% of the global burden of podoconiosis with approximately 1.5 million people living with podoconiosis in the country. In districts where it is common, it has a higher prevalence (more than 5%) than HIV, which is considered a high priority by governments and donors.



“Being unable to earn an income while I could, looking at myself and feeling desperate, and being unable to move from here to somewhere else, all of these contribute to the sadness I have in life.”

Research participant affected by podoconiosis in Rwanda

Photos: A Rwandan woman affected by podoconiosis sits outside her home. People with podoconiosis often struggle to travel to the locations where treatment is available due to limited mobility and travel costs. *Image by Corinna Thellmann, 2023*

Patients receiving treatment for podoconiosis in a remote rural clinic. Settings in remote clinics are essential to ensuring access to care for podoconiosis sufferers with low mobility and/or means. *Image by Jelle Visser, Sodo, Ethiopia, 2020*

The social dimensions of **mycetoma** and their implications for prevention and care



Social science research shows us that skin-NTDs cannot be understood separately from both human-made and natural environments, and their intersections with social contexts. Nowhere is this clearer than in the case of mycetoma, where our research in Sudan suggests that mycetoma occurrence may be shaped by infrastructure failure, such as, via poorly maintained irrigation systems, settlement expansion and drainage systems.


The nature of women's everyday lives exposes them to more environmental and cultural risk factors, through tasks such as wood cutting and collecting, water fetching, and house cleaning.

The pathways that people affected by mycetoma pursue for treatment and care are influenced by their social relations and economic circumstances. This can lead people to delay seeking help or to access less-effective forms of treatment and care.

Because of the stigmatising nature of mycetoma, those affected can purposefully mask it with other diseases and their symptoms as a strategy for avoiding these negative associations which in turn can delay accessing appropriate treatment.

“My husband always complained to me because of my condition, he used to tell me that it was all my fault. His words caused me immense pain and I was doing anything to satisfy him. Ultimately, he left me with a miserable situation. This made me vulnerable, heart-broken, shy, and hesitant. Whenever I get out of the house I use a specific method of walking. I walk two steps, stop one, and look behind me until I ensure that no one is looking at me. I tried to straighten my walk and hide the limp, but in the end, I failed to do so.”

Research participant affected by mycetoma, Al Andalous area, White Nile state, Sudan.



Mycetoma is a chronic infectious disease of the subcutaneous tissues that spreads to affect the skin, deep tissues and bone. Mycetoma can be caused by different species of bacteria or fungi. Mycetoma occurs in tropical and subtropical environments with short rainy seasons and prolonged dry seasons that favour the growth of thorny bushes.

Global burden is unknown, but the disease is endemic in Africa, Asia, Europe and Latin America.



“This disease is more painful than going through war. At least, in war, there is hope for peace or escape from the battle without any injuries. But, with Madura (mycetoma), you can't survive without removing part of the body.”

Research participant affected by mycetoma, Al Andalous area, White Nile state, Sudan

Need for a people-centred approach

Policies and strategies concerned with skin-NTDs need to explicitly incorporate the needs and circumstances of people who are affected by them, paying specific care and consideration to those who are marginalised and vulnerable

To achieve this, social science research – the scientific study of human beings, their social relationships, and how they organise themselves – is essential. For example, social science research can help to understand the experiences associated with skin-NTDs

and point to alternative strategies for treating chronic conditions that cannot be treated by mass drug administration programmes.

Social science research can provide theoretical insights and methodological approaches to inform the framing of programmes and interventions. For example, these concepts could help devise strategies to strengthen buy-in and ownership amongst affected people and other key actors, such as community health practitioners or local government officials, as well as to aid the sustainability and scale-up of programmes.

Unpack structural conditions

Exploring the 'gap' between knowledge and practice can point to structural conditions that may influence people's exposure to and experiences of skin diseases. It can help to draw attention to marginalised communities, such as those living in refugee camps, where social, political and economic circumstances that cause preventable and treatable conditions like scabies deepen affected people's vulnerability.

Without understanding and engaging with these structural conditions, interventions can inadvertently exclude, stigmatise, or harm people, particularly those who may already be vulnerable and marginalised.

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Photos: Portrait of a woman affected by podoconiosis at a community treatment centre. *Image by Jelle Visser, Sodo, Ethiopia, 2020.*

Right: Participants at a Community of Practice discussing the best way to support people affected by podoconiosis. This group brought together representatives from the community including health workers, local authorities, podoconiosis affected people, clergy, school leaders, women and youth. *Image by Alemu Tesfaye, Shime Kebele, Ahmara region, Ethiopia 2022.*

Change how we measure suffering and success

A fundamental shift is needed in the way that policymakers use evidence to set priorities. Most skin-NTDs don't cause immediate death, but they do cause massive suffering. The most common way global policymaking has so far measured this suffering is the 'disability-adjusted life year' or 'DALY'. This is a statistical measure where one DALY represents the loss of the equivalent of one year of full health. Seeing a reduction in DALYs related to NTDs is a key road map indicator of success, and the measure has been hugely useful in highlighting the impact of NTDs to policymakers.

However, by summarising the suffering of affected people as a single figure, DALYs can mask the real, day-to-day struggles and experiences of people affected: communities, health providers, and policymakers. Qualitative social science approaches can shed light on what it really means to be affected by diseases. A rethink of how both suffering and success are measured, that encompasses insights from the social sciences, is necessary.

Programme evaluation design must also incorporate ongoing learning of practitioners at all levels, flexibility and sustainability of practices and outcomes, rather than focusing on measures that quantify participation and project indicators.

End the neglect of lived experience

We need to find better ways to bring the experiences and voices of people affected by these diseases into discussions on all aspects of policy and practice: from the design and implementation of treatment and prevention programmes, to local, national, and international policymaking.

Qualitative research can help to expose these often hidden experiences and voices by sharing the stories of individuals affected, their communities and skin-NTD practitioners. Our research has shown that more space should be made, and support provided, to put the people affected themselves at the heart of policy and practice.

There must be a deeper exploration of affected people's perspectives on the structural inequalities that can make them more vulnerable to the diseases and shape their experiences living with the conditions.

Research is needed to examine the cultural, social, political and economic contexts of skin-NTDs; to understand the power dynamics and dimensions of stigma experienced by people affected; and to evaluate the effectiveness of some of the measures currently used to reduce this stigma.

Better understanding the social strategies people adopt to seek support or avoid stigma can help with the design and implementation of effective psychosocial interventions. Our research reveals that people are adept at devising creative strategies to seek support to meet their holistic needs, including self-help groups and other forms of community association. However, these are currently not properly incorporated into interventions. Programme designers and implementers need to find ways to work more productively together with affected people and their communities.

Bring treatment and care closer to people affected

Access to effective treatment of skin-NTDs is widely regarded as a litmus test of progress towards Universal Health Coverage (UHC): the idea that everyone, everywhere should have their basic health needs met.

Historically, services for NTDs have been centralised and siloed. This can mean that marginalised, impoverished people are forced to spend money they do not have, including transport costs, to access treatment they cannot live well without. These circumstances can be exacerbated in conflict-affected settings where services may not be functioning and population movement may be difficult or dangerous. Our research shows it is vital to mainstream services, and to bring them as close as possible to people affected. Doing otherwise makes achieving UHC impossible.



“By empowering individuals affected by NTDs to advocate for their own needs and those of their communities, a Community of Practice can contribute its fair share to break the cycle of neglect and stigma associated with NTDs, leading to more equitable and effective health outcomes.”

Alemu Tesfaye, Public Engagement Officer, OSSREA

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About the 5S Foundation

The Social Sciences for Severe Stigmatising Skin Conditions (5S) Foundation is a £3.5million social science research partnership working in Ethiopia, Rwanda and Sudan on three skin conditions: mycetoma, podoconiosis, and scabies. The 5S Foundation is supported by the UK's National Institute for Health and Care Research through its Research and Innovation for Global Health Transformation (RIGHT) programme.

The 5S Foundation partnership's central aim is to evidence that social science

research for NTDs is essential for the successful translation of key biomedical advances in elimination and control programmes. By bringing social science perspectives into interventions at the level of the patient, the community and national and international policy it is possible to improve the health and wellbeing of people affected.

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Funded by:



This research was funded by the NIHR 200140 using UK aid from the UK Government to support global health research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK government.

