

## Background

“Though neglected tropical diseases impair the lives of an estimated 1 billion people, they are largely hidden, concentrated in remote rural areas or urban slums and shanty towns. They are also largely silent, as the people affected or at risk have little political voice.”

Margaret Chan (WHO, 2010)

In the first World Health Organization (WHO) report on neglected tropical diseases (NTDs) in 2010, its director-general, Dr Margaret Chan, made a salient statement about a group of diseases that together affect an estimated one-eighth of today's global population. Despite affecting such a significant portion of the world, these diseases have been largely overlooked. Chan indicates that the most vulnerable groups include not only those deprived of resources but also those who are politically marginalised.

The WHO has prioritised 21 NTDs and scabies was one of the three conditions added to the list in 2017. Scabies is a neglected skin disease caused by the mite *Sarcoptes scabiei* var. *hominis*. It arises when a female mite burrows into the skin, laying eggs that trigger a host immune response, resulting in intense itching and rash. The disease is often associated with significant burdens, including on physical, psychological, economic and social wellbeing. Overcrowded and under-resourced settings such as prisons, home care, religious schools and refugee camps often experience a high prevalence of scabies.

In Ethiopia and Rwanda, scabies is a significant public health concern. A meta-analysis of previous studies estimated that the prevalence of scabies in Ethiopia is 14%. In addition, repeated outbreaks of scabies have been documented in Ethiopia since 2015, especially during human-made and natural catastrophes. According to a report by the Rwandan Ministry of Health, scabies affects more than 100,000 people annually. However, there is limited evidence about the context of scabies among refugees in Ethiopia and Rwanda and religious students in the case of Ethiopia.

In Sudan there have been no reports by the Ministry of Health regarding scabies as a health concern. However, in 2017 a local radio station called “Radio Dabanga” stated that more than 500 people had been infected with scabies in El Gedaref state, and in 2014 another local radio station, “Radio Tamazuj”, reported an outbreak of scabies in Sennar State, with more than 50 cases recorded.

The three countries are home to sizeable numbers of refugee populations from neighbouring countries. For example, as of March 2024, Ethiopia was hosting 972,835 refugees and asylum seekers (UNHCR, 2024). According to a 2023 UNHCR report Rwanda

was sheltering more than 133,628 refugees and asylum seekers from the Democratic Republic of the Congo and Burundi. In 2024, UNHCR reported nearly 2.32 million South Sudanese people had fled to neighbouring countries, including 800,000 living in Sudan, while 2.22 million remained internally displaced in South Sudan owing to ongoing violence.

Ethiopia, Rwanda and Sudan are all committed to providing refuge to people fleeing violence and conflict. However, their continued reliance on encampment of refugees as a protection approach has failed to address refugees' long-term needs, contributing to their deprivation and marginalisation. These are among the determinants of the prevalence of scabies in refugee camps around the world, although this has not been adequately addressed in the body of scientific literature in these countries.

On the other hand, while previous studies on scabies in Ethiopia have confirmed a significant prevalence of the disease among religious students, they have not adequately explored the underlying factors sustaining this problem. We argue that the crux of refugees' and religious students' vulnerability to scabies in these countries is perpetuated by the systematic marginalisation processes inherent in policy and practice. To this end, we conducted four multisite ethnographic studies on refugees and religious students in Ethiopia, Rwanda and Sudan.

## The social dimensions of scabies and their implications for prevention and care – key findings

This brief drew from ethnographic fieldwork visits carried out in Ethiopia, Rwanda and Sudan as part of a multi-country and multi-disease research project by the 5S Foundation.

Three studies were conducted in refugee camp settings (on South Sudanese refugees in Bantui refugee camp in Sudan, Nguenyiel refugee camp in Ethiopia, and Kigeme refugee camp in Rwanda). The fourth piece of fieldwork was conducted in Debre Elias district in the Amhara Region of Ethiopia and involved religious students, also called *yekolo temari* in Amharic, the national language of Ethiopia. In addition to interviews (with patients, caregivers, service providers, governmental and non-governmental organisations at both regional and federal levels), this study involved participant observations, focus group discussions and review of pertinent documents.

Our findings depict that scabies is a highly stigmatised skin disease among refugees and religious students. The prevailing neglect of these populations in health policy and strategies helps the disease thrive in refugee camps and premises of religious education. The findings of our studies can be summarised under the following themes.

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# Leveraging social science knowledge for action on scabies:

a call to end the neglect and stigma among refugees and religious students in Ethiopia, Rwanda and Sudan

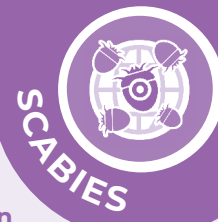


## Scabies

“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.”

Religious student affected by scabies in Debre Elias

Scabies is highly prevalent in the Amhara region of Ethiopia where Mass Drug Administration (MDA) is often used to contain the disease. Despite this, scabies is persistent in different districts of the Amhara region including Debre Elias district. It is locally known as *meshe mekeraye* (‘the agony of the night’) because its severe itchiness worsens in the evening. Image and interview by 5S PhD Dereje Wonde, Ethiopia, 2022



SCABIES

Scabies is 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.

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 among affected people, top-down narrow biomedical interventions can even contribute to the persistence of the disease.

Emerging from four ethnographic studies conducted by the Social Sciences for Severe Stigmatising Skin Conditions (5S) Foundation, this brief calls for targeted action against scabies in marginalised groups in Ethiopia, Rwanda and Sudan. It underscores how social, cultural and economic factors exacerbate neglect and stigma, advocating for culturally informed health interventions to ensure effective treatments for affected refugees and religious students.



## Key messages

- Overcrowding and refugees' socio-economic and cultural circumstances exacerbate the presence of scabies in refugee camps, a significant public health issue. This situation results in a widespread sense of shame and distress.
- The challenges faced by refugees affected by scabies reflect larger problems of systemic violence and a lack of focus on addressing the underlying political reasons for displacement, as well as insufficient support from humanitarian organisations.
- To address health disparities, practices and policies concerning scabies among refugees must consider the principles of structural violence including culture, living conditions, environment, gender and religion.
- Research in Sudanese refugee camps shows that the failure of health providers to understand and acknowledge the stigmatising nature of scabies has an adverse effect on the people affected by the condition, causing them to be socially isolated and in some cases to develop suicidal thoughts.
- Despite the medication being easily accessible for most people, except for the religious students in Debre Elias, factors like its unpleasant nature contribute to resistance to scabies treatment, highlighting the need for culturally appropriate medical interventions.

"You see my body and my baby's body; we itch all day and all night. People stopped knocking on this door, they find me disgusting! I don't want my baby to suffer like me, I just want to die. I'm tired of itching."

Woman affected by scabies in Bantui refugee camp

Stigma associated with scabies is not fixed, but changes over time and across contexts. Breast-feeding women and children are more at risk of contracting the disease due to regular skin to skin contact, and experience greater stigma as a result.

Image and interview by 5S PhD Hala Elmalik, Sudan, 2022

## Societal perceptions of scabies causations and dynamics of scabies stigma

Perceptions of health, including associations of scabies with inadequate diets, poor personal hygiene, a lack of immunity, and poor living standards, reflect severe deprivations of these populations. Scabies is deeply stigmatised, often erroneously associated with other severe illnesses, and viewed as a sign of extreme poverty. For instance, in Debre Elias a person with scabies might be called ekekam – an adjective that denotes an impoverished and deprived person.

In Nguenyiel Refugee Camp in Ethiopia, the growing challenge of scabies compels people to normalise it as an inevitable facet of refugee life in the camp. Adults sometimes view young patients with scabies who show signs of shame as unfit – people who succumb to a trivial issue rather than the other critical socio-economic challenges and uncertainty that they experience in their everyday lives. The normalisation and trivialisation of scabies in the camp shape the general perceptions of disease, the dynamics of stigma, and health-seeking behaviour in the camp.

## The context of available treatment options

Scabies treatment was provided free of charge for refugees in Ethiopia and Rwanda. In Sudan, it was also free in refugee camps but not in governmental hospitals. However, the treatment, primarily benzyl benzoate, is underutilised in Rwanda because of its foul smell and the stigma attached to its use. In Ethiopia, however, lack of scabicide was one of the major challenges that the healthcare providers were grappling with. This was found to discourage refugees from visiting the healthcare providers opting for home-made remedies and medicines from clandestine pharmacies run by refugees themselves. Low healthcare-seeking behaviour was found to contribute to repeated reinfestations and treatment failures in Nguenyiel.

With regard to religious students in Debre Elias, since they are not part of the community health insurance scheme, access to scabicides is often rare and religious students attempt to self-medicate using traditional treatments, including holy water and herbal medicines.

**Photo right:** Pictured here is a University of Khartoum Team Member distributing scabies awareness leaflets at a refugee camp in El Gezira state in Sudan as part of their public engagement activities. Refugee camps were found to be particularly conducive to the spread of scabies due to the crowded living conditions. Our research showed that some view scabies as an unavoidable consequence of camp life, leading to treatment apathy. The focus on symptom alleviation, without addressing underlying living conditions, has fostered a cycle of poor adherence, reinfestation, and low healthcare seeking behaviour. Image by Ahmed Elfaig, Sudan, 2023

## Structural constraints and health vulnerabilities

The prevalence of scabies among refugees and religious students in the case of Ethiopia symbolises their struggle and the convergence of infection and deprivation. The inadequate international response to the causes of displacement coupled with shortcomings in the refugee protection approach exacerbates health issues like scabies.

The issue of scabies transcends health and is tied to structural violence and political neglect within the refugee global governance framework, which relies on encampment as a solution to refugees' plights. Refugee camps create a conducive environment for scabies to spread because of close proximity and inadequate preventive measures, reflecting systemic injustices experienced by marginalised communities. In Nguenyiel refugee camp, significant deprivation and marginalisation embedded within the encampment policy and regulated service provision prioritises survival instead of the holistic wellbeing of refugees. The healthcare system in the camp operates at critical capacity, often struggling to adequately provide preventive and curative services. Whilst in Ethiopia, reporting of scabies as a health condition at a national level occurs on a weekly basis, this is not the case in refugee camp settings.



## Recommendations

These recommendations aim to create a health system that is attentive to the intricate needs of refugees. By considering both the immediate treatment concerns and the underlying structural factors, a more comprehensive and effective approach can be taken to manage scabies in refugee populations and religious students.

### Customising treatment based on cultural and contextual factors

- A disconnect between medical provision and culturally attuned acceptance demonstrates the need for a treatment approach that respects the refugees' cultural context.
- Promote the development of healthcare practices that are aligned with and respectful of different cultural beliefs and values.
- Develop and disseminate culturally sensitive alternative remedies for scabies.
- Medications that have a neutral aroma could help reduce the resistance currently caused by the negative perception of the odour of benzyl benzoate.

### Enhancing health education and engaging with the community

- Enhance and broaden health literacy initiatives: implement community-driven educational initiatives to debunk misconceptions about scabies, highlighting that it is not a condition exclusive to poor people or one that is associated with other diseases. This would diminish social stigma.
- Mobilise and include influential members of the community: harness the power of local religious and community leaders to foster comprehension and embrace therapeutic methodologies.

### Advocacy for policies and interventions that address structural issues

- Champion policy change: advocate for international discussions of policies that tackle the underlying causes of refugee displacements and the resulting health consequences. Emphasise the link between scabies and structural violence.
- Strengthen UNHCR's ability to engage in political activities: advocate for increased participation of the UNHCR and other humanitarian agencies in political dialogues focused on resolving conflicts in order to reduce displacement and its negative impact on health.
- Revisit the community-based health insurance system to recognise that family members can live in different locations. This will significantly increase religious students' access to healthcare, helping them prevent and respond to various health problems, including scabies.
- Develop contextually and culturally adequate interventions that also consider the social, ecological and economic dimensions of scabies, beyond the biomedical-oriented scabies control interventions.

### Combining indigenous practices and biomedical approaches

- Promote comprehensive approaches to health and wellbeing: to optimise the acceptance and effectiveness of scabies treatment among refugees, it is imperative to incorporate alternative views and practices into the treatment regimen, thereby promoting the refugees' physical and emotional wellbeing.
- Show how current biomedical interventions per se are not sufficient to prevent and mitigate scabies in the refugee camps and religious education centre of Debre Elias; enhancing the collaboration between biomedicine practitioners and traditional healers would be beneficial to mitigate the recurrent scabies incidence.