

Leveraging social science knowledge for action on NTDs:

a call for the effective mainstreaming of neglected tropical disease interventions into health systems and community assets



Podocniosis

“My husband is also a patient. He went to a healthcare station without informing me; and he received three bars of soap and shoes.”

Woman affected by podo in Ethiopia

Interventions for podo should consider 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.

Image by Jelle Visser, Ethiopia, 2021



Podoconiosis is 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.

Historically, services for neglected tropical diseases (NTDs) provided by national health systems have been centralised and siloed, limiting their reach and availability for marginalised populations. This has resulted in impoverished people being forced to choose to either spend what little money they have on transport and access to traditional or biomedical treatment or, more often, use homemade medicine or go without care. Non-governmental organisations (NGOs) have often stepped in to offer treatment for NTDs in affected areas using their own staff to provide services, but they have struggled with sustainability, scale-up, building community rapport and securing funding.

Drawing on an evaluation of an intervention jointly implemented by two NGOs working on podoconiosis in Ethiopia, this brief addresses the effectiveness of mainstreaming health services for NTDs such as podoconiosis into local healthcare facilities, revealing the factors that could influence the effectiveness of interventions and proposing ways of improving the design of complex interventions for NTDs.

Shifting from direct to mainstream intervention management

NGOs play a significant role in the delivery of interventions to control NTDs. Many NGOs have taken a direct approach to the design and implementation of interventions, working with their

own resources, capacity and infrastructure to prevent and treat NTDs and support affected people.

However, although direct intervention models have proved to be important in expanding access to services for affected communities, NGOs have struggled to sustain and scale up these interventions. Faced with these challenges, NGOs are increasingly identifying the need to mainstream interventions into existing packages of health services delivered through formal health services, with the ambition of enhancing their sustainability and increasing cost-effectiveness.

While mainstreaming strategies for NTDs and other health issues, is increasingly evident in policy and practice discourses, more needs to be understood about the factors that influence the effectiveness of such interventions, particularly in the case of NTDs that cannot be treated or cured using drug therapies.

Among these conditions is podoconiosis, which causes debilitating physical injury and psychosocial challenges. Preventing and controlling the disease focuses on increasing awareness, reducing pain and suffering, and trying to delay the disease's progress.

Several interventions have been conducted in Ethiopia, a country that bears 25% of the total global burden of podoconiosis. Two Ethiopian NGOs – the National Podoconiosis Action Network (NaPAN) and the International Orthodox Christian Charities (IOCC) – have been working together since 2010 to deliver podoconiosis interventions in the rural Amhara region of Ethiopia. Between 2020 and 2023, the two NGOs implemented an intervention aimed at improving the lives of patients and increasing community awareness by providing support via local healthcare facilities.

The Social Sciences for Severe Stigmatising Skin Conditions (5S) Foundation studied the effectiveness of an intervention in controlling podoconiosis and the key factors influencing this. Drawing on a mixed method approach, we studied implementation design and process, the physical setting of the NGOs, and contextual factors including the sociocultural, economic, political and geographical factors that can influence the outcome of the intervention.

Key messages

- NGOs have expanded health services for NTDs by direct intervention management, for example by using their own resources and staff to provide services. However, because of difficulties achieving reach and sustaining services, NGOs are increasingly shifting towards a mainstreaming approach, embedding intervention activities into local healthcare facilities.
- Our evaluation of the intervention improved access to treatment and health resources for affected individuals, enhancing the capacity of local health professionals to provide treatment.
- Some of the programmes were not implemented as intended by the NGOs; for example, the cascading of treatment through to health extension workers was not achieved, and the intervention activities were curtailed because of limited budgets at local healthcare facilities.
- Evaluating interventions that aim to mainstream programmes into healthcare facilities requires going beyond measuring immediate outcomes to registering improvements in health systems.
- By understanding and incorporating contextual factors and patients' lived experiences, NGOs can develop appropriate, targeted and sustainable mainstreaming approaches.
- NGOs still need to go a long way to institutionalise NTD intervention into local healthcare systems and community assets.
- To successfully mainstream NTD interventions, NGOs need to strengthen their capacities and diversify their funding sources.
- If sustainability were placed at the heart of programme design and actors at all levels of the health system were engaged at inception, mainstreaming of NTDs would become more likely.

Photo: At the clinic patients and their families are guided through the steps of lymphoedema management including foot hygiene, application of emollient, use of bandages, socks and shoes, exercises and elevation. It costs £52 per person to treat patients and set them up to continue independent self-care. By contrast, the economic burden per patient is nearly 3 times that amount per year. Image by Alex Kumar, Ethiopia, 2019

Key findings

1 Implementation

The implementers utilised government healthcare centres in a bid to mainstream podoconiosis services within local healthcare structures. The intervention provided training for health professionals and both affected and unaffected community members where the disease is endemic. Supplies were distributed to affected individuals over a three-month period. The intervention reached 63% of affected people, and 88% of these reported continuing to implement the intervention as learned 18 months after the completion of the intervention. Worryingly, female patients' participation was lower. About 18% of affected and unaffected individuals engaged in health education interventions. Nearly all reported they fully understood the messaging from the training. Involvement in the intervention resulted in improved shoe wearing practice and a reduction in stigmatising attitudes.

2 Setting

The physical environment – i.e. the NGOs' office spaces and equipment – the profile of the staff, the programme design, and the NGOs' organisational culture and structure were vital in implementing the intervention. The effort to implement and scale up a mainstreaming approach was compromised by NGOs' lack of funding and the subsequent ability to institutionalise the intervention activities into community assets, e.g. schools. Funding is a particular challenge, as funders have little interest in supporting conditions that are not amenable to drug therapies; this in turn limits the capacity of local healthcare facilities to continue health services. As a result, the NGOs placed too high an emphasis on individual-level, quantifiable short-term outcomes, and this overshadowed efforts to evaluate the success of the intervention in institutionalising the activities.

One member of staff noted: "Funders are less motivated to fund non-life threatening and drugless diseases that are not amenable to advertise manufactured drugs."



Recommendations

- NGOs should consider designing programmes that can withstand the constraining effects of contextual factors and incorporate the lived experience of patients to effectively deliver activities.
- By empowering patients, changing health related norms and improving local healthcare systems, NGOs can improve NTD services.
- Using a human rights-based approach would strengthen NGOs' ability to hold governments accountable to sustaining NTD service provision.
- By emphasising that the consequence of NTDs such as podoconiosis go beyond health and intersect with gender, disability and ageing, NGOs will attract more funding and collaboration.
- Innovative strategies should be created to mainstream NTD services into local healthcare structures, incorporating outcomes that:
 - focus on changing cultural values, community health practices, policy programmes, power relations, and the socio-economic status of patients;
 - produce indicators that include assessment of progress in institutionalising programme services at local healthcare facilities;
 - present podoconiosis and similar NTDs as conditions that exacerbate existing poverty, inequality and migration around the world, thereby increasing the attention paid; and
 - strengthen NGOs' capacity in resource mobilisation, programme learning and evaluation and improving their fundraising strategies to ensure NGOs are well equipped to work towards the mainstreaming of NTD services.
- National governments should demonstrate strong commitment to the control of NTDs by allocating budget and providing resources to local healthcare facilities and other community assets such as traditional associations and schools to address the wider dimensions of wellbeing and social justice.



3 Contextual factors

Contextual factors such as sociocultural, geographical, political and socio-economic factors and patients' lived experiences affected the intervention outcome. Among these factors, gender inequality, the remoteness of resident areas and the patients' economic status, experiences of community stigma and self-stigmatisation negatively affected involvement in and adoption of the intervention.

An affected woman said that "husbands remain ... the leaders of the family ... So, females go to healthcare stations [take part in health intervention] and buy medicine when husbands give permission."

Political factors also influenced the intervention activities. The study indicated that, although the Ethiopian Government was committed to including podoconiosis in national policy programmes, attempts to secure the establishment of a dedicated budget line for podoconiosis were unsuccessful and because of this health services could not be sustained at the healthcare facilities.

This was reinforced by a key informant who confirmed: "The Ministry [of Health] has not allocated any budget for podoconiosis in the years 2022 and 2023."

Photo: This subsistence farmer is pictured outside her house in Yilmana Densa, a rural district and part of West Gojjam Zone in the Amhara Region of Ethiopia. She did not wear shoes when growing up and developed podoconiosis in her early twenties. *Image by Alex Kumar, 2019*



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