



**PROCEEDINGS OF THE 19TH ANNUAL CONFERENCE OF THE ETHIOPIAN SOCIETY OF
SOCIOLOGISTS, SOCIAL WORKERS AND ANTHROPOLOGISTS**

Conference Theme

Social Medicine for Neglected Tropical Diseases

Ras Amba Hotel, Addis Ababa

May 31, 2024

Summary

The Ethiopian Society of Sociologists, Social Workers, and Anthropologists (ESSSWA) convened its 19th General Assembly on May 31, 2024, at the Ras Amba Hotel in Addis Ababa. The assembly, themed "Social Medicine for Neglected Tropical Diseases," brought together distinguished speakers and participants to address critical issues surrounding neglected tropical diseases (NTDs) in Ethiopia. The event commenced with a registration of participants, followed by welcoming and opening remarks from Dr. Ezana Amdework, ESSSWA EC President. A keynote address was delivered by Prof. Getnet Tadele, the Principal Investigator and Country Lead for the 5S Foundation Ethiopia, setting the tone for the day's discussions.

The assembly featured insightful paper presentations covering various aspects of NTDs, including interventions for podoconiosis reduction, everyday life implications of scabies in Debre Elias, and the susceptibility of street children in Addis Ababa to scabies. Researchers shared their findings on the lived experiences of rural podoconiosis patients and public engagement initiatives of the 5S Project. Discussions were interspersed with health breaks, allowing participants to network and exchange ideas. The event also included recognition of members and organizations for their contributions, a presentation of ESSSWA's 2023 audit and activity reports, and the 2024 annual plan. The assembly concluded with discussions and approvals of the reports, ensuring a collaborative and forward-looking approach to addressing NTDs in Ethiopia.

1 Introduction

Tigest Tefera, Secretary of the ESSSWA Executive Board opened the meeting officially by welcoming introducing the meeting's agenda. This was followed by an opening speech by Dr. Ezana Amdework President of the ESSSWA Executive Board. In his speech, he highlighted ESSSWA's commitment to improving education, building member capacity, enhancing societal contributions, increasing international standing, and benefiting the community. Despite significant progress, Dr. Ezana emphasized the need for a strategic approach to tackle challenges such as education quality, professional identity, and decolonization of education.

He outlined the necessity of strengthening educational frameworks to be inclusive, indigenous, and reflective of diverse perspectives. Dr. Ezana called for the adoption of new methodologies and interdisciplinary collaboration to address social issues. He stressed the importance of mutual learning through voluntary service to build member capacity and enhance collective knowledge. Additionally, he advocated for increasing ESSSWA's international standing through global partnerships and active participation in international forums.

Dr. Ezana highlighted the critical role of sociology, social work, and anthropology in addressing Ethiopia's dynamic social processes and issues, including population growth, migration, urban transformation, conflict, post-conflict reconstruction, and public health crises like the COVID-19 pandemic. He concluded with a call to action, urging members to work together to overcome challenges and advance their disciplines for the benefit of society.

Professor Getnet Tadele, Principal Investigator of the 5S project, presented a comprehensive overview of the initiative aimed at ending neglect on multiple levels. The project addresses the neglect of three skin-stigmatizing conditions—podoconiosis, mycetoma, and scabies—highlighting the significant social and health impact these diseases have on affected individuals and communities. By focusing on Ethiopia, Sudan, and Rwanda, the project targets endemic countries that are often overlooked.

The 5S project emphasizes an interdisciplinary approach, involving medical, sociological, anthropological, political science, and health economics perspectives to tackle the multifaceted issues surrounding these neglected conditions. The project's vision includes situational, strategic, and capacity-building aims to understand the cultural, social, and economic contexts of the diseases, refine intervention frameworks, and support training posts to build local expertise.

Public engagement and capacity building are critical components of the project, ensuring that the benefits of higher education and research are shared with the public and that local capacities are strengthened through workshops, training plans, and mentorship. The project's socio-

ecological model underscores the importance of addressing neglect at individual, interpersonal, organizational, community, and public policy levels.

In his address, Professor Tadele expressed gratitude to the project's partners, including the National Institute for Health Research (NIHR) and UK Aid, for their support and collaboration, which have been instrumental in advancing the project's objectives. He underscored the timeliness of the project, given the pressing need to address neglected tropical diseases and the critical role of social sciences in developing culturally informed interventions and reducing stigma.

2 Presentations

2.1 1st Session Presentations

Following Professor Getnet Tadele's summary, the conference featured two insightful presentations.

The first presentation, titled "The Interaction of Contextual, Setting, and Implementation Factors on a Health Intervention Against Podoconiosis in Rural Ethiopia," was delivered by Dr. Kibur Engedawork, a Postdoc Researcher at Brighton and Sussex Medical School, Sussex University, and Assistant Professor of Sociology at Addis Ababa University. Dr. Engedawork's research explored how various factors influenced the effectiveness of health interventions targeting podoconiosis, a debilitating and neglected tropical disease prevalent in rural Ethiopia.

The second presentation, "Everyday Life and Scabies in Debre Elias (Ethiopia): Implications for Disease Control," was presented by Dereje Wonde, a PhD candidate at Brighton and Sussex Medical School, Sussex University, and Assistant Professor of Sociology at Bahir Dar University. Wonde's study examined the daily experiences of individuals affected by scabies in Debre Elias, Ethiopia, and discussed the broader implications for disease control and management in similar contexts.

A short summary of the presentations is presented below.

1. **The interaction of contextual, setting, and implementation factors on a health intervention against Podoconiosis in rural Ethiopia** By Dr. Kibur Engedawork (Postdoc Researcher at Brighton and Sussex Medical School, Sussex University, and Assistant professor of Sociology, Sociology Department, Addis Ababa University)

The 5S project conducted a study to evaluate an intervention implemented to improve the lives of people affected by podoconiosis in North-western Ethiopia. The presentation, entitled “The interaction of contextual, setting and implementation factors on a health intervention against podoconiosis in rural Ethiopia” by Dr. Kibur Engdawork, a postdoctoral research fellow at the 5S foundation, at the 19th Annual Conference of ESSWA, aims to disclose the interactive effects of contextual factors on health intervention.

The presentation emphasized how podoconiosis and similar neglected tropical diseases (NTDs) should be seen as social diseases as individuals' exposure to the condition and access to health services are highly influenced by individuals' social position. The presentation indicated that although several interventions have been implemented to enhance the lives of patients, there has been little information about the outcome of implemented interventions, particularly from a social science perspective. Due to this, the presentation noted, that there was little information about factors such as context that may either promote or restrain social interventions. Employing a mixed methodology and an evaluation framework known as Context and Implementation of Complex Intervention (CICI), the study evaluated an intervention known as next steps for podoconiosis patients in rural Ethiopia implemented by International Orthodox Christian Charities and National Podoconiosis Action Network, the presentation revealed. The presentation discusses the major successes and limitations of the implemented interventions in improving the lives of patients.

The presentation also showed the relevance of conducting evaluation studies guided by a social science perspective. The effort resulted in identifying structural, institutional, and agential factors, thereby indicating which factors are difficult to change within the lifespan of a health invention and which factors can be amended. The presentation includes recommendation points to implementers including Home-based interventions for affected individuals with mobility problems; Provision of psychosocial support and design of economic empower programs to reduce stigma; Conducting health education at institutional settings and traditional associations to expand accurate understandings and discarding wrong beliefs; Utilization of community assets to sustainably expanding intervention activities; and Presenting NTDs as a global health phenomena and considering domestic funding to increase the financial abilities of NGOs working on NTDs. The presentation finally underscored that diseases like podoconiosis need a social response as preventive actions are socially mediated. Developing an optimal person-centered intervention should take note of social and structural factors, their interactions, and tensions arising from these interactions. Understanding these critical factors will better equip interventions to limit the structures and institutions that create and sustain risks, the presentation showed.



2. Everyday life and scabies in Debre Elias (Ethiopia): Implications for Disease Control By Dereje Wonde (PhD candidate at Brighton and Sussex Medical School, Sussex University, and Assistant professor of Sociology at Bahir Dar University)

Scabies are highly prevalent in the Amhara region of Ethiopia where the Mass Drug Administration (MDA) is often used to contain the disease. Despite this scabies is persistent in different districts of the Amhara region including the Debre Elias district. Most scabies research in Ethiopia and globally uses medical and public health perspectives and is patient-centered and conducted within hospitals or schools. No research explores scabies in the real settings in which it occurs, or the particular experiences of people with scabies and how these may influence disease onset and management. To fill this knowledge gap we explore people's everyday life about scabies, with a focus on how people in Debre Elias understand and seek to manage scabies.

We used a rapid ethnographic study design. Fieldwork was conducted from February to July 2022 and included 57 semi-structured interviews with people who had active scabies symptoms during fieldwork or in the past year, those without scabies symptoms, local health workers, traditional healers, and government officials. It also included participant observation and key document analysis. People with or without scabies were recruited with the support of Health Extension Workers. They lived in five kebeles of Debre Elias (Debre Elias town, Degolma, Guay, Gofichma, and Dejiba kebele). These were purposively selected because they host four health centers and a primary hospital in the district. The participants of this study were recruited by using purposive

and snowball sampling strategies. Thematic and narrative analysis was used to analyze the collected data.

Scabies is locally known as *meshe mekeraye* ('the agony of the night') because its severe itchiness worsens in the evening. Some people with scabies and traditional healers described two types of scabies based on the salient symptoms: *abash ekek* ('active scabies') and *denkoro ekek* ('dormant scabies'). This is not a biomedical classification. Some people with scabies conceptualized scabies as a disease synonymous with poverty as extremely poor people are addressed in Amharic as *ekekam* (bearer of scabies) regardless of their asymptomatic status. Not all people are equally vulnerable to scabies as living conditions, gender roles, socio-economic status, lack of water, and religious practices make some people more vulnerable. Infants, breastfeeding women, and religious students are the standout scabies-affected groups in Debre Elias. The superposed factors simultaneously influence some individual's vulnerability to scabies and their different responses. Scabies is so common in Debre Elias that it is often conceptualized as a trivial illness people simply learn to live with. A combination of disease normalization and the perception of harmlessness influences people's tendency to delay or take no action. Most people with scabies initiate their treatment either by self-medicating or visiting traditional treatment centers (holy water and herbal medicine), seeking treatment from biomedical health facilities.

The existing scabies control interventions prioritize biomedical solutions uniformly administered in different settings, which are not sufficient to mitigate the recurrent scabies outbreaks in the community. We suggest the need to shift to more context-specific interventions targeting the broader social, ecological, and economic dimensions of scabies to address the fundamental social determinants of the disease.

2.2 Discussion

During the Q&A session, several pertinent questions were raised regarding the presentations:

1. **Effectiveness of Interventions:** One question focused on the overall effectiveness of the interventions related to podoconiosis and scabies. This inquiry aimed to understand how well these health interventions were performing in terms of reducing the prevalence and impact of these diseases.
2. **Evaluation Study and Longitudinal Data:** Another question was directed at Dr. Kibur Engedawork, asking whether his evaluation study, which is not longitudinal, provided any insights into how the prevalence of podoconiosis has changed over time. This query sought to understand whether the disease incidence was increasing or decreasing based on available data.

3. **Contextual Factors Mapping:** There was a question about whether the contextual factors influencing the health interventions were adequately identified and understood. This question aimed to clarify the comprehensiveness of the contextual analysis in the study.
4. **Socio-Cultural Factors and Rapid Ethnography:** A question was raised regarding the brief presentation of socio-cultural factors according to their contribution to the diseases. The inquiry also sought clarification on the concept of "rapid ethnography," the observed impact of gender on the diseases, and the extent of participant observation conducted in the research.

Summary of Answers Provided During the Q&A Session:

Dereje Wonde:

- **Effectiveness of Traditional vs. Medical Interventions:** Dereje noted that most people in the study area prefer self-medication using homemade herbals and traditional methods. However, in complicated cases, these methods are not helpful, prompting patients to seek medical support.
- **Rapid Ethnography and Participant Observation:** Dereje explained that he employed rapid ethnography, staying six months in the study area. He emphasized his cultural familiarity, speaking the local language, and growing up in the community, which helped him build rapport. He clarified that his role was more observation than participation, attending some health interventions by professionals.
- **Socio-Cultural Factors and Disease Transmission:** Dereje highlighted that certain socio-cultural factors facilitate disease transmission, such as communal sleeping and sharing living spaces, especially in religious schools. He noted that 5-7 students often share small huts and sleep together, facilitating disease occurrence.
- **Gender and Disease Prevalence:** Gender was identified as a crucial variable. Nursing and breastfeeding women were more affected than their male counterparts. Gender also impacted health-seeking behavior, as women often needed their husband's approval to seek medical help.

Dr. Kibur Engedawork:

- **Prevalence and Future Trends of Podoconiosis:** Dr. Kibur reported that in the two districts studied, 5-10% of the population is affected by podoconiosis, with adults and elders being the most affected. He expressed hope that the prevalence would decrease but highlighted a concern about children preferring to walk barefoot due to misunderstandings about red clay soil, keeping the districts endemic.
- **Mapping Contextual Factors:** Dr. Kibur mentioned that their study used the Comprehensive Contextual (CC) framework to identify and map contextual factors

affecting interventions. He stated that their approach was comprehensive, incorporating additional contextual factors to ensure thorough analysis.

- **Gender and Health-Seeking Behavior:** Dr. Kibur noted the impact of gender on health-seeking behavior, with men having more opportunities to get medical attention compared to women. This gender disparity was a significant finding in their study.

2.3 2nd Session Presentations

The second session of the conference featured three engaging presentations.

Bewenetu Zewede, a PhD candidate at the Sociology Department of Addis Ababa University and staff member of Wolayita University, presented "Neglected Tropical Disease Meets Neglected Community: Street Children's Susceptibility to Scabies in Addis Ababa, Ethiopia." This presentation shed light on the vulnerability of street children in Addis Ababa to scabies, emphasizing the intersection of neglected diseases and marginalized populations.

Bikila Ayele, a PhD candidate at the Sociology Department of Addis Ababa University and staff member of Selalle University, discussed "The Lived Experiences of Rural Podoconiosis Patients' Management of Lymphedema Illness in Western Ethiopia: An Intersectional-Hermeneutic Study." This study explored the daily challenges and coping strategies of podoconiosis patients in rural Western Ethiopia, employing an intersectional-hermeneutic approach to understand their lived experiences.

Alemu Tesfaye, Regional Programs Manager at the Organization for Social Science Research in Eastern and Southern Africa (OSSREA), presented "Taking the Research to the Public: A Glimpse into the 5S Project's Public Engagement Initiative." This presentation highlighted the 5S Project's efforts to engage the public and disseminate research findings, emphasizing the importance of public involvement in tackling neglected tropical diseases.

Below is a short summary of the presentations:

1. **Neglected Tropical Disease Meets Neglected Community: Street Children's Susceptibility to Scabies in Addis Ababa, Ethiopia** By Bewenetu Zewede (PhD candidate at the Sociology department, Addis Ababa University and Staff member of Wolayita University)

Scabies is a neglected tropical disease (NTD) with a high prevalence rate in resource-limited settings. Though street children are susceptible because of lack of sanitation and contact with

vectors, few attempts have been made to identify their lived experience of NTDs in the global south.

This study explored the lived experiences of street children infested with scabies in Addis Ababa. Using in-depth interviews, we collected qualitative data from selected children on the street to identify their understanding of the causes of scabies, their experiences of managing the condition, and their health-seeking behavior. Informants were recruited to include maximum variation in terms of age, sex, and experience of infestation.

The study showed that street children are highly susceptible to scabies and that the infestation has physical, psychological, and social impacts. Study participants believed that scabies had its origin in their living conditions (including poor environmental sanitation and lack of personal hygiene), with lice playing a significant role as vectors of transmission. The informants reported visiting modern healthcare facilities, traditional healers, and self-care in response to infestation.

By uncovering the embodied experience of a stigmatized skin NTD in a neglected community in the global south, this study contributes to combating neglect and addressing health disparities. Having identified living conditions as the major factor contributing to susceptibility, efforts need to be exerted to change street children's living situations and other structural conditions through reunification with their families or other communities, reintegration, and other exit strategies.

2. The Lived Experiences of Rural Podoconiosis Patients' Management of Lymphedema Illness in Western Ethiopia: An Intersectional-Hermeneutic Study By Bikila Ayele (PhD candidate at the Sociology department, Addis Ababa University and Staff member of Selalle University)

Podoconiosis is a neglected tropical skin disease causing lymphedema of the lower legs, primarily affecting rural populations in low-income countries. It has substantial physical, economic, and psychosocial impacts on patients, including severe social stigma. Managing podoconiosis illness requires context-specific programmatic interventions. Successful interventions necessitate understanding the socio-cultural context surrounding the illness. However, the complex social aspects of chronic skin illness management are understudied from social sciences perspectives. This research utilizes an intersectional hermeneutic lens to address the knowledge gap in illness management for podoconiosis in rural areas. It aims to contribute to podoconiosis intervention programs. Interviews were conducted with 22 podoconiosis patients across different age, gender, and disease stages at four health facilities. Key informant interviews were also conducted with local elders and Health Bureau officials. The data was analyzed using hermeneutic interpretive thematic analysis.

The results reveal that podoconiosis disease stages have varying names and meanings: early stages are trivialized and perceived as reversible, while later stages are considered stigmatizing

and degrading. The disease stages-based perceptions about podoconiosis coupled with intersecting social determinants influence the timing and type of care-seeking and the illness burdens the patients' experience. Based on their unique social positions, patients experience complex and distinct challenges in dealing with the condition. The burdens and responses to the condition are influenced by various social factors, including economic status, gender, social capital, age, and rural daily life. In conclusion, patients' understanding and response to the disease change with illness stages, impacting care-seeking timing and type, and burdens of the illness. Intersecting social factors shape perceptions, experiences, and management of the illness. Interventions should be context-specific and tailored to the interests and needs of the patients and prioritize awareness, prevention, early detection, and treatment, and need to be gender and age-sensitive.

3. Taking the Research to the Public: A Glimpse into the 5S Project's Public Engagement Initiative By Alemu Tesfaye (Regional Programs Manager, Organization for Social Science Research in Eastern and Southern Africa (OSSREA))

The 5S Project's public engagement initiative, presented by Alemu Tesfaye, Eyerusalem Kassahun, and Gardew Yilma on May 31st, 2024, aims to take research findings to the public to improve engagement and policy debates on skin diseases and associated stigma, with a focus on Podoconiosis and Scabies. The initiative operates on multiple levels: nationally, regionally, and individually, to refine NTD policy documents, increase the number of actors involved, and enhance community awareness and individual well-being through strategic interventions.

Objectives of the Public Engagement Initiative

The public engagement initiative aims to enhance engagement and policy debates on skin diseases and associated stigma at the national and regional levels (Macro Level) by refining NTD policy documents and involving a broader range of stakeholders. At the community level (Meso Level), the initiative seeks to eliminate or reduce stigma against NTDs through engagement activities, raising awareness about the conditions, their impact, and economic costs. On an individual level (Micro Level), the project strives to increase awareness among those affected, improve their health and well-being, and advocate for better access to treatment and services.

Achievements and Activities of the 5S Project

Significant progress has been made in the 5S Project Public Engagement Initiative, including establishing communities of practice (CoPs) at various woredas in the Amhara region and securing support from regional health bureau NTD teams and local NTD focal persons. Despite disruptions due to conflict, the community of practice promised to be a platform that helps community members to have regular meetings and consensus among CoP members to address issues collaboratively. The project has established partnerships with NaPAN (National

Podoconiosis Action Network) and organized numerous workshops and high-level events, such as the national advocacy workshop on Podoconiosis and Scabies. The team has also participated in global events like World NTD Day and the National NTD conference. Various communication products, including brochures and posters on Scabies and Podoconiosis, have been developed in collaboration with the Ministry of Health to enhance community engagement. Efforts to reach a broader audience include blog articles, interviews on TV, radio, and newspapers, and active social media presence on platforms like Twitter, Facebook, and Telegram. Additionally, the initiative has conducted several capacity-building activities, including research ethics and methodology training for ESSWA members and health extension workers in the Amhara region. Training sessions have also been provided for local theatre and dance clubs, elementary and high school students, and the creation of documentaries and musical theater performances to raise awareness about NTDs.

2.4 Discussion

Discussion

During the Q&A session of the second presentation session, the following questions were raised:

- **Ethical Challenges and Trust Building in Research with Street Children:** Questions were directed to Bewenetu Zewede regarding ethical challenges faced during the study, the influence of his adulthood status on interpreting children's voices, how he gained the children's trust during data collection, and whether proper research methods facilitated exploring the case with the children.
- **Podoconiosis Transmission and Prevention:** Bikila Ayele was asked to explain why more than one individual in a family might be infected with podoconiosis, despite it being non-communicable. He was also asked about the timing and effectiveness of shoe-wearing in preventing the disease.
- **Ethical Considerations and Methodology in Research with Vulnerable Populations:** Additional questions for Bewenetu Zewede focused on ethical considerations, the number of interviews conducted in each sub-city, consent procedures, Institutional Review Board (IRB) approval, and recommendations for future research.
- **Impact and Sustainability of the 5S Project:** Alemu Tesfaye was asked to share the achieved impacts of the 5S project, pathways with policymakers, sustainability of the impact, and community-based strategies. Additionally, a question was raised about any connections found between the studied diseases and other diseases.

- **Scabies and Socioeconomic Factors:** Questions about scabies included whether well-to-do families or individuals ever have scabies, if simple hygiene can prevent it, and the connection between poverty and scabies.

Responses and Reflections

Bewenetu Zewede:

- **Ethical Challenges and Trust Building:** Bewenetu shared that he did not face significant challenges in accessing the field due to his previous work with street children. He emphasized that critical ethical issues were not overlooked, with ethical clearance obtained from ESSWA, privacy and confidentiality maintained, and financial compensation provided. Referral linkages were also created for serious cases of scabies. Regarding his adulthood status, he tried to blend in by using the children's language and being physically and emotionally close to them. He noted that street children in Addis Ababa have good awareness of scabies and health-seeking behavior, and further research is being conducted to see if this awareness extends to regional cities.

Bikila Ayele:

- **Podoconiosis Transmission and Prevention:** Bikila explained that the prevalence of podoconiosis in multiple family members is due to genetic susceptibility combined with walking barefoot in red clay soil, common in high rainfall areas. He stressed the importance of wearing shoes and washing legs at all stages to prevent or control the disease. He also highlighted the strong relationship between stigma and health-seeking behavior found in his study.

Alemu Tesfaye:

- **Impact and Sustainability of the 5S Project:** Alemu outlined several achievements, including raising awareness about the importance of social science perspectives in addressing neglected tropical diseases, engaging stakeholders such as church leaders and officials, and getting the Ministry of Health's NTD task force involved in intervention activities. Sustainability efforts included ensuring ongoing work by partners like NAPPA. Major challenges faced were expectations of financial handouts and conflicts throughout the country.

Professor Getnet Tadele:

- **Ethical Considerations and Project Impact:** Professor Tadele questioned the fit of global ethical standards formulated by the West for the local context, suggesting the need for alternative approaches tailored to local situations. The major challenge to the project was the onset of COVID-19, which disrupted planned activities and necessitated improvisation. He highlighted the project's impact in establishing a baseline for issues, interlinking academic research with public engagements, and involving the Ministry of Health in discussions. He noted that there is no direct causal relationship between scabies, pododermatitis, and poverty or hygiene, nor a correlation with other diseases.

3 Afternoon Session

During the afternoon session, ESSSWA's organizational affairs were conducted. The association awarded acknowledgment certificates to six former Institutional Review Board (IRB) members for their dedicated service, as well as to key partners including the Ministry of Women and Social Affairs (MoWSA), the Social Sciences for Severe Stigmatizing Skin Conditions (5S) Foundation, USAID Ethiopia, and UNICEF Ethiopia.



Professor Getnet Tadele receives a certification of recognition on behalf of the 5s Foundation

In addition, the 2023 annual activities report and the activity plan for 2024 were presented. The session concluded with Professor Dejene Gemechu, Chair of the ESSSWA general assembling thanking all participants and stakeholders for their involvement in the 19th annual workshop of ESSSWA.