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Social Science for Severe Stigmatized Skin Diseases (5S Foundation) Ethiopia Project

Report on Research Dissemination and Stakeholder Engagement Workshop in Gambella



Figure 1: Participants of Research Dissemination & Public Engagement Workshop in Gambella Regional State

November 2023

Contents

1. Introduction	3
2. Opening Session	3
3. Presentations	4
3.1. The context of NTDs program in Gambella Region and efforts underway.	4
3.2. The overall context of scabies in Ethiopia, intervention gaps and the need for social science 5	
3.3. Understanding how precarity and marginalization affect vulnerability to, the experience of, and response to scabies among refugees in the Gambella Region, Ethiopia	6
3.4. Major Achievements of the 5S Project Public Engagement Activities	6
4. Discussion – Questions and Answers	7
5. Closing and Way forward	9
<i>Annex i: Workshop Agenda</i>	10
<i>Annex ii: Workshop Participants</i>	11

1. Introduction

The Organization for Social Science Research in Eastern and Southern Africa (OSSREA) is collaborating with the United Kingdom's Department of Global Health and Infection at Brighton & Sussex Medical School (BSMS) to implement a research project called "Social Sciences for Severe Stigmatizing Skin Diseases (The 5-S Foundation)" in the Amhara, Oromia, and Gambella regions. This research project focuses on two neglected tropical diseases (NTDs): podoconiosis and scabies. The project aims to enhance and transfer social science research skills to emerging researchers in social science to address the limited role of social science professionals in NTDs research.

One of the research projects conducted in Ethiopia focused on "*Understanding how precarity and marginalization affect vulnerability to, the experience of, and response to scabies among refugees in the Gambella Region, Ethiopia.*" This research project was carried out in the Nguenyiel Refugee Camp from February 2022 to July 2022.

Thus OSSREA, in collaboration with Refugees and Returnees Service (RRS) Gambella Branch and Gabella Regional Health Bureau, conducted a one-day consultative workshop with key stakeholders on November 07, 2023, at Ethiopia Hotel, Gambella Regional State. The aim of the workshop was to disseminate and validate the research findings and set the stage for discussions and collaboration on scabies among refugees and similar vulnerable groups.

A total of 23 stakeholders (4 female) from different sectors and structures participated in the workshop. The participants were drawn from Gambella Refugee and Retirees Service Branch, Gambella Health Bureau, and Nguenyiel Refugee camp.

The workshop was fully financed and supported by the UK's National Institute of Health Research (NIHR) through the Brighton and Sussex Medical School (BSMS).

2. Opening Session

The opening session began with Mr. Alemu Tesfaye, the Public Engagement Officer of the 5S Ethiopia, welcoming the participants and providing an overview of the workshop's purpose and agenda. Alemu then invited the participants to introduce themselves, their roles, the institutions they represented, and their expectations for the workshop. Following this, Mr. Leulseged Solomon, the Health and Nutrition Coordinator at RRS Gambella Branch, made a welcoming remark, expressing gratitude for the 5S Foundation project of the validation and dissemination

workshop in Gambella city and sharing his hopes for valuable outcomes. He also expressed his expectations for the research dissemination workshop.

After Mr. Leulseged's remarks, Professor Getnet Tadele, the Country Lead and PI of the 5S Foundation Ethiopia, delivered an opening speech. He warmly welcomed and thanked all the participants for attending the workshop, emphasizing the importance of considering the social science perspectives in addressing disease. Professor Getnet highlighted the inequalities and unfair distribution in economic, social, political, and psychological factors and stressed the importance of considering vulnerabilities in future interventions.

Professor Getnet explained that the main aim of the workshop was to share the research findings from a refugee camp in Gambella and to discuss potential interventions. He also emphasized the need for collaboration among key stakeholders to address the needs of refugees and bring about meaningful changes for scabies patients. He concluded by highlighting the importance of identifying the roles of concerned institutions such as RRS, Gambella Health Bureaus, NGOs, and other relevant stakeholders in addressing these issues.

Following the opening remarks, Garedew Yilma, Coordinator of the 5S Foundation Ethiopia Project, presented an overview of the aim, vision, and focus of the 5S project. Garedew discussed the major achievements and key research findings from the 5S project research team, highlighting the project's focus on research, capacity building, and public engagement. Garedew also emphasized the project's aspiration to bring about change at three levels (Macro, Meso, and Micro).

3. Presentations

3.1. The context of NTDs program in Gambella Region and efforts underway.

Mr. Adane Mekonnen, an expert from the Gambella Regional Health Bureau's NTDs Elimination & Eradication Team, then presented on the situation and efforts made regarding Neglected Tropical Diseases in the Gambella region. He provided background information on the region's geographical and population size, climate conditions, administrative structures, infrastructures, number of health centers, and profiles of the region. Mr. Adane also discussed the different refugee camps in the region and the population in each camp, as well as the health strategic and programmatic directions. He highlighted the Gambella region health bureau's focus on eliminating five NTDs: Trachoma, Soil-Transmitted Helminthes (STH), Schistosomiasis (SCH), OV, and Lymphatic Filariasis (LF). Finally, Mr. Adane also outlined

the progress made in eliminating these NTDs in the region and noted that mass drug administration (MDA) had been conducted in six out of seven refugee camps.

3.2. The overall context of scabies in Ethiopia, intervention gaps and the need for social science

Mr. Dereje Wonde, 5S Ethiopia PhD student, presented the overall context of scabies in Ethiopia, intervention gaps and the need for social sciences.

Dereje's presentation highlighted the following points:

- He provided an overview of the landscape of scabies in Ethiopia, including the responses undertaken by different actors to contain scabies outbreaks in the country.
- His presentation showcased that the 2015 large scabies outbreaks in the Amhara region was a watershed moment in the recognition of scabies as a public health emergency issue in Ethiopia, leading to national, regional, and local interventions to control scabies.
- The introduction of the Interim Scabies Control strategy in 2015 and the National scabies surveillance and control guideline in 2018 were major developments in scabies control endeavours in Ethiopia.
- The use of mass drug administration (MDA) targeting to treat the entire population when the prevalence of scabies is more than 15%, and intensified disease management (IDM) when the prevalence is less than 15%.
- Scabies is conceptualized as a WASH NTD in Ethiopia and is included in the third National Neglected Tropical Diseases Strategic Plan 2021-2025.
- The interventions and activities conducted in the Amhara region to control scabies incidence, including training of health workers and health extension workers at the village level. However, he noted attitudinal challenges and lack of collaboration with religious institutions in controlling scabies in the region.
- Biomedical-oriented scabies control strategies alone are not enough to bring sustainable control and end outbreaks, emphasizing the need for social science research to inform policy makers with culturally sensitive and context-specific evidence.

Dereje concluded his presentation by reiterating the need for social science-based research in the control of scabies.

3.3. Understanding how precarity and marginalization affect vulnerability to, the experience of, and response to scabies among refugees in the Gambella Region, Ethiopia

Mr. Addisu Tsegaye, 5S Ethiopia PhD student, presented his key research findings.

Addisu's presentation highlighted the following:

- Understanding the ethno-aetiological understanding of scabies in the camp, such as the view of scabies in relation to lack of quality water and personal hygiene, environmental and geographical factors, lack of immunity and nutrition, and God's wrath. He showed how this perception of the cause of scabies could be related to structural issues in the camp.
- The illness experience and how it influences caregiving and women's time to engage in socio-economic activities, such as endeavouring alternative livelihood income activities.
- Dynamics of stigma in the camp and how adults developed a sense of powerlessness to avoid contracting the ubiquitous scabies in the camp, while believing that it should be viewed as normal and not be stigmatized.
- Adults were critical of young people who showed shame and self-stigma for their concern about their looks lacking masculinity amid the test of minor issues when there were more pressing issues to worry about in the camp.
- There was neglect of scabies at household level, community level, and national level, where the patients' caregivers, community members, and national refugee and health policy lacked integration leading to a situation where the refugee health system did not match with the national standard.
- Lack of coordination between the regional health bureau and the RRS on the issue of scabies, where the disease is not reported adequately and left unaddressed in the camp.

3.4. Major Achievements of the 5S Project Public Engagement Activities

Mr. Alemu Tesfaye, the 5S public engagement officer presented the key public engagement activities which have been conducted so far starting from the project inception till now. Alemu stated that the 5S Foundation in Ethiopia has launched a comprehensive public engagement initiative with the goal of creating positive change across different levels of society using the 5S framework at the macro, meso, and micro levels. He outlined some of the key public engagement activities that have been carried out thus far, including the establishment of community of practices in the Amhara region, forming partnerships and co-organizing events

with important stakeholders, conducting capacity building activities, and creating community engagement, production of communication materials such as music, documentaries, short films, brochures, and posters. Additionally, Alemu indicated that the 5S team has engaged in media outreach by appearing on various platforms. Finally, Alemu then discussed the upcoming plans of the 5S Ethiopia public engagement team until the conclusion of the project.

4. Discussion – Questions and Answers

Following the four detailed presentations, Prof. Getnet summarized the key issues addressed in the presentations and reiterated the messages. Some of the key points emphasized by Prof. Getnet from the presentations were:

- There was no discussion on scabies while a presenter from Gambella Health Bureau presented about the progress of the NTDs program in the Gambella region. It is not clear why this happened, and it seems to be a neglect of neglect.
- Dereje's presentation highlighted the implications of scabies on policies and prevalence in the Amhara region.
- Addisu presented the situation of scabies in refugee camps in Gambella, mentioning that lack of coordination among stakeholders is a major problem in fighting scabies in the refugee camps, how scabies is a disease of poverty associated with migration, and how the problem is perpetual.
- Alemu presented the main public engagement activities conducted by the 5S project, emphasizing the importance of engaging the community and communicating the project's research to the community to bring meaningful impact on the issue.

Prof. Getnet then invited the participants to reflect on their opinions, add anything missed from the presentations, and ask questions related to the issues presented. He also provided guiding questions on how stakeholders can connect the findings with reality and implement them into practice.

Mr. Leulseged from RRS:

- Responding to the coordination among concerned stakeholders, RRS and UNHCR are supporting and closely working on refugee camps. Ethiopia is considered as home of refugees, and recently different strategies have been developed and are being implemented to benefit the refugees.

- Currently, due to the global situation, there is a reduction of up to 40% in budget from donors. This will have implications on the work of refugees and affect the health service systems in the refugee camps.
- The health service systems in the refugee camps are not included in the national database system, which is a problem.
- NTDs, particularly scabies, are neglected in the region and in the refugee camps as well. It is generally reported as a skin disease without being specifically named and not regarded as a major health problem in the refugee camps, which is the main challenge.
- The shortage of water supply in the refugee camps aggravates the situation of scabies. Though the shortage of water is relatively better than at the national level, there are still things that must be done to maximize the supply.

Dr. Bethelhem from RRS:

- Skin disease is neglected in the refugee camps because the number of health centers, health facilities, and population size is not proportional. The priority is given to acute health conditions like malaria, with less focus on scabies. In addition to this, human resources and health facilities are not sufficient to treat the problem of scabies as expected.
- There is a guideline prepared by MoH on how to treat scabies disease; however, in the refugee camp setting, practitioners or health professionals may not properly follow the guideline due to lack of medications and treatments. The available resources don't allow health professionals to follow procedures properly.
- The research findings of the 5S project may not be fruitful unless we work beyond the research to implement the findings.

Mr. Missaw from Gambella Health Bureau:

- Up to now, there has been no intervention plan and sufficient data for scabies in the region. However, the MoH has recently given us direction to consider the issue of scabies in the Gambella region. The region's health bureau is now moving to include scabies in its NTDs program implementation and will consider the research findings in its implementations.

A female participant from Nguenyiel refugee camp:

- There is a serious shortage of soap and water in the refugee camp, which exposes us to various diseases, including scabies. Additionally, there is no pharmacy, health center, or medication in the refugee setting, which aggravates the problem of scabies in the refugee camps.

Mr. Luelseged from RRS:

- It would be important to include recommendations in the study that would help improve the situation of refugees related to scabies, clearly stating the specific roles and responsibilities that each stakeholder should take.

Prof. Getnet concluded that the study will have recommendations when it is completed and will be shared with all concerned stakeholders in the region working on refugees. Additionally, a few stakeholders from the Gambella region will be invited to participate in the final national validation and dissemination workshop held in May 2024 in Addis Ababa.

5. Closing and Way forward

Finally, Prof. Getnet thanked all the participants for coming and participating in the validation and dissemination workshop, emphasizing the importance of thinking and discussing how to take the research findings further and implement them to change the lives of people in general and refugees in particular. With this remark, the workshop came to an end.

Annex i: Workshop Agenda

Time	Activity	Facilitator/Presenter
8:15 - 8:30	Registration	5S Team
8:30 - 8:40	Welcoming Remark	Ato Yewlsey Nigussie
8:40 - 9:00	Opening Remark	Prof. Getnet Tadele
9:00 - 9:15	An overview of the 5S Ethiopia project	Ato Garedew Yilma
9:15 - 9:40	The context of NTDs in Gambella Region and efforts underway	Ato Adane Mekonnen
9:40 - 10:05	The overall context of scabies in Ethiopia, intervention gaps and the need for social science	Ato Dereje Wondie
10:05 – 10:20	Coffee Break	
10:20 - 11:00	Understanding how precarity and marginalization affect vulnerability to, the experience of, and response to scabies among refugees in the Gambella Region, Ethiopia	Ato Addisu Tsegaye
11: 00 – 11: 20	Major Achievements of the 5S Project Public Engagement Activities	By Alemu Tesfaye
11:20 - 12:00	Discussion on Presentations	Prof. Getnet Tadele
12:00 - 12:30	General Discussion and Way forward	All
12:30	Closing	Gambella Health Bureau Representative

Annex ii: Workshop Participants

Social Sciences for Severe Stigmatising Skin Diseases (SS Foundation) Project
Research Dissemination and Stakeholders Engagement Workshop
Date: 07 November 2023 Gambella, Ethiopia

S. No/ ተ. ቁ	Name / ስም	Sex/ ፆታ	Organization/ የመጠብቅ ተቋም	Telephone ስልክ	Signature/ ፊርማ
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Social Sciences for Severe Stigmatising Skin Diseases (SS Foundation) Project
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S. No/ ተ. ቁ	Name / ስም	Sex/ ፆታ	Organization/ የመጠብቅ ተቋም	Telephone ስልክ	Signature/ ፊርማ
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