

Abstract for REDRESS Project 2: Exploring wellbeing among persons affected by skin NTDs in Liberia.

Background: Skin-related Neglected Tropical Diseases (skin NTDs) are endemic to many countries with tropical and sub-tropical climates. In low- and middle-income countries (LMIC), these diseases can be neglected due to factors such as a poor healthcare system, limited healthcare availability, and lack of understanding of these conditions. This can result in severe and preventable consequences, including lifelong disability. For many years, skin NTDs have been viewed as a solely physical issue, through a biomedical model of disease. However, there is increasing recognition that skin diseases can impact on all areas of life: physical, social and psychological. Those living in poverty are disproportionately affected.

Purpose: This study explored the wellbeing of persons affected by skin NTDs. The research was performed working closely alongside REDRESS, an implementation research consortium aiming to reduce the burden of severe stigmatising skin disease in Liberia, through an integrated, holistic approach putting people at the centre of disease management.

Methods: Qualitative methods were used, including body-mapping, a creative participatory research method. This was used with persons affected alongside group discussion, to explore participants' wellbeing status and factors influencing their wellbeing. Focus group discussion (FGD) was used with community members, to understand their perspective on skin NTDs and persons affected by these diseases. The data collected through these methods was analysed through thematic analysis in order to understand priority areas for intervention, from the perspective of persons affected and their communities. These data will be used to form part of the REDRESS intervention baseline to enable evaluation.

Data collection was undertaken in Liberia in June 2022, across two counties, Lofa and Margibi. Four body-mapping sessions with 25 persons affected and four FGDs with 24 community members were conducted, including participants with a range of gender, disease, age and socioeconomic background.

Findings: The findings from this research show that persons affected by skin NTDs in Liberia experience a significant psychosocial burden, with low mood, anxiety and suicidal ideation common. High levels of stigma, uncertainty and limited access to care negatively impact wellbeing, whilst finding new purpose, faith and companionship had a positive influence. Community perceptions of skin NTDs revealed issues with inaccurate knowledge and cultural beliefs, which contribute to stigma.

Conclusion: In order to improve psychosocial wellbeing of persons affected by skin NTDs, persons affected and community members highlighted financial and psychological support as priorities for intervention, alongside targeting stigma and access to care. The findings from this research will inform psychosocial support interventions by REDRESS, such as peer support groups. In the future this will improve care for wellbeing of people affected by skin NTDs in Liberia and further afield.

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