

A Qualitative Exploration of the Relationship Between Violence and Neglected Tropical Diseases That Affect the Skin: Implications for Person Centred Care in Liberia



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REDRESS: Reducing the Burden of Severe Stigmatising Skin Diseases through equitable person centred approaches to health systems strengthening in Liberia



Introduction

Neglected Tropical Diseases (NTDs) that affect the skin cause lifelong disfigurement and psychosocial impacts, due to social stigma. People with disabilities, particularly women, face 1.5-fold increased risk of violence, impacting mental health, health-seeking behavior, and self-management. COVID-19 is exacerbating violence and there is a research gap. Liberia is among the 1st countries globally to launch an integrated case management programme for skin NTDs and a recent REDRESS study highlighted violence as an issue. In response, this study sought to *explore experiences of violence in people with skin NTDs in Liberia and identify opportunities to strengthen person-centred care.*



Methodology

Study site: Lofa, Bong, Nimba, Grand Gedeh and Montserrado counties

Data collection:

- Formative research: Literature review and secondary analysis of in-person key informant interviews (KIIs) with people with skin NTDs (PWSNTDs)
- 6 remote KIIs with professionals working in Liberian violence and disability services
- 3 remote vignette activities (VAs) with patient advocates living with skin NTDs
- Secondary analysis of 8 in-person illness narratives (ILNs) with PWSNTDs

Analysis: data were transcribed and analysed using the thematic framework approach and an intersectionality lens applied.

Key Findings

	Key findings	Illustrative quotes
Determinants of violence	<p>Determinants are intersectional:</p> <ul style="list-style-type: none"> • Perceived lack of power and personal capacity • Myths/misconceptions around cause of condition e.g. due to witchcraft • Liberian conflict • Gender, time of day and age - interrelated 	<p><i>"I said what should I confess on [...] I'm not a witch, I never ate anybody child." (ILN, male)</i></p>
Experiences of violence	<ul style="list-style-type: none"> • Emotional violence is most prevalent and SGBV is common • Violence forms overlap • PWSNTDs report physical violence as rare, diverging from KII views • Healthcare workers are among perpetrators • Informal networks are a source of support and violence 	<p><i>"When she got married and they went to her husband parent home, they told him why have you brought us a leprosy woman" (VA, female)</i></p>
Coping mechanisms	<ul style="list-style-type: none"> • Avoidance e.g., migration or seeking healthcare at night • Peer-to-peer support and communities • Friends and family • Religion and hobbies • Taking agency 	<p><i>"I wanted to drink poison, but God kept me." (ILN, female)"</i></p>



Barriers to health seeking behaviour

Impact

Outcome

- High costs
- Physical barriers
- Lack of support
- Mental health
- COVID-19
- Lack of decision-making

- power
- Staff attitudes and violence
- Denial
- Concealment
- Internalised stigma

- Delayed health seeking behaviour
- Engagement with informal sector
- Health seeking inaction

- Worse disease outcomes
- Adherence barriers
- Internalised stigma
- Social stigma

Recommendations

- 1) Education and awareness
- 2) Peer-to-peer support
- 3) Livelihood training

- 4) Community orientated support
- 5) Community mobilisation
- 6) Further research by REDRESS

Conclusion

Violence against PWSNTDs is highly prevalent across all levels, with overlapping forms being common. Impacts of this societal issue are profound and multifaceted, ranging from health impacts to gender inequity. It is vital that programmes take an intersectional, multisectoral approach, utilising informal networks. REDRESS has developed interventions for health workers at facility and community level, and informal providers to support health and wellbeing for people affected. This includes a focus on combating stigma. See the manual here: <https://www.redressliberia.org/resources/>

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