REDRESS

Reducing the burden of
Severe Stigmatising Skin Diseases

Participatory approaches, training and new relationships reduce stigma and violence experienced by persons affected by NTDs and promote participation and inclusion

Summary

- ✓ Participation and inclusion of persons affected by skin NTDs is key to REDRESS which aims to implement a holistic, person-centred integrated skin neglected tropical disease (NTD) programme in Liberia.
- ✓ Formative research found that stigma and violence towards persons affected by skin NTDs is highly prevalent in Liberia. Health workers, friends and family are amongst perpetrators and violence is impeding treatment, participation and inclusion of persons affected.
- ✓ Through implementing numerous anti-stigma activities, communities and health workers have been supported to become key sources of support, the quality of care and referrals has improved, and PAs are successfully completing the treatment pathway, regaining autonomy and rejoining society.

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Background

What is participation and inclusion and why is it so important?

Persons affected by skin NTDs typically belong to marginalised groups and experience poverty and societal exclusion, presenting barriers to accessing essential services (Tsegay., 2018). Moreover, persons affected face lifelong disfigurement and psychosocial impacts due to stigma and violence, with persons with disabilities being 1.5 times more likely to experience violence globally (Dunkle., 2020). Stigma is associated with harmful myths and misconceptions (e.g., skin NTDs being caused by witchcraft), takes numerous forms (anticipated stigma; enacted stigma; courtesy stigma and internalised stigma) and is both a determinant and form of violence (Njelesani., 2018).

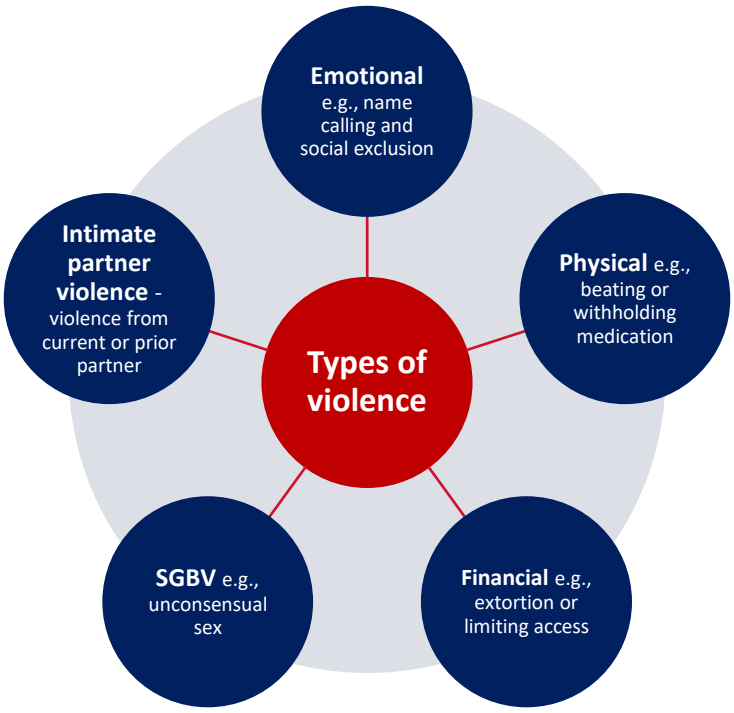

Figure 1. Main forms of violence

Relevant study outcome(s)
Generating evidence on patient and community priorities that meets the needs of vulnerable populations and promotes social inclusion.

REDRESS formative research found high levels of stigma and discriminatory views among health workers and persons affected. Moreover, violence, particularly SGBV and emotional violence (figure 1) is prevalent across all levels, with health workers and friends and family being key perpetrators and women and girls disproportionately impacted. Violence is shaped by power differentials and intersecting social dimensions (e.g. gender, (dis)ability) within numerous societal belief structures (e.g., patriarchal structures and traditional beliefs), which may be shaped by discriminatory and unique circumstances (e.g., ableism and poverty). Aside from negatively affecting mental health, self-management, and livelihoods, experiencing stigma and violence impedes participation and inclusion within society, including seeking healthcare and partaking in community activities. Hence, addressing stigma and violence was crucial.

Baseline health worker survey data showed that 7% to 18.9% of community health workers (CHWs) believe NTDs are caused by witchcraft across counties. Beliefs about stigma - people with skin NTD should be isolated at home was also common 19.6%, and people with skin NTDs are not helpful to their families/communities (24.6%).

What was the impact?

Overall, the intervention strengthened participation and inclusion of persons affected by skin NTDs at multiple levels. The key impacts amongst communities, health workers and persons affected themselves is discussed below:

1. A marked decline in stigma among health workers has improved referrals and shifted the nature of their relationship with PAs, improving quality of care

Through learning that skin NTDs are not caused by witchcraft or curses, are treatable and not something to be feared and recognising the impact of stigma on mental health, there has been a statistically significant reduction in stigma among health workers (stigma scale reduced from 6.30 to 5.50, p=0.0004). At endline, just 6.8% of CHWs believe NTDs are caused by witchcraft. Moreover, health workers have learnt to counsel persons affected, communicate in a non-stigmatising manner, and maintain privacy and confidentiality. This, combined with the strengthened relationship between formal and informal health workers is strengthening referrals.

Mental health referral pathway review workshop with health workers in Monrovia, March 2022

Read: Case Studies on Traditional and Faith Healers and Case Detection

Finally, there has been a shift in the nature of the relationship between health workers and PAs, with the prioritisation of long-term follow-ups and relationship building (e.g., through informal conversations and eating together) being commonplace and some health workers going the extra mile through providing PAs with food or money out of pocket. Overall, these changes are improving the quality of care, the nature of relationships and driving participation and inclusion.

"I have learned people with NTD are also human like us, you cannot discriminate them from us the only thing they need consoling so that is what learn."

Grand Gedeh health worker reflective diary

2. Through community sensitisation, peer support groups and community advisory boards, communities and families have been transformed to sources of support

Community sensitisation activities and peer support groups are reducing stigma and driving acceptance of PAs. Moreover, Community Advisory Boards (CABs) are dispelling harmful myths and uniting PAs with communities; this has shifted attitudes and behaviours towards PAs, with some CAB members building friendships and supporting their referrals. Consequently, CAB members have newfound motivation to challenge harmful myths and discriminatory views among other community members through engagement activities, further reducing stigma. Additionally, some CAB members are delivering vocational training to persons affected and supporting income generation activities e.g., through providing seeds for vegetable gardens. Consequently, persons affected are reconciling with families and community members, and some are adopting supportive roles e.g., through accompanying persons affected to appointments.

Community Advisory Board members delivering community awareness activities in a market

"I can say yes [there has been change] because the fact that in the community somebody was there hiding, they don't want to expose their selves, but because of my voice or this work I been doing with the REDRESS, the community advisory board, going to talk with people and …My voice has been able to change people to bring improvement in the community because somebody that was having those diseases that hiding they coming out now."

Lofa CAB FGD baseline

2. Persons affected by skin NTDs are experiencing holistic, person-centred care in a more inclusive environment, enabling them to participate in society and decision-making

Treated with empathy and care
Health workers actively seek cases and treat them with care and empathy – all persons affected reported no longer facing stigma from health workers.

Counselled to seek treatment
Persons affected are counselled to recognise that their illness is not self-inflicted, incurable, nor highly transmissible – this instils hope and self-acceptance, motivating them to seek healthcare and reducing internalised stigma.

Access treatment, improving condition
Through accessing holistic healthcare, which maintains privacy and confidentiality and considers the physical and psychosocial impact, gradual improvements in mental and physical condition, including reduced wound odour and leakage, is achieved.

Peer support groups build self-esteem and outlook
Peer support groups enable sharing of success stories and socialising and livelihood activities, further improving mental wellbeing (e.g., reduced anxiety and loneliness), building self-esteem and strengthening persons affected positive outlook.

Participatory activities and CABs strengthen self-perception
Involvement in participatory activities and CABs also strengthens capacity for advocacy and enables persons affected to influence policy and programmes, empowering persons affected and positively impacting self-perception.

Rejoin society and contribute to communities
These changes, combined with reduced community stigma, means persons affected are actively participating in society once again; playing among friends, participating in decision-making, contributing to community development and community events. Some are returning to work/education and taking on patient advocate roles following successful treatment.

Drives stigma reduction and acceptance
Aside from positively impacting PAs and treatment adherence, this shift in participation, including livelihood contribution, further drives stigma reduction and inclusion.

Figure 2. Patient journey following REDRESS intervention

"She used to be too shame because her foot used to leak with pus. She used to be embarrassed even in school, whole day. Even when she put skirt on her, the uniform, before she go home, the uniform, the pus will be coming out, will be having leakage, but […] when I met her to the hospital and I brought her here. She say, great changes had taken place. now she is feeling comfortable to be in the midst of her friends."

Grand Gedeh reflective diary

How did REDRESS address inclusion and participation?

Training session for traditional and faith healers in Margibi county, Liberia

The intervention included numerous components related to inclusion and participation, including anti-stigma activities – all tools are available in the REDRESS intervention manual:

- **Established CABs:** composed of persons affected, health providers and community leaders. Raised awareness through community engagement (e.g., radio interviews) to challenge myths.
- **Embedded a participatory research approach throughout:** using participatory research methods and co-researchers to meaningfully engage affected.

  Read: Empowerment Case Study

- **Integrated mental health and stigma reduction within the NTD care pathway:** introduced mental health screening tools and delivered Mental Health Gap Action Programme (mhGAP) training to mid-level workers, including a component on violence and mental health.

  Read: Mental Health Case Study

- **Trained formal and informal health workers:** including components on psychological support and stigma reduction, including dispelling harmful myths among health workers.

  Read: Health Workforce Management Case Study

- **Provided job aids for health workers:** including aids for referring people in mental distress; Basic Package of Psychosocial Support for People Affected by NTDs (BPS-N); guidance for communicating in a sensitive, non-stigmatising manner; Patient Treatment Cards including messages on addressing stigma; aids for informal workers challenging stigma and supporting participation of persons affected.

  Read: Health Workforce Management Case Study

- **Trained persons affected:** including myth busting; NTD cause, signs, and symptoms; look listen link basic psychological support and setting up PSGs.
- **Initiated awareness activities:** formal and informal health workers delivered various activities, including household visits where they actively encouraged participation in communities and health systems, counselling patients to seek treatment, through addressing misconceptions and sensitisation events in communities, via radio discussions and health facilities.
- **Established 6 PSGs:** provided mutual experience sharing and support, as well as helping to identify and refer other persons affected to join the group.

  Read: Peer Support Group Case Study

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