REDRESS

Reducing the burden of
Severe Stigmatising Skin Diseases

Involving a diverse range of community actors strengthens case detection for skin NTDs

Summary / Synopsis

REDRESS sought to increase case detection and care-seeking of persons affected by skin neglected tropical diseases (NTDs) through a range of community structures as part of strengthening person-centred care for people with skin NTDs. Comparing 12 months before REDRESS and the intervention itself (12 months), we significantly increased case detection across all diseases (Buruli ulcer, leprosy, yaws, lymphedema, hydrocele and onchocerciasis). Community engagement and case detection led by the community advisory board, peer advocates, informal providers, community health assistants and promoters prompted improved knowledge about skin NTD causes, signs and symptoms, leading to changed beliefs around the cause of NTDs (biomedical rather than supernatural) and prompting earlier health seeking within the formal health system. Early case detection successes which involved a diverse range of community actors within Liberia have the potential to strengthen case detection at scale within Liberia as outlined in the MoH Liberia NTD Masterplan 2023-2027. There are also global implications for these successes.

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Background

Why is early case detection important and who needs to be involved?

Early case detection is known to improve outcomes for people affected by NTDs and to enhance NTD control. Early case detection is shaped by existing inequities, for example, those who live far from health facilities, the poor, women and girls are most likely to be diagnosed and to start treatment later, by which time they may already have a chronic condition and/or disability. In keeping with this priority, one of REDRESS' objectives is to "Identify effective strategies to detect, refer, treat and support people living with skin NTDs that are acceptable, affordable and sustainable especially amongst the most vulnerable."

Key barriers and enablers to care-seeking are documented within our scoping review; identifying that community actors, both formal (e.g. community health workers) and informal (traditional/faith healers), play significant roles in identifying and managing people affected by skin conditions (including NTDs) and in providing social support to people who are ill (McCollum et al. 2022).

Read: Beyond the Biomedical Case Study

Prior to the REDRESS intervention in Liberia, we identified that:

- the surveillance structure was focused on community health assistants (CHAs) and community health promoters (CHPs) who carried out active case detection and referral of patients. This was undermined by a lack of needed supplies to do their job (e.g. no rain gear, no fuel for supervision, a lack of ledgers for record keeping).

Within the community, there was:

- a lack of awareness about skin NTDs, with many community members believing them to be due to supernatural causes, which limited recognition of the need to seek formal health care among persons affected.
- barriers to seeking care include fear of experiencing stigma if confirmed to have skin NTD
- long distances to reach the health facility
- the perception that there will be drug stock outs coupled with high costs of buying drugs
- belief that persons affected will be unable to get a cure from the facility and
- fear that a health worker would turn a person away if they show signs of having received country medicine (e.g. chalk) and so people were reluctant to seek care.

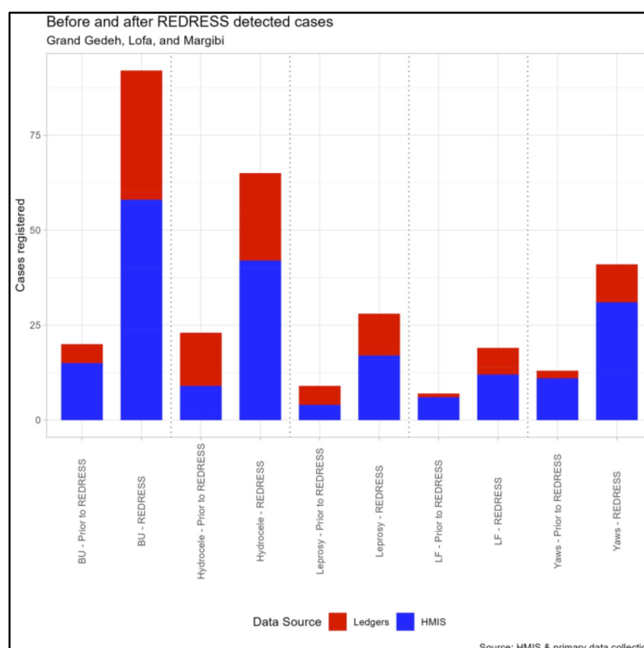
31.7% of persons affected had visited an informal provider

Photo 1. Community awareness raising

What was the impact of REDRESS interventions?

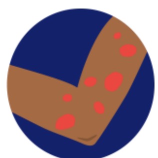
Increased case detection across all three counties was one of the greatest successes of the intervention.

Comparing 12 months before REDRESS (October 2021 –September 2022) and the intervention itself (12 months) (October 2022 – September 2023), we found a statistically significant increase in case detection across all diseases.



171% rise

Before the intervention, in a year, there were 7 lymphedema cases. During the intervention, this increased to 19 cases, reflecting a 171% rise



215% increase

Before the intervention, in a year, there were 13 yaws cases. This number rose to 41 during the intervention, indicating a 215% increase

360% rise

Before the intervention, in a year, there were 20 new Buruli ulcer cases detected. During the intervention, this increased to 92 cases, indicating a 360% rise

183% increase

The number of hydrocele cases in a year before the intervention was 23, increasing to 65 during the intervention, resulting in a 183% increase

325% increase

The number of new leprosy cases increased from 9 in a year before the intervention to 28 during the intervention, representing a 211% increase

4 cases

There are also 4 detected cases of onchocerciasis
(no comparison data in HMIS)

Earlier case detection was linked to greater community engagement, with the training received across participant groups, supporting the changing belief around the cause of NTDs (biomedical rather than supernatural) changing care seeking pathways as a result.

Working in partnership with a range of actors is critical to enhancing case detection

> ***"I share my knowledge with traditional healers, with the training received we were able to teach them how to refer patients from the community to the health facility."***
>
> CHSS and co-researcher

- A wide range of actors within both the community and health system played a role in enabling early case detection. For example, informal providers, such as traditional and faith healers, are key, due to the persisting supernatural health beliefs relating to the causation of these conditions.
- Appropriately trained and supported community health workers (CHWs): 1) improved knowledge and understanding about skin NTDs within their community by sharing information about skin NTD signs and symptoms, challenging myths and stigma and; 2) Conducted active case finding of persons affected by skin NTDs through home visits/during mass drug administration campaigns to strengthen case identification and links for referral, reduced delays in reaching care-seeking decisions, increased patient enrolment and reduced permanent impairment at diagnosis.
- Surveillance actors (such as district surveillance officers in Liberia), carried out active case finding and surveillance to ensure no one is left behind.
- Patient advocates played a critical role in building trust and strengthening pathways between persons affected and formal health actors.
- To carry out effective case detection, all health workers needed knowledge & good communication skills to ensure patients understand their condition and future treatment.

Read: Beyond The Biomedical & Centring Lived Experience Case Studies

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Sensitisation and awareness activities within communities are critical to improved detection rates

- CHAs and CHPs followed a series of steps when carrying out awareness and when trying to increase case detection. These steps included: making formal introductions and building friendships with community members; using posters to give key awareness about NTDs and referral pathways and showing compassion and patience. They also emphasised that being a member of the community is also crucial.
- Alongside identifying possible persons affected, CHAs/CHPs also sought to strengthen referral by raising awareness that NTDs can be treated at the health facility, and that drugs and supplies are now available at the facility and are free and effective.
- CHAs and CHPs emphasised the need to address and dispel any myths that might be held about NTDs.
- When carrying out case detection CHAs and CHPs use this opportunity to raise awareness of how to prevent NTDs, including avoiding swamp work, wearing boots, and using mosquito nets.

Photo 2. Traditional healer managing a person's wound

Trust shapes a patient's care seeking pathway

- Trust was the most commonly described enabler to seeking care with CHAs in particular describing building friendships with persons affected, which also helped that person to accept their condition and seek care.
- Trust in the health system (and health worker) must be protected, with health workers trained in confidentiality and good diagnostic communication skills to better communicate with patients, alongside support on how to provide holistic care, given the mental health needs of people with skin NTDs (Dean et al. 2019).
- People with symptoms of skin NTDs in the community often feel able to share their symptoms with a person with lived experience of an NTD, rather than other health workers (see peer to peer video). Awareness raising about skin NTDs by peer support groups and their members was felt to have increased community acceptance of persons affected.

> ***"We work together. Sometimes they call me, and I go and share my story with the person and definitely they feel motivated, and they go to the facility."***
>
> Emmanuel Zaizay Co-researcher and person affected, Lofa County

- Faith and traditional healers expressed changed perceptions about the cause of NTDs, with many describing new understanding of the need to seek medical advice before starting their healing practices. These cadres are critical due to the trust placed in them by people affected.

Read: Beyond the Biomedical Case Study

> ***"…cases are flagging up, it is because of the community involvement, most especially the traditional healers. Because they agreed for us to expose those cases and they agreed for us to work together."***
>
> County level respondent KII, Lofa County

Involving persons affected by NTDs makes a BIG difference to case detection and NTD programming

Persons affected can play a vital role within case detection, by nature of the trust placed in them by people with possible NTDs due to their own experience and recovery. Peer support groups were felt to have increased community acceptance of persons affected.

Read: Five Key Learnings

Read: Centring Lived Experience

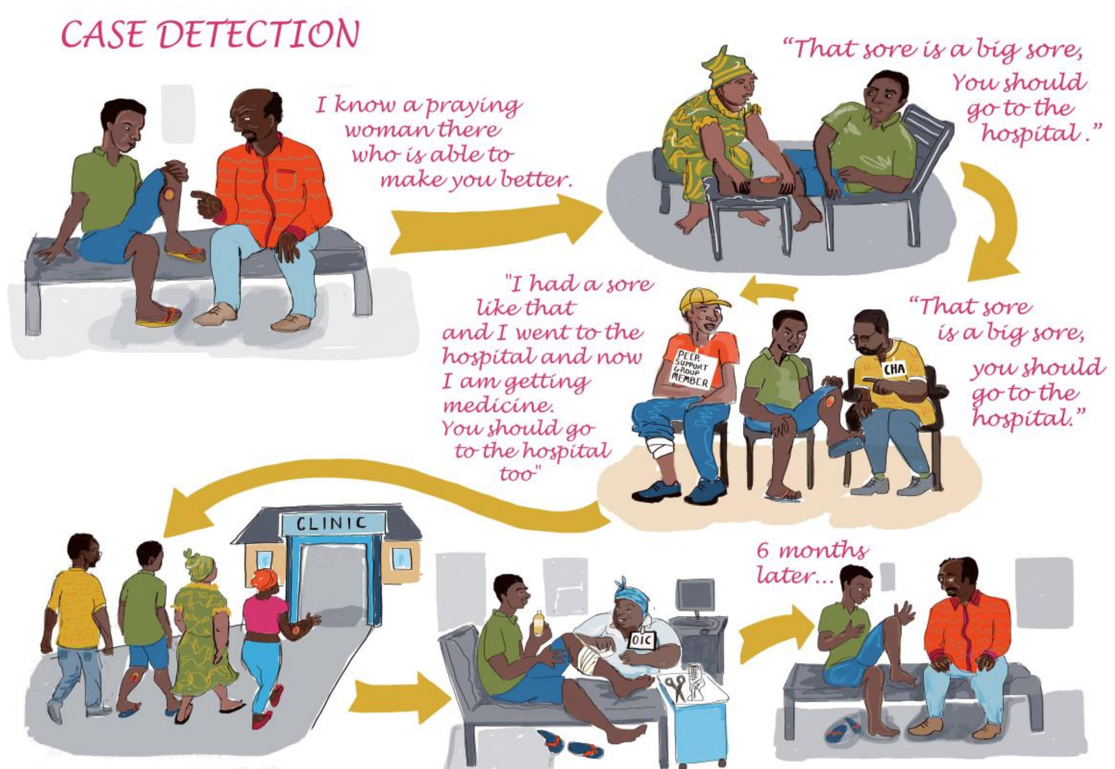
Photo 3: Peer support group, Lofa County

How did REDRESS address case detection?

REDRESS sought to increase avenues for community engagement and early case detection through training of informal providers, persons affected, community health assistants (CHAs) and community health promoters (CHPs), establishment of peer support groups, mobilisation of community advisory board and awareness campaigns by the county health team. These activities took place across all our intervention counties (see executive summary).

- **Training of informal providers**, including faith and traditional healers (n=294 faith healers and 294 traditional healers) (to address myths, understand the cause of NTDs, how to identify and refer NTD cases, basic psychological support and stigma reduction). Dialogues were facilitated between health facilities and traditional and faith healers to support collaborative action, with supervision from county and national supervisors (see Integrated case management manual).
- **Informal providers (faith and traditional healers) received job aids** to use in their community.
- **Training of persons affected** to address myths, understand the cause of NTDs, the signs and symptoms, look listen link basic psychological support and how to set up a peer support group.
- **Peer support groups (6) were established** following the training of persons affected and group members helped to identify and refer other persons affected to join the group.
- **Training of health workers including CHAs and CHPs**, who are supported in community awareness and case detection by their supervising CHSS.
- **Community advisory board (CAB) members were mobilised** to carry out community awareness activities, including raising awareness in marketplaces and helping to raise awareness through radio discussion panel.
- **Awareness campaigns by county health teams:** County health teams (CHT) in each county were provided with the opportunity to determine their own priority activities, with some CHTs choosing to carry out awareness activities such as radio campaigns, and/ or community awareness outreach.

Alongside strengthening case detection, there must also be emphasis on supporting drug and supply chain and laboratory strengthening. If universal access for NTD care is to be achieved there needs to be holistic collaboration and multi-sectoral approaches for the management of people affected by skin NTDs, as outlined in the WHO NTD 2021-2030 roadmap (WHO 2020).



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