

**Leadership within communities: Community leaders as co-researchers to guide holistic care for people affected by severe stigmatising skin diseases 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 (RIGHT Call Round 2)

**DETAILS OF PROJECT**

REDRESS uses participatory action research approaches to evaluate, develop and adapt health systems interventions for the equitable management of severe stigmatising skin diseases (SSSDs) in Liberia.

- People affected by SSSDs frequently experience stigma, isolation and discrimination within their community.
- Spiritual beliefs are often influential factors determining where care is sought.
- Community leaders (traditional healers, faith healers, Community health workers (CHWs)) all play strong leadership roles at the community level and enjoy trusting relationships with community members.
- This trust enables them in their roles, for example CHWs can enter people's homes as part of active case finding for SSSDs.

We work with community leaders as co-researchers in order to deepen understanding of these roles and to jointly identify actions to more effectively and equitably combat stigma and support holistic care for SSSDs.



One on one discussion with photovoice co-researcher in Lofa County



Group discussion & analysis with photovoice co-researchers in Lofa County

*"They [people affected by skin disease] are not living a good life, they are not healthy in body, ... people mocked at them, others are going to school without good care, but still we talk to them and we took their photos. (through photovoice methodology) .. So, I feel so happy about the REDRESS family. It gives us experience again pertaining to the CHVs...that we can go on the field and talk to other people and they understand us."* CHV co-researcher

**Co-Researcher Reflections**

*"It was something that cut my heart (evoked compassion) ...When you come for healing, the other person with the big foot (lymphoedema)..some of those that [are] suffering when you take their [photo] and some people see them maybe some of them will like to help."* Traditional Healer co-researcher

**APPROACH TO THEMATIC RESEARCH CAPACITY DEVELOPMENT**

Participatory methods, involving community leaders and co-researchers were carried out in two counties in Liberia – Lofa County and Grand Gedeh County. This included: piloting and conducting participatory research methods and co-analysis.

Photovoice research was carried out with four groups of community leaders co-researchers in each county (eight groups involving 30 participants (10 women, 20 men) across both counties).

Co-researchers were trained about photovoice and took photos over a period of three weeks, with three one-to-one researcher discussions during this period. A final group discussion was held for each group to discuss & co-analyse emerging findings from their photos and identify actions together.

**FINDINGS**

There were more men than women in community leadership roles, particularly for traditional healers (1 women, 6 men) and CHAs (2 women, 6 men). All respondent groups described leadership responsibilities within their community, including conflict resolution, health advice, care & treatment for people affected by SSSDs.

Trust was apparent between community leaders & community members. Duality of belief in biomedical and spiritual causes of ill health was common, along with the need to distinguish the cause of illness and to refer/treat accordingly. Across groups a willingness to refer patients was described. Some beliefs about illness causation and management practices, may increase stigma, e.g. enforcing isolation of patients with SSSDs as part of treatment.

All groups of participants described empathy towards people affected & a desire to provide holistic care, including spiritual support (prayer), social support (food & finances) & psychosocial support (talking with & 'counselling' people affected).

Clear gender roles for men & women emerged in findings about community activities & health actions these roles and relations were seen to shape stigma. For example, the spouse of some people affected having left due to their condition, or women were unable to marry in consequence of their condition. Impact of this was commented upon as most challenging for women when they needed to fulfil traditionally 'male' roles.

**THEMATIC RESEARCH CAPACITY STRENGTHENING GOOD PRACTICE**

Participants across research groups reflected on their experiences as co-researchers, commonly noting that they now have a deeper awareness of the challenges faced by people affected by SSSDs, particularly the social impact occurring as a result of stigma and discrimination.

Co-researchers described how their photography skills developed through their participation.

CHAs and CHVs highlighted that photovoice had allowed them to step back and observe the changes that they have brought to their community. Many found this encouraging and a recognition for the hard work which they do. Traditional healers expressed hope that the photos they have taken could be used to raise awareness and garner support for people affected by SSSDs. Across groups there were multiple calls for action to better support people affected by SSSDs, including resources to support referral and social support, training to identify people with SSSDs & pictorial guides to promote community awareness.

**REFLECTIONS & LEARNING**

Managing co-researcher expectations is a key aspect of photovoice research. Emphasising the critical nature of consent during training and discussions throughout the research process is vital, as people affected by SSSDs are often reluctant to be photographed and it is important to avoid coercion by co-researchers. Participatory methods can bring out negative as well as positive practices. Reflecting on these together to avoid further stigmatising people affected is important for participatory method best practices.

**CO-RESEARCHER REFLECTIONS**

We invite you to watch the video at the link below to hear reflections from our co-researchers (Satta Kollie and Anthony Korvailay) about their experiences participating with REDRESS so far.

