



REDRESS

Reducing the burden of
Severe Stigmatising Skin Diseases



Executive Summary: Findings from County, Facility and Community Key Informant Interviews

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Introduction

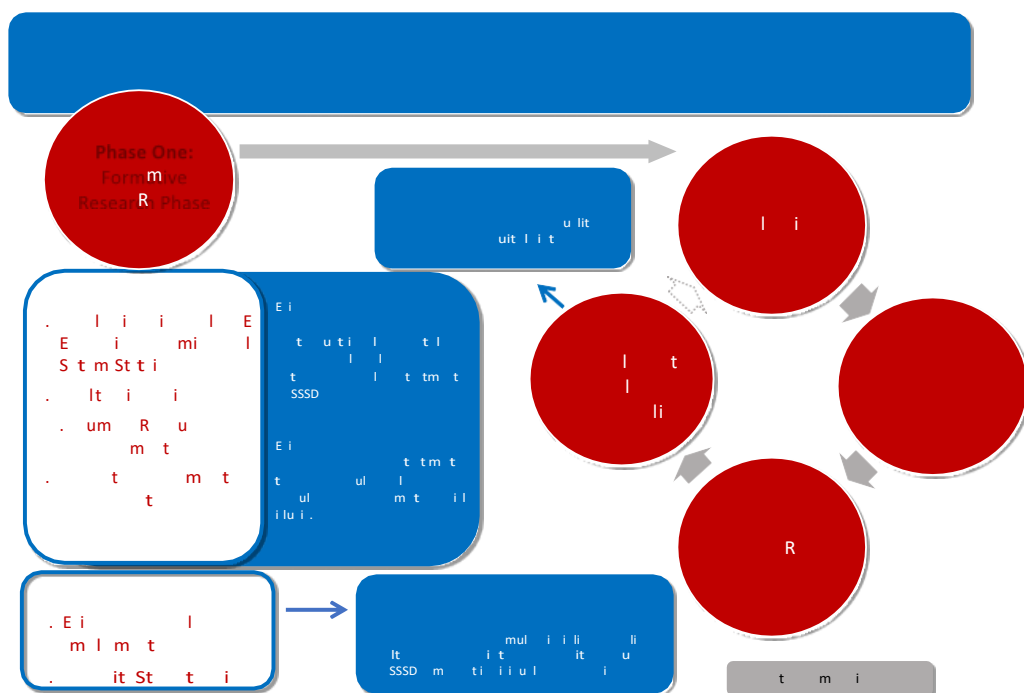
Liberia became one of the first countries in the world to develop, adopt and begin implementation of a national integrated approach to managing severe stigmatising skin diseases (SSSDs) or Neglected Tropical Diseases (NTDs) (Buruli Ulcer, lymphoedema, hydrocele, and yaws). The approach seeks to address issues of equity and effectiveness previously neglected through fragmented approaches, whilst contributing to health systems strengthening.

REDRESS uses a participatory action research framing to put persons affected by SSSDs at the centre (see Figure 1). REDRESS' multi-disciplinary team has applied a systems approach to the evaluation of existing integrated approaches to the management of SSSDs through an expanded situational analysis or formative research phase (Phase One). The formative research phase has involved:

- Key informant interviews with participants from national level
- Key informant interviews with participants from community to county level
- Focus group discussions with health workers
- Photovoice research with community providers (traditional healers, faith healers, community health assistants and community health volunteers)
- Vignette based research exploring treatment practices with informal health providers (traditional healers, faith healers, black baggers)
- Rivers method with patient advocates who are affected by a condition typically associated with stigma, e.g. people affected by disability, mental illness, Ebola Virus Disease.
- Life histories with patient advocates.

Evidence generated from a systems perspective in phase one will shape the co-creation of new and existing SSSD interventions (phase two) for implementation, observation, and reflection within existing health systems structures (phases three to five).

Figure 1- Action Research Cycle



This report summarises the findings from one component of this formative research, collected through key informant interviews with participants from community to county level. Data from other study components are summarised elsewhere. We consider how social and structural factors shape care-seeking, as well as detection, referral and treatment (both curative and chronic) pathways for SSSDs. Where bottlenecks were identified, they were investigated further to identify how these should be addressed to reduce barriers to access and delays in care seeking for SSSDs.

Methods

This study used qualitative methods to evaluate existing integrated approaches for the early detection, referral and treatment of SSSDs from the perspective of REDRESS core themes (Clinical effectiveness, epidemiology and laboratory systems strengthening; health financing; human resource management; patient engagement and person-centred approaches). Peer researchers, including people affected by SSSDs and people working as part of community health service delivery (for example community health volunteers) formed part of the core team involved with data collection and analysis. Peer-research approach and critical to the identification of solutions to develop more person-centred services.

Key informant interviews were carried out with 86 participants from three counties (Grand Gedeh (41), Lofa (42) and Nimba (3) Counties. Across the sample 63 participants were male and 23 were female. Despite the endorsement of the national strategic plan for the integrated case management of NTDs in 2016, implementation of the strategic plan has only been funded and supported by non-governmental development organisations in five counties, presenting an implementation gap in the other 10 counties. Integrated case management was introduced in Lofa and Nimba Counties in 2016. It has not yet been introduced within Grand Gedeh County. Lofa and Grand Gedeh were purposively selected to enable a comparison of the management of SSSDs across supported and unsupported counties to learn lessons for the quality improvement and scale up of existing approaches. Nimba county was included as this is the only county in Liberia with integrated management of SSSDs, and informants with specific tacit knowledge of existing management approaches targeted. Across Lofa and Grand Gedeh county, respondents were purposively selected according to their role and experience caring/ supporting people affected by SSSDs from across community and health systems levels.

Topic guides explored with participants their current practices and experiences with providing care, in line with the respondent's knowledge and experience. Interviews were audio-recorded following participant informed consent, with a selection of transcripts quality checked. Following familiarisation with the data, a workshop was held to inductively develop a coding framework. This was then discussed and checked with peer-researchers. NVIVO 11 was used to support data analysis, following which charts were developed and data analysis carried out through the writing of summaries, to compare and contrast findings according to participant groups. All analysis processes were undertaken in collaboration with REDRESS' multi-disciplinary team and interpretations were discussed and cross-checked.

Results

During project inception, in collaboration with national and community stakeholders and based on emerging evidence, three hypothesised intervention pathways were co-developed for consideration and adaptation during REDRESS phase two. To understand their ongoing applicability and feasibility,

key informant interview data has been analysed and summarised thematically in relation to each of these intervention pathways. Each intervention pathway can be found in annex one. All intervention pathways and findings presented here are linked and addressing challenges in a holistic and coordinated manner. It is REDRESS' overarching health systems approach.

Thematic Pathway 1: Promoting early case detection, referral and diagnosis

This pathway is focused on factors influencing patient progression from experiencing symptoms of SSSDs through to receiving appropriate treatment and care. This is shaped by both demand side barriers (based on community understandings of disease) and supply side barriers (based on services currently provided by the health system). The results from key informant interviews presented in this section focus initially on demand side related barriers (awareness, structural barriers, and adherence) before moving on to consider supply side related barriers (surveillance and active case, diagnosis and management and supply chain).

Demand Side Factors

Demand side barriers to formal health seeking were identified as being attributed to awareness and health belief systems (see also thematic pathway three), geographic access to facilities, fear of stigma and discrimination (see also thematic pathway three), and costs related to health seeking.

Awareness

Health belief systems and lack of awareness of SSSDs within communities results in limited recognition amongst affected persons of the need to access formal health services. Consequently, many people use informal service providers and herbs (see thematic pathway 3). Informants highlighted three main avenues to promote greater awareness of SSSDs amongst communities, namely: Increase existing knowledge through radio campaigns; train existing trusted community members, such as community leaders, community health assistants (CHAs) and community health volunteers (CHVs) to increase awareness and promote care seeking as needed; and develop the role of patient advocates.

Structural Barriers

Fear of experiencing stigma and discrimination if confirmed to have a SSSD; financial constraints to affording transportation/ costs of drugs and dressings prescribed; long distances to walk between home and health facility; and drug stock-outs at the health facility were all highlighted as structural barriers to health seeking for people affected by SSSDs. These barriers impacted initial health seeking as well as referral of patients through the system and the ability to attend facilities for follow up care. For example, due to lack of maintenance of ambulances, patients usually travel to referral hospital by their own means, often by hammock or chartered vehicle/ motorbike or walking (can be two to four hours walk). This is in contrast to the ideal situation, where the referral hospital sends an ambulance to collect the patient. Thus, ability to take up the recommended referral depends on the patient having a relative or caretaker to accompany them to the hospital and being able to afford the transportation costs.

Adherence

Where people had accessed services and been diagnosed with SSSDs, they were described by informants as defaulting from completing their treatment, due to several reasons: 1) Long duration of treatment required; 2) Irregular supply chain and stock-out of essential treatments, rendering medicines and resources inaccessible; 3) Costs associated with treatment. Participants suggested

adherence could be improved through better support, advice and guidance from health providers including: community wound management by CHAs/CHVs; health worker(s) to provide clear advice about the condition (including causation) at diagnosis; advice about how and when to take medications and perform self-care/ other treatments; and possible drug side effects and treatment timelines.

Supply Side Factors

Supply side barriers to health seeking were also identified, frequently as a result of ongoing health system weaknesses. Specific barriers were described in relation to: surveillance and active case finding; clinical knowledge gaps and poor laboratory infrastructure hindering case identification; and weaknesses in the supply chain leading to drug stockouts causing significant treatment delays.

Surveillance and Active Case Finding

The SSSD surveillance structure in each county is based on CHAs and CHVs who carry out active case detection during house-to-house visits, to search for possible cases within their communities. If a suspected patient is identified, the person is referred to the facility. The CHA may contact the CHSS or the OIC whenever they identify a suspected case. The officer in charge (OIC) is responsible to inform the district surveillance officer who informs the NTD county focal point. Hydrocele, Buruli ulcer (BU) and leprosy are the most commonly reported conditions.

Challenges with surveillance include the lack of needed supplies for those involved, including: no transportation (bike/ fuel), no rain gear or phone. SSSDs are not included in the weekly bulletin (which is a report provided at county level each week), and as a result they are not prioritised for follow up in the same way conditions in the bulletin are. Monitoring and evaluation (M&E) weaknesses may undermine surveillance efforts due to lack of ledgers for record keeping, inadequately trained staff who may make an incorrect diagnosis, and not all SSSDs are captured within health management information system (HMIS) (yaws, BU and leprosy only).

Surveillance recommendations included: Providing adequate communication cards and needed supplies and ledgers for surveillance staff and health facilities. Create missing case definitions, add SSSDs to weekly bulletin, SSSD trainings to include M&E staff.

Diagnosis and Management

Table 1 provides an overview of the current best practices for the diagnosis and management of SSSDs of focus. These practices were implemented to varying degrees based on the descriptions provided by participants and many barriers to their implementation exist across counties based on ongoing health system weaknesses. Key gaps in knowledge of diagnosis and treatment practices were specifically identified in relation to onchocerciasis and yaws.

Table 1 Overview of diagnosis and management practices for SSSDs

Condition	Diagnosis	Diagnostic Test Process and Level of Completion	Management
Buruli Ulcer	Some facilities have an evaluation form that is used to screen patients suspected to have Buruli Ulcer.	PCR test to be completed by LIBR (national lab). (NB: this was previously available in selected districts, but reagents	For diagnosed BU patients, the treatment comes from central Ministry of Health (MOH) and is supplied at the facility level. The health facility complete treatment via direct observation therapy for 56 days.

Condition	Diagnosis	Diagnostic Test Process and Level of Completion	Management
	Following examination, specimens are collected by NTD focal person (NTD FP) and transported by Riders for Health to the reference laboratory for PCR testing.	are no longer available to support this)	<p>If patient already has an ulcerated wound, the patient is commenced on treatment (Rifampicin and clarithromycin) while awaiting lab confirmation.</p> <p>When there is no medication available, health workers carry out twice daily dressings for the patient while awaiting lab results.</p> <p>Health workers do prevention of disability (POD), by teaching the patient to move and flex the affected limb(s) to prevent disability.</p>
Hydrocele	Patients are examined physically by clinicians at primary health centres, to reach a clinical diagnosis and then referred to a treatment facility that provides surgical services.	Clinical diagnosis hypothesised by health facility and confirmed by NTD Focal Point at county level.	For hydrocele, the only management described is surgery.
Lymphoedema	Patients are examined physically by clinicians at primary health centres, to reach a clinical diagnosis	Clinical diagnosis hypothesised by health facility and confirmed by NTD Focal Point at county level.	In the case of confirmed lymphedema, patients are provided with a bucket, soap, towel, anti-fungal cream, and are taught how to take care of their legs, what footwear to use, how to wash their foot and apply cream. How to elevate the affected limb.
Leprosy	Patients with leprosy are diagnosed following physical examination based on the number of patches identified during screening and as a result of sensitivity tests.	Clinical diagnosis hypothesised by health facility and confirmed by NTD Focal Point at county level.	Once confirmed, patients are started on treatment for 6 to 12months, or referred to a facility that provides treatment services, with follow up to ensure treatment adherence. If the patient has a wound, the patient is advised to attend daily for dressing changes, or dressing materials are provided and CHAs/ CHVs are taught how to do the dressing.
Yaws	Patients are examined and a blood sample is collected and sent to the reference laboratory for testing.	Rapid diagnostic test (RDT) yaws at county level LIBR	Limited discussion about how to manage yaws from any respondent, perhaps indicating a key gap in knowledge and care.
Onchocerciasis	Not described	Not described	Mass drug administration is distributed for everyone in the community to prevent it. No discussion about management.

Confirming Cases and Laboratory Systems

Across all diseases, and in both counties, it was described that there are knowledge gaps in case identification and management at district and facility level. The majority of the knowledge and skills

for case identification and management was described as sitting with the County NTD focal person. Consequently, participants described a delay in the patient pathway, as one person often held all the needed knowledge and skills to confirm a diagnosis within the county.

In relation to Buruli ulcer and yaws, providers frequently identified a lack of access to laboratory testing and delays in hearing back from national facilities as a key barrier to diagnosis, rendering them reliant on their clinical judgement. The NTD focal person was described as responsible for specimen collection and starting treatment as appropriate based on laboratory confirmations. Typically results are shared with either the county health officer (CHO), NTD focal person or the surveillance officer, who then shares this information with the requesting clinician, who will then inform the patient of their diagnosis. However, stock outs of needed consumables, such as reagents undermined laboratory services across every health systems level. When available, communication of laboratory results varied.

Supply Chain

Medicines and other goods are provided by the Central Medical Store (CMS) to the county health team, who are then responsible to deliver these to the facilities. There was, however, a lack of clear responsibility for supply chain functions, resulting in blame shifting when stock-outs occur. The process was described as follows:

- County pharmacy prepare requisition forms for medicines and supplies within county, receive and consolidate reports from facilities.
- Requisition forms are forwarded to CMS or SCMU for resupply, where historical quantification takes place to determine amount needed.
- Distribution then occurs on quarterly basis from CMS to county, and from county to facility, based on request, with monitoring of consumption.

For SSSDs, facility level respondents request drugs only if they have a patient, at which point they fill HMIS (and drug request form) and inform the district surveillance officer (DSO)/ NTD Focal person. Drugs are then transferred from the county to the facility. If the NTD focal person is not within the county at the time the diagnosis is made and the requisition forms are completed, then this can create delays with being able to start treatment. Previously some drugs for SSSDs were included as part of the essential drug list, with leprosy included within TB control. However, the template was revised and there are no longer any drugs for treating SSSDs included in the essential drug list. Temperature control for drugs is a challenge across health systems levels, with inability to run air conditioning due to lack of consistent electricity supply. A series of reasons for stock outs were highlighted, including:

- National stock-out(s) create knock-on stock outs within the counties.
- Failure to quantify drug needs, or to communicate this with partners who make the procurement, results in a failure to procure drugs, with stock outs as a result.
- Rainy season makes roads impassable.
- Distribution is not used in time, leading to waste.
- Lack of allocated budget to distribute NTD medications within the county.
- Communication gaps, with inadequate information sharing when drugs are distributed.

If drugs and other necessary supplies for disease management are unavailable, then patients are typically given prescriptions to go and buy medications from drugstores or pharmacies.

Thematic Pathway 2: Enhancing the performance of a core management team for SSSDs

This pathway is designed to support health workers who are involved in the delivery of care and support to people and communities affected by SSSDs. Providing resources and ensuring health workers have the relevant skills and competencies to deliver such activities is essential to maintaining a motivated and supported health workforce, which is necessary in providing holistic support and care for SSSDs. This section summarises findings relating to roles and responsibilities for health workers caring for people affected by SSSDs. It also provides specific details about human resource (HR) recruitment and factors which influence motivation and performance for health workers caring for people affected by SSSDs. Across counties the majority of findings were similar, unless otherwise stated.

Recruitment and Attrition

The Civil Service holds responsibility for recruitment of all government staff. Each government ministry or agency must work alongside the Civil Service for the recruitment and employment of staff. Almost all discussions surrounding staff recruitment involved staff in management positions. There were a number of HR gaps described, with limited clarity surrounding planning for and recruitment processes. There were delays with recruitment to fill replacement positions, creating frustration for staff working voluntarily in these posts. Senior county level jobs were typically recruited for internally within the county and filled by staff already working at district level. The role of experience, qualifications or application of selection criteria was not clearly described by any participant.

Staff attrition was a challenge described by several respondents, felt to be due to study leave, family issues, promotion, and migration between geographic areas (typically, health workers prefer to move to less remote/ more urban areas). This has contributed to the appointment of OICs who have not been trained in how to diagnose and manage people affected by SSSDs/NTDs. As a result, there are critical knowledge gaps (as described above within confirming cases and laboratory systems) and a need for strong mentorship.

Role

Study participants were purposively selected due to their experience supporting people affected by SSSDs; their key roles and responsibilities relating to SSSD care are highlighted in table 2.

Table 2 Participant Role

Position	Role
County Management	
Nu ' S i Director for the County referral hospital	Both Counties: Regulates nurses, midwives and u ' i es at all levels. Ensures adequate health services are provided to patients (including people affected by SSSDs). Reports all clinical activities to the Medical Director. Lofa only: Ensures staff employment and timely salaries.
Mental health coordinators	Leads, supervises and orientates all clinics on mental health. Grand Gedeh: Works with churches where mental health clients are to conduct counselling and mentoring. Lofa: Visits prison health services and also does advocacy for people with disabilities in schools and communities.

	No specific role related to mental health services for people affected by SSSDs was described by respondents from either county.
NTD focal person	Tracks all neglected tropical diseases in the community. Provides mentorship to clinicians, CHAs and CHVs. Collects specimen for testing for NTDs.
County pharmacists	Forecasts, provides quantification and requisition for drugs and medical supplies for all facilities. Coordinates distribution of drugs from CMS to county to facilities. Provides technical expertise to clinicians.
Clinical Supervisor	Supervises the District Health Officers (DHOs) and all clinical activities at the various facilities. Reports to the Community Health Department Director. Coordinates and supports the Joint Integrated Supportive Supervision (JISS) at all the facilities.
County Health Officer (CHO)	General oversight responsibility of the entire county. Supervises the various programs conducted in the county, district and communities. E u i i t l t ' l i i i m l m t .
Community health focal person	Works with all implementing community partners to ensure all community health programmes are implemented. Supervises the CHSS and CHAs. Identifies community triggers for action.
Surveillance focal person	Informed about cases seen. Reports to national level.
District management	
District health officer (DHO)	Coordinates all health activities and ensures they are in accordance with the Essential Package of Health Services (EPHS) standard at the district level. Provide mentorship. In consultation with the County HR, recruits clinical staff when needed.
District surveillance officer	Informed about cases seen. Reports to county level and onward to national.
Diagnosis	
Lab supervisor	Supervises all technicians, lab staff and provide mentorship to the entire department. Specimen testing.
Diagnostic officer	Ensures the lab meets its standards. Specimen testing.
Quality officer	Ensures the potency of materials or reagents. Specimen testing.
Lab technician	Supervises his staff. Conducts testing of specimen and does work as per TOR
Clinical (normally present within each health centre)	
Dispenser	After testing, the dispenser dispenses medications. Provides health education to the patient.
OPD general supervisor	Ensures patients receive fair treatment which meets their needs. Supervises second screener.
Second screener	Carries out screening of patients who present to the facility.
Ward nurse	Responsible for patient admission to ward.
Surgical nurse	Engaged with patient care and management during surgery and pre-post operatively.
Community health	
CHSS	Supervision and mentorship of CHAs for surveillance. Referral of patients with suspected SSSDs, with the support from the surveillance team. Ensure CHAs receive drugs to treat under 5s in the community. Serve as a link between the community and health facilities, including follow up for de-faulting patients. Devote 20% of time at the facility and 80% of time in the communities.
CHA	CHAs create awareness (including about SSSDs). Identify and refer patients (including those with possible SSSDs). Follow up with patients when counter referred. The community have confidence in the CHAs and confides in them.
CHV	CHVs create awareness (including about SSSDs).

	Identify and refer patients (including those with possible SSSDs). They more specifically work with and treat children under 5 presenting with uncomplicated conditions and pregnant women. May take part in contact tracing during the COVID-19 and other outbreaks.
Informal health providers	
Black bagger	Help to heal SSSDs affected persons. Normally a trained nurse or health professional who is working independently of government employment.
Traditional healer	Cures big foot, hydrocele, rheumatism, broken bones, poisoning and infection. Usually draws u t i l i t ' i S i '.
Town crier	Make announcements in community on issues pertinent to health.

Knowledge and Training

Knowledge gaps were described across participant groups and training in various aspects of SSSD identification, diagnosis, management and reporting, was frequently described as needed by almost all participant groups (most strongly expressed by surveillance, M&E and laboratory staff).

The leading challenge to carrying out trainings for SSSDs included a lack of funding available, due to lack of donor priority for SSSD initial and refresher training. Where training has been conducted previously, it has been undermined by lack of the needed resources to put skills learned into practice.

Motivation

There were strong associations between motivation and money. Not receiving a salary (which was a frequent challenge) was a strong demotivator. Other demotivators include not having the needed drugs and supplies to be able to provide patients with quality care or to enable them to carry out their tasks.

Clinical and community health workers described strong intrinsic motivation, being driven by love of the work, a desire to help their community and a commitment to fulfil the oath taken upon graduation from training.

Supervision

Supervision was infrequently discussed across all levels. Those in management positions spoke more about supervision, however, information was still sparse. Joint Integrated Supportive Supervision (JISS) was often the primary supervision method. Clinical supervision involved stock checks, review of staff duties against the job description, with mentoring performed if gaps were identified. Supervision of CHAs by the CHSS was an established supervision method. Supervision for SSSDs was hindered by lack of funding (available supervision funding from the donor prioritised maternal and child health). Other barriers also included a lack of resources to support the logistics of supervision e.g. motorbikes, and lack of training on supervision best practices.

Human Resource Management and Salary

E t i t i t l t m t ' l each year, but according to one participant, this is usually not granted except in case of death of a close family member. There was frequent discussion about salary, with many staff working voluntarily and not having been added to payroll. This led to discontent (see motivation theme), with implications for staff performance, with many staff not working, as a result of not receiving a salary.

Performance

Key ways to manage performance were described by participants. These largely included: supervision and training; seeking advice from the senior nursing director about poor staff performance; development and evaluation of work plans through bi-annual performance appraisal sessions; pairing of staff with good and poor performance to provide mentorship and build skills; and collecting patient feedback through evaluation forms, followed by staff meetings to reflect on the findings.

Performance based financial and non-financial incentives were widely described and applied at district, facility and individual levels, described as follows:

- District: The counties host programs to award best performing districts.
- Facility: Performance is tracked during quarterly review meetings where facilities are appraised, certificated and given some financial motivation based upon submission of reports. The FARA (US AID funded) project tracks performance through JISS with related mentoring and coaching. A lot of pressure is on health facility workers to perform to achieve the milestones and awards are given to the best performing facility. Financial awards are given (service delivery bonus) if targets are achieved. A portion of the financial award is given to the staff and a certain amount is also provided for infrastructure development of the health facility. However, this does not cover any SSSD related activities.
- Individual: Under the NTDs program, in counties where integrated case management has been supported, US\$5.00 is given to CHAs when a case is identified and confirmed. In counties where they work, Last Mile Health presents certificates to well-performing staff. Staff promotion is also based upon good performance.

Any issues with poor performance are usually channelled through the nursing director and onwards to HR if necessary. The nursing director was often approached for guidance by the OIC and other staff supervisors when they had issues with managing staff performance. Some HR measures such as issuing written warning for staff with poor performance; pursuing staff to return to work; or removing poor performing staff to a non-clinical role were described.

Gender

Gender balance differed according to the type of position. Typically, management roles of participants interviewed at county and district levels were filled by men. Surveillance and M&E staff were also more frequently male. Clinical staff, including OICs were more balanced, with slightly more women than men in OIC roles.

Recommendations for Better Human Resource Management

A series of HR related recommendations were provided, including:

- Training and refresher trainings for all relevant staff, including training vaccinators, OIC and midwives about SSSD case detection and referral.
- Include SSSDs in pre-service training for nurses.
- Regional visits by clinicians to promote learning about best practices.
- Provision of needed supplies following training, to put skills into practice.
- Provide staff with required materials to carry out their role, e.g. rain gear, bag, flash light, personal protective equipment (PPE) for CHAs.
- Provide CHAs covering long distances with bicycle to facilitate their work.

- Provide scratchcards and wifi to facilitate communication and reporting.
- Develop motivation package for health workers working away from family, e.g. accommodation for nurses.
- Ensure salary is timely for community health staff.
- District Surveillance Officer to multi-task as NTD focal person, in addition to surveillance officer role (to be facilitated with training and adequate compensation for extra duties).

Thematic Pathway 3: Establishing Equitable Approaches to Psycho-Social Support and Stigma Reduction

This pathway is designed to support stigma reduction as well as the integration of SSSDs and mental health services. The pathway prioritises the delivery of community-based interventions that enable a holistic response to supporting individuals and families affected by SSSDs. The pathway has a specific focus on working with informal health providers to strengthen links and collaborations between more traditional forms of health care provision and formal health systems. The findings presented in this section focus on existing health belief systems and how they shape responses to illness at community level, including: who people chose to seek healthcare from; how they shape trust with the formal health system; and how they perpetuate cycles of stigma, violence and mental ill-health. Findings related to opportunities for collaboration between the formal and informal sector are also discussed.

Health Beliefs

Knowledge and awareness of SSSDs, particularly in Grand Gedeh county were identified as a key barrier shaping health access (as described in thematic pathway one- awareness). Traditional belief systems were described as identifying witchcraft as one of the key causes of disease in both counties. These belief systems were described largely by county and facility level respondents as key in shaping health seeking, leading to a reliance on traditional forms of healing. This pattern in health seeking was also identified for mental health conditions.

Spiritual and faith healing took different forms in different counties depending on the type of provider, treatment options were also shaped by diagnosis processes. For example, some traditional healers in Liberia used 'spiritual' faith-based treatments 'tiki mli'. In Liberia, faith-based healers tended to be preferred, whereas within Grand Gedeh county traditional healers and herbalists were more widely described. Some treatment practices, such as the chaining of patients by traditional healers could be perceived as harmful.

Trust

Trust was identified across all intervention pathway areas as being central in shaping health related decision making. Across levels, there was widespread recognition of the role that community beliefs play in who individuals place trust in and where they seek care. Typically, the community placed trust in the provider that they felt would treat the underlying cause of the disease (as described above in Health Beliefs), which often resulted in a reliance on informal health providers (including traditional and faith healers). Reliance on traditional healers was also described as being a consequence of the historical importance this group had played in 'being the first people to deliver health services to the community'. Due to the trust that communities place in informal health providers such as traditional or faith healers many health facility respondents felt that training these

types of providers in SSSD case detection and or provision of psychological first aid could be of great benefit to people with SSSDs.

The community were described as also placing greater trust in those 'local' health system actors who were closer to the community, for example CHAs or CHVs. The onset of COVID-19 has undermined community trust in formal health services, with patients fearful to seek care at a facility due to fear of contracting COVID and/ or having to be quarantined.

Stigma and Violence

People affected by SSSDs were described as experiencing multiple forms of violence including physical, verbal, emotional, and sexual. Participants also described neglect as common. Across levels of informant the most pervasive forms of violence described varied, however, sexual and gender-based violence was identified as critically important at community level, with both men and women being described as sufferers of such violence. Women were also identified as more likely to experience sexual and gender-based violence often triggered by an inability to fulfil gendered roles within the home.

Violence was largely underpinned by stigma as a result of belief systems surrounding the causes of illness and a lack of education, particularly in rural areas, regarding possible other cause. Other structural factors, such as previous conflict/civil crisis and reliance on illegal drugs were described as particularly amongst people in Liberia.

Self-referral and community action were described as the main responses to the management of violence, particularly SGBV. Respondents described the importance of community health actors, e.g. CHAs, CHVs, teachers etc. as first responders related to a lot of these issues. Adequate training and understanding were described as needed for these cadres to not stigmatise and knew how to support. However, reporting of issues related to violence was not easy and those who were impacted by violence were often reluctant to report. Despite this, the empowering benefits of reporting violence were noted.

Community based solutions were identified as ways to support people impacted by violence and those who were marginalised (for example as a result of SSSDs), including: multiple methods of awareness raising e.g. through radio, community meetings, CHAs/CHVs etc; safe housing for survivors of violence; support and training for teachers, and the provision of school lunch clubs around the issue.

Mental Health

People with chronic health conditions or disabilities, including SSSDs, must be supported physically and mentally. The welfare and education of the person must be taken into consideration, to reduce the mentality of other people who had the belief 'that in as much you have this chronic disease you are less important in the society'. Councillors and mental health clinicians must be involved before people accept their condition. Stigma amongst health workers, staffing shortages, limited training of staff and absent logistical support for patients were identified as key barriers to the provision of mental health services in Liberia. Mental health service provision was described as particularly weak in Lofa county where the Carter Center was less active.

Across both counties, informants described that there was a gap in community level individuals who are trained in service provision. Opinions on how to fill this gap varied, with some believing that, with the right training, informal health providers (traditional and faith healers) could fill this gap (e.g. psychological first aid), while others perceived that quality of care would be compromised.

Multiple mental health screening and support tools were cited by participants as being beneficial in delivering mental health services. However, their use within the health system varied, with many respondents, even if they had undergone training, feeling reluctant to use the tools as they felt they were not particularly regarding interpretation of outcomes was requested.

Collaboration with the Informal Health Sector

Current forms of collaboration between the formal and informal health sector varied across counties, but it was widely accepted that this is an area that could be strengthened and improved. Enhanced collaboration was largely discussed in relation to referral between services and informants gave key suggestions of how this could be achieved. For example; referral from informal to formal after one week if illness symptoms persisted; and allocation of faith and traditional healers to specific health facilities so they could collaborate to address spiritual and traditional (e.g. African signs) causes of ill-health. These approaches would need further discussion.

Training activities in Lofa county were described as beginning to enhance collaboration between sectors, but informants identified that further training and dialogue was needed to build trust between sectors and shape new forms of collaboration. Some informants also described that this was necessary to support informal providers to recognise signs and symptoms of specific health conditions so they can identify specific dangers and prioritise referral.

Supervision of informal providers by formal health workers to understand the number of patients they currently have in their care, how they are being treated and what the benefit of such collaboration are likely to be to the health system was also described as important by some key informants.

Key challenges to collaboration were identified as: financial impacts on informal health providers if they were to collaborate; time taken to train them; and the risk of losing their medicine although providers trusted their medicine they feared getting in trouble if they were to collaborate.

Collaboration requires further dialogue with community stakeholders and informal providers who were less vocal on these issues.

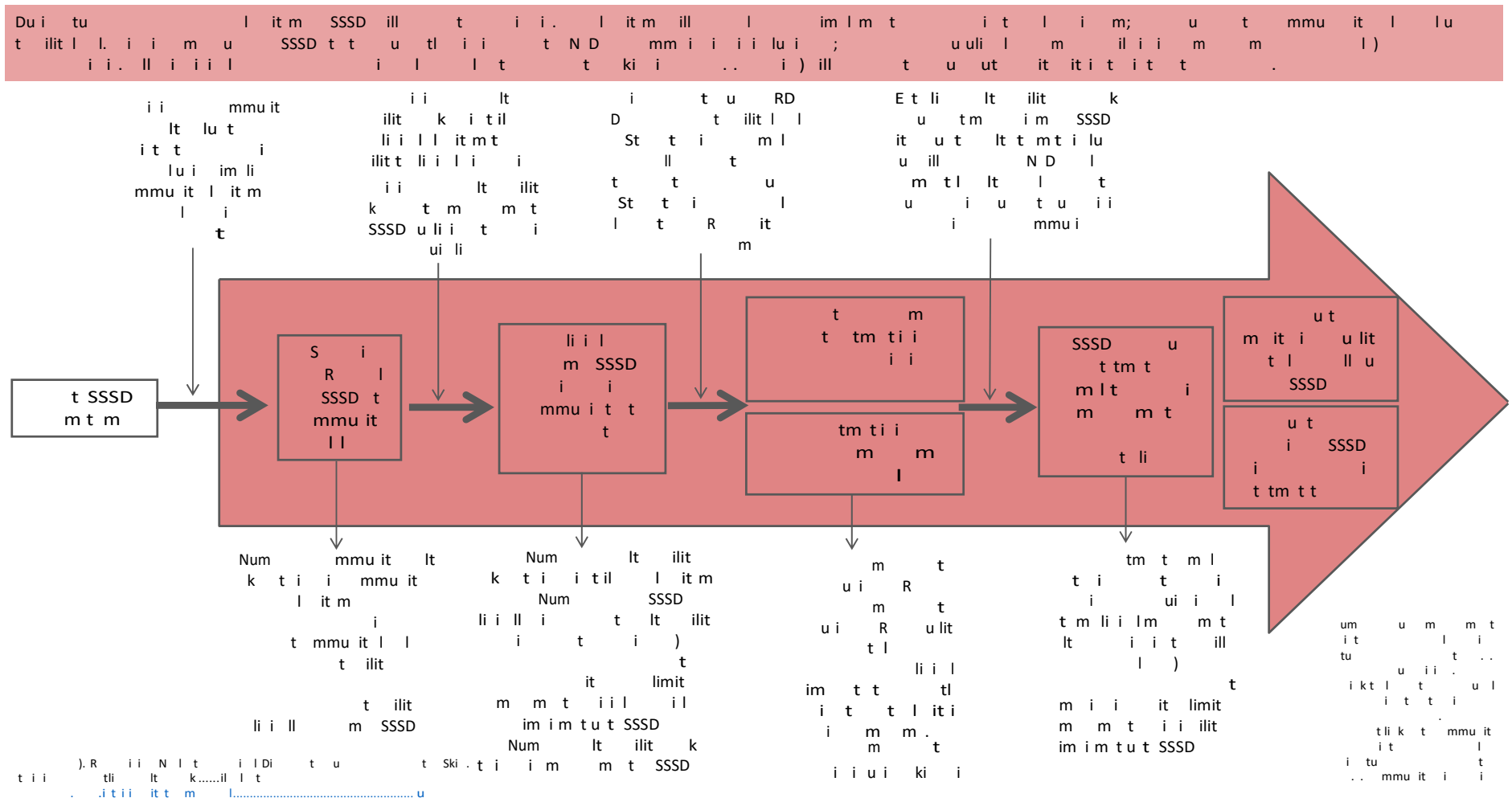
Conclusion

This study has highlighted current practices, gaps and recommendations relating to the care of people affected by SSSDs. Findings have been summarised around three intervention pathways: Improving case detection, diagnosis and referral; Enhancing the performance of a core management team for SSSDs and Equitable approaches to psycho-social support and stigma reduction. These findings will be used as the basis for developing, person-centred, evidence-based interventions to improve the equitable and effective management of SSSDs, whilst seeking to contribute to health systems strengthening.

Collaborating partners:



Annex One -Intervention Pathways



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