

Project Summary Brief:

Establishing a community-based support system to improve health and wellbeing of people affected by stigmatizing skin Neglected Tropical Diseases affecting the skin in Kaduna and Kwara states

Background to the study

Neglected Tropical Diseases (NTDs) affect around one billion people, mainly those living in the poorest parts of the world and many more still remain at risk of infection. Many NTDs lead to serious long-term physical impairments which affect people's health and wellbeing. Restrictions to livelihood activities, social, family and community interactions resultant from associated stigma and reduction in participation often lead to a disabling impacts of NTDs. Over the last few years, impacts of chronic impairment and potential disability as a result of NTDs, and their associated negative implications on mental health, has gained increasing recognition in NTD research. However, there is still a significant lack of research that focuses on the holistic health and wellbeing of persons affected by NTDs. This study partnered with affected persons, caregivers, and programme implementers to support in addressing this gap - through the co-design of implementation of community-based support groups, focusing on both physical and psycho-social wellbeing.



Fig.1: Study Sites: Selected States

Kaduna and Kwara States were selected as study sites because of their geographic variance, they are both endemic for two or more of NTDs affecting the skin, and there are established case detection processes in both states.

Aim: To establish a community-based support system to improve the health and wellbeing of people affected by stigmatising skin diseases and their caregivers in Kaduna and Kwara State, Nigeria.

Methods:

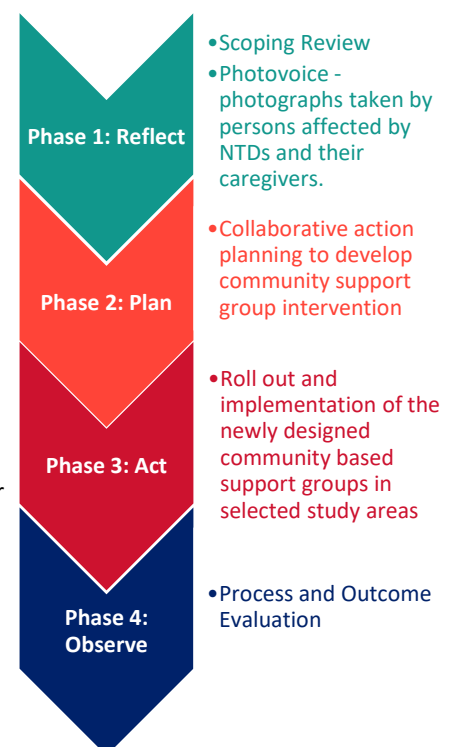
This study used Community Based Participatory Research (CBPR) to design an intervention in collaboration with people affected by skin NTDs. The study was split into **four phases**:

PHASE ONE (REFLECT) sought to understand experiences of health and wellbeing of people affected by stigmatising NTDs and their caregivers using a scoping review and photovoice. We conducted a scoping review to consider relationships between NTDs, mental health, stigma and disability in Sub-Saharan Africa and to understand existing and possible support structures. For photovoice, co-researchers were recruited as part of the core research team and included people affected by NTDs as well as their caregivers. Co-researchers trained people affected as photovoice participants to photograph and document their experiences and perspectives to identify needs and priorities to be focused on in support groups.

PHASE TWO (PLAN) Collaborative action planning meetings were held with co-researchers and health system stakeholders to co-design community-based support groups aimed at addressing core health and wellbeing challenges identified from phase one. Priority issues for support groups to address were identified by persons affected, including components of disease management and psycho-social support.

PHASE THREE (ACT) was the implementation of support group intervention over 5 months.

PHASE FOUR (OBSERVE) involved a process and outcome evaluation using photovoice with support group leaders, semi-structured interviews with support group members, participant observation of support group activities and key informant interviews with State and Local Government Area (LGA) NTD programme staff, and the research team.



Phase 1 Findings from Photovoice

Findings from photovoice were analysed into key themes within focus group discussions with co-researchers and photovoice participants. Key photos were developed into photo booklets per State (fig.2). These booklets showcase the photos, showing the realities of people affected by NTDs through their lens, focusing on multiple themes including stigma, psychosocial wellbeing and support.



Fig.2: Photo booklets developed from Phase 1 Photovoice per State

Key themes included:

Physical Functioning and Pain: Limitations were identified in relation to pain and discomfort from conditions, which hindered participants from being able to undertake activities they were able to do prior to their illness.

Impact on Source of livelihood: Impact on income and livelihoods was significant for all participants. This was often in relation to loss of livelihoods as well as having to sell livestock or crops in order to pay for hospital bills or medicines to treat their ailments.

Stigma: Stigma was often deeply felt and experienced by participants across gender and disease. Internal stigma was depicted whereby young men affected by Lymphedema and Buruli ulcer reported feeling useless, broken, shame, and depression because of enlarged legs or obvious wounds.

Quality of Health: Participants highlighted receiving good quality of care, in reference to close proximity and availability of health centres, and trust and gratitude in health care providers.

Relationships, Support and Acceptance: Participants spoke of the support they receive from friends and family and were keen to give recognition to their caregivers, expressing their gratitude to them.

Psychological wellbeing: Negative impacts on psychosocial wellbeing as well as coping mechanisms were highlighted by participants.

Promoting good health: Food, environmental interactions, and the built environment were depicted as factors that positively affect the health of participants.

Phase 2: Dissemination and Intervention Planning Meetings



Findings from Phase 1 were displayed in a photo exhibition in dissemination and intervention planning meetings held in Kwara and Kaduna which brought co-researchers, photovoice participants, and the research team together with stakeholders within the State and LGA ministries of health (fig.3). Support groups were designed collaboratively based on the emerging findings from the photovoice.

Fig.3: Photo Exhibition in Dissemination and Intervention Design Meetings

Phase 3: Implementation of Support Groups

The support groups were implemented from March 2021 – July 2021. Support groups were held at district and community levels in Kwara and Kaduna, with co-researchers acting as support group leaders. A support group guide was developed with people affected to outline the steps taken to establish community led support groups (fig.5). Support groups focused on general health, wound care, psychosocial support and vocational training.



Fig.4: Support Group at LGA Level, Kwara

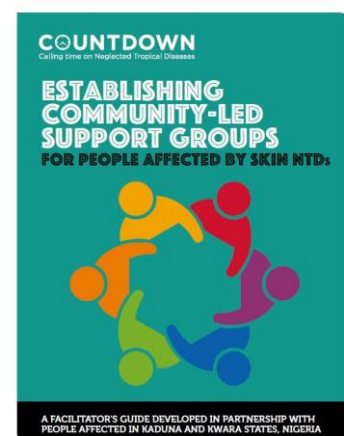


Fig.5: Support Group Guide

Phase 4: Evaluation on Impact of Support Groups

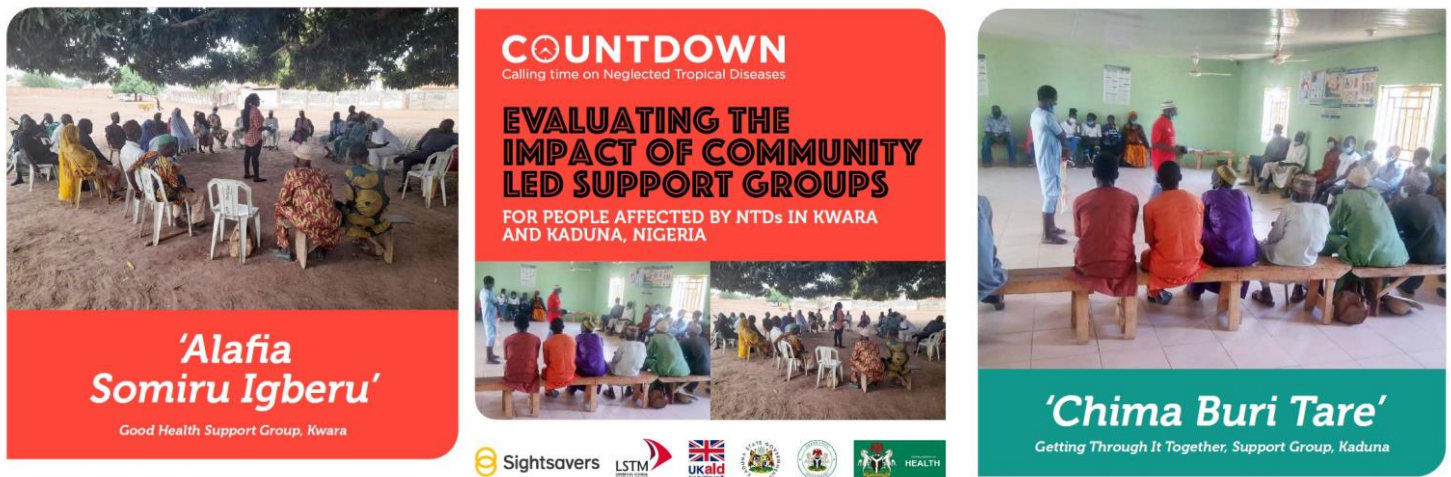


Fig.6: Photo booklets developed from Phase 4 Photovoice

Impacts

On Persons Affected and Caregivers

Social connection and stigma reduction: Many support group members described how the support groups have led to a sense of belonging, building relationships, and strengthening social connection between group members, families and communities. Participants expressed being able to eat together from the same bowl with relatives whereas before they used to distance themselves. Many expressed feeling encouraged to talk openly about their feelings and experiences after hearing from others who had similar circumstances. Through participant observation, it was noted by the research team that support group members became more comfortable and familiar with each other as the groups progressed. As well as linking to the themes above, caregivers also described the benefit of the support groups in supporting them to interact freely with other community members and people affected by skin diseases, suggesting contribution to increased community interaction and participation of the support group processes.

Improved self-esteem of many group members and a significant reduction in internalised stigma. While many participants isolated themselves before, they now expressed feeling more confident about themselves and therefore, this has increased their participation in the community. Group members described how they now pay less attention to how others look at them, feeling more confident to go out to public places such as markets and mosques.

Community Acceptance and advocacy: Participants highlighted the importance receiving support and acceptance for the group's existence from the community. The community, including religious and community leaders, had become aware of the support groups and often came to observe and support the group. However, this also raised challenges in inclusion particularly in communities where resources were scarce as many other community members, who did not have NTDs, wished to join the groups as they felt it could improve their social and economic situation.

The photo represents that the meeting has made the members pay less attention to people looking at them like they are different. They now feel free to discuss among people and go to public places. The meeting has been able to make participants encourage each other by sharing personal experiences. Adamu Hauwa, female, Ilesha Baruba community group leader, Kwara

Before now, I would always stay away from other people in the household and thinking to myself that I am ashamed to associate with them because of my condition. But now I beginning to feel good about myself and my family is happy to see me this way. I feel very happy that it is not just us that has benefitted from the support group but our family members too. Habibat Suleiman, female, District support group leader, Kwara

I learnt to associate freely with affected person with stigmatizing disease I used to think I could not associate with them but as a result of this support group, I am able to freely relate with them, I also learnt hygiene and trading skills like soap making and I appreciated it. Caregiver, male, SSI, Kaduna



Capacity Building and Independence - Co-researchers and key informants expressed how support group meetings have strengthened the skills, abilities and resources of group members. Many participants expressed the importance of how skills sharing, has led to ownership and independence. Co-researchers described their capacities being built through learning how to operate cameras as well as soapmaking, which has led to many being more accepted in the community. Support group leaders expressed building their confidence to lead and support other members of the group.

Improved Health Knowledge and Health Outcomes: Support group meetings were described as providing spaces for learning, which has led to improvements in both physical and mental wellbeing. Co-researchers, State NTD staff, LNTD coordinators and the research team mentioned that the support group has empowered members to take care of themselves through learning and gaining new knowledge. Many shared how the different training sessions have enlightened them on how to look after their general health as they now know the importance of taking medicines, going to the health facility for regular check-ups and using mosquito nets to avoid mosquito bites which can cause lymphatic filariasis. The training on wound management and general health was also highlighted as leading to physical improvements in symptoms

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Programmatic Impact

Improved referral - there were several instances where persons affected, after hearing about the support groups, were referred by the research team to the LNTD and TBLS for confirmation of diagnosis and treatment including hydrocele surgeries. This is a role that support group leaders could continue to play to support case detection and referral. This encouraged state implementers to focus more on the activities happening at the communities as more cases are identified.

Impact of the group on role of State and LGA Staff: At the LGA level, it has made it easy for the LGA coordinators to identify the needs of the people and to assist them promptly. It has also helped the coordinators in case filing as more people join the support group, new cases are identified, and this has improved their weekly and monthly report to the State level. One LGA officer stated that sending his report to his superiors regularly shows that he is doing his job well and he is seen as a diligent staff member.

Sustaining Groups

A measure of success of the groups is the growth and increase in membership in both Kaduna and Kwara. All key stakeholders, co-researchers and research team maintained that there is collaboration between the State ministry of Health and the NTD unit of the LGA, to work towards mobilization, sensitization and advocacy of the support groups. The LGA team stated that they will ensure that the meetings are held as scheduled and offer their support when and where needed. The ownership of the group by persons affected was also described as a foundation for sustaining the groups as they had raised funds themselves through membership fees and had skill acquisition training where they learnt how to make soap. This has also built their capacity and provided a source of income generation.

'The opened window signifies how we are now enlightened through this support group, before it seemed we were in a room with doors and windows closed. This support group has shown us how we can cater and take care of ourselves.'

Bashir Ibrahim, male, Group leader from Dan Alhaji community, Kaduna



'I learnt how to care for myself and the person I care for. I am able to see things differently. I am been able to associate freely with persons. I see myself as been responsible as I have been made the facilitator of my community.' **Support group member, caregiver, SSI, Kaduna**

'We noticed people who normally hide their disease have started coming out and this is helping our case file and records. We have more cases and we are able to treat them as we discover them. This has helped in the control of the disease' **State TBLC Program manager, Kwara**