

A holistic approach to well-being and neglected tropical diseases: evaluating the impact of community-led support groups in Nigeria using community-based participatory research

Shahreen Chowdhury^{a,*†}, Oluwatosin Adekeye^b, Ayuba McRae^b, Temitope Olorunfemi^b, Linda Dubukumah^b, Oluwabunmi Makinde^b, Edward Ozokede^b, Jude Ewemade^b, Shuaibu Abdulkadir^c, Rebecca Ayuba^c, Suleiman Habib^d, Matthew Gurma^d, Rachael Thomson^{a,†}  and Laura Dean^{a,†}

^aDepartment of International Public Health, Liverpool School of Tropical Medicine, L3 5QA, Liverpool, UK; ^bSightsavers Nigeria, 800241 Kaduna, Nigeria; ^cLere Local Government, 811104, Kaduna, Nigeria; ^dBaruten Local Government, 242102, Kwara, Nigeria

*Corresponding author: Tel: +44 151 702 9436; E-mail: shahreen.chowdhury@lstmed.ac.uk

[†]Present address: Department of International Public Health, Liverpool School of Tropical Medicine, L3 5QA, Liverpool, UK

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Background: Neglected tropical diseases (NTDs) affect around 1 billion people, many living in the poorest parts of the world. NTDs often lead to serious long-term physical impairments. Stigma, disability, poverty and social isolation interact, resulting in poor quality of life and significant psychosocial impacts. The holistic health and psychosocial needs of persons affected by NTDs are often overlooked in integrated NTD programme design and research. Furthermore, the viewpoints of persons affected are often absent and spaces for empowerment and advocacy are limited.

Methods: Using a community-based participatory research design, our study partnered with persons affected and caregivers as co-researchers to address this gap. Through the process, we co-designed and implemented community-based support groups in Kaduna and Kwara, Nigeria, where NTDs are endemic. This paper utilises photovoice with support group facilitators (persons affected); participant observation of group meetings; rapid micronarratives with support group members; and key informant interviews with programme implementers at the state and local government area levels to explore the impact of the support groups from the perspective of people affected by NTDs and other health system actors.

Results: Perceived impacts of the support groups included a sense of ownership and empowerment, stigma reduction, improved self-esteem, improved health knowledge and health outcomes and capacity strengthening through vocational training.

Conclusions: Support groups, as community spaces of healing, offer a low-cost holistic intervention for chronic disease and disability.

Keywords: disability, mental health, NTDs, participatory, psychosocial, stigma.

Introduction

Neglected tropical diseases (NTDs) affect around 1 billion people globally, affecting the most marginalised, mainly those living in impoverished conditions, with many more remaining at risk of infection.¹ Many NTDs result in significant morbidity and disability, profoundly impacting health and quality of life. Due to associated stigma, persons affected are often marginalised and face restric-

tions to livelihood activities, social and community participation, which can lead to poor mental well-being, increasing the burden of disease.^{2,3} Impacts of chronic impairment and potential disability as a result of NTDs, and their associated negative implications on mental health, have gained increasing recognition in NTD research. However, there is still a significant lack of research that focuses on the holistic health and well-being of persons affected by NTDs, there remains a disconnect between physical and

mental health and there is a lack of consideration of individual needs. To date, research has often prioritised the causal links or associations between NTDs and changes in physical or mental condition, with little exploration of how to translate knowledge of the links into integrated packages of physical and psychosocial support for affected individuals and their families.⁴ Furthermore, where integrated intervention design is considered, the viewpoints and priorities of persons affected by NTDs are seldom included, thus presenting a critical research gap. The disabling impacts of NTDs are not only physical but also inherently social, therefore the design, implementation and evaluation of control and treatment programmes must also address psychosocial impacts as well as the provision of medicalised management of disease conditions.

Nigeria has the largest burden of NTDs in sub-Saharan Africa, accounting for 25% of the total burden of NTDs in the continent.⁵ In Nigeria, Buruli ulcer (BU), leprosy and clinical manifestations of lymphatic filariasis (LF), specifically lymphoedema and hydrocele, are skin NTDs being prioritised for integrated case management. Integration focuses on the management of multiple diseases within one integrated programme and within existing health systems infrastructure. However, integration to date tends to focus on case detection and training, with limited focus on longer term support and management beyond medical intervention. Ministry of Health (MoH) partners at the federal and state level, and non-governmental development organisations (NGDOs) currently supporting NTD programme delivery, acknowledge that the provision of long-term holistic support and management for persons affected is a critical gap in current service delivery. The value and benefit of support groups in other settings has been recognised⁶ and there is a desire to consider their use as part of the integrated approach in Nigeria.

Within this study, we worked with persons affected and caregivers to support them to address this gap in service delivery in a way that was both acceptable and accessible. Person-centredness for NTDs is critical, in part due to disproportionate impact on the vulnerable, and their stigmatising nature; however, there is a disparity in how few practical examples of this exist in practice. As ‘neglected’ diseases both in terms of research and development, there is a particularly unique place for community-led initiatives and advocacy. Thus, we used community-based participatory research (CBPR) to initially explore understandings of holistic health and well-being, and experiences of illness from the perspectives of persons affected by NTDs and their caregivers through photovoice (see Adekeye et al., also in this special issue).⁷ These findings were then used to support persons affected to collaborate with health system actors to highlight challenges and suggest solutions through a photoexhibition and intervention design meeting with stakeholders; this led to the co-development of the intervention—integrated community-led peer support groups—focused on facilitating improvements to physical and psychosocial health and well-being. This paper presents a critical evaluation on the impact of the co-developed intervention (support groups) from the perspective of the persons affected, the NTD programme and the wider community. The lessons learnt in establishing support groups for NTDs in Nigeria are applicable across contexts, and in supporting community-led chronic disease management in low-resource settings.

Methodology

Theoretical approach

This study used a CBPR approach to co-develop the support group intervention. CBPR was chosen due to its central principles of equity with a partnered approach to research that involves community members, researchers and stakeholders in all phases of the research process to action change led by the community. Its onus is on shared knowledge and ownership of the project among all participants.^{8–10} CBPR is an opportunity to support underserved communities and marginalised groups as co-researchers (participants with lived experience) to have more decision-making power in research and therefore increase the likelihood of success of the support groups.¹⁰

CBPR involves the use of iterative participatory action cycles, incorporating research, action and reflection that can be applied in different ways. Figure 1 outlines how we utilised the four steps of the cycle in this study: Phase 1 (Reflect), reflection on the current situation for persons affected by NTDs; Phase 2 (Plan), developing and planning interventions to better support the holistic health needs of persons affected; Phase 3 (Act), acting to implement the plan; and Phase 4 (Observe), observing and evaluating the perceived impact of the interventions on the well-being of the persons affected. This manuscript is specifically focused on study phases 3 and 4. Table 1 provides an overview of the methods used in each phase of the study to orientate the reader regarding the process of intervention (support group) development, design, implementation and evaluation. However, for more detail on study phases 1 and 2, see Adekeye et al.⁷

Study site and co-researcher selection

Two states were purposively selected for this study, Kaduna and Kwara, based on endemicity for NTDs, programmatic need and variance in geography and sociocultural differences. Within each state, one local government area (LGA) was selected: Ilesha Baruba in Kwara and Lere LGA in Kaduna; two wards were then selected in each LGA, as depicted in Figure 2. Study sites and co-researchers were identified and selected by working in close collaboration with the national, state and LGA NTD programmes and the TB and leprosy control programme (TBLCP). For further detail on study site and participant selection, please refer to Adekeye et al.⁷

Within this study, we included two levels of co-researchers: core co-researchers and photovoice co-researchers. Core co-researchers included people affected by NTDs who were recruited as part of the core research team to support the design and delivery of the study. Two co-researchers per state were selected, with the aim to balance gender and disease condition, as detailed in Table 2. Training was held with core co-researchers and their capacities were strengthened through orientation on the study and training to deliver photovoice training for other persons affected and caregivers as photovoice co-researchers. Core co-researchers facilitated analysis and dissemination, as well as intervention design, delivery and evaluation of the study.

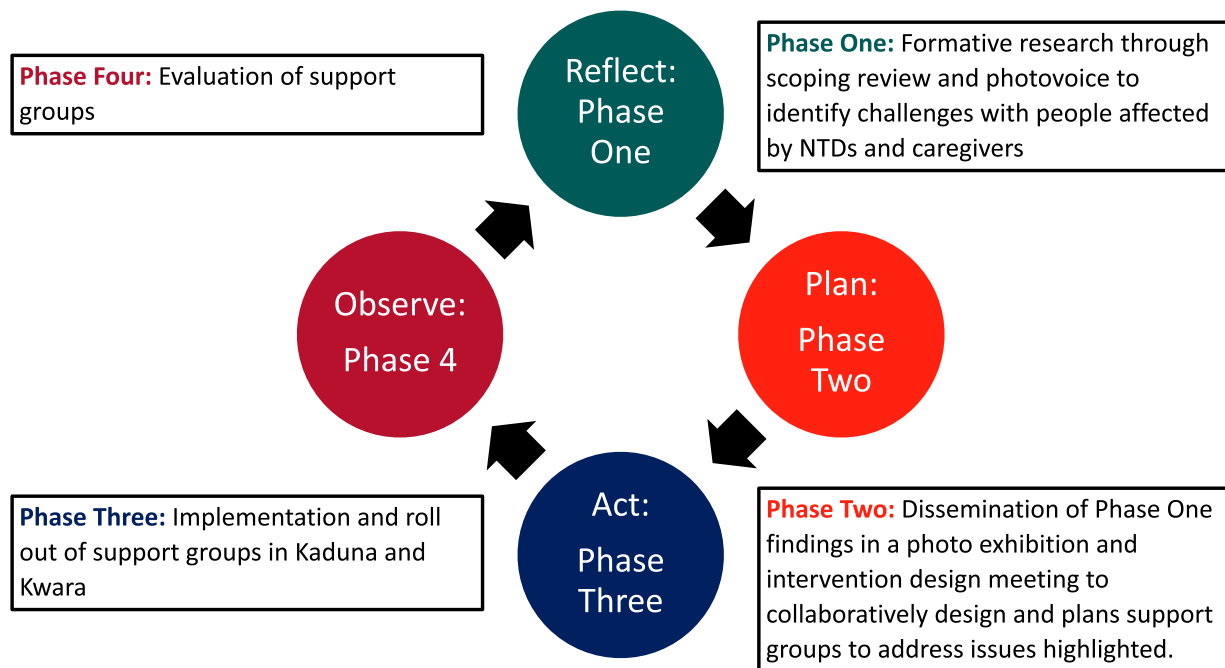


Figure 1. Overview of the CBPR cycle utilised in this study.⁷

Intervention implementation and data collection

Phase 3: Act

Establishing peer support groups was collaboratively identified as a key strategy to support persons affected and their families to overcome barriers to their well-being. Barriers were identified in study Phase 1 and are summarised in Table 3 and detailed further within Adekeye et al.⁷

The support groups were established and supported from March–July 2021 at district and community levels in Kwara and Kaduna. Support groups were held monthly, with five meetings at both district and community levels, totalling 10 support group meetings conducted during the duration of the study. Support group meetings have continued since the study evaluation period ended. Co-researchers acted as support group facilitators to help organise and coordinate the running of support groups. A [support group guide](#) was developed with people affected to outline the steps taken to establish community-led support groups including the venues and times of meetings, selecting facilitators, agreeing on membership rules and fees as well as proposed meeting agendas. Support group members collaboratively chose to focus on general health and wound care, psychosocial support and vocational training as priorities within their group meetings. External facilitators were identified by group members for specific sessions and the NTD programme also supported where appropriate. Topics covered within groups are detailed in Figure 3. Support group members were identified through the LGA NTD programme as well as through word of mouth between persons affected and community leaders. There was a total of 32 support group members in Kaduna and 26 in Kwara; support group member details per state are included in Tables 4 and 5.

Phase 4: Observe

Photovoice as a creative participatory methodology was used by support group facilitators to document their experience of establishing the support groups and its impact on themselves and other group members. Facilitators from each support group (10 across the study) were asked to take part in the photovoice activity. The photovoice process is described in Figure 4, adapted from Ronzi et al.¹¹ All participants were provided with one day of training, facilitated by the research team to provide an overview of photovoice, how to use the cameras and the ethics of photography. Participants were asked to explain the meanings behind their photographs in one-on-one discussions with the research team where they picked key photographs. In groups per state, support group facilitators shared key photographs collectively to co-analyse and develop main themes. The findings of this photovoice activity related to ‘Evaluating the impact of community led support groups’ are presented in a [photo-booklet](#).

Participant observation: researchers used observation grids to observe the planning meetings and support group meetings, totalling 12 observation grids. A structured observation grid was used to document reflections and observations of interactions, participation and content of the meetings. All observations of meetings were conducted with the agreement of meeting attendees. Discussions and power dynamics between the different participants and stakeholders were noted.

Rapid micro-narrative interviews were conducted with 58 support group members throughout the implementation of the support groups to explore their impact relating to their learning, feelings and experiences of being a part of the group.

Table 1. Methods per phase of research

Phase of research	Steps and methods	Description and purpose of method	Total no. of participants
Phase 1: Reflection January 2020– January 2021	Scoping review	A scoping review was conducted to consider relationships between NTDs, mental health, stigma and disability in sub-Saharan Africa and understand existing/possible support structures in sub-Saharan Africa in integrated case management	N/A
	Photovoice	Photovoice was used as a creative participatory methodology whereby people affected by NTDs and caregivers were engaged and trained to take photographs within their communities to understand their current reality in relation to health and well-being and to support the identification of actions for change	32
Phase 2: Plan February 2021	Dissemination and intervention Design meetings	Findings from phase 1 were shared via phototoxhibitions in dissemination and intervention design meetings with co-researchers and health system stakeholders to co-design community-based support groups	2 meetings
Phase 3: Act (March 2021– July 2021)	Implementation of intervention	The support groups were implemented over 5 mo at both the district and community levels in Kaduna and Kwara	See Table 3
Phase 4: Observe (March 2021– October 2021)	Photovoice with support group leaders	Photovoice was used in Phase 4 with support group leaders who were asked to photograph their experiences of facilitating and participating in the support groups	10
	Semi-structured interviews with co-researchers	Face-to-face individual interviews with co-researchers to explore perceptions and experiences of being a part of implementing the support group and its impact on them	13
	Rapid micro-narratives/rapid semi-structured interviews with support group members	Rapid micro-narratives/rapid semi-structured interviews were conducted with support group members throughout the implementation of the support groups to explore the impact of the support groups relating to their learnings, feelings and experiences of being a part of the group	58
	Participant observation of support group activities	Participant observation was conducted by members of the research team at the support group meetings. A structured observation grid was used to document reflections and observations of interactions, participation and content of the meetings. All observations of meetings were conducted with the agreement of meeting attendees	12
	KIIs with state and LGA NTD programme staff	KIIs to understand experiences and perspectives on the strengths and weaknesses of the implementation of support groups with programme implementers at the state and LGA government levels	11
	KIIs with the research team	KIIs to understand experiences and perspectives on the strengths and weaknesses of the implementation of support groups with research team members	6

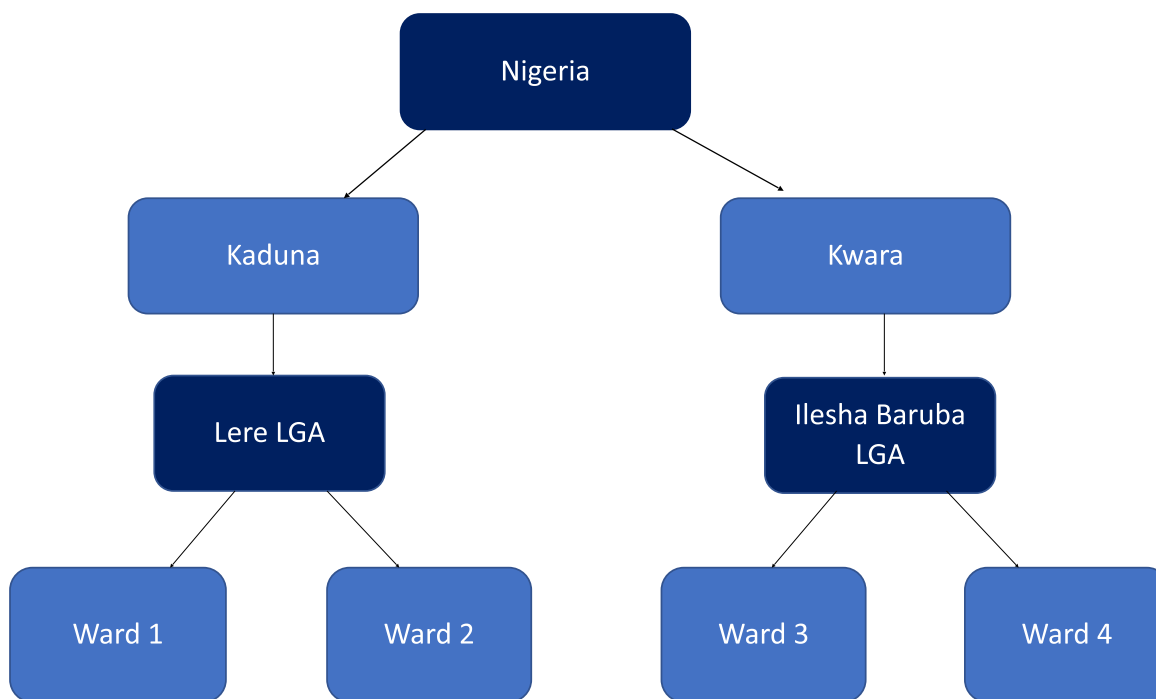


Figure 2. Study site selection.

Table 2. Core co-researcher selection

Name	State	Gender	Disease	Occupation	Educational level
Rebecca Ayuba	Kaduna	Female	Leprosy	Farmer	Primary level
Shuaibu Abdulkadir	Kaduna	Male	LF	Farmer	Tshangi education
Suleiman Habib	Kwara	Female	LF	CHV	Tertiary level
Musa Guruma	Kwara	Male	Leprosy (CG)	Farmer	No education

Abbreviations: CG, caregiver, CHV, community health volunteer.

Semi-structured interviews with co-researchers: face-to-face individual interviews with 13 co-researchers across Kaduna and Kwara were conducted to explore perceptions, experiences and the impact of implementing the support groups.

Key informant interviews (KIIs) with State and Local Government Neglected Tropical Disease Programme: KIIs explored the perceptions and experiences of stakeholders on their involvement in the intervention and how they think it can be sustained and rolled out in other areas. Eleven key informants were purposively selected, according to their knowledge and experience of working with persons affected by NTDs, mental health and disability, including LGA health staff and MoH representatives, who have been engaged in supporting the establishment and supervision of support groups.

KIIs were also conducted with six members of the Nigeria research team to understand experiences and perspectives on

the strengths and weaknesses of the implementation of support groups.

Impact of COVID-19 on the study

This study took place during the COVID-19 pandemic. We initially faced significant delays in being able to establish the peer support groups (i.e. transitioning from Phase 3 to Phase 4 of this study). However, during March–July 2021, lockdown was lifted in Nigeria, and by following national guidelines, including wearing masks and only conducting training and support groups where maintaining social distancing was possible, we were able to commence the intervention. This resulted in support groups running for 5 months with core project support as opposed to the 12 months initially planned. Nevertheless, since the study ended, peer support groups have continued to be facilitated in Nigeria through the self-organisation of study participants.

Table 3. Key themes from photovoice in Phase 1

Key theme	Summary
Physical functioning and pain	Limitations were identified in relation to pain and discomfort from conditions that hindered participants from being able 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 lymphoedema and BU 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 healthcare 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 well-being	Negative impacts on psychosocial well-being 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

MEETING TOPIC	FACILITATOR
Establishing meeting structure including community meeting and roles	Selected Group Leaders
General health Care and Disease Management and financial issues (registration fees & support for members)	Invited Community Health workers
Wound Care & financial issues (registration fees & support for members)	Invited Community Health workers
Vocational Training/Skills Acquisition, financial issues (registration fees & support for members)	State NTD team
Social Skills, building self-esteem re-engaging with the society, coming out of isolation financial issues (registration fees & support for members)	State NTD team

Figure 3. Meeting topics.

Analysis

Text based data was transcribed and translated verbatim into English and quality checked. Co-analysis of the photovoice findings was conducted using thematic analysis. These discussions were also transcribed verbatim. All qualitative data was then analysed using a thematic framework approach¹² and coded using NVivo 12 qualitative analysis software (QRS International, Burlington,

MA, USA). Thematic analysis of the transcripts identified themes and subthemes from data. Themes and subthemes were refined and validated by co-researchers. We then triangulated emerging themes from the different sets of data collection, including photovoice, rapid micronarratives, semi-structured interviews, participant observation and KIIs, into charts. All analysis was brought together through looking across different charts.

Table 4. Support group members in Kwara

Kwara support group members	Gender	Age, y	Role/health condition	Level of education	Primary source of income	Total
	Female	45–54	Lymphoedema	Other	Agriculture	1
	Male	55–64	Hydrocele	Primary	Agriculture	1
	Male	55–64	Leprosy	Other	Agriculture	1
	Male	45–54	Leprosy	Other	Agriculture	1
	Female	55–64	Lymphoedema	Other	Small scale enterprise	1
	Female	45–54	Leprosy	Other	Small scale enterprise	1
	Male	55–64	Leprosy	Other	Agriculture	1
	Male	55–64	Lymphoedema	Other	Other	1
	Female	45–54	Leprosy	Other	Agriculture	1
	Female	45–54	Lymphoedema	Tertiary college	Civil servant	1
	Male	18–24	BU	Primary	Agriculture	1
	Male	55–64	Leprosy	Other	Day worker	1
	Male	45–54	Leprosy	Primary	Agriculture	1
	Male	25–34	Leprosy	Junior high	Other	1
	Female	45–54	Leprosy	Other	Small scale enterprise	1
	Male	18–24	Leprosy	Other	Agriculture	1
	Male	>65	Leprosy	Other	Agriculture	1
	Male	55–64	Caregiver of relative with lymphoedema	Tertiary college	Civil servant	1
	Male	35–44	Caregiver of relative with caregiver of relative with hydrocele	Primary school	Agriculture	1
	Male	45–54	Caregiver of relative with leprosy	Secondary school	Civil servant	1
	Female	18–24	Caregiver of relative with lymphoedema	Junior high school	Small scale enterprise	1
	Male	55–64	Caregiver of relative with leprosy	Other	Agriculture	1
	Female	45–54	Caregiver of relative with leprosy	Other	Other	1
	Female	18–24	Caregiver of relative with lymphoedema	Secondary school	Other	1
	Male	35–44	Caregiver of relative with leprosy	Other	Agriculture	1
	Female	45–54	Caregiver of relative with BU	Primary school	Agriculture	1
Total						26

Table 5. Support group members in Kaduna

Kaduna support group members	Gender	Age, y	Health condition	Level of education	Primary source of income	Total
	Male	55–64	Leprosy	Other	Other	1
	Male	25–34	Lymphoedema	Junior high school	Agriculture	1
	Female	45–54	Leprosy	Other	Small scale enterprise	1
	Male	25–34	Lymphoedema	Primary school	Small scale enterprise	1
	Male	45–54	Hydrocele	Other	Agriculture	1
	Female	25–34	Leprosy	Other	Agriculture, small scale business	1
	Male	35–44	Lymphoedema	Secondary school	Small scale enterprise	1
	Female	45–54	Lymphoedema	Other	Small scale enterprise	1
	Male	>65	Leprosy	Other	Agriculture	1
	Male	>65	Leprosy	Other	Agriculture	1
	Male	45–54	Lymphoedema	Other	Agriculture	1
	Female	>65	Leprosy	Other	Agriculture	1
	Male	55–65	Lymphoedema	Primary school	Small scale enterprise	1
	Male	18–24	BU	Primary school	Small scale enterprise	1
	Male	18–24	BU	Secondary school	Small scale enterprise	1
	Male	45–54	Hydrocele	Primary school	Agriculture	1
	Male	45–54	BU	Other	Day worker	1
	Male	18–24	Lymphoedema	Other	Other	1
	Female	18–24	Leprosy	Secondary school	Small scale enterprise	1
	Male	25–34	BU	Secondary school	Small scale enterprise	1
	Male	25–34	BU	Other	Other	1
	Female	45–54	Lymphoedema	Secondary school	Agriculture	1
	Male	18–24	BU	Secondary school	Small scale enterprise	1
	Male	45–54	Leprosy	Other	Other	1
	Male	25–34	BU	Other	Other	1
	Female	45–54	Leprosy	Primary school	Small scale enterprise	1
	Female	55–64	Caregiver of relative with lymphoedema	Primary school	Small scale enterprise	1
	Female	25–34	Caregiver of relative with lymphoedema	Other	Agriculture	1
	Male	35–44	Caregiver of relative with leprosy	Secondary school	Agriculture	1
	Male	45–54	Caregiver of relative with leprosy	Other	Small scale enterprise	1
	Male	45–54	Caregiver of relative with leprosy	Primary school	Agriculture	1
	Male	45–54	Caregiver of relative with leprosy	Secondary school	Agriculture	1
Total						32

Results

Social connection and stigma reduction

The support groups have led to a sense of belonging, building relationships and strengthening social connections between group members, families and communities. Support group members in Kaduna and Kwara expressed that they used to distance

themselves from their relatives due to both external and internal stigma. However since attending the support groups, members mentioned now being able to interact closely with their families; for example now eating together from the same bowl as highlighted in figure 5. Many expressed feeling encouraged to talk openly about their feelings and experiences after hearing from others who had similar circumstances.

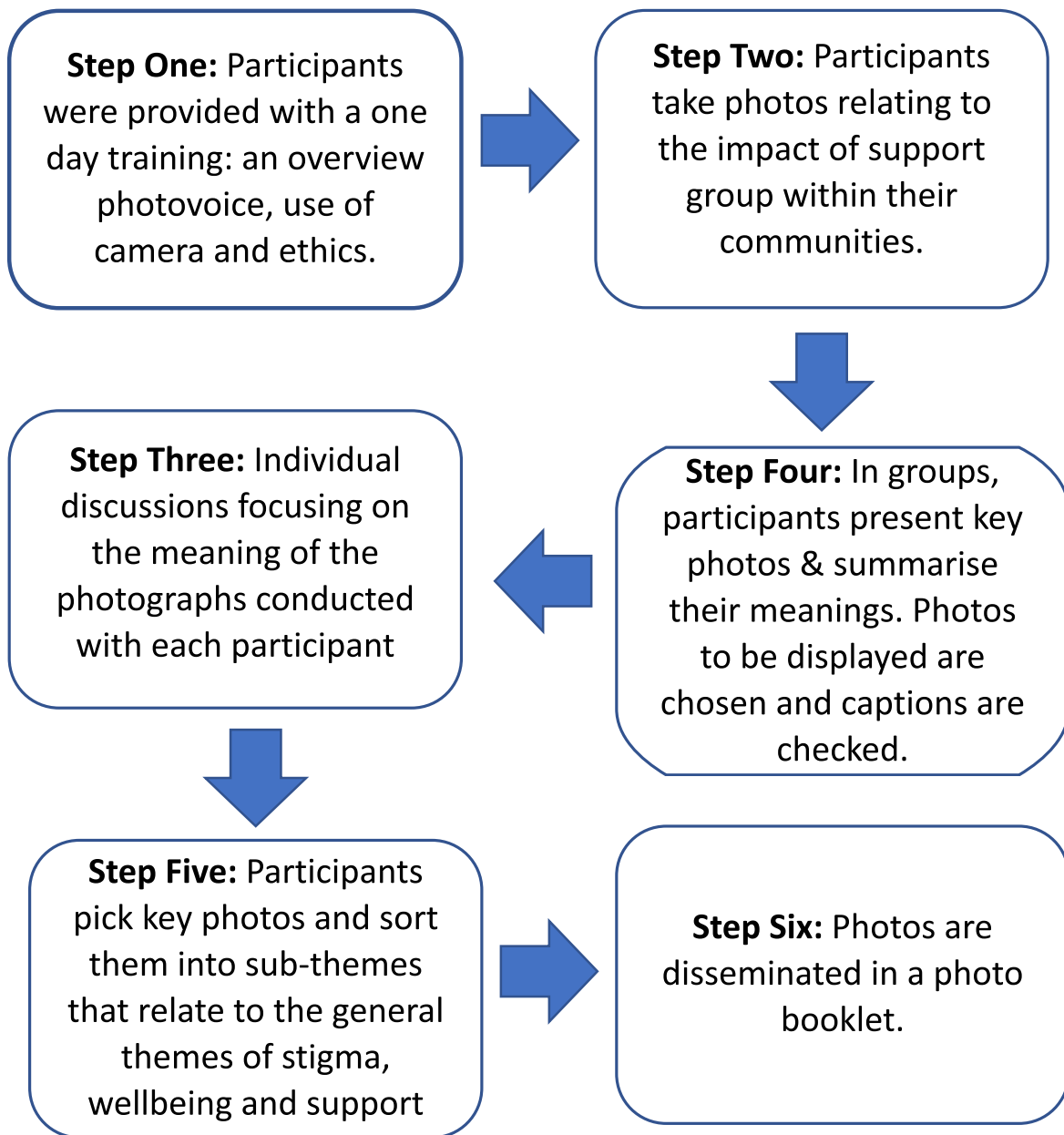


Figure 4. The process of photovoice.¹¹

[A]bout mental health, we discussed the need to associate ourselves with people groups and societies instead of isolating ourselves and being exposed to depression. When we freely interact with people join groups like this, we enjoy peace of mind, and we are happy. (Co-researcher, male, BU, Kaduna).

We were taught not to isolate ourselves and not to allow ourselves to feel like we are less of humans, we should see ourselves as people too who can help others and do things that those healthy may not be able to do and these lessons

have built our confidence and self-esteem (Co-researcher, male, LF, Kaduna).

Support group facilitators expressed becoming more comfortable and familiar with each other as the groups progressed as highlighted through participant observation and photovoice. Improved self-esteem and a significant reduction in internalised stigma were widely reported by support group members and co-researchers. Through encouragement and positive stories from fellow support group members, many expressed now having the courage to participate more within the community. For example, group members described how they now pay less attention to



Figure 5. Social connection and stigma reduction by Habibat Suleiman, female, District support group leader, Kwara.



Figure 6. Social connection and stigma reduction by Adamu Hauwa, female, Ilesha Baruba community group leader, Kwara.

how others look at them, feeling more confident to go out to public places such as markets and mosques (Figure 6). Some support group facilitators also mentioned how the support groups have encouraged them to return to their former occupations following group discussions on strategies to cope with internal and external stigma.

Before now, I would always stay away from other people in the household... thinking to myself that I am ashamed to associate with them because of my condition. But now I am 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 benefited from the support group but our family members too (Figure 5. Habibat Suleiman, female, District support group leader, Kwara).

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. I feel happy that the support group is making the members not to be shy any more (Figure 6. Adamu Hauwa, female, Ilesha Baruba community group leader, Kwara).

The support group has made most of the members to not feel shy about their condition anymore. They now feel better about themselves. I also do not feel shy to stand by them during prayers [at the mosque]. I was thinking that the positive stories that the participants share among each other gives them courage to live a normal life (Issa Sabi, male, Assistant district group leader, Kwara).

Community acceptance and advocacy

The importance of receiving support and acceptance of the groups from the community was highlighted. The community, including religious and community leaders, had become aware of the support groups and often came to observe and support the groups in both states. However, in Kaduna, this also raised challenges in inclusion, particularly in communities where resources are 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.

They are elders of our community. They...heard about the group and have come to encourage us and advise us on how to live in the community and enlighten people concerning our condition. I feel happy how people have accepted the process 100%...I am encouraged by the support received from them (Bashir Ibrahim, Group leader, Community Lere LGA, Kaduna).

Capacity strengthening and independence

Co-researchers and key informants in both states widely 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 strengthened through learning how to operate cameras as well as vocational training such as soapmaking, which has led to many being more accepted in their community (Figure 7). Support group leaders expressed building their confidence to lead and support other members of the group.

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).

The photo represents income. This soap when sold would be a source of money for the group. With this money we



Figure 7. Capacity strengthening and independence by Adamu Hauwa, female, Ilesha Baruba community group leader, Kwara.

can support group members that need assistance and run the group activities with the money. I feel very happy to see that the group will sustain itself with this business (Figure 7. Adamu Hauwa, female, Ilesha Baruba community group leader, Kwara).

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 well-being across Kaduna and Kwara. 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 (Figure 8). 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 LF. The training on wound management and general health was also highlighted as leading to physical improvements in symptoms.

Apart from the vocational skills we were taught, we have also been taught on how to take care of our bodies. Those with leg diseases (lymphoedema) have been taught on how to clean and care for their legs. We were told to make use of clean towels and also how to apply the medicinal ointment (Support group member, female affected by leprosy, Kaduna).

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 (Figure 8. Bashir Ibrahim, male, Group leader from Dan Alhaji community, Kaduna).



Figure 8. Improved health knowledge and health outcomes by Bashir Ibrahim, male, Group leader from Dan Alhaji community, Kaduna.

Programmatic impact

Improved referral was reported as a result of the support group in both states; key informants, as well as support group members, described several instances where the persons affected, after hearing about the support groups, were referred by the research team to the LNTD and Tuberculosis and Leprosy supervisor (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. The impact of the group on the roles of state and LGA staff in both Kaduna and Kwara was also mentioned; LGA coordinators mentioned how the support groups have helped to identify the needs of people affected and to assist them promptly. It has also helped the coordinators with case surveillance, because as more people joined the support group, new cases were identified and this has improved their weekly and monthly reporting at state level. One LGA officer stated that sending his report to his superiors regularly demonstrates that he is doing his job well and he is seen as a diligent staff member.

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 NTD staff, KII, Kaduna).

Sustaining groups

A measure of success of the groups is the growth and increase in membership in both Kaduna and Kwara. The collaboration between the state MoH, the LGA NTD programme and community and religious leaders has been critical in the mobilisation 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 where needed, while also increasing awareness of the groups to encourage others affected by NTDs to join. The ownership of the group by persons affected was also described as a

foundation for sustaining the groups. Initiation of group savings processes through membership fees that can be channelled into livelihood activities was established. Furthermore, skills acquisition training has provided a source of income generation that can also feed into maintaining the groups.

Coming together to carry out these businesses is not a challenge because they agreed to contribute funds so they do not fully depend on anyone. They move around the community to make sales in order to make income for themselves (LNTD staff, KII, Kaduna).

The peer support group is a welcome innovation to integrate those who are affected by disability back into the society and to provide them a means of livelihood. It deserves to be sustained. The group should also be given special recognition at social gatherings and events to also make other people to join. The local government should also create a structure for the group in terms of monitoring and encouragement to help to sustain the support group (state NTD staff, KII, Kwara).

Discussion

Collaborating with people affected by stigmatising NTDs in a CBPR cycle is essential in designing inclusive and holistic interventions to address stigma and well-being. Community-led support groups were a valuable service and resource that brought people affected by similar conditions together, which enabled them to explore solutions to overcome shared challenges and feel supported by others who have had similar and shared experiences. Support groups resulted in significant improvements in physical well-being and mental well-being across states, as reported by participants. Ownership of peer support groups is key to the success and sustainability of groups as they are run by members for members, so the priorities are directly based on their needs and funds have been raised through membership fees.¹³

Empowerment was a key theme from the evaluation that reflects literature on the benefits of support groups led by persons affected that focus on self-care. These benefits have been documented in studies that have evaluated the benefits of support groups for LF in Haiti and leprosy in Mozambique, Ethiopia and Nigeria.¹⁴⁻¹⁶ This study adds to this evidence base, demonstrating the value of integrated support groups, including persons affected by leprosy, LF and BU, as many experienced similar challenges across diseases. Although Kaduna and Kwara were selected because of their geographical variance and sociocultural differences, findings were similar across both states and across conditions, which would indicate that this integrated approach can be applicable in other settings.

The support and strong collaboration of community leaders as well as LGA staff are instrumental in sustaining the groups. The role of community leaders and the state and LGA NTD programmes were integral in their engagement and support of the support groups for increasing recognition and participation within the community; many of these relationships were facilitated by the research team. The CBPR process allowed different levels of stakeholders to form unique relationships and networks that may not otherwise have been possible; co-researchers felt empow-

ered to share their stories through photovoice, which illuminated issues such as mental well-being that had not been prioritised before. Photovoice provided a platform that centred co-researchers with lived experience as the experts of their own lives, providing a holistic story of their illness and experience as opposed to the increasing medicalisation of NTDs.

This evaluation could have been strengthened with a longitudinal quantitative component. For example, the quantitative evaluation of indicators for well-being, such as PHQ-9 to assess depression; SARI Stigma scales to evaluate the different forms of stigma; and the P scale to assess participation, would have been a valuable addition to this study to assess the impact on mental well-being at baseline, midpoint and endpoint.¹⁷ However, using the creative participatory methodology of photovoice was a strength as this method supported co-researchers to share their experiences in an accessible, visual format on the themes of emotion and mental well-being, as well as strengthening capacity to advocate for themselves.^{18,19}

Conclusions

Working in partnership with persons affected, caregivers and programme implementers to co-design and implement community-led support groups can positively impact physical and mental well-being as community spaces of healing. Support groups have had a positive impact on members as they offer a safe space for peer support, particularly for groups who are often marginalised, as well as providing a base for gaining health knowledge and skills acquisition. Co-designing support groups offered a low-cost support intervention for chronic disease and disability in resource-poor settings, with impacts on improved self-esteem and stigma reduction, improved relationships with family and the wider community and improved health literacy. The results contribute to our understanding of ways in which community resources for the case management of NTDs can be utilised. This can inform the establishment of similar community-led support networks in other settings to provide holistic care.

Author's contributions: SC, OA, LD and RT conceptualised the study; AM, TO, EO, LD, OM, JE, OA, SH, MG, RA and SA conducted data collection and led the implementation. All authors conducted the analysis and read and approved the final manuscript.

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Ethical approval: Ethical approval was granted from the Liverpool School of Tropical Medicine (19-091) and National Health Research Ethics Committee of Nigeria (NHREC/01/01/2007-19/11/2019B). Prior to selection, the study was explained to all participants verbally as well as with an information sheet, for those who were literate. Written or verbal informed consent was taken from all participants prior to inclusion in the study. Confidentiality has been maintained within data collection, analysis and dissemination through the removal of all identifiable information from transcripts and analysis accounts, unless specified by photovoice participants. Photovoice requires consideration of the ethical implications related to the ownership of photographs. Participants were given consent forms and asked to obtain written consent from people who appeared in the photographs and informed not to photograph identifiable images of children aged <18 y. Participants were informed how their photographs would be used and shared through photoexhibitions and publications. All data were collected in private spaces suitable for participants.

Data availability: Data can be available upon request from the authors.

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