

COUNTDOWN

Calling time on Neglected Tropical Diseases

EVALUATING THE IMPACT OF COMMUNITY LED SUPPORT GROUPS

FOR PEOPLE AFFECTED BY NTDs IN KWARA
AND KADUNA, NIGERIA





'Alafia Somiru Igberu'

Good Health Support Group, Kwara

INTRODUCTION

Neglected Tropical Diseases (NTDs) often affect the most marginalised groups in society, with Nigeria carrying around 25 per cent of Africa's NTD burden. NTDs affecting the skin often significantly impact health and wellbeing, leading to restrictions in livelihood activities and participation in society. In this project, we sought to understand the lived experiences of people affected by NTDs and their caregivers to co-develop community support groups to address challenges and improve physical and mental wellbeing.

Using Community Based Participatory Research (CBPR), we partnered with affected persons and caregivers as co-researchers in this project. Co-researchers were actively involved in all stages of the research process from training, data collection, analysis and the development and design of the support groups and their evaluation.

We used photovoice, as a creative participatory method, to initially explore experiences of stigma, psychological wellbeing and support.

Our co-researchers took photographs within their communities to capture their experiences¹. Their photos and stories were presented in stakeholder meetings to inform the co-design and implementation of support groups, in partnership between affected persons, caregivers and programme implementers. Support groups to facilitate improvements in both physical and psycho-social wellbeing were established at district and community levels in Kwara and Kaduna States, Nigeria. The impact of support groups was evaluated through photovoice, where support group leaders and members were asked to capture photos in relation to their experiences of the support groups across five months.

This booklet presents the photographs taken by group members to show the impact of the support groups through their lens. It is separated into themes to highlight the key findings from their photos and stories, as they present how the support groups have impacted them individually as well as their communities.

¹ *The findings from the initial photovoice can be viewed here:*

<https://countdown.lstmed.ac.uk/sites/default/files/centre/COUNTDOWN%20Kaduna%20Photovoice.pdf>

<https://countdown.lstmed.ac.uk/sites/default/files/centre/COUNTDOWN%20Kaduna%20Photovoice.pdf>



'Chima Buri Tare'

Getting Through It Together, Support Group, Kaduna

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Sightsavers



UNITY AND TOGETHERNESS

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THEME SUMMARY

***'A person can achieve a little,
but a group can achieve a lot
more when they work together.'***

*Adamu Saleh, Group leader Kayarda community
Lere LGA, Kaduna State*

Participants expressed how the support groups have brought persons affected with NTDs together, despite their health condition, being from different backgrounds, age and gender in supporting each other to improve their wellbeing. Many participants described their appreciation for being part of a group, and highlighted the value of team work and combined efforts to strengthen the support groups through unity, shared learning and encouragement.



They are farmers heading to the farm. One person cannot lift that bag of maize by himself but coming together they were able to lift it up, thereby achieving their goal. Therefore, we must all put in our efforts together to lift up our support group to a higher level just like these people came together to lift up the bag of maize. If we do that, I believe we will all achieve our goal and objectives.

Adamu Saleh *(Male, Kayarda community group leader, Kaduna)*



These are my group members and all of us from different background and culture come together to become a group. **I have learnt to live together with people and be proactive and do something to improve my health and livelihood.**

Esther Musa (Female, Ladimaigam community group leader, Kaduna)



...We are joined together in the group with different kind of diseases with no discrimination. It is important we continue to join hands together.

Adamu Saleh (Male, Kayarda community group leader, Kaduna)



They are a group of goats. I showed the group members how the animals have grouped themselves and are working together to encourage us on the need to grow together as a group.

Adamu Saleh (Male, Kayarda community group leader, Kaduna)



This is a picture of some group members during one of our district meetings, during one of our health talks. The photo represents that the importance of the meetings to the group members. Members make sure they don't miss a meeting day because of the things that would be learnt and the opportunity to interact with one another. The number of people that attend the meeting has also increased since we started, and some people do not mind standing just to listen to the talks to learn how to improve their health and wellbeing. **I feel happy that the support group is bringing people together to learn new things about their health and wellbeing.**

Issa Sabi (Male, Assistant District support group leader, Kwara)

SOCIAL CONNECTION AND STIGMA REDUCTION

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THEME SUMMARY

Many participants described how the support groups have led to a sense of belonging, building relationships, and strengthening social connection between group members, families and communities. Support groups were described as bringing people together in a safe space to interact and share personal experiences with each other without discrimination. Members felt increasing ownership over the groups as their space. The exchange of ideas and working together has led to 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 and therefore feel more confident to go out to public places such as markets and mosques. Participants also described how the support groups have led to strengthening relationships with their relatives; participants expressed being able to eat together from the same bowl whereas before they used to distance themselves. Taking ownership and responsibility for their own wellbeing has led to achieving positive outcomes; participants expressed how interactions and connections in the support groups have given them courage to live and perform everyday functions within the community and in their own homes, with renewed hope for the future.

This is a picture of the community mosque. It represents feeling better about yourself. 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. **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)

This is a picture of some group members during one of our district meetings sitting on a bench, talking with each other. The meeting has increased the way members now communicate and encourage each other about issues relating to their health by sharing personal experiences. **I feel happy that the support group is bringing people together to achieve better health and wellbeing for the group members.**

Hajiya Hauwa

(Female, Ilesha Baruba community group leader, Kwara)





This is a picture of us eating together, my siblings and I. Before, we all used to eat on different plates. This is as a result of the unity I have learned in our group. Just as we are united in the group, we should also be united together with all our family members. It relates how we have been enlightened. I feel very happy because they also agree with what I am saying.

Adamu Saleh

(Male, Kayarda community group leader, Kaduna)



This is a picture of people fetching water at the borehole tap. **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 anymore.

Adamu Hauwa

(Female, Ilesha Baruba community group leader, Kwara)



This is picture of a transformer. The transformer stands alone. It relates to how everything of ours used to be at a stand still. We have become more enlightened with the formation of this group. We used to be in a stagnant position but people are beginning to come close to us now. **That door beside the transformer used to be my business area which was closed because of the sickness on my leg but now another door is beginning to open through this support group, I have also started mingling with other people, this is a great achievement for me.** I feel sad when I look at the closed door but I feel happy when I look at the opened door. **I am happy now because I have high hopes in the future because of this support group and how we are trying to support one another.**

Alhassan Musa (Male, Saminaka community group team leader, Kaduna)



This is a photo of me eating with my family together from the same bowl. The photo shows the progress made so far in our daily lives since we started the support group. 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 benefited from the support group but our family members too.**

Habibat Suleiman (Female, District support group leader, Kwara)

This is a picture of people trading in our local market. I have had discussions with some members of the group who are affected by lymphedema and one of them did not like to go out especially to the market because he felt people would always stare at his legs and that would make him feel bad. But since we started the support group meetings and he heard positive stories from other people about the way they don't feel bad anymore when other people stare at them, he too does not feel shy about going out.

Issa Sabi (Male, Assistant district group leader, Kwara)

The photo shows one of the group members making his contribution to the group. Here in this picture, we were asking for ideas on how to get more people to join us to progress the group and this man made a vital input. **This shows that members are coming out of their shell and are seeing this support group as their own.** Seeing a member contributing their view in the meeting will encourage others to also make contributions. I feel very happy to see that the support group is helping every member to know things they didn't know before and learn new things.

Habibat Suleiman

(Female, Ilesha Baruba District leader, Kwara)





This is a photo of one of our group members and her caregiver after the group meeting, boarding a commercial motorcycle to go home. **The photo represents the progress the group activities has had so far on the way the members feel about themselves.** When we started, she used to trek from home with her daughter to attend the meetings because they were felt that nobody would want to take them on the motorcycle because of her swollen legs, but **since she now knows that she should not look down on herself because of her condition, she now has the courage to stop a motorcycle to board home.**

Adamu Hauwa (Female, Ilesha Baruba community group leader, Kwara)

COMMUNITY ACCEPTANCE AND ADVOCACY

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THEME SUMMARY

Participants highlighted the importance receiving support and acceptance for the group's existence from the community. Many participants illustrated how the community, including religious and community leaders, had become aware of the support groups and often came to observe them to express joy and support for the group.

Leaders were also described as further enlightening the group on how to live in the community and provided their support, asking the members to reach out where they had challenges. Participants described acceptance and advocacy from the community as a great source of encouragement. However, the recognition of the value of the support groups in the community also raised challenges in inclusion as many other members of the community, who did not have NTDs, wished to join the groups.



This is a truck pusher heading to the market. He is a healthy person looking for what will sustain him. There are some group members who could not do this type of hard labour but some of them can now in Kayarda community. This person in the picture once asked if he could join the group. He was captivated by our discussion and stopped to listen, and he showed interest in joining the group. As the chairman of the group in Gunduma Kayrada, I said eligible persons to join the group are only those with any of skin diseases and he doesn't have any of the diseases. I think he can join the group if he is given the privilege because he had shown interest.

Adamu Saleh (*Male, Kayarda community group leader, Kaduna*)



They are elders of our community. They too 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.

Religious leaders prayed for the community group to continue with what it has started. Their prayer and encouragement are a good support to all the activities we do in the group. They encourage us to sensitize other people on every information we receive for the growth of the community. I feel very happy as they have come to identify with us.

Bashir Ibrahim

(Male, Group leader, Dan Alhaji community, Kaduna)



LEADERSHIP

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THEME SUMMARY

Support group leaders expressed feeling happy that their positions have given them the opportunity to lead, organize, motivate and support other members of the group into participating and learning together. Habibat, a support group leader in Kwara, who is a health worker and also affected by lymphedema, expressed how the opportunity to lead has helped build up her courage and confidence in speaking publicly; she describes encouraging other people to attend the group because of the benefits and outcome seen so far in her own health and that of other members.

The photo shows the opportunity the support group has given me to be a leader and improve on myself and the lives of others like me as a health worker. **Before now, I used to be very shy and would not come out and speak. But now I have to lead the support group and encourage people to attend because of the benefits and outcomes I have seen so far in my health and that of other members.** I feel very happy for the opportunity to lead. I am very grateful.

Habibat Suleiman

(Female, District support group leader, Kwara)



This is our community group meeting where we discuss on how to move the group forward in my community. We work together to see that this group progresses and that means we agree on certain decisions so that all of us have a skill that will bring in resources for us. **The things I have learnt in the district meetings has helped me and boosts my confidence as a leader in my community,** such that I am able to communicate it to my group members and they in turn can teach others and bring them in.

Esther Musa *(Female, Group leader, Ladimaigamo community, Kaduna)*





The photo represents good health and progress. It shows that I can stand well on my leg to mix the liquid soap and even though I am on duty on this day, I still created time for my support group meeting because I know there are always new things to learn any time we come together for a meeting. I was thinking that being a health worker and also a member of this support group will encourage people to join this group and we are all learning together. No matter how busy I might be at the clinic, I always note my community meeting days to ensure I don't miss it.

I feel great seeing that we are all learning from one another and are encouraged not to miss the group meetings.

Habibat Suleiman

*(Female, Ilesha Baruba
District leader, Kwara)*

LEARNING, ENLIGHTENMENT AND IMPROVED HEALTH

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THEME SUMMARY

The support group meetings were described as providing spaces for learning, which has led to improvements in both physical and mental wellbeing. The participants expressed their joy that the support group has enabled them to take care of themselves and emphasised the value of 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 participants described how they have put their learning into practice which has significantly improved their health and wellbeing; a participant with lymphedema described how the training on wound management has now led to reduced swelling in her leg and now being able to move more freely.



This is the photo of a drainage along one of the roads I pass. The photo helps me to explain a big difference in how I feel and some of the results of the health talks during the support group meetings. **After the health talk when we were taught how to take care of lymphedema and reduce the swelling, I began to practice what I was taught and as a result of that my legs don't swell so much again. Now I can jump across drainages like this.** I feel very happy because before, I would avoid crossing drainages like this and search for other routes because of my swollen legs but now I can cross it easily.

Habibat Suleiman (Female, Ilesha Baruba District leader, Kwara)



This relates to hygiene. As you can see the ducks are walking in the gutter. I encouraged the community to make sure the gutters are clean because the mosquitoes that transmit the diseases live in the gutter. I feel happy because I understand what is happening by joining this group and I am making effort to enlighten those that just joined the group.

Adamu Saleh

(Male, Kayarda community group leader, Kaduna)



This is an electric bulb. The picture show how we are now enlightened, we didn't know about the group but are now members and have benefited from the support of the group. I thought of how we were in the dark...now light has shone on us. I feel happy because we didn't know much but through this support group a lot have been communicated to us and we hope to get more knowledge. **We hope that the group will progress further and will keep shining just like the light and grow from the level it is.**

Bashir Ibrahim

(Male, Group leader Kayarda community, Kaduna)



This is the picture of me assisting my mother to wash her swollen legs. **The photo represents the things we learnt from the support group meeting. The teaching by the health worker on how to care for swollen legs of a lymphedema patient was very useful for my mother and me.** I now know how to assist her to take care of her legs and I also always remind her to do all the things the health worker said, like raising it at night when she sleeps. I was thinking of the benefits of this teaching to members of the group. My mother feels so much better now and her swollen legs is not heavy like before. I feel very happy to learn more about lymphedema.

Sakirat Ibrahim (Female, Support group secretary, Kwara)



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. I thought of the condition we were in before, the position we are now is in the form of a room with ventilation. I took the picture as a reminder to our former state because if you notice one of the window is closed and the other one is wide open, the closed one represent us when we knew nothing, and the one open represents us now with our eyes open to so many things as a result of the support group and we are glad to be part of it. I am happy because as a group we are taught how to maintain good hygiene, I can now mingle with people, take care of my house, and eat a good diet.

Bashir Ibrahim (Male, Group leader, Dan Alhaji community, Kaduna)

This is a picture of one of our community meetings. Group members are sitting down to talk about things that affect us as a group and as individuals. The photo represents support. **This group has served as a source of support and encouragement for so many of the group members. We talk about our challenges and other group members suggest ways to overcome it.** The group has helped both physical health and also mental health. I feel happy that the support group is getting stronger every time.

Issa Sabi (Male, Assistant district group leader, Kwara)



This is the picture of toothpaste. It represents one of the lessons we have learnt so far from the health talks in the support group meetings. The health worker advised us on the importance to keep good hygiene. I was thinking that we have learnt a lot in the health talks, and I should share what we have learnt in the group so far. I also like that after brushing your teeth you feel bold enough to smile and talk to anyone. **I feel very happy that we are learning how to take care of our body and health. Now we can share what we learn with other members of our households.**

Sakirat Ibrahim (Female, Support group secretary, Kwara)





This is the newly renovated hospital in our district. It represents good health. **Some people who are affected by lymphedema rely on local herbs, but the members of the support group have stopped using herbs since they listened to the health talk at the support meeting, they see the importance of visiting the hospital for their drugs and mosquito nets and they also advise others to do so.** We are lucky that the hospital has just been renovated in our district. **The support meeting is a place to learn about how to improve our health. I am happy to see many of our support group members now advising others about taking care of their health.**

Issa Sabi (Male, Assistant district group leader, Kwara)

**MOVING
FORWARDS,
PROGRESSION
AND PERSONAL
GROWTH**

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THEME SUMMARY

Participants expressed through photos how the exposure and knowledge they have received from the support groups have translated to progress for them individually, as a group, as well as their communities. Growing trees and a structure of a house were used as a metaphor to describe the formation and growth of the support groups. While the groups were described as being stagnant at first, participants describe how they have grown and become established through increased membership in communities. Participants expressed that they now have good knowledge of their health and how to stay healthy, and that community members are also benefitting from the group through their shared knowledge. Personal growth was recorded by participants who described progress socially and mentally, through relating with people freely, feeling good about themselves and being more confident in the community. They mentioned there is now a difference between who they were before and who they are now since the group began.

This is the picture of a house. This photo represents the support group. A group is like a building that houses people and they live together there. When we started the group, it didn't have a form or shape but as we continued receiving information and teachings now it has taken a particular shape like this house. This shows that we are working together and there is understanding among us.

Esther Musa (Female, Group leader
Ladimaigamo community, Kaduna)

The pawpaw tree was not as big as it is now, so I relate to how our group has grown to the extent that we must check our membership list to know the members, that is why I took the picture. **The group has grown and enlarged as the tree has grown branches with larger green leaf which signify the tree is in good condition. Most of us were not like this before this project started but now, we look good socially and mentally because we know how to manage and take care of ourselves.**

Bashir Ibrahim (Male, Group leader *Kayarda community, Kaduna*)





Like this farm our group started small but it is now sprouting and ready to bear fruits that the entire community will benefit from.

Alhassan Musa

(Male, Group leader, Saminaka community, Kaduna)



Usually, trees from their roots grow and spread and this shows to me that this group started as one and now it has other groups under it and many communities are now benefitting from it. The group has spread, and people can now enjoy it.

Rebecca Ayuba

(Female, Ladimaigamo community group member, Kaduna)

This photo expresses the joy in my heart as regards to this support group we established in our Local Government Area and communities. When the support group in the community, which I facilitate, started, it was at a standstill, because members were not coming for meetings. Then I had to follow them up and encourage them on what we stand to gain as a group regarding all that we have been taught. Then suddenly events started happening and **we started moving forward just the way we ride a motorcycle forward and not backward.** People started taking the support group seriously and coming for meetings, sharing ideas, and contributing, even new members from the community decide to join us because they have seen the benefit of our first meeting. They were impressed with our discussion and how we are willing to push each other forward.

Alhassan Musa

(Male, Group leader Saminaka community, Kaduna)





This is the picture of group members during one of our community meetings in Bode Babana ward. **The photo represents freedom. The group members see the group meetings as a place to talk and are free to talk about how they feel.** When we started, group members were not too free to talk and share ideas and experiences. But as the meeting progresses, members now are eager to listen to each other share experiences and also give words of encouragement when necessary. I feel very happy to see that the group is really a place where we support each other.

Koto Yerima (Male, Bode Babana community leader, Kwara)

**REVIVING
LIVELIHOODS,
INDEPENDENCE
AND HARNESSING
GROUP
CAPABILITIES**

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THEME SUMMARY

This theme depicts how the activities in the support group meetings have contributed in harnessing, developing and strengthening the skills, instincts, abilities, processes and resources of group members. Persons affected as well as caregivers mentioned benefitting from the vocational training and expressed the need to survive, adapt, and thrive in a world where their source of livelihoods were disrupted both due to physical impairments of the illness as well as associated stigma. Participants expressed their happiness to have learnt new skills from each other that can give them new streams of income. Some other participants also mentioned how the support groups have encouraged them to return to their former occupations as a result of the motivational talks on strategies to cope with internal and external stigma, as emphasised in the theme on social connection and stigma reduction. Many participants expressed the importance of how skills sharing, has led to ownership and independence. One participant described how he has been transformed from the group, through learning how to operate cameras as well as make soap, which has led him to now be more accepted and popular in his community through being associated with the support group.



This is a picture of women in the group making soap. The photo represents support. We decided to support ourselves in the group by making soap in large quantities to sell in the market. The meeting has been able to make participants engage in business by making soap and sell it to get income to run the group. This would help us sustain the finance of the group for it to run smoothly. **I feel happy that the support group is making the members not to depend on any one for money.**

Adamu Hauwa (Female, Ilesha Baruba community group leader, Kwara)



This is the picture of soap making. **The photo represents the things we learn from the support group meeting. The meeting is very good because we learn new things that help us to improve our life.** I was thinking of the benefits of this teaching to members of the group. We were told how to make liquid soap in the group, they could sell it and make money or they could use it in the homes and save money for buying soap.

Sakirat Ibrahim

(Female, Support group secretary, Kwara)



This is the picture of the soap the group made to be sold in the market. The photo represents income. This soap when sold would be a source of money for the group. With this money we 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.

Adamu Hauwa

(Female, Ilesha Baruba community group leader, Kwara)

I sew. My wife snapped the picture and imagined how we would cope without a business. She is encouraging the group members to learn a trade to be independent. I feel satisfied because I can sew, and I have those that are learning under me. I took the picture to encourage the group members on the importance of learning a trade. I am happy again we will be taught how to make body cream, soap, for everyone to be independent.

Adamu Saleh

(Male, Kayarda community group leader, Kaduna)





This is the picture of meat sellers in the market. The photo represents hope. My brother used to sell meat at the local market before he was diagnosed with leprosy. Since the group, he started having the courage to go out more often and seeing people in the market, he says he has hope that one day he would be able to go back to his trade. **I was thinking that whenever we have anybody that is sick around us, we should encourage each other and make each other feel good about ourselves instead of making them feel bad, it helps them to get better quickly.** This is what I have learnt from the support group. I feel very happy to see that the group is really a place where we support each other.

Koto Yerima (Male, Bode Babana community leader, Kwara)

The well is old and closed, it signifies how a person can be secluded from everything. It relates to how the group was dormant but now we sincerely see the essence of the group. I can now operate a camera just by joining this group and learn the business of soap making to be independent. **I don't feel happy when I look at this picture because it reminds me of my former state but things are beginning to change now.**

Alhassan Musa (Male, Group leader Saminaka community, Kaduna)

They are carpenters roofing a house, they are all working and that is why it is good to own a business. I just felt happy how they are independent of themselves. You see they have helped us by teaching us this soap making business and in a short time it will sustain us to take care of ourselves.

Adamu Saleh (Male, Kayarda community group leader, Kaduna)





As a result of the organization, we have been transformed and can make soap, snap pictures and we are grateful. The organization has benefits me in the sense that I have become a popular person by associating with the organization. I have shared with the people in one of our meetings about a type of savings where we contribute a sum of N100 every month... now the money has accumulated to some level. In some time, the money will be a good capital for us to make the soap and for everyone of us to sustain ourselves. We will sell them at a very affordable price instead of buying other detergents that are expensive, that way the community will benefit including those who are not members of the organization. **I feel happy within me because I know we have progressed.**

Adamu Saleh (Male, Kayarda community group leader, Kaduna)

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