COUNTDOWN

Calling time on Neglected Tropical Diseases

SKIN STORIES

LIFE THROUGH THE LENS OF AFFECTED PEOPLE IN KWARA, NIGERIA

Sightsavers

LSTM
LIVERPOOL SCHOOL OF TROPICAL MEDICINE

UKaid
from the British people

KWARA STATE GOVERNMENT

FEDERAL MINISTRY OF HEALTH

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INTRODUCTION

Neglected Tropical Diseases (NTDs) affect around one billion people globally who are often the most poor and marginalised groups in society. Nigeria carries around 25 per cent of Africa's NTD burden. NTDs affecting the skin (for example Buruli Ulcer) often lead to long-term functional limitations and disability, significantly affecting health and wellbeing. Associated stigma can also have disabling impacts through restrictions in livelihood activities, participation and social interactions. Despite these significant impacts, the long-term health and psycho-social needs of persons affected by NTDs are often overlooked in integrated NTD programme design and research. In this project, we sought to understand the day to day experiences of people affected by NTDs and their caregivers through photovoice.

Photovoice is a creative participatory method, which aims to empower participants to tell their own story. Over the course of two weeks, people affected by NTDs and their caregivers took photographs within their communities to capture their experiences.

The process involved training of photovoice participants on the use of cameras and ethics of photography. Co-researchers who were people affected by NTDs were recruited as part of the research team to train and support other affected persons within their communities to become photovoice participants. After the two weeks of photo-taking, participants came together to discuss their photographs and experiences and cluster them into themes.

This booklet presents the findings of the photovoice activity. The booklet is separated into themes identified in partnership with participants, including impacts on functioning, stigma, psychological wellbeing and support. These photos will be presented in stakeholder meetings to inform the co-design and implementation of support groups, in partnership with affected persons, caregivers and programme implementers. We aim to show the realities of people affected by NTDs through their lens.

This project took place in Baruten, a purposively selected Local Government Area (LGA) in Kwara State, Nigeria.

BEHIND THE LENS

PHOTOVOICE PARTICIPANTS

Kwara Photovoice Participants

My name is Aishat Adamu and I am 36 years. I am a housewife and affected by leprosy. Photovoice has made me realise that our thoughts and what we go through can be expressed through photos. I am from Ilesa community and I am a participant in the wellbeing study.

My name is Musa Alfa Shero and I am 60 years of age. I am a participant in this wellbeing research and I am a person affected by leprosy. This condition has been on for the past 20 years and first symptoms was pains all over my body and then it was confirmed it is a skin disease called leprosy.

I am Adamu Sabi. I am 40 years old. I am a person affected by leprosy. My leprosy started 4 years ago. I am glad to be a participant in this study.

Aliyu Fatimah Agee, I am 18 years old. I am a student and living with my father. I am a person affected by lymphedema. It started 5 years ago, it started with fever, cold and headache overnight. I am from Gwanara and I am a participant in the wellbeing study. My experience with photovoice is such that I can snap pictures by myself and give it a meaning relating to my condition, it is such a good experience.

I am Hajara Audu. I am 42 years old. Five years ago, I had fever and swelling on my legs, that was when I got diagnosed with lymphedema. I am one of the participants in this research.

I am Dembo Sani, 50 years of age, I am married and a farmer. I am affected by lymphedema and this started 5 years ago. It started with a serious fever, joint pain, itching and tightness on my left leg, then it gradually became swollen.

My name is Lawal Jimoh and I am 60 years of age. I am a person affected by Hydrocele and I have been living with this condition for the past 5 years - it all started with stomach pain and it later develop into hydrocele. I am from Tumbuyan community in Ilesa baruba and I am happy to be part of this research.

My name is Zaniab Yakubu, I am 54 years old and I am affected by lymphedema. It started 10 years ago, I notice my legs were seriously hurting and heavy. My experience with photo voice has made me realise the importance of healthy living and how to get necessary support to improve our health and wellbeing.

I am Sekinat Audu, I am 18 years old. I am a caregiver to Audu Hajara a person affected by lymphedema. She is my mother.

My name is Mohamed Saliu and I am 18 years of age. I am a person affected by leprosy and this condition started 2 years ago and I have been having symptoms of wounds on my hands and foot. I am from Ilesa baruba. I am a participant in this wellbeing research.

I am Koto Yerima and I am 45 years of age, I am from Bode community and I am a caregiver to the person affected by leprosy. I have been taking care of my father ever since we discovered he has this skin condition. My Photovoice experience has been a wonderful one because it actually made me realise my effort in assisting my father.

My name is Adamu Hauwa, I am 51 years old, married and a Civil servant. I am a caregiver to the person affected by leprosy. My experience with photovoice has taught me the importance of food and fruit to improve the wellbeing of my sister. I am from Ilesa community and I am a participant in the wellbeing study.

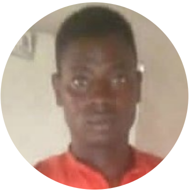
I am Yusuf Yahaya Agee. I am 52 years old. I am a caregiver to Fatima Agee, she is affected by lymphedema.

My name is Issa Mohammed Sabi, I am 56 years old, married and a Civil servant. I was a caregiver to the late Ibrahim Saidu, who was affected by lymphedema. I am from Gwanara community and I am a participant of the wellbeing study.

I am Idris Kareem. I am 50 years old. I am the father and caregiver to Dauda Idris a young boy affected by hydrocele. I am one of the participants in this study.

I am Ishaik Yaru and I am 45 years old. I am a caregiver to Mohammed Saliu a person affected by leprosy.

I am Modinat Tone and I am 40 years of age, married and a full house wife. I am person affected by leprosy and it started 15 years ago. I noticed discoloured patches on my fingers, serious itching, stiff, thick and dry skin that later led to my limbs folding. My experience with photovoice has been good because this kind of research makes the world know what people are passing through and provide support where necessary.



I am Ibrahim Tairu, I am 29 years of age, single and I am a farmer, living with parent. I am a person affected by lymphedema. It started 6 years ago, it starts like an internal bite on my right leg while helping my parent with farming. It was so painful and days after, my leg started growing bigger and bigger till date. My experience with photovoice has taught me that my condition and wellbeing can be expressed with photos and people will also understand it without much explanation.

PHYSICAL FUNCTIONING AND PAIN

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THEME SUMMARY

The physical impact of conditions on day to day functioning was mentioned across participants. This was often in relation to pain and discomfort which could worsen when completing daily activities such as cooking. Conditions were mentioned as depriving and hindering participants from being able to partake in activities they were able to do before the illness. Many participants described these limitations as leading to periods of sadness or distress. Physical limitations ranged from Modinat Tone, a woman affected by leprosy having difficulties in being able to feed herself due to limited functioning of her hands, while Fatimah Agee, a younger woman affected by lymphedema mentioned no longer being able to wear shoes and dresses they could previously wear before. Men affected by hydrocele and lymphedema mentioned no longer being able to break firewood and difficulties in moving.

To feed is very difficult for me, I can't do anything with my hands, I have no source of income. I am not happy seeing myself in this condition. My family are always scared of what the community will think.

Modinat Tone

(Younger female affected by Leprosy)

I used to be a very hard working young guy, since this leg started I can't even do things for myself. This photo depicts pain and discomfort, I could cook with firewood but now I can't, any time I move close to fire, my leg hurts badly. Moving from one place to another also has been affected because my swollen leg is heavy. I can't farm, my suya business has stopped because of my condition.

Ibrahim Tairu

(Younger male affected by Lymphedema)

This is photo of beautiful shoes with heels. I cannot wear them because of my swollen leg. The shoes have heels which makes it difficult for me to wear them, my legs hurt badly if I wear heeled shoes. I feel unhappy because I bought these shoes when I was healthy, and I cannot wear them again.

Fatimah Agee
(Young female affected by Lymphedema)

This is a picture of my mother's slippers. This is the only pair she can wear because her legs often get swollen as a result of her illness. This picture reminds me of the limitations the illness brings to my mother's lifestyle. I feel sad because I see how other people wear nice shoes and my mother is not able to wear nice shoes anymore because they don't fit her swollen legs.

Sekinat Audu
(Caregiver to Hajara Audu, an older person affected by Lymphedema)

It is my sister's leg, the photo shows some of the condition of her leg as a result of her illness. The injury on the leg is one of the side effects of leprosy. I feel sad because these injuries make her feel uncomfortable especially when the ground is cold or wet. I wish we had the right ointments and drugs to make her condition better.

Adamu Hauwa

(Caregiver to Aishat Adamu, a younger person affected by Leprosy)

IMPACT ON SOURCE OF INCOME AND LIVELIHOODS

COUNTDOWN

Calling time on Neglected Tropical Diseases

THEME SUMMARY

The impact of NTDs and poverty was intrinsically linked for all participants, including caregivers. Livelihoods were disrupted both due to the physical impairments of the illness as well as stigma; male participants mentioned no longer being able to work on farms due to pain, while stigma affected a male participant's business. Women also lost their sources of income through laundry and selling charcoal. Participants expressed their distress at no longer being able to support their families. The financial burden of caregivers was also highlighted; for example, Modinat Tone, a woman affected by leprosy mentioned relying on her children financially while Adamu Sabi, a man affected by leprosy described now requiring his daughters to help him with the farm to support the family income. He mentioned his sadness in no longer being able to fulfil his gendered role of providing for the family. Some participants had adapted their livelihood strategies, for example, older male participants mentioned the need to pay for medicines and therefore raise and sell small livestock such as goats and chickens in order to provide for themselves.

It shows my daughters helping me on my farm, I can't work on my farm because of my condition…my sores cause serious pain whenever I try to farm. My daughters have been very supportive, this is our only source of income - if they stop helping on my farm, that means we will have to become beggars to earn a living. I feel very sad knowing too well that I am the one who is supposed to be working for my farming just like other men or I would hire men to work for me but I am not financially capable to do that…seeing my children working for me on my farm makes me feel bad.

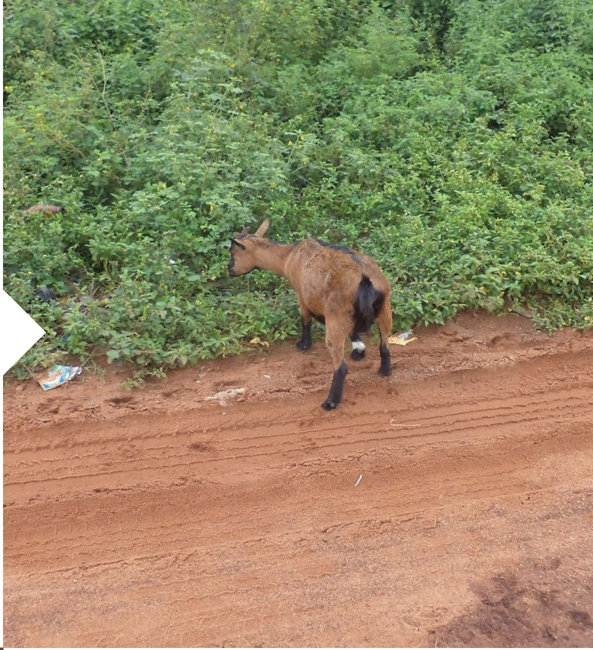
Adamu Sabi

(Younger male affected by Leprosy)

This goat represents a source of my livelihood. I sell these goats whenever there is a need for me to buy things or get medicine for my wellbeing. I just take one or two to the market to sell and use the money to cater for my needs. My main means of livelihood is farming, I have a tomato farm and I also rear goats and this is where I get the little money I use to take care of myself.

Musa Alfa

(Older male affected by Leprosy)



When I was healthy I use to help people to do their laundry and I get paid for my services, now because of the way my fingers are I cannot again. I feel very sad. I really wish and pray to God I get the help to get well again.

Modinat Tone

(Younger female affected by Leprosy)

I just passed by the shop and wished that I had this kind of business to have enough money to assist my brother with his condition. The picture represents a good source of income for me to be a better person and in assisting my brother. Most of his basic needs require money and I should be able to support him as this will aid his quick recovery of his condition… because he cannot do anything by himself due to his present condition (leprosy).

Musa Guruma

(Caregiver to Matthew Tartatha,
an older person affected by Leprosy)

This is charcoal my children are the one helping me financially, there is no other person that assisting me financially apart from my children. No group helps me. It is a very good source of income during rainy season like this, people cannot use fire wood because they are wet due to constant rain, people buy it in sacks and portion them into smaller size. I need support to take care of my family.

Modinat Tone

(Younger female affected by Leprosy)

I rear these chickens and this is where I get money to buy medicines and any other thing I need for my wellbeing. These chickens serve as a source of income to me. I also kill some to eat.

Musa Alfa

(Older male affected by Leprosy)

I make these wood into charcoal and sell. Before I had this ailment (Hydrocele), I usually made them in large quantities but my condition has really deprived me from making it…I am only able to make this in small in quantities so I can get money from it too. Had it been I am healthy, I would have done this charcoal business on a large scale but my condition has really hindered me from doing such but with the little I am doing, I am grateful for it and it serves as another source of livelihood and support to me.

Lawal Jimoh

(Older male affected by Hydrocele)

When I was healthy, I had hectares of farmland where I planted rice and I used to have enough sales… but when my condition started, It was very difficult for me to go to the farm and plant rice and gradually I lost my rice business to this condition. This picture made me remember my rice farm and I wish I still had it because rice is one of the most staple food in our society today and doing business in this area will serve as a means of livelihood. I sincerely need support so that I can do something meaningful with my life.

Lawal Jimoh

(Older male affected by Hydrocele)

I took this photo because money answers all problems. If I had enough money I would get the best treatment for my daughter, I would send her to the big town to stay because that is where most of her friends are. But her illness has made her stay back at home. I took the photo to show that with enough money you can get access to the best of whatever you want.

Yusuf Yahaya Agee

(Caregiver to Fatimah Agee, a person affected by Lymphedema)

I took this photo because it is this job that brought me to this town. [But] nobody is patronizing me, I have been stigmatized because of my condition. My condition has made living very challenging. [With] no source of income, I depend solely on my small farm.

Ibrahim Tairu

(Younger male affected by Lymphedema)

STIGMA

THEME SUMMARY

Lived experiences of stigma were documented by participants and described as causing psychosocial distress, particularly for men and women affected by leprosy and lymphedema. Experiences of stigma manifested as internalised, enacted and anticipated and some cases of hereditary stigma were also described. Internalised stigma relates to how individuals perceive themselves; this was illustrated through an example of a young woman affected by lymphedema no longer feeling able to wear her old clothes as they cannot conceal her leg. Desire for concealment also related to previous experiences of enacted stigma. For example, Mohamed Sailu, a young man affected by leprosy expressed feeling depressed due to no longer having friends or being able to participate in the same activities as his peers - his experiences of stigma were related to visibility of his wounds. Enacted stigma was experienced through verbal abuse, exclusion and segregation. For example, many participants affected by leprosy illustrated their experience of being forced to live isolated away from the community and their families, which sometimes led to additional health risks. Anticipated stigma was illustrated by participants being unable to take certain routes through the community due to risk of verbal or physical abuse, which they attributed to fear within the community regarding their condition. Finally, stigma also extends to relatives and caregivers in association (hereditary stigma). The emotional impact on caregivers was also described as they expressed their sadness for the way their relatives are treated in the community.

The reason why we took this photo is because my condition crippled my fingers. I can't do anything with my fingers…I feel bad because I can't do what children of my age can do, I can't play football, I can't go to farm, no support, no help from anybody; Yes, I do go out, I suffer stigma, people don't want to associate with me. It is very depressing, all my friends, we grew up together are no longer my friends. They are scared of my condition, I have wounds on my leg, my hand. People feel irritated with the wounds.

Mohamed Saliu

(Younger male affected by Leprosy)

This is one of my clothes that I love, my inability to wear beautiful clothes that I would love to wear represents discomfort. The dress is beautiful but short and I am not able to wear it because it cannot cover my swollen leg.

Fatimah Agee

(Younger female affected by Lymphedema)

This picture shows how I have been stigmatised because of my condition (Leprosy). We are not allowed to live where other healthy people stay and I am not happy seeing that we are separated from others. This picture also represents the pain I go through staying in the bush as it exposes me and my family to mosquitoes, black flies and other dangerous things around us.

Abdulmimini Hussain

(Older male affected by Leprosy)

This illness has made my mother stop her food selling business. My mother makes food and sells before she got sick. People around often avoid my mother because of her illness, this affected her cooking business negatively. That was why she stopped it. The heat from the fire while cooking also hurts her legs.

Sekinat Audu

(Caregiver to Hajara Audu, a person affected by Lymphedema)

This photo shows the place my brother is allowed to sit. He is often stigmatised when he is among his peers due to his illness (leprosy). I feel sad, because stigma is more damaging to the patient's health than the illness itself. I took this picture to show that stigma is bad and should be discouraged. Treating sick people well goes a long way to help them heal faster.

Ishiak Yaru

(Caregiver to Mohamed Saliu, an older person affected by Leprosy)

This is the well where we fetch water. It is the source of water for us, but when we go there to fetch water, people always chase my children and I away. They do not allow us to use it. I need help to educate people that the disease can be treated and it is not contagious if treated.

Modinat Tone

(Younger female affected by Leprosy)

This is my house. I feel sad because this is not how my house should be but am forced to stay here because of my condition. I am being stigmatized so my family members brought me here. [People] insult our family members by calling them names of my condition. Now that I have left that community, they have stopped being stigmatised.

Aishat Adamu

(Younger female affected by Leprosy)

This is my father's room. He stays here alone because he is isolated from everyone else. I feel sad, because he is sometimes stigmatised and treated badly in the community because of the nature of his sickness. He does not have friends and spends most of his time alone in this dark room.

Koto Yerima

(Caregiver to Abdulmumini Hussain, an older person affected by Leprosy)

QUALITY OF HEALTHCARE

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THEME SUMMARY

Access to and quality of healthcare emerged as a key theme. Access was challenging due to distance to health facilities, often through poor road conditions, and a lack of availability of transportation. Dembo Sani, also described that the physical limitations they experienced made travelling for care more difficult. Fear of attending health facilities was also depicted; however, Matthew Tartatha, described that having understood the importance of reporting cases early and having been treated himself, he now encourages and informs others with similar conditions to seek medical help. Participants also indicated that quality of services was a key barrier to health seeking, for example, infrastructure and equipment available at facilities was often poor or lacking and this often acted as a deterrent to health seeking. Limited availability of medicines was shown by many participants and resulted in medicine substitution / mis-use when those required were not available. These health seeking challenges strongly impact the wellbeing of participants and their ability to receive appropriate treatment or management of their condition.

This is my basket of medicines kept inside my room. I use some of these medicines when the need arises even though these are not the real medication for my condition. I use these for itches and pains whenever there is no medication for leprosy treatment on ground.

Musa Alfa

(Older male affected by Leprosy)

This is a picture of a car although it is not mine. I took this picture because I like it as a better means of transportation instead of the bicycles or motorcycles or even trekking when going to the hospital. I believe having this kind of car will make my transportation to places easy most especially when I have to go to the clinic. The road to the clinic is so bad which makes trekking there cause a lot of discomfort to my swollen leg.

Dembo Sani

(Older male affected by Lymphedema)

This leg is actually one of my neighbours' and she's affected with leprosy, also facing the same pain and discomfort like me. This person did not want to report herself just like me when I first had it but after I started receiving treatment, I feel a lot better and I wish this person also gets better too. This picture made me realised that reporting an illness early could assist in its treatment. Although I didn't report early but the treatment so far has improved my wellbeing so whenever I see anyone with any condition like mine, I do not hesitate to inform such a person to seek medical help.

Matthew Tartatha, co-researcher

(Male affected by Leprosy)

My brother goes to this store to buy medicines to ease his pain but he never gets the right medicine to use. This photo depicts lack of adequate medicines to treat my brother's illness. I feel sad about this situation and I hope he gets support to get adequate treatment to make him feel better.

It is the picture of the hospital. It is dilapidated and falling apart, windows and doors are missing in some of the rooms. The hospital is the closest to where my patient can get health care but because it is in a poor condition, he has to travel to another community to access health care. This is tiring, and even more expensive for him.

Issa Mohammed Sabi

(Caregiver to Ibrahim Saidu,
an older person affected by Lymphedema)

This photo shows the only sphygmomanometer we have in our hospital. We can't attend to more than one patient at the time because we don't have the tools to do that. I took this photo to show how lack of equipment reduces our capacity to attend to the patients at the time they may need our services. Looking at this photo, I feel concerned.

Adamu Hauwa

(Caregiver to Aishat Adamu,
a younger female affected by Leprosy)

This is a photo of a hospital signboard. I took this photo because whenever we see this signboard, we know that help is nearby, and we can always take our sick people there when they feel ill. This is one of the hospitals in our district that most people go to, I wish they had more equipment so that they can offer more help to sick people.

Adamu Hauwa

(Caregiver to Aishat Adamu,
a younger female affected by Leprosy)

I go through trekking from our camp to town where we can have access to health facility, the road is very bad, most time crossing the river is very dangerous, getting our medicine to stay healthy is not easy because of the bad state of the road.

Aishat Adamu

(Younger female affected by Leprosy)

RELATIONSHIPS WITH OTHERS, SUPPORT AND ACCEPTANCE

THEME SUMMARY

Caregivers presented different ways in which they support affected persons to complete daily activities. The reasons they provide this support were illustrated as to mitigate against pain through the application of ointments and ensuring medicines were taken on time, as well as trying to reduce additional environmental vulnerabilities by going to collect water where mosquitoes are. Provision of financial support was described as causing concern, particularly when people with NTDs had to beg at the local mosque.

This is an image of a wall clock. The importance is that it reminds me of the time to give my sister medication and time to eat her meals. I am happy I am educated enough to read the time. Administration of medication that has to do with timing has made things easy for me and my sister because if she takes her medication at the right time it makes the medicine work better.

Adamu Hauwa

(Caregiver to Aishat Adamu,
a younger person affected by Leprosy)

This is the photo of our mosque where we worship where my brother often goes to beg for alms so that he can afford to buy his drugs. I feel disturbed, because I am not always happy when he has to go and beg people for money to get his drugs because they are expensive. He does not work anymore because of his illness.

Issa Mohammed Sabi

(Caregiver to Ibrahim Saidu,
an older person affected by Lymphedema)

The picture represents a better source of water and the support I give to my mother in fetching this water. My mother got bitten by mosquitoes at the riverbank which made her leg swollen. So finding a well close to where we live to get water was such a relief to us from being infected by mosquitoes at the riverbank and this well has really saved us the stress of going to the river.

This is the cream my mother uses to rub her leg as this helps to relief her pain. The picture represents the support I give to my mother in relieving her pain. In the morning when she wakes up, I always assist to wash her swollen leg and also rub it with this cream, I also repeat the same procedure for her in the night before she sleeps. This is just to ensure that she doesn't feel pain as a result of this condition.

Ibrahim Sakirat

(Caregiver to Suleiman Habibat, an older co-researcher affected by Lymphedema)

PSYCHOSOCIAL WELLBEING

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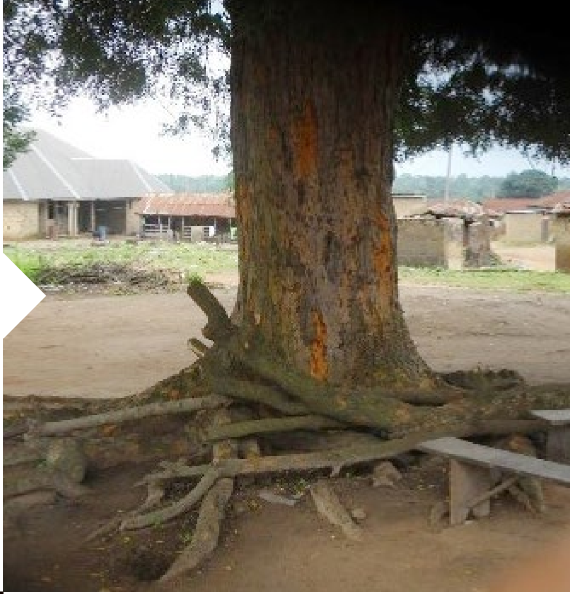
THEME SUMMARY

The different ways participants experienced both positive and negative impacts on their mental and social wellbeing included spiritual wellbeing, music, safe spaces amongst nature as well as loss of participation in activities they could previously do before their illness. Psychosocial wellbeing was often linked to factors described in other themes identified as well as described through standalone images. Younger men and women affected by lymphatic filariasis described isolation, worries and thoughts and the negative psychosocial impacts of being unable to join in activities with their peers or work due to their conditions. However, trees were often photographed to depict safe spaces of relaxation and fresh air to promote positive wellbeing while a radio and music was described by a female caregiver as helping to entertain her sister affected by leprosy, and reduce her feelings of loneliness. Spiritual wellbeing was highlighted by a man affected by lymphedema who described his belief that his faith and worship would provide him with good health.

The photo represents a place of relaxation where I come to rest after I have worked and feel tired, I come here often to take fresh air and I always ensure I raise my swollen leg when resting too. I believe relaxation in any form is a way of living healthy so...I always find time to rest under this tree...This is good for my mental wellbeing.

Ibrahim Saidu (late)
(Older male affected by Lymphedema)



It is the photo of a small radio; I took this photo to show how my sister entertains herself and it makes her happy. She won't feel lonely when no one is around her. It entertains her and makes her to forget about the stigma she faces due to her illness.

Adamu Hauwa
(Caregiver to Aishat Adamu,
a younger female affected by Leprosy)

It is the picture of a shea tree and under the tree is where we sit to get fresh air. This tree offers shade and whenever we sit there, we feel at ease with my body and relax. It is also an economic tree…when it is time to harvest the shea seed, we can make shea butter and shea nuts out of it for sale. We also use the leaves to make soups and local herbs.

Adamu Hauwa

(Caregiver to Aishat Adamu, a younger female affected by Leprosy)

This is the photo of my classroom showing tables and chairs, it also shows my classmates are playing. It depicts isolation. If my health was good, I would be playing with my classmates but I have to sit alone and watch them play because I cannot walk around with my condition.

Fatimah Agee
(Younger female affected by Lymphedema)

This is a shrine. It represents a place of worship and a religious lifestyle. This is the god I worship and I have it in my house. I believe if I worship this god, I will be healthy.

Dembo Sani
(Older male affected by Lymphedema)

This photo shows the dilapidated condition of the house am staying with my family. [I have] various thoughts about my past, because I was not idle, I was very hard working but now this my leprosy has denied ability to work, my legs have sores; the fingers are stiff this has it very difficult to handle farm tools.

Adamu Sabi

(Younger male affected by Leprosy)

FOOD AND ENVIRONMENTAL SECURITY

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THEME SUMMARY

Food security, environmental interactions and the built environment were depicted as emerging themes of factors that positively, or in some cases negatively affects the health of participants. Food was widely captured across participants who emphasized the importance of nutrition for strength, energy and overall wellbeing; good foods included bananas and maize. Some foods were described as medicinal whereas others, such as kolanut were perceived to worsen health. Health in relation to the built environment was highlighted by Adamu Sabi, a young man and Aishat Adamu, an older woman affected by leprosy who photographed their houses in collapsed and poor conditions to describe how their illnesses have resulted in them having to live in unhealthy conditions that expose them to additional environmental risks such as mosquitos and scorpions. Environmental interactions in the form of access to clean water was mentioned by participants; Dembo Sani, an older man affected by lymphedema described his concern of drinking unsafe water from the river while a male caregiver expressed his happiness at being able to store water safely in order to promote good health.

FOOD

I believe eating banana keeps me healthy because of its numerous vitamins embedded in it. So whenever I eat it, I believe I am eating something that will improve my health and not worsen it.

Dembo Sani

(Older male affected by Lymphedema)

This is a lemon grass and it is medicinal so I use it often to keep me healthy.... Whenever I take it, I feel relieved. It represents healthy living because if you have pains in you body and you use it, you will be relieved.

Dembo Sani

(Older male affected by Lymphedema)

I feel happy, banana is very good to our body, banana improves our health and wellbeing. When our well being is improved we stay healthy, whenever I eat banana I feel stronger. This bananas are fresh, I wish I can stay healthy just like this banana.

Zainab Yakubu

(Older Woman affected by Lymphedema)

This is a picture of maize and pepper. It represent good health and healthy living when you eat maize and also pepper because of the carbohydrate and other minerals present. Food is so much related to my health because whenever I eat this food or any other good food, I feel I am eating food that improves my health and wellbeing.

Lawal Jimoh

(Older male affected by Hydrocele)

ENVIRONMENTAL INTERACTIONS

Drinking from this river is not a good one but what choice do I have? The place to get clean water is very far and with my swollen and hurting leg, it becomes difficult for me to walk long distances to get clean water and so I had to get water from this river because it is close to my house. Drinking water from this river is very dangerous to our health even though it is flowing and we don't know where it is flowing from. The water is unsafe to drink and it can worsen the state of my health.

Dembo Sani

(Older male affected by Lymphedema)

BUILT ENVIRONMENT

It is unhealthy to live in this type of house. It can fall at any time and endanger the life of people living in it. I feel bad staying here, erosion has affected my house badly making it very difficult for me to step out whenever it rains. I pray to God to heal me so I can go back to my normal life. I am not happy staying here. This illness has come upon me and I am still hopeful that everything will be better when I eventually get well.

Adamu Sabi

(Younger male affected by Leprosy)

This is a photo of a partially collapsed building, I was thinking that...if your agency could create a public awareness letting people know we are also human being like them, letting them know that leprosy is not communicable, is not transmittable, this will give us also the opportunity to stay in a better place. This place exposes me to bad weather, cold, insects bites, scorpions etc., because the place is not conducive to stay, I can not go to the other community due to people stigmatizing us.

Aishat Adamu

(Younger woman affected by Leprosy)

RESEARCH TEAM AND REFLECTIONS

COUNTDOWN
Calling time on Neglected Tropical Diseases

My name is Suleiman Habiba, I am 51 years of age. I am a co-researcher in this wellbeing study and I am affected by Lymphedema. This condition has been there for the past 20 years and it all started with a fever and headache and then I realised one of my legs was swollen. I am from Ilesa Baruba community.

CO-RESEARCHERS

I am Musa Guruma, I am 40 years old; I am a care giver to Mathew Guruma affected by leprosy. I am a co-researcher.

My name is Matthew Tartatha, I am 45 years old and married. I am a co-researcher in this wellbeing study and I am affected by Leprosy. It started 7 years ago, I slept and when I woke up in the morning my body were swollen and since then I cannot do anything. My experience with photo voice I learnt how to take picture depicting our condition and how to get necessary support to improve our health and wellbeing.

CO-RESEARCHERS

I am Ibrahim Sikirat.
I am 25 years old; I am a care giver to Sulaiman Habiba who is affected by lymphedema. I am a co-researcher in this research.

Kwara Team Co-researchers (From left to right: Ibrahim Sakirat, Matthew Tartatha, Musa Guruma and Suleiman Habibat)

‘The use of photovoice research methodology is a unique way of disseminating research findings to a larger audience. My experience with photovoice has made me realise that pictures can pass a whole lot of scientific message and meaning just like words would do. My exposure to this research technique has been very interesting and educative and I am so grateful for the privilege to have learnt another exciting method of conducting a qualitative research.’

***Temitope Olorunfemi**, Field Co-ordinator, Sightsavers, Nigeria*

‘I am happy for the program, I learnt so many things. Now I know pictures has meaning and you can use them to explain a lot of things like emotion.’

***Kareem Idris**, caregiver, photovoice participant*

Kwara Research Team (From left to right: Temitope Olorunfemi (FC), Jude Ewemade (FA) and Bunmi Makinde (FA))

'I thank God for this privilege because I have never heard of this type of research before, neither have I taken part in such before, It is actually my first time engaging in this kind of research and I am excited to be a part of it. I have learnt that this research and the photovoice method emphasized majorly on our wellbeing, which is the most paramount desire for me. I sincerely want to get better and be in sound health because the strength to do most things has greatly reduced due to my illness (Hydrocele) and I need support to get better so as to do something for myself.'

Lawal Jimoh*, affected by Hydrocele, photovoice participant)*

Cross section of the research team and the co-researchers for the wellbeing study

'The pictures help me to showcase my problem and challenge in life, the picture shows I need help. It has really help me to be able to tell the world my problem that I have been keeping to myself.'

Modinat Tone*, affected by Leprosy, photovoice participant*

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'I have a better understanding that picture is not only for memory, it also has a voice in which it can communicate to people who are not our immediate family so they will understand [our experiences] .'

Mohammed Saliu*, male affected by Leprosy, photovoice participant*

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COUNTDOWN

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