‘I think as a leader you should also be somebody who will have a cool mind, patient, and always willing to listen to people. As a leader, you should not be the first but always be the last; that is some of the parts of leadership.’
The Role of Faith in Healing: A Photovoice Study

Neglected Tropical Diseases (NTDs) affect around one billion people globally, often the most poor and marginalised groups in society.

For many persons with severe stigmatising skin diseases (SSSSDs) such as leprosy, buruli ulcer, yaws, onchocerciasis, hydrocele and lymphedema, lack of access to effective services results in significant physical, financial and psycho-social impacts. Delayed diagnosis and disease progression cause greater and largely irreversible physical impairment; and alternative treatment is sought from outside the health system, often with economic and social consequences for patients and their households. In-depth understanding of the role and treatments provided by community level providers, both formal (community health assistants [CHAs], community health volunteers [CHVs]) and informal (faith healers, traditional healers) are often lacking. In this project, we seek to understand the experiences of CHAs, CHVs, faith healers and traditional healers in providing care for persons affected by SSSSDs through photovoice.
This booklet is one of a series of four, with one booklet created for each group of participants, incorporating findings across two counties (Lofa and Grand Gedeh) and presents the findings of the photovoice activity to identify core issues and themes. These photos will be presented in stakeholder meetings to inform the co-design and implementation of interventions to strengthen the provision of services for people affected by SSSDs at community level. We aim to show the unique role played by these community level providers in supporting people affected by SSSDs and identifying opportunities for earlier identification and initiation of treatment, along with options for the provision of more holistic care of people affected. From this point onwards we will refer to NTDs/SSSDs as skin diseases.
This project is led by REDRESS, a collaboration between the Liberia Ministry of Health, the Liverpool School of Tropical Medicine (LSTM), the University of Liberia-Pacific Institute for Research and Evaluation (UL-PIRE), Actions Transforming Lives (ACTS), Effect Hope, American Leprosy Mission- AIM Initiative, Queen Margaret University, and is funded by the National Institute for Health Research (NIHR).
Photovoice Methods and Consent
Photovoice is a creative participatory method, which aims to empower participants to take ownership and be the storytellers of their own narratives.

Over the course of three weeks, these four groups of participants took photographs within their communities to capture their lived experiences in relation to their work, their interactions with their community and the health system, with a particular focus on skin diseases.

The process involved training of photovoice participants on the use of cameras and ethics of photography. Co-researchers were recruited as part of the core research team, which included people affected by and/or providing care for people affected by skin diseases who then supported and trained other people affected within their communities as photovoice participants to take photographs and articulate their meanings. The study took place in Lofa and Grand Gedeh Counties, within Liberia. These counties were selected to provide comparison between counties where integrated case management of NTDs has been introduced (Lofa County) and not yet introduced (Grand Gedeh County).
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Big Bag</td>
<td>Liberian jargon to refer to Hydrocele</td>
</tr>
<tr>
<td>Big Belleh</td>
<td>Liberian jargon to refer to a pregnant woman</td>
</tr>
<tr>
<td>Big Foot</td>
<td>Liberian jargon to refer to Lymphedema</td>
</tr>
<tr>
<td>Black Baggers</td>
<td>Informal service providers who sell medication and treat sick people within the communities</td>
</tr>
<tr>
<td>Community Health Assistants (CHAs)</td>
<td>Health workers not employed by the formal health system. They work outside of a 5km radius to health facilities and are trained frequently to treat common illnesses at community level</td>
</tr>
<tr>
<td>Community Health Services Supervisor (CHSS)</td>
<td>Has undertaken a 3-month period of training and supervises CHAs/CHVs at community level</td>
</tr>
<tr>
<td>Community Health Volunteers (CHVs)</td>
<td>Work within communities that are located within 5km radius to health facilities to support the delivery of health services on an adhoc basis</td>
</tr>
<tr>
<td>Everlasting Sore</td>
<td>Liberian jargon to refer to Buruli Ulcer</td>
</tr>
<tr>
<td>general Community Health Volunteers (gCHVs)</td>
<td>Some CHAs were formerly referred to as gCHVs</td>
</tr>
<tr>
<td>Grand Gedeh County</td>
<td>One of Liberia’s 15 counties located in the South-East and the second largest county. One of 10 counties that is not implementing MoH integrated case management plan</td>
</tr>
<tr>
<td><strong>Lofa County</strong></td>
<td>One of Liberia’s 15 counties located in the North and the fourth largest county. One of the five counties implementing case management plans</td>
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<tr>
<td>-----------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Mid Upper Arm Circumference (MUAC)</strong></td>
<td>Measurement to detect acute malnutrition</td>
</tr>
<tr>
<td><strong>Neglected Tropical Diseases (NTDs)</strong></td>
<td>Disabling or debilitating diseases that usually affect poorer populations in tropical and sub-tropical countries</td>
</tr>
<tr>
<td><strong>Open Mole</strong></td>
<td>Refers to migraine headache and is often used to describe mental distress</td>
</tr>
<tr>
<td><strong>Papay</strong></td>
<td>An older male</td>
</tr>
<tr>
<td><strong>Severe Stigmatising Skin Diseases (SSSDs)</strong></td>
<td>Diseases that affect the skin and are associated with negative attitudes or discrimination</td>
</tr>
<tr>
<td><strong>Tablet People</strong></td>
<td>Also referred to as black baggers</td>
</tr>
<tr>
<td><strong>University of Liberia-Pacific Institute for Research and Evaluation Africa Center (UL-PIRE)</strong></td>
<td>A research center and one of REDRESS’ collaborating partners</td>
</tr>
<tr>
<td><strong>Zoe</strong></td>
<td>Traditional spiritual personnel believed to possess supernatural powers to curse people and heal diseases</td>
</tr>
</tbody>
</table>
Behind the Lens

Reducing the burden of Severe Stigmatising Skin Diseases
“Rebecca Nugba: My mother told me that I used to like the praying business, like when people are praying then I will go there; when the people are having the church service then I will go there, she said I was small at the time. So when I got big now through direction [in] my dreams, sometimes in my dreams, I pray over people and when day breaks the spirit will lead me and when I pray for you the healing will take place. Where God directs me is where I am.

Yes, when I have dreams and day breaks then I go back to heal. Anything God directs me I go by it. Sometimes he says today take a fast for this person, I will put myself to fast for those three days, and after the fasting, if I lay hands and bless you, even if it is with water, your healing will take place. They take bath with it. But when he says give it to the person, and then I give it to you to carry it.”

“I am James K. Varney. I am a pastor of the Episcopal Church. I want to say thank God for the time that I was trained with the Samaritan Purse and they helped us and I put up a church. I am also teaching in a school for the government since 2006. I am also a farmer. I am married and I have six children. One is graduating from the Community College. For being part of the photovoice I was one of few selected. I have not seen or I didn’t know but now through this program I am trying to acquire more knowledge of most of their [community] activities, so I thank God for this program.”
“I am **Prophet Robert Martin** from Prayer Warriors Evangelical Ministries. The work I do I am a Prophet. I work for people and God gave me the power to deliver people not only in Liberia but in places like Sierra Leone and Guinea. God has blessed me with his power to move for those people that are sick. He sends me to move everywhere from village to village, from town to town, to pray for those people, to pray to ask God deliver [heal] them.”

“**Frances Gaye:** Yes, and God called me in 1968. In 1968 he did a bold, great job. In those days there was no [olive] oil and we used to use palm tree oil. Because I love the work of God when I see God’s people I serve them, as a child of God I serve them; I see the child of God, I serve them. I bring myself down so from there God started to use me. I met a pregnant woman, a mother, a church mother, she was pregnant and they tied the stomach and God sends me there and said, go this woman will deliver. I went there and I only say press your cloth like this, the next day she delivers a child. Just yesterday, 2010, at that time this sore foot [lymphedema] it has not yet spread, nobody knew about it only one man that came from the Ivory Coast was having it and the spirit of God used me and the man was healed. So from here all the way the sore come in front and had spread plenty. I used prayers and the power of God, no oil at all.”
“Nancy Gaye: The work that God gave me I cannot tell the history about it, because, according to my mother at the beginning of this work there was no pastor that did preach to me. I didn’t get my salvation from angels. My grandmother was the one who was a prophetess and then when she was carrying a message somewhere the witchcraft beat her and became deaf in her ears. I did not get it from any pastor, like they say you go to a pastor, you go to church the pastor preaching and the spirit falls on you.”

“I am Pastor Adam Isaac; I am running this church, formally known as Winner Chapter International. I have been in this ministry for five years where our work is ministering the word of healing, faith, and salvation to the oppressed. At the ministering level, we work with people who get sick. I also minister to people who feel that they have been ostracised, who feel that they have been abandoned absolutely by society. I am also in the field of education, we have a school built to give out teacher’s education. I was motivated to be in this place because Christ calls us to continue the good work that he started. I deem it necessary at this time because I want to be part of the mandate left by the command of Christ.”
“Julius Nollen: I started this work in 1999. The first person that God made me heal was a pregnant woman that was impregnated for one year two months. From there God was able to pass through me. But before even doing this work, when the first vision came to me, I rejected God’s will. I said I was not going to do it because I never wanted people to laugh at me, so it made me start to drink liquor. I even went as far as smoking, but if God says this is what he wants you to do, he has to make some taking from you. At last, he gave me punishment when I lied down where the rain drizzles for one month. I lied down for one month and the people thought I was dead. But afterward, when God got ready for me I was able to wake up and started to do his work.”

“My name is Mother Favor [Rose Nyumah] from Jerusalem Healing Ministry Mbalotahun. God is the one that sent me. I call people, I encourage them to come so they can get their healings and people are getting their healings. In my Ministry, people come from Sierra Leone, Guinea, and from all the surrounding villages, they are coming, and they can get their healings. I give thanks to God for that. God is working so I want to tell him thank you. I pray for them. Some people come with mental problems, stomach problems, headache.”
Chronic Ill Health and the Role of Faith

Faith healers identified the importance of prayer and spiritual connectivity in managing chronic health conditions/chronic ill health. Prayer was always seen as a critical component of the healing process, but this was particularly emphasised in the absence of good quality ‘formal health care’ e.g. at the clinic. For some faith healers, prayer was prioritised above all other cures. However, for others, faith alone was described as a last resort and having a greater understanding of what was going on in people’s bodies was hoped for.
‘Many people in our settings have decided to take almost every sickness to be spiritual, but as Faith Healers we have identified that [it is] not everything that is spiritual, some are medical.’
“This man, I met him sick, he had gone to the hospital and the doctor treated him but there was no way that he could get healed. But as God could have it, I went there, and I prayed. If you had seen that foot, you would have seen the bones because they had cut his flesh several times until the doctors gave up, the nurses gave up...I told him that God was going to heal him. I began to pray for him, and he is trying to get heal and I believed that he will get healed...Sometimes we would think that it is cancer; sometimes we say, maybe, it is tetanus, but we won’t know what is really inside that body. Now the man can sit down by himself but before you could see the bone and for God to cover this bone it was not an easy task.”

Frances Gaye, Grand Gedeh County
“This is the work that we do…I am a praying person. I am happy for her to see...to let her go under the healing because that is the prayer that went on before the other people [health workers] came, so let her tell them to show that this is the thing that we can do before they heal other people.”

Rebecca Nugba, Grand Gedeh County

“This is a photo of a lady who had an accident and the leg was broken but unfortunately, even in the clinic no proper attention was given, so she has been going through severe pains. I would like to name this an emergency case. It was an accident. It was in the hospital. I went there on a visit; every week I go there. I have an appointment with the hospital where I go to look at patients. If some of them need prayer I pray for them. It was from that I came across this sister. But no proper attention has been given, so I believe if proper attention is given I think she will recover quickly.”

Pastor Adam, Lofa County
As you can see in this picture, I am holding this man had spent about two months two weeks at the hospital...now, by the grace of God, he can walk around. So, I took this photo so that people can see how the word of God can heal; how our God is great. And I took it again so that I can remember that I was having this person who was sick and that anybody like that can be healed by God. I took this picture so that I can show it to you.”

Julius Nollen, Grand Gedeh County

“I am a mother, people come to me for prayers with different problems and they hold their fast, they go through with their fast and we came and sat down and we start praying.”

Mother Favor, Lofa County
“This man nothing hurt him, but his foot was just itching and, according to him, blister came on him. The blister turned into big-foot, and the big-foot turned into a sore. He went to the hospital, according to him, one doctor told him that he was going to cover this sore, so he needed to cut some of his flesh from his body to cover the sore... everything got rotten...when he found me, the power does not belong to me; it belongs to God... So from there I began to pray and God began to work mightily for him and the mighty power began to take place in his life... God healed him and it was not my power because I never give him tablets a single day; I don’t know any leaves but only the power of God. Washing the foot with the water that I prayed over and God answered and the foot... I am very, very happy.”

Nancy Gaye, Grand Gedeh County
Stigma

Faith healers described feelings of empathy toward people affected by skin conditions as well as those experiencing mental distress. In some instances, the language used by faith healers could be perceived as stigmatising, however, they often described a key purpose in describing issues in this way was to raise awareness about what was happening in their communities. Faith healers described that people affected by skin conditions often concealed their illness due to a fear of being stigmatised by the community. Others described that some individuals in the community had been abandoned by their spouse and/or family members. Faith healers also described a desire to use these photos to make change in their communities.
‘When you see those people some of their family has already neglected them and they do not even know because they have spent money, they have passed from place...when we talk about everlasting sore when we talk about big bag, some people are now hiding it because their families have tried their best but no solution. And some of them they don’t have. What they will do is they will hide and not expose themselves.’
“In this photo, as you can see is an old man. He has a problem of big-bag [hydrocele] that has been with him for a long time. He has been suffering from this problem. He is ashamed to even wear small shirts, he always wears big trousers, big shirts because he does not want to expose his sickness outside to the public. This is what enthused me, I engaged him while in the village and I snapped him so we can find a solution that he can have help to assist him, that is why I took this photo.”

Prophet Robert, Lofa County
“The skin disease people, I am looking at them today, we have their photos, we are so concerned about them. But totally they are not happy because of their conditions they are in: their conditions are not making them happy. We are counseling them for them to be happy...their families are caring for them...but that man who has that bag trouser [hydrocele] he lives with his people because his wife ran away. The man has been having the sore for over two years now, almost three years now.”

Julius Nollen, Grand Gedeh County
Absent Care and Community Connections

Faith healers identified the lack of connectivity that communities face due to bad road conditions and the distance to health facilities. As a result, they also described how challenging it is to frequently seek healthcare at the facility for people affected by skin diseases. In these instances, faith healers often described stepping in to support affected persons and doing their best to also provide medical care, for example wound management and dressing.
'These are cases that have been long forgotten or abandoned. Some of them have decided to take it as a part of life.'
"In this photo is a big-foot (skin disease). This man has been suffering from this foot for a long time. The foot is just getting big and it has been treated for a long time but yet no solution. He has been suffering from this foot and this is what encourages me that this guy is suffering. So we can put it under sickness; it is a big sore that is really disturbing him and this is the condition that he is going through."

Prophet Robert, Lofa County
“In this photo is a road. This road leads to Foya Borma Hospital. During the dry season, we see this road to be very fine but when it comes to the rainy season, even when you climb here you will fall. Once I met a car, an ambulance running going out with a patient and it almost had an accident due to the road condition. So I looked at it and said this is some of the challenges we faced in the community that when this road is not fixed to take a patient to climb that place anything can happen. So I look at it to say that, yes indeed, these are some of the challenges we faced in this community and this is our hospital, a district hospital, so this is what enthuses me to snap this photo.”

Prophet Robert, Lofa County
Faith healers described delivering talk therapy and counselling as a particularly important part of their role. They described providing these activities to the general community as well as people affected by skin diseases. They described this part of their role ‘as a form of giving hope to people that seem to be hopeless or seem to be rejected’. We give them words of encouragement and a word of hope that support them to cope with life no matter their circumstances. Counseling helps morally, socially, and mentally with their conditions we still say yes, they are still part of the human race and important in society.’
‘Trauma healing is based on the character of people who have gone through a long period of time with mental challenges. We believe that some of the challenges that these people have been going through are the results of long challenges of the long 14 years’ war... it has impacted negatively on other people, especially those who have any of these skin diseases, it makes more breakdowns. The mind is the engine of the body; when the mind is healed or transformed the entire body follows up, which is the meaning of trauma healing.’
“This is a trauma healing class we have at the church for some of our people. There are many people who go through challenges not just because they are sick or they are incapable of doing things. But they are being traumatised maybe later before the 14 years’ war some are going through some form or level of trauma, so this is a trauma healing class.”

Pastor Adam, Lofa County

“This photo is showing that this person has leprosy and he does not have anybody to assist him. He always sits down outside of the house fixing climber [device used to climb palm trees] just for him to eat. So [I] meet him and I counsel him, I talk to him.”

Mother Favor, Lofa County
“I was going to the other village and I met this woman in the bush; she was going in the bush to hang herself because of frustration. It was during that time that I met her; I called her, counselled her, and then took her to my Ministry. Now she is staying with me; her parents came and asked that I counsel her.”

Mother Favor, Lofa County

“This is a picture taken in the church’s compound or the church auditorium. There are about three people, the lady, and two young men who I called abandoned people in society because of their lifestyles people considered them to be bad people, so they are traumatised and they are neglected and to make them return to other activities to be helpful to society. So they are being collected in the church to give them trauma counseling so that they can become washed out of whatever trauma or stigma they [have] been going through.”

Pastor Adam, Lofa County
Faith and fellowship were photographed as important parts of everyday life in communities. This was an important part of togetherness, promoting good hygiene in the community leading to better health and wellbeing, as well as supporting marginalised people to gain skills and experience to support livelihood activities.
Fellowship means oneness, it means togetherness in the Lord. You will see that there will be some kind of movement in the society, not negative but positive. When people share fellowship they are able to put ideas together, you will see that development will forge ahead. This fellowship to join together with people or to sympathise with people that have various sicknesses. When you are doing this, each time that you go in the village and you have four or five persons sitting in that place that you have been talking to them, you have been speaking to them, counseling them, then you carry these people to go have a fellowship you give them empowerment. They will say it is good to be in the things of God and it is good to serve God and in serving God they will think in their minds that when they continue to move with you people their lives will change.”
This is a photo of a brother, a mechanic, he is in the church but he was abandoned and we the church decided to help him to put him at work in someplace to learn something so as to make a living.

Pastor Adam, Lofa County

“I took this photo in the church during the time they were preaching. This one tells the people that everybody that was attending was attentive because they were willing to hear the words of God…to hear the word of God so to at least live by it, to change their lives.”

James Varney, Lofa County
“You can see this photo also talking about worship. So this is a photo showing that the people were all prepared to come to God or to go at least maybe confess, or knowing what they are doing. So this is the time that they come here because we have the opening prayer everybody always bows their heads for prayers. So this photo shows that people are getting ready for service.”

James Varney, Lofa County
“This is a toilet. I met this toilet not too properly clean and I explain to them how to take care of their community, how to take care of the toilet and the people reasoned with me.”

“In the other picture the last time I went I met this compound dirty; I talk with the people. And I went for the second time I met the compound clean.”

Mother Favor, Lofa County
“This is an area where we have the information we changed the calendar almost every day, so it makes you be informed; it has the date and then the months, and the year, so almost every day it makes you go out and you can know...because some people will sometimes ask, my man, today is what date? And one will say, my man, let me tell you my time ...but as you go there every day you only need to stand and see today is Thursday, the 16th of December 2020. So this photo is there every day people can go there to know the days of the week and the month and the year. It was done by me. I did it that every day people will be able to see it.”

James Varney, Lofa County
Recommendations of Actions for Change from faith healers

Faith healers highlighted the need for resources to be able to provide persons affected by skin diseases with social support for clothing, food, hospital bills and transportation fare to reach the health facility when referred. They also emphasised the need for further training to be able to identify people who may have skin diseases and to understand their causes so they know what type of treatment that people need.
“We need empowerment because if you don’t even know the constraints that the person is facing, the only thing you will only say, oh, my brother or my sister, if I had something at least I would have shown that kindness by giving you a little thing [money]. The environment where we don’t have it [money], we are not working, all we can do is to continue praying for them. But if you have something [money] you will need to bring that person closer, maybe, you carry that person to the hospital, and even you could use your own money to go for the person to go for a check-up.”

“I will like to support that because those people in Weala need shoes, food, like money to pay for the hospital bills, like a motorbike to go...we can’t do it in our community where we live. There are many places that are far distances; we need help. Not all of the time we go to them because especially when we started this program other people we could not reach to because of the transportation, like the motorbikes and that disturb us...these are some of the things that we need, the support that we need, that yes indeed, we will be able to reach those people.”

“It is true the empowerment also remains to build our capacity in terms of knowledge. Knowledge is not limited; nobody knows all. So we too need the relevant information with regard to those cases [skin diseases] so that we can possibly depend on to get more information to reach them. So we need empowerment to gain some knowledge and capacity building in terms of having workshops.”

Lofa Faith Healer Discussion

“Training us and educating us, it is making us gain experience, so we love it working with you.”

Grand Gedeh Faith Healer Discussion
Reflections on the Photovoice Process

from faith healers

Faith healer participants reflected about the greater awareness that they have about the lives of people affected by skin diseases as a result of having participated in the photovoice study.
“One of the experiences I had doing this process was I got to understand that there have been a lot of people in our society that are going through challenges that have [been] abandoned and need care. I never knew that there are cases that could be resolved until I encountered these people. During the visitation, I was able to realise that some of these issues could be addressed but just they have never been attended to.”

“When I joined this program it made me be more exposed to people and we saw some constraints that were in our community that I never had time for before, but as I went through the workshop I decided to do it as my business. I made sure I met people, interact with them and I saw some of the problems that are in the community. I tried to make an alarm to get the people informed that this thing is not to be so, we need to do this. I saw in the community that there are some development that needs to be done in my area that people did not know so I tried to encourage them that let us do this, if we carry this we will be able to forge ahead.”

“They [people with skin disease] have their own innate potential, some need education, and if the sensitisation is given to help build up their own empowerment to know that indeed they are not just vulnerable; despite their conditions they have a place in society.”

Lofa Faith Healer Discussion

“In Jesus’ name! I am so happy for taking these photos that I have because I want those that are in Liberia to really know what is going on in this Southeast. The problems that we are facing here, even we that are doing the work of God, the problems that we faced, and those whose picture that we are taking, the problem that we are all going through, so this is my experience.”

Grand Gedeh Faith Healer Discussion
Acknowledgements

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For further information please see:

- [www.redressliberia.org](http://www.redressliberia.org)
- Twitter: @REDRESS_Liberia
Reducing the burden of
Severe Stigmatising Skin Diseases

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