Leprosy discrimination tactically crushed!

Sunday Ukpong Akpan

Profile: 70 years, Male, Married, Farmer
Place of origin: Ikpe Annang, Essien Udim, Akwa Ibom State.
Diagnosed with Leprosy in 1959; treated and got a discharge certificate in 1969 at Itu Leprosy Colony

> *"In Itu leprosy colony, 'whole' persons were not allowed to sit with 'sick' people. There was a demarcation. My mother used to bring food for me in the colony but cannot come close to me."*

Early childhood and leprosy history

I am Sunday Ukpon Akpan from Ikpe Annang, Essien Udim in Akwa Ibom State. I started leprosy treatment in 1959 when I was 10 years old. I took the treatment and was discharged in 1969. I lived in Itu Leprosy Colony during the time I was receiving treatment for leprosy. In 1959 when I started, the treatment that time was injection which they applied on the affected areas of the skin. Then in 1960 they started having dapsone tablets.

Discrimination against leprosy patients in the 1960s

During that period if anyone is found to have leprosy, he will be transferred to the leper colony. Then he cannot come home and his people cannot visit him. Even though I was stigmatised, my mother did come to see me. My mother used to visit me in the hospital but cannot come close to me. If she needs to sleep over the night, she would stay with the hospital staff and not come where leprosy patients stayed in the ward.

In Itu Leprosy colony, 'whole' people were not allowed to sit with 'sick' people. There was a demarcation. My mother used to bring food for me in the colony but could only stay in the place where 'whole' people were. At all times, separation between the sick and whole had to be maintained. Because of the disease and problem, I would have ended my life in Itu but God so loved me. He made me to come out and used somebody to make me who I am today.

Stigma from family and community members

Here in the family compound, I was not allowed to stay. I was asked to go to Ido and stay. However, after a person had completed treatment and gets his discharge letter, he won't be stigmatized anymore. Although, being sick was still a very shameful thing. In the leprosy colony, the white people there took good care of us. But for others in the village, we suffered discrimination - not allowed to attend church or family meetings. I was only allowed inside my family, even with the discharge papers that I collected in 1969. The hospital in Itu was an open place and you know that it was the whites (foreigners) that managed the place and they were kind to us.

I got my discharge letter in 1969 before the Nigeria-Biafra civil war, so everybody in the community knew I had been discharged so the discrimination was not much. The only problem was the physical deformities on my hands and that was why some people were a little bit scared of me. Moreover, as long as you don't have a disability, no one will stigmatize you.

Leprosy and marriage

I was schooling in the leprosy colony, after my discharge I stayed with a white man in the leprosy colony. I did not come back to meet my people immediately. On my return, my family compound was still there, I stayed there and later on, my father asked me to marry a wife, and then I got a wife and we had children. Though, my wife did not have leprosy, she didn't refuse to marry me. There was no problem. People feel that once this person has gone to hospital and come back, they believe that the treatment has made the risk of the disease low.

Sunday Ukpong Akpan and wife

Worst moments due to leprosy

Because of the sickness I would have gone to school to be somebody. I would have stayed with my parents and get to know them very well. But because of the sickness I had to live in Itu, staying without our family and anybody; and I stayed there for a long time. So that is one bad thing the sickness has done to me.

Happiest experience so far

In those days the discrimination was there, such that there was no sharing of food. There was no sharing of anything. You don't even stay in your family compound. But now, everybody shares everything in common. They stopped discrimination. This was the only thing that encouraged me and made me so happy. Today, I am a farmer. I have a piggery farm.

Additional story: From a healthcare worker (Mrs. Charity Utuk)

This patient has a success story of overcoming discrimination from his family and community members through his strategic entrepreneurial skills.

While he was deserted by community members due to leprosy, he co-ordinated a successful project (on financial loan scheme) for a group of persons affected by leprosy. The scheme was diligently managed through the dynamic and skilful leadership of Sunday Akpan. They met regularly in his house and the scheme had tremendous progress. The success story of economic empowerment experienced over time attracted other persons without leprosy in the community who desired to benefit from the loan scheme joined the group of persons affected by leprosy in their meeting in his house. They did not mind his hideous deformities and loss of fingers anymore.

Sunday Ukpon Akpan's house became a cherished rallying point for all. Community members – with or without leprosy in need of socio-economic empowerment joined his group. This way, leprosy discrimination was defeated in his community..

Echoes of Injustice

UFOT PETER UDO

Profile: Male, Married, retired leprosy health staff. Started work at QIC Leprosy Hospital, Ekpene Obom in 1965; retired 19/07/2000

Down memory lane – leprosy work from the 1960s!

> *"In those days, if any leprosy patient dies in Ekpene Obom, most of them were rejected by their relatives who insisted that they should be buried there."*

A life of segregation in the "leper colony" away from home

My name is Ufot Peter Udo from Mkpat Enin, Akwa Ibom State. I was about 22 years when I got employed in the QIC Leprosy Hospital, Ekpene Obom. I was connected through my relation who was working there when I finished primary school in July 1965. Within those my early years, I worked among persons affected by leprosy. I retired from service on 19th July, 2000. Leprosy patients came to Ekpene Obom from all over the State – from Ika, Onna, Essien Udim, Uyo, Mkpat Enin, Ikot Ekpene, even Abia and Cross River, everywhere!

In the 1960s, there was a market outside the leprosy hospital, where patients usually go and buy their food or whatever they need. It happened that some germicide was placed in the market, so that when traders were to receive money from leprosy patients, the money was put there, so that others may not contact leprosy. Above all, a leprosy patient cannot shake hands with any "clean" people for any reason. They can't eat together.

In those days, there was a man from Cross River State who was sent from Itu Mission hospital. They sent the man to take care of leprosy patients in Ekpene Obom. His name is Elder Bassey Apih Bassey. He was the one doing everything in the hospital, dressing, in fact, all things! He was the one leading the patients to go and fetch water. After calling the names of women, to see that all of them were available, then he will lead them to the stream and back. On return, he will call the names again (to be sure none escaped). Then he will move to where the male patients stay, call them out one after the other and lead them to the stream. When they come back, he will call their names again to ensure that no one sneaked out. If he wants to send men to repair some structures in the female quarters because it was thatch house, all the females will go over to the church as soon as the men enter. After finishing, the men will go back to their quarters while the females will go to their own quarters too. Patients were given 3 shillings for feeding every week. So, every Monday, they will get 10 shillings for those who have no relatives. For those who have, their relatives will feed them.

Then, if anybody died among the patients, the hospital will send someone to go and get his or her relatives. The patient will not be buried until the person that was sent on an errand is back and narrates his/her ordeals. The usual story was that they will instruct the management to bury them there, that they were not coming to collect the dead body. If any leprosy patient dies in Ekpene Obom, most of them were rejected by their relatives who insisted that they should be buried there.

Relationship between the health worker and persons affected by leprosy

So, in the aspect of treatment, leprosy mission international sponsored all the treatments given to the patients. The patients cannot touch anything belonging to a staff, if he/she does, the staff will reject it. When it comes to relationship, it was not all that cordial as it is today, between the health worker and the patient. In those days, during medication, as patients stand in a queue, the staff will give them water. Sometimes, they will carefully pour the water directly in their mouth, so that leprosy patient does not touch the cup. After a while, they discovered that it was not so good, so twice a week, the water is kept in the jug for the patients to drink after swallowing their medicines. Years later, they stopped avoiding the patients in this manner and began to interact cordially with them.

Persons affected by leprosy revolts against ill treatment by heath workers

In the 1970's, a patient protested against the maltreatment that they suffered, bitterly complaining that it was not good. This led to a misunderstanding between the hospital authorities and leprosy patients. It involved other authorities like the Commissioner of Police from Cross River State and Permanent Secretary, Ministry of Health. They blamed the authorities for poor management and inhuman treatment of the patients by staff and other health workers. Before the revolt, it was the leprosy patients themselves that did almost all the work. They were used for everything that involved manual labour and repairs in the hospital.

So, after the negotiations, the patients were exempted from any form of manual labour activities. The management thereafter employed workers (labour force) to help out in those areas.

Relationship between community members and persons affected by leprosy after treatment

In the 1970s to 80's, when a patient has recovered and now strong enough to go home, he was sent back to the community. But we have to go with the patient and explain to them that the patient is fit to live among others, that the patient is no longer contagious. Some will agree and accept them while some will not. They will send the patient back after we had left. But from the 1980's there was nothing like that again as patients associated freely with the general public. Even at Ekpene Obom, other patients who do not have leprosy were admitted to sleep among leprosy patients in the same ward; unlike the 1960's where such was never allowed.

There was this lady named Macken Matthew. She started receiving leprosy treatment in 1941 at the clinic; until she had ulcer, she was now referred to Ekpene Obom for treatment. She was trained to be a seamstress and we bought sewing machine for her and took her home. Surprisingly, she returned to the hospital empty-handed. It happened that her relations seized the machine, and sent her away. This happened for more than three times and the only alternative was to allow her to remain in the hospital, perhaps all through her life.

Another person is James Peter from Ika. He received the same harsh treatment as Macken, and we went to his village and spoke to the village head until they allowed him to enter the village. Friday John Usuang, also from the same Ika, was rejected by his village and was sent back to Ekpene Obom.

Happiest moment as a health worker in leprosy settlement

Yes, I can remember that I had no money before I started working here. There was no job then. After the first month, they paid me money. So, I earned my first savings from this work and my social status was improved – I achieved something great. I was able to buy a bicycle, whereas it was not possible for some young men to have bicycle in those days.

My monthly salary was 3 pounds. From the 3 pounds, they will deduct 3 shillings (providence fund), 3 & 6 for tax, 1 shilling for electric light; then I will be left with 2 pounds, 12 & 6 shillings. Then my feeding money will be 12 and 6 for the whole month. Things were very cheap. Whatever you needed, you could get it very cheap. But today, 12,000 naira cannot feed a family for one month.

Bitter moment as a health worker in a leprosy settlement

You see, anything sweet, there must be bitter part (laughs). The bitter moment was that, I was a mail runner; I worked in the kitchen department, and I was also an engine operator. But they will give me salary for just one work, while I thought I will be paid differently for the various jobs. There were few staff. So, I had to handle many things.

At some point, I felt like quitting my job and joining my people in Lagos. That was a tough experience for me. In fact, I had already written my resignation letter. Then I called one of my friends, and he was very happy for me to come to Lagos. He advised me not to resign from work; instead that I should come over to Lagos for a visit. And then after my visit, if I could not find a job, then I can go back to my job, because Lagos was so hard. After reading the letter he sent me, I tore the resignation letter and assured myself that no matter how hard this job is, I will continue with it till the last day. I thank God that I was able to stay till the last day. I retired from this work on 19th July, 2000.

Personal experience, in the community, church and how people reacted to health workers in the leprosy hospital

On the issue of church participation, we had a church situated at the hospital premises. But after sometime, things were changing and everywhere I attend church services in Ekpene Obom, they regard me like others. There were no problems; sometimes, I might decide to attend service at the main town; people began to realize that leprosy is just like any other disease, so there was no need discriminating against anybody that contracted leprosy.

You know, one thing? People are thinking that once you step into the leprosy hospital, then you get leprosy and become a leprosy patient. But the experience I have is that, those working here are on the safer side, because they can easily identify a leprosy patient anywhere unlike the lay man.

Experience of leprosy patient rejection of treatment

Some patients refused treatment, because they were ashamed. We tried as much as we could to plead with some of the patients to receive treatment, but after many pleadings, we will be left with no choice than to leave them to their fate. Some even died in the process.

But there was a rich man, who despite his wealth came every month for his treatment unlike those that are too proud and think that they cannot have leprosy. Leprosy work was very hard in those days because it will take many months, even years before you can convince a patient to come to Ekpene Obom. And some of them went to the church for prayers and counseling. One example is Nyakpan Ufot from Essien Udim who spent two years in the prayer house and after that, somebody met her and brought her down to Ekpene Obom.

Some medical doctors dread Leprosy and avoid treatment of leprosy patient!

There was another patient by name Uyiogon George. He was admitted in Ikonobia Hospital. Then when one leprosy staff from Ekpene Obom went there and saw the patient, the staff drew the doctor's attention to the patient, thus:

Leprosy staff: *Doctor, sorry. This is not your case.*

Doctor: *You want to tell me that you are very brilliant? You know something that . . . ?*

Leprosy staff: *No! This is a leprosy patient.*

Doctor: *(exclaimed) Whaaat? Take him! Take him away!!*

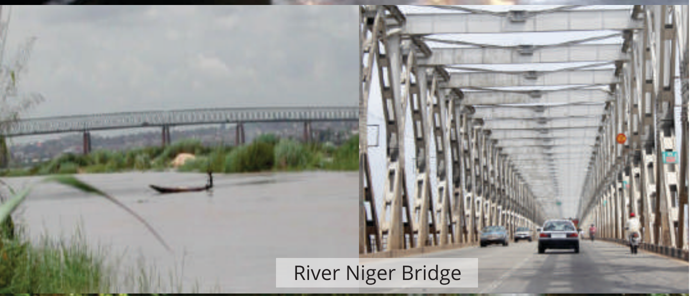
Immediately, the doctor ordered that the patient should be taken away. Moreover, the patient was eventually a positive (confirmed) leprosy case.

So many doctors are scared of leprosy patients. The first black doctor, that I saw sitting (compassionately) on the bed of a leprosy patient was Dr. Akpan. There was a particular doctor that when called upon for antenatal clinic (for leprosy patients), will not like the patients to approach her or come closer.

Yes, it was very bad. The first black doctor to work in this leprosy hospital is Dr. B.A. Ibanga of blessed memory, who is the first black doctor willing to come and work there. He was the first doctor that was willing to work in the leprosy hospital, we were very happy (not only me), even the European doctor that was in charge, Dr Esther Davis was very happy. He was sent to Ethiopia to receive leprosy training. Then when he came back, he worked very well with leprosy patients. Sometimes, we went for fieldwork with him and from our experience, the doctor was so happy to work in the hospital. After a period of time, he was transferred out and Dr. Ntia came in alongside other doctors like Dr. Bassey.

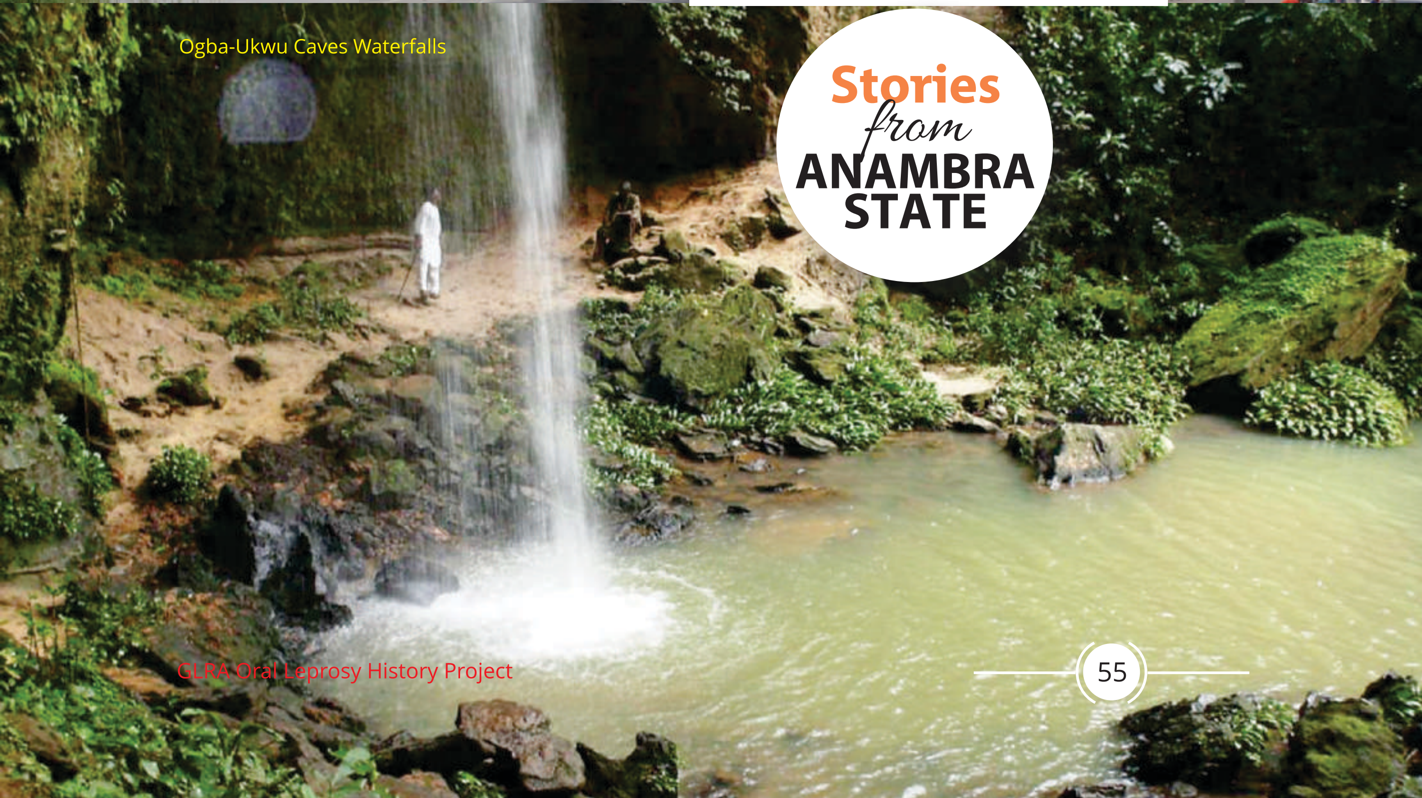
There is nothing like discrimination presently. All black doctors are quite willing to work better with leprosy patients. We had European doctors who persuaded the black doctors to work among the leprosy patients. Anytime, there was a seminar at the hospital, she will publicize it so that any doctor willing to come and serve will do so. Then, some of the African doctors agreed to come and work with the leprosy patients. One doctor worked with the leprosy mission until when Dr. Ntia came as a national youth corps doctor. Because of her relationship with patients, the patients appealed to the State government, to retain Dr. Ntia at the leprosy hospital and it was granted. Currently, Dr. Ntia has been transferred to the Ministry of Health as a Control Officer.

Aroma Flyover, Awka



River Niger Bridge

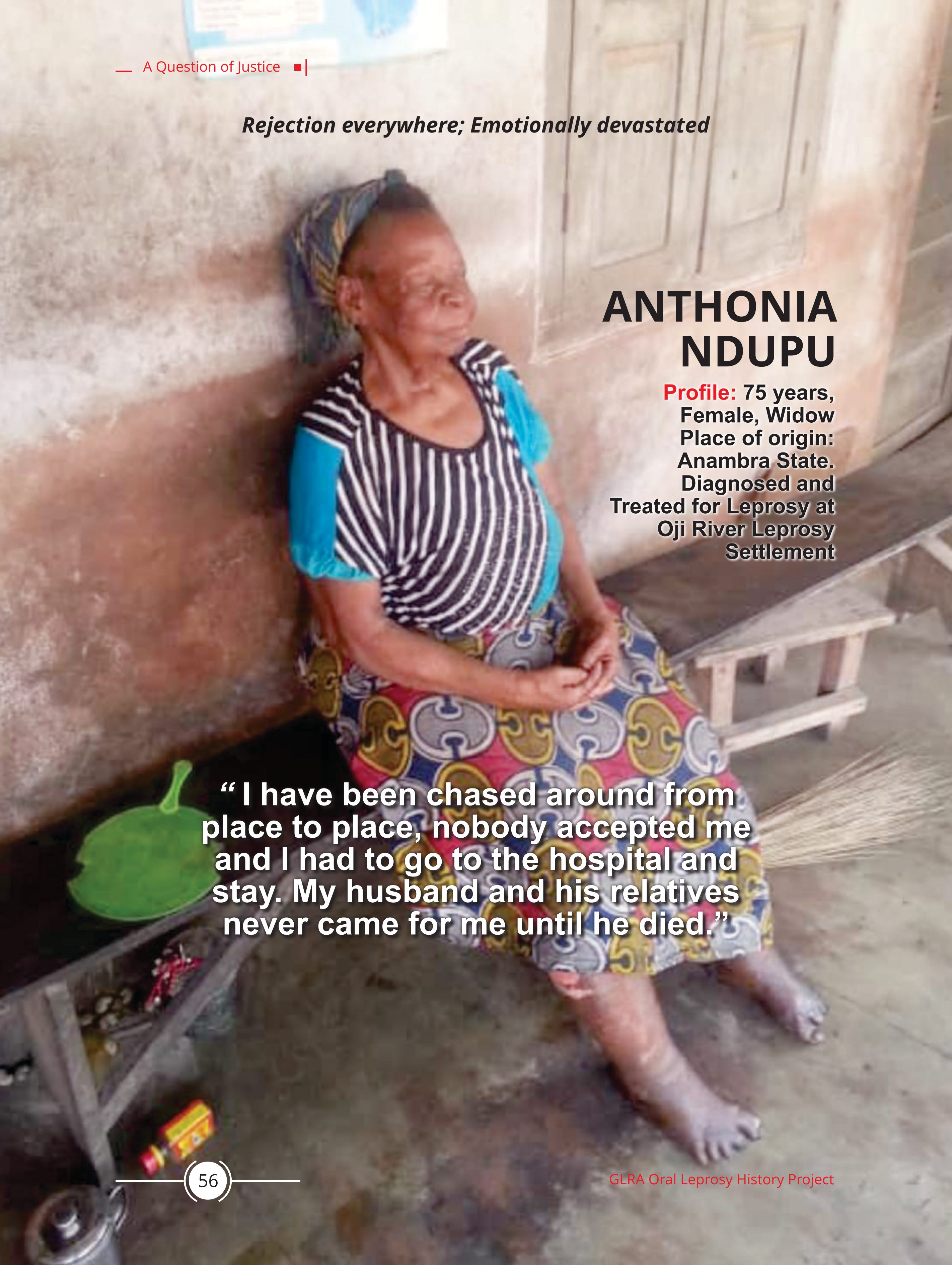
Seedlings of hope at Leprosy settlement, Nnewi



Ogba-Ukwu Caves Waterfalls

Stories *from* ANAMBRA STATE

Rejection everywhere; Emotionally devastated



ANTHONIA NDUPU

Profile: 75 years,
Female, Widow
Place of origin:
Anambra State.
Diagnosed and
Treated for Leprosy at
Oji River Leprosy
Settlement

“ I have been chased around from place to place, nobody accepted me and I had to go to the hospital and stay. My husband and his relatives never came for me until he died.”

Yes, I will like to tell the world my travails. I have been chased around from place to place, nobody accepted me and I had to go to the hospital and stay. The fact that I don't associate with people, makes me to feel bitter and I had to flee from home to come and stay in the hospital. It was the missionaries that were taking care of me all this while.

They *(family and friends)* discriminated me a lot. I lost both of my parents and I was the only child but I had to flee because they were making things miserable for me. Nobody accepted me.

I was in my husband's place when the illness started. It came after my first pregnancy. And then, the family of my husband chased me away. On coming back home, since I had no parents, they neglected me. I was really young when I got married (and) my husband didn't come back for me. He is late now. His family members never asked of my whereabouts.

I went to Oji settlement and later to Okija. I had only one child who is now deceased. I have been living in the settlement since then. I wish my parents were alive. My husband and his relatives never came for me until he died.

Because of my condition, my eyes were affected too. I have been operated twice with little improvement.

Children at leprosy settlement, Nnewi

Rejected by teachers at school

CELINA OZOR

Profile: 68 years,
Female, Widow.
Place of origin: Abagana,
Anambra State.
Diagnosed and Treated
for Leprosy in 1973 at
Oji River Leprosy
Settlement

“Some of my close friends vanished from me immediately the sickness began...”

I was in school before the sickness started and since then, the teachers rejected me at school and I had to drop out.

My name is Celina Ozor, I am from Abagana. We are in Okija Leprosy Centre.

When this sickness started, I was not aware about the nature at first. My family took me to various places for treatment but all to no avail. When I was finally diagnosed of Leprosy, they took me to Oji settlement clinic.

It was the sickness that prevented me from going to school. I was in school before the sickness started and since then, the teachers rejected me at school and I had to drop out. Some of my close friends vanished from me immediately the sickness began while some were with me and never abandoned me.

Leprosy and Marriage

I was almost an adult then when the sickness started. It just prevented me from marrying those without leprosy. I got married to a leprosy patient but he is now late. I was there with my husband who was also suffering from the sickness and we settled down there and began a family. My husband is from Ihiala. Now I am the only one taking care of the family. I have three children, all are still alive. I haven't noticed that people discriminate my children yet.

Immediately I got married, I began to make friends with a lot of people and I even go to meetings with my fellow women, and I felt comfortable.

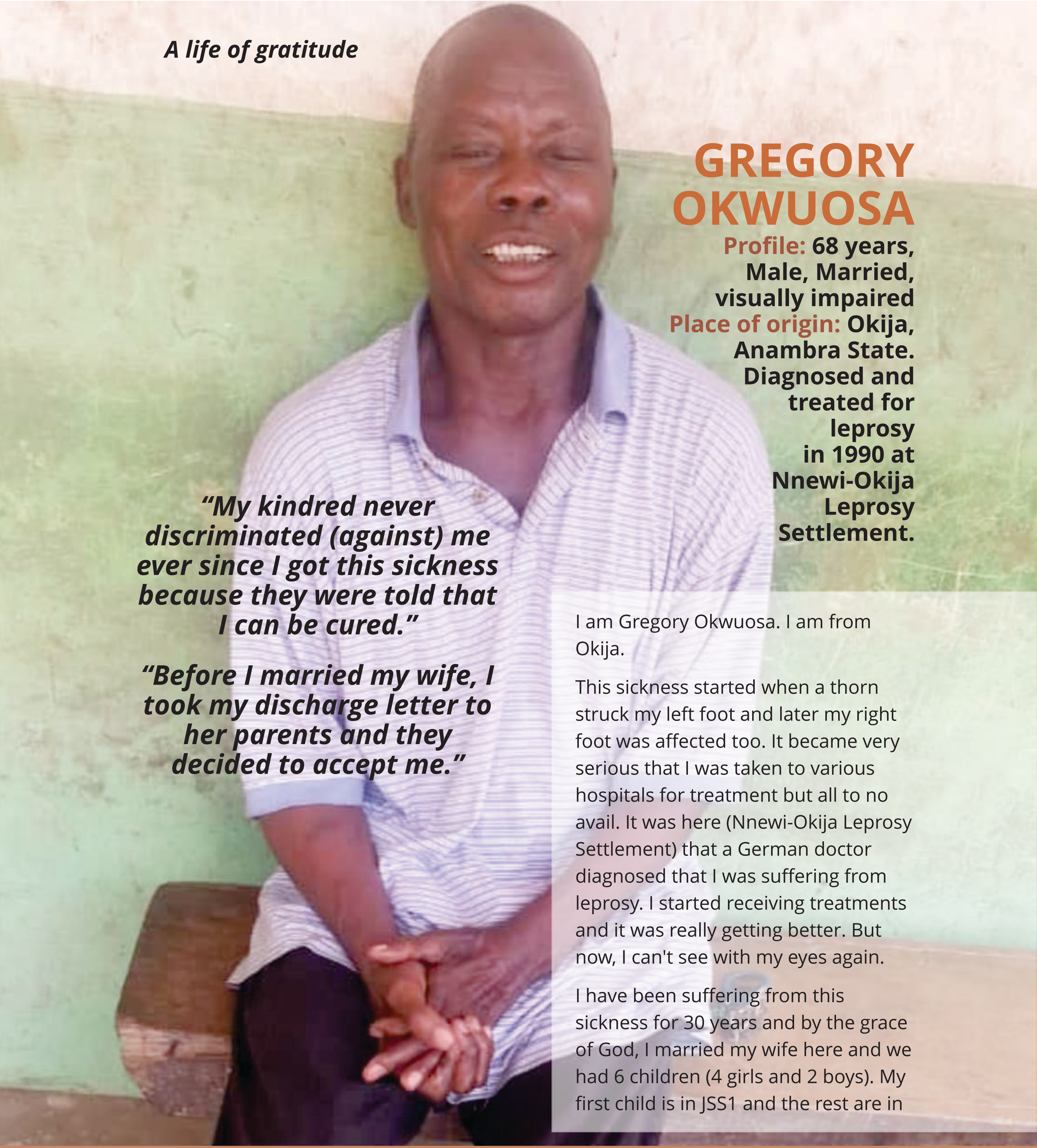
Okija Leprosy Settlement Centre after the Civil war

When I went there, it was no longer the whites that were taking care of the leprosy patients. Yes, the Civil war had ended. It was the blacks that took over the management of the settlement. Dr. Chiegboka was the doctor in charge then. I can't remember others.

My struggles and health challenges

My eye problem has been up to 4 years but I still manage them despite the pains. Like now, my knees and eyes are really paining me and I find it very difficult to adapt. So, I am really appealing for financial assistance in order to take good care of myself.

Another thing that this sickness prevented me from doing was that, I was unable to learn a trade because of the various disabilities that I sustained as a result of this sickness. So, I was helpless and confused and I resorted to God for help and hope. We survive here from the little assistance that we get from people and other organisations.



A life of gratitude

GREGORY OKWUOSA

Profile: **68 years, Male, Married, visually impaired**
Place of origin: **Okija, Anambra State. Diagnosed and treated for leprosy in 1990 at Nnewi-Okija Leprosy Settlement.**

> ***"My kindred never discriminated (against) me ever since I got this sickness because they were told that I can be cured."***

> ***"Before I married my wife, I took my discharge letter to her parents and they decided to accept me."***

I am Gregory Okwuosa. I am from Okija.

This sickness started when a thorn struck my left foot and later my right foot was affected too. It became very serious that I was taken to various hospitals for treatment but all to no avail. It was here (Nnewi-Okija Leprosy Settlement) that a German doctor diagnosed that I was suffering from leprosy. I started receiving treatments and it was really getting better. But now, I can't see with my eyes again.

I have been suffering from this sickness for 30 years and by the grace of God, I married my wife here and we had 6 children (4 girls and 2 boys). My first child is in JSS1 and the rest are in different colleges and the whole burden has been on my wife to take care of the family. I thank God almighty for bringing you people here to assist me and my family.

My kindred never discriminated (against) me ever since I got this sickness because they were told that I can be cured. Before I married my wife, I took my discharge letter to her parents and they decided to accept me, since it was their daughter's wish to get married to me. My wife does not have leprosy. She never discriminated me, she comes here more often and a lot of people here, already know her.

I was born in 1950 so I am 68 years old. I was around 40 years when the sickness started. Leprosy patients then were being discriminated, but they (people) will only accept after you convince them with the discharge letter and then, there will be no sign of the sickness on you. My family, never discriminated me.

As for the community, I didn't engage in any activities with them until I was discharged. Even at that, people do come to visit me and we interact and drink together. I was a qualified cabinet maker before I was struck by this sickness.

I stopped my furniture business because firstly, I can't see again and secondly, I don't have enough finance for the business. If I can be assisted, then, I can still start it again since I already have the basics of furniture and I can design it for them. It is up to 7 years since I lost my sight.

The most memorable thing in my life is that I am always in tears remembering the fact that, I cannot see again and also the responsibilities awaiting me as a father; especially payment of my children's school fees. The only thing is that, if not for this leprosy, I would have been living a very comfortable life, but I remain grateful to God for everything.

(However), building this house was a great thing of joy to my life. And also staying alive till today is a reason to thank God. I also thank everyone for their support, especially German Leprosy Association, who come here so often, to assist us. The house that I am talking about is my family house which is nearing completion; it requires around 300,000 to complete it.

The fact that I can't see, makes me to feel bitter; but I remain grateful to God almighty for the gift of life. I have stayed here (Nnewi-Okija leprosy settlement) for around 30 years. I was the 15th leprosy patient when I came here (and then) there were a lot of people. The major challenges that we had then, was that thieves always attack us at intervals and it made us to feel restless all the time. They attack us, and made away with the valuables that people gave us for survival. Some are even food thieves, while some are after money and also valuables. I think that this place should be fenced so the patients can actually have a piece of mind at night. My eye condition became very severe because on some occasions, the thieves attacked me and they tampered with my eyes. Only 2 people are remaining now, Me and a woman.

What I will like to say is that I need serious financial assistance in order to take care of my family, and also to pay for my children's tuition fees. I also wish to further my eye treatment.

VERONICA OKORIE

Profile: 75 years, Female, Widow, had Limb Amputation

Place of origin: Lives at Nnewi Leprosy settlement, Anambra State. Diagnosed and Treated Leprosy at Oji River Leprosy Settlement

> *“My experience is that people neglected me and nobody was there to assist me. I couldn't even attend the burial of 2 of my children; I had no choice to go - my legs were amputated. Leprosy is very painful, it has brought a lot of sorrows and pains in my life.”*

My name is Veronica Okorie, I hail from Arochukwu.

It was actually in Arochukwu that my sickness began. I came down here (Damien Leprosy Centre, Nnewi, Anambra State) because I cannot feed myself and I depend on the little people and the government give us, to survive. If it was discovered earlier, I would not have been in this kind of condition. I was not taken to the hospital till it became very bad and I went to the leper colony (Use of the terminology “leper” is highly discouraged as it connotes stigmatization).

When I came back (after initial treatment), I got married and had 4 children before the sickness later came back. It happened because of the fact that I didn't take proper precaution on time. It was then that I discovered that I was carrying my last pregnancy, before my husband died.

He (my husband) was the one that took me to Oji settlement, and from there, I came down here. My husband did not have leprosy. When he saw that I had contracted leprosy, he took me to the hospital. During my sojourn, I lost my husband and my kids. (About the reactions of her family and friends), you should know how the relationship between sick patients and the healthy patients are, among the Igbos. The relationship is sometimes, very poor and pathetic.

My husband was always visiting me till he died. It is based on the fact that I have nobody to assist me, that I resign to my fate; and I pray that God's wish will be done in my life. Even if I am asked to go home, there is nothing tangible that I will be able to do again; following the fact that I am incapacitated. That is why I am pleading to the general public to assist me.

My experience is that people neglected me and nobody was there to assist me. I couldn't even attend the burial of 2 of my children; I had no choice to go -my legs were amputated. Leprosy is very painful, it has brought a lot of sorrows and pains in my life.

Initially, those suffering from leprosy were disowned and banished from participating in the affairs of others. If not for the coming of the white missionaries, a lot of leprosy patients would have been wasted because people ran away from them, leaving them in a miserable state.

If I should explain all that I went through, this your tape recorder will not be enough. I really suffered as a leprosy patient, to the extent that I now see it as a normal routine in my life. What I pray for is just for God to provide me with my daily bread. Why I was taken to the hospital was because of the fact that leprosy was very contagious at that time. Then, everyone avoids people suffering from leprosy, but now, people think that leprosy no longer exists.

From the symptoms that is associated with leprosy, one can actually see the need for any leprosy patient to be avoided, the signs are always very dangerous and incapacitating - it can render someone useless. It is not really easy for women at all, based on the fact that once leprosy sets in, the future of the lady becomes scattered as regards to marriage. So, I thank God for everything.

My most painful moment is the fact that I have lost my children. Apart from that, there is nothing that pains me the most; even when people neglect me, I see it as a normal routine in my life. I'm grateful to God for everything; despite everything, I am still alive.

Treatment at the earlier stage matters a lot when treating leprosy. My days are being counted as it stands since German Leprosy Association stopped supporting us and hunger is about to kill us. It was just the white missionaries that brought enlightenment to us. When I came here, the white missionaries were already gone except one white woman who was in charge of the clinic. There were many of us here.

The only piece of advice that I will like to share with you is that, everyone should hope in God and keep his/her hands clean. There is nothing God cannot do. I also want to appreciate the working of all for us.

Stories from BAYELSA STATE

Bayelsa State Leprosy Hospital

Old Leprosy Settlement in Yenagoa, Bayelsa State

Yenagoa City

Stigma precedes leprosy deformities

DANIEL MAXWELL

Profile: Male, Married, Leprosy Health Worker in Bayelsa State
Place of origin: Bayelsa State
Period of Leprosy Work: Since 2009 at TBL Referral Hospital, Igbogene

> ***"...My parents would not allow me to even greet, not to talk of talking to them (leprosy patients). They were rejected and sent into evil forests."***
>
> ***"Almost 90% of the cases I discovered are Grade 2 disability problems, and I asked and found that due to this stigmatization from the community and the family and the society as a whole, makes these people hide in places where they could not get the right information and before we found them, it would be late... I can probably tell you about 50% of cases that I have managed have deformity, disability problems."***

My name is Daniel Maxwell. I work with the State Ministry of Health under Tuberculosis Leprosy Referral Hospital. I started this program work in 2009, I went to Zaria for training, Leprosy TB training and have got my Local Government Supervision Certificate.

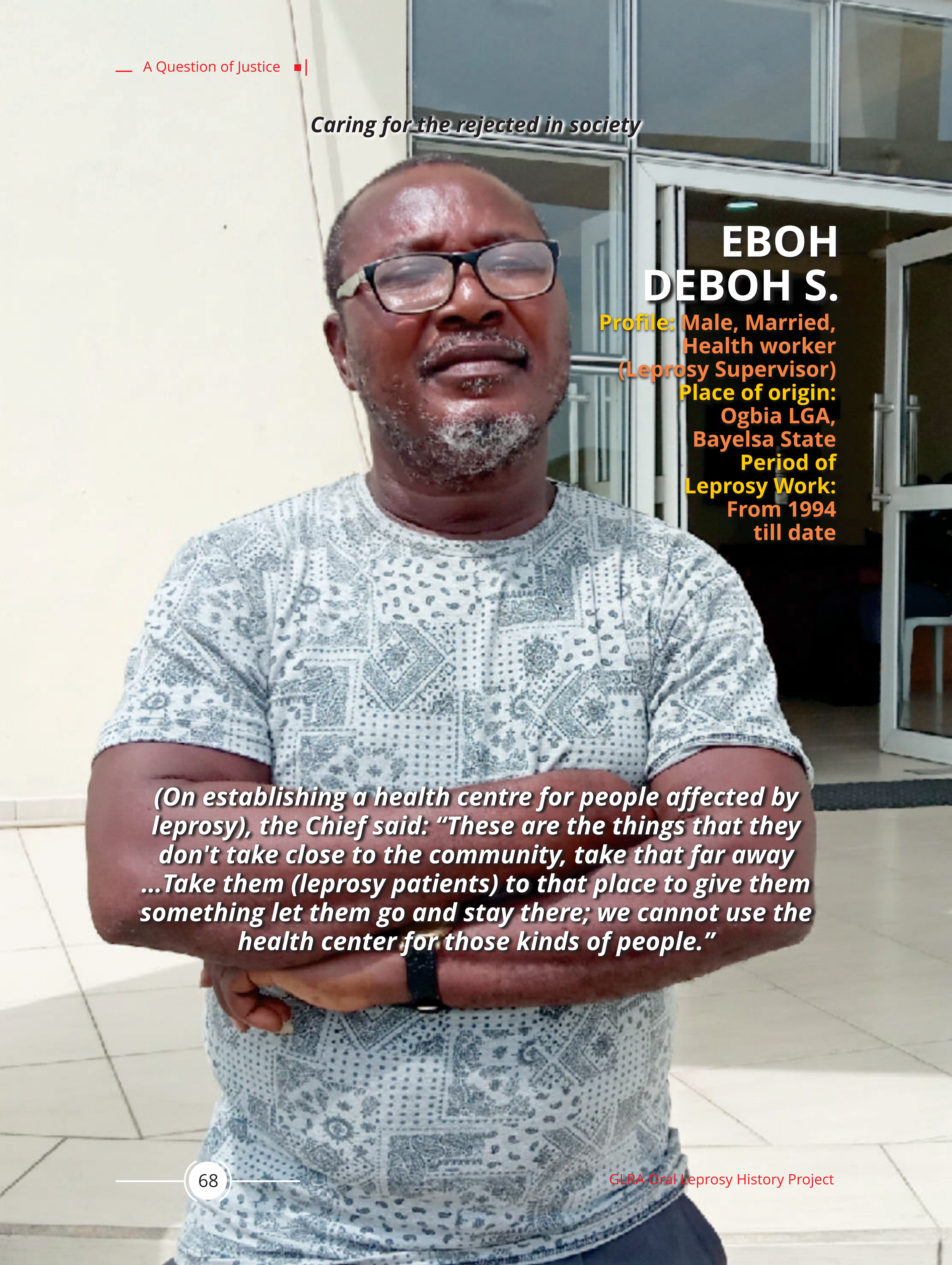
I know that leprosy is a disease caused by bacteria, it's called "Mycobacterium leprae". It's a disease that is curable but my little experience when I became a health worker, I came to experience that the disease is a very simple disease that can even be managed in our communities.

When I was young in my community as at 1982 thereabout, I saw some leprosy patients who suffered from leprosy but before I would see them, my parents would not allow me to even greet not to talk of even talking to the patient. They were rejected and sent into evil forests that even the parents, certain parents will carry food to them in the forest.

They were not even meant to come to the community at all, that's how I saw it at that 1982-81 when I was about finishing primary school. In fact, with what I saw at that time, the people said it is caused by gods of the land and the patients totally rejected even till today as I am talking to you right now, leprosy is rejected in the human fold but with the coming up of GLRA and other donor agencies, I believe we are making this campaign to at least a 50-50 level right now that some members of the community are beginning to believe that this disease is caused by bacteria.

Though as a person, I have my own experiences. I interacted with a lot of people, while some were cured, while some were not cured. But one thing I feel that I experienced in Bayelsa State as a State is almost 90% of the cases I discovered are Grade 2 disability problems, and I asked and found that due to this stigmatization from the community and the family and the society as a whole, makes these people hide in places where they could not get the right information and before we found them, it would be late. I can probably tell you about 50% of cases that I have managed have deformity, disability problems; some hands were amputated, some, both hands and legs were already amputated, some have permanent mobile claw, six-claws and thereabout. Some have ulcers that I can manage.

This is my submission; leprosy exists in Bayelsa State. We have up to about twenty something patients right now from this our difficult way of getting them. But if we can take the campaign to the community on daily basis, I think we can get a good number of them.



Caring for the rejected in society

EBOH DEBOH S.

Profile: Male, Married, Health worker (Leprosy Supervisor)
Place of origin: Ogbia LGA, Bayelsa State
Period of Leprosy Work: From 1994 till date

(On establishing a health centre for people affected by leprosy), the Chief said: "These are the things that they don't take close to the community, take that far away …Take them (leprosy patients) to that place to give them something let them go and stay there; we cannot use the health center for those kinds of people."

My name is Eboh Deboh. I joined this work far back, in 1994 specifically.

I attended School of Health Technology, Port Harcourt, Rivers State. After graduation, I was posted to Niger hospital which was the hospital that took care of TB patients. Back then, leprosy was not merged with Tuberculosis. Leprosy cases were handled by a different unit, TB was under a different unit but as time went on, there was a merger; the two diseases had some similarities and they had to combine *them* under one program so, that came to become "TBL".

In the process of my work *experience*, I have come to realize that the people are human beings, they are supposed to be taken care of. But because of their conditions, they are so neglected to the background both from their families, their friends and relations. Even when they are engaged in Government jobs, they are sacked because they don't want them to mingle with people, that is the history and stories *(that happened)* then. But in the process of *time,* I see that there are organizations, you know, that are so friendly that are fighting to see that these people are well taken care of both in treatment and in welfare.

You know there is *(a place)* for them, there is treatment for them and even certain token is given to them in certain times. Along this straight road I use to see some people hanging around and begging and from time to time one Government or the other will persuade them to go away and they will come back again. In persuading them to go away, they will give them some money and tell them to go back home. Sometimes, when big men have burial ceremonies, they don't want these people to be seen on the road, they don't want to associate with those people. Then they will pay them a lot of money but at the end, after going to their homes, at home too, they are neglected so, they feel rejected and they will still come back again. So, that is the scenario we find these people and right now, most of the patients that I treated, they hardly find anything to do.

I have been opportune to work with "Daughters of Charity", Sister Falon in particular in Nchia-eleme. And that woman takes care of these leprosy patients and TB patients combined and we go out to the centers that treat these diseases. It was that time I got to know about Igbogene, got to know about Egbowa, got to know about Omoko and even Auda; all those activist centers even Odi in Bayelsa State. That was far away Rivers State and after some time, I think, I left them because I was going to take care of the Tuberculosis side while they are taking care of the leprosy side.

When it became a combined work; we were independent doing this work and so, I was taking care of the patients in Ogbia Local Government in particular because we were assigned to a Local Government and far away Rivers State. Ogbia Local Government was under my care. And so, we went out, combed for who and who were affected by leprosy. We accessed them, if there is an activity, we register them and put them on treatment. If there is need for prosthesis?, we give the necessary materials for their POD and a lot of things like that.

So, these people that cared for them had a lot of literatures that we read and came to *the conclusion* that the disease is even curable, especially if they are found early. If you don't find them early to get them treated, it is then that they get destroyed along the line and since it was not known to the persons, it was not known to humans that this disease has a cause. The cause of the disease is bacteria, it's a bacterial infection and this is called "Mycobacterium leprae" and this other one is "Mycobacterium tuberculosis" so that's where they have a common father.

So, going by that trend, you will see that those people that we catch early anytime we went out for surveys, we see that those people that we catch early get treated, get cured and they pass it *'vamoose'* with time but those ones that have already gotten a deformity, we hardly reverse them but for claw hands and all those things, probably with long time of exercises, they get their hands to straighten and they still handle machetes and do some menial jobs. But for those of them that are destroyed, we hardly get them back to normal work life. So, they are left alone if their relations leave them uncared for, they are just like that, some of them even think of committing suicide and we are opportune to be talking to them, to take life easy, talk to the communities to accept them as human beings because they belong to families and talk about the history of the disease that it is not their cause, it is a gem.

The Breakthrough Medication

With time, these drugs were found and they started using them on them (the patients). When it was a monotherapy, like the Dapsone that was used in those days - 60s, I happened to read one of Dr. Chukwu write-ups concerning Uzuakoli center and I saw that the Dapsone trial started in Uzuakoli itself and so, one Harcourt-Whyte was a very prominent person, one of the affected persons and that area, they just bury people in mass because they are just exposed to trial treatment and when I read that book, in fact, I started appreciating the effort of Dr. Chukwu in Nigeria. And this Harcourt-Whyte in fact, blessed memory those people were buried right there and the tomb is there he has been immortalized, the tomb is there just by the church. He was a chorister, that is, from the history I read from the book, I have this knowledge. But on my own back home, the little I know about leprosy orally, oral history or evidence from the people I saw, they were neglected people, dejected you know, segregated from the community.

Establishing Health Care Centres for People affected by Leprosy

So, it came to a time when I wanted to establish centers, health centers in different locations, so I happened to say my community should be included. So, I traveled from Port Harcourt with Dr. Tekena, my Control Officer then and then we came to Anyama after traveling all the way from Nembe to Ogbia town, to Anyama, my home town. We were supposed to sleep there and, in the morning, we gathered the community, the chiefs; my father inclusive. One of the chiefs as I could still remember, one Chief Kennedy Omons said; “these are the things that they don't take close to the community, take that far away”. He was calling one rejected place, it's the people who go to farm that pass through that side. So, that we should take them to that place to give them something let them go and stay there, that we cannot use the health center for those kind of people. This was in the community meeting where Dr. Sakara was there and in fact, I even burst out in quarrel with them because they were ignorant, they didn't know what they were saying, you know, we had to talk mild with them. My Control Officer who knows how to approach them did the needful and at the end, we got those centers established.

Then we started with only 3 centers: Anyama, Oguata and Kolo before we started spreading. In fact, because I am opportune to be from Anyama, that place got established first because I used my pressure to *establish* the health center. And today, I think if we're looking for leprosy cases, we hardly find them except to go combing community after community. Most of the people that we come across are people that have been affected before.

On the Attitudes of Healthcare Workers, and Government Support

Thank God for Daniel today who has the zeal to do the work. A lot of the health workers don't have the zeal to do the work because they don't want to touch these people, they say it's leprosy. They come to ask for another bathroom. Some people when they see us, they will say “that's leprosy”. But not for people like Daniel and our kind of people. With the literature and the approach of Government, partners helping in this work, I think the attention is getting a little different from what it was.

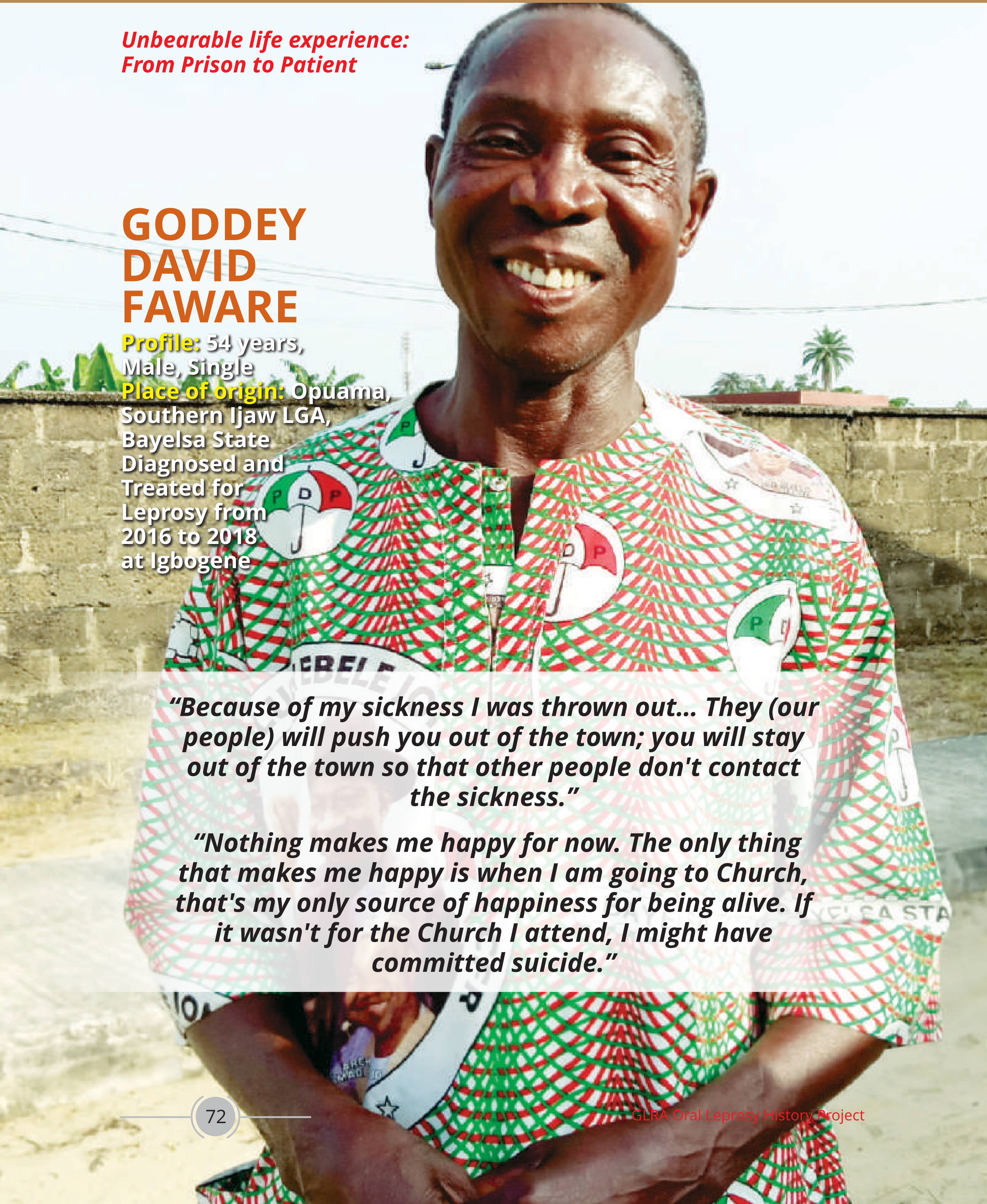
But all the same, the patients or the ex - leprosy patients are still not taken care of as it is expected even though we have a charter for them. Government is not doing enough for these people because for those people that have their hands chopped off by the disease, they are still not doing anything and they are still exposed to hazardous works. Some of them do fishing, from time to time, they give them some net but these days, we don't see those things again, we are not seeing all the assistance they used to give.

When we were working in the old Rivers State, GLRA was sending nets, axes; depending on the fitting of that person. So, at Ebube in Elimi where Sister Falon was working, there was one of these rehabilitation centers that they took these people. So, if I have to suggest, it would be a good thing for every State and every Local Government to have rehabilitation center for these people, the leprosy people.

Most of the people that have their hands cut or their legs because of the long-standing illness, don't know it's even a disease that is caused by a germ that can be treated by medication. Rather they go *(about trying to)* find out from native doctors; and these native doctors too, they don't do well because they don't see anything and so, they keep on saying “somebody has harmed you, somebody is offending your family” and they keep on doing sacrifice upon sacrifice and the more they do the sacrifice, the more the disease is graduating to different levels and so, they come to these deformities.

So, in fact my dear able colleagues, the little I know to say is that the modern life is not like in the 1950s or 60s where people were so ravaged by this disease.

Unbearable life experience: From Prison to Patient



GODDEY DAVID FAWARE

Profile: 54 years, Male, Single

Place of origin: Opuama, Southern Ijaw LGA, Bayelsa State

Diagnosed and Treated for Leprosy from 2016 to 2018 at Igbogene

> ***"Because of my sickness I was thrown out... They (our people) will push you out of the town; you will stay out of the town so that other people don't contact the sickness."***

> ***"Nothing makes me happy for now. The only thing that makes me happy is when I am going to Church, that's my only source of happiness for being alive. If it wasn't for the Church I attend, I might have committed suicide."***

My name is Goddey David Faware, I'm from Opuama town.

I was condemned to death in 1989. I was in the Port Harcourt prison in 1997 when I contacted this disease. Barb wire injured me and I slept and woke *(up)* to see a wound on my leg with blood; I was shocked. I removed the slippers and I saw there was a wound. I boiled water and put my leg in it and by morning, it was swollen; I couldn't move it. Then I went to the medical doctor at the prison yard, and to the controller and complained, I was treated. They sent me to Rumuigbo.

Chinyere was in the leprosy section. They told her to come and search my body, that the illness is leprosy. From there I was being treated for one year. After the one year they left me; that the sickness wasn't cured *(and)* that after one year there is no more treatment. I was suffering there - no brother, no sister; there was no help from anyone.

I stayed there till they brought another medical team to come and examine my body. After they scanned my body, they said there was no problem. The doctor said this man is complaining and look at his condition; *(said that)* they should run another test. They said it is a onetime test and can't be taken twice, so they didn't treat me afterward. I suffered there from 1998, no more treatment and the sickness came back.

The Governor said they should release me from the court out of mercy, I was released. I went back home heard there is a leprosy center here so I moved down here and the doctor tested me and confirmed there was something wrong with me. He gave me drugs to use for another year. After using it the illness didn't get healed, he tried his best but all to no avail and I went back to him. He said drugs will be administered as soon as they have it but the drugs were not forthcoming. The wound didn't get healed and also the sickness, since 1998. I didn't get any treatment till 2017.

Because of my sickness I was thrown out, by the help of God one of my younger brothers paid for this place that I should stay here and manage. I have nothing as you can see where I am sleeping. I have no helper, see my body, no money, no nothing. You people should help me, some people said I should write to the State Governor as I stayed in the prison for 27 years before I was released with no helper. Please help me in any way you can render help, I have nothing, please help me in any way you can help me so I can associate with the society. My hometown is Opuama town, Southern Ijaw Local Government. They *(our people)* will push you out of the town; you will stay out of the town so that other people don't contact the sickness.

Anytime am in pain, am always unhappy. If it wasn't for your visit I'd be sleeping. When I sell pure water there, I come back here and sleep. Nothing makes me happy for now. The only thing that makes me happy is when I am going to Church, that's my only source of happiness for being alive. If it wasn't for the Church I attend, I might have committed suicide. As I go to Church and I come back, that's my happiness.

A Question of Justice

EMMANUEL KENIWENIMO

Profile: 40 years, Male, Single
Place of origin: Agudiama,
Bayelsa State.
Diagnosed in 2008 and Treated
for Leprosy from 2018 to 2019
at Igbogene, Bayelsa

“They don't touch the things I touch, so it is very difficult for me to cope with people around me. At times, it makes me want to even commit suicide”

“…As soon as the three passengers who were already in it saw me, they quickly disembarked. Several would-be passengers came along but one after the other, they shunned the tricycle in which I sat.”

My name is Emmanuel Keniwenimo from Agudiama, Bayelsa State.

During this period that I was having this problem or let me say presently now as I am going through this problem, people are really running away from me, that's the truth. They don't eat from the same plates with me, they don't even shake my hands, I can't even sit where they sit. They despise me.

For my immediate family, it's kind of difficult too because at times, they don't clean my room and then even, they don't touch the things I touch, so it is very difficult for me to cope with people around me. At times, it makes me want to even commit suicide but ever since I went to the center over there in Igbogene, I met Mr. Bene who gave me that encouragement and has been a source of help to me. Some other persons; particularly a lady who has been so good to me, has been giving me food because it's hard for me to eat and also for me to take transport. So living is very tough, it's not easy for me and I think it's not for me alone. I think that other people that are going through this problem also find it difficult. So definitely, if the Government can do something to help us, I think it will go a long way in our lives.

I never went to any higher institution or secondary school. I stopped at Primary 5, that's where I stopped my education. I am a welder but for now, there is no work, people really don't want to give me job to do.

I stayed in different places because my father was a retired soldier. He was a soldier, so he used to travel; they used to transfer him so we went from place to place and the last place they transferred my father to was Lagos. So, after his death, I came back to the village. Although the sickness came with me all the way from Lagos around 2008, I think so. It's about 10 years now. I am the only person *(affected by leprosy)* in my family.

I faced numerous incidents of discrimination. Like the bathroom we have now, I cannot share it with anybody so, I go to the river to have my bath; sometimes, I am kind of shy to undress fully in public. So, I want to bath in the bathroom but I can't share the bathroom with my family so, I do my own things myself. Even the plate I hold, if my mummy holds it, she will wash her hand. It makes me feel bad, it makes me feel like I am just alone, I don't have anybody. But there are good parts of her though. Like, she does give me food and stuffs like that, I think that's the only thing that really makes me want to stay and because of the kind of person I am, my mindset is not like every other person's, I free my mind and play with anybody that wants to play with me. So, that's one of the major challenges I am having and being segregated to a corner; like, you really can't shake anybody, nobody wants to come close to you, everybody wants to be at a distance from you, talking to you from a distance, sometimes I will just look at myself. And again, one worst part I really don't like; I love children, I love children a lot but if I want to play with other people's children, they don't allow their children to come to me, it makes me feel so, so bad.

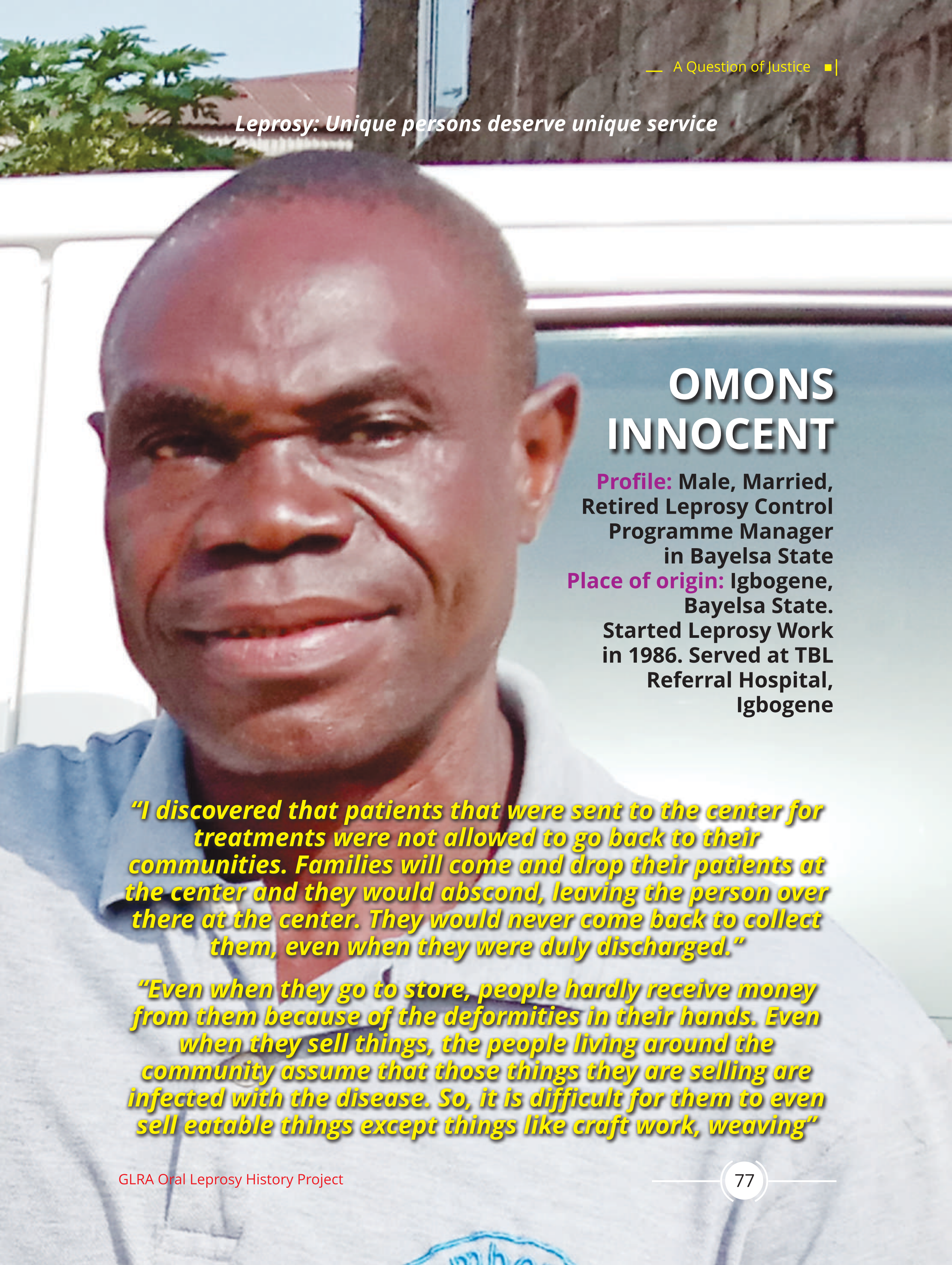
I'll never forget one incident when I went to the market to buy food stuff with the money which I made from carrying blocks

at a construction site in our neighborhood. I arrived the market with the sum of six thousand, five hundred Naira. In all, I purchased items worth five thousand, three hundred Naira, leaving me with a balance of one thousand, two hundred Naira. I hailed a 'Keke' (tricycle) for a ride home. As soon as the three passengers who were already in it saw me, they quickly disembarked. Initially, the driver sounded disdainful of their conduct and assured me that I had a right to board the vehicle. Several would-be passengers came along but one after the other, they shunned the tricycle in which I sat. After over an hour of frustrating wait, the cab driver asked whether I was willing to pay for all the seats so that he could take me home. I pleaded with him that I didn't have more than one thousand, two hundred Naira on me. Finally, he agreed to accept that sum and took me home. I was so shaken by the experience that I couldn't eat when I got home. I simply locked my door and lay down in my bed wondering whether life was still worth living.

The good aspect? I don't think there is any good aspect because anybody who finds himself in what am going through today, that person would always regret being alive like myself. Because the way people treat you, the way people interact with you is different from the way they deal with other people; we are all normal because we are all humans, the way they see you, they see you as nobody because we are all humans, their heart is different, we are not like God that can accept anything that comes His way, that is it.

For me let me just use myself as a contact to every other person too. For me, what I want the Government to do is to open a place for us where they can fix us where we can work, to be having our own income so that we will not depend on anybody and also, to find a lasting solution to this illness by making everybody happy and also to certify the people in Bayelsa State and every other state so that people will understand that this illness cannot affect anybody except the person that has it. So, if they can put all these measures in place, I think the society will be a better place for us to live.

Leprosy: Unique persons deserve unique service



OMONS INNOCENT

Profile: Male, Married, Retired Leprosy Control Programme Manager in Bayelsa State
Place of origin: Igbogene, Bayelsa State.
Started Leprosy Work in 1986. Served at TBL Referral Hospital, Igbogene

"I discovered that patients that were sent to the center for treatments were not allowed to go back to their communities. Families will come and drop their patients at the center and they would abscond, leaving the person over there at the center. They would never come back to collect them, even when they were duly discharged."

"Even when they go to store, people hardly receive money from them because of the deformities in their hands. Even when they sell things, the people living around the community assume that those things they are selling are infected with the disease. So, it is difficult for them to even sell eatable things except things like craft work, weaving"

I am from Yenagoa. I'm native of Igbogene in Bayelsa State. I started the leprosy work since 1986.

Immediately the posting was published, that was the beginning. I saw how fellow colleagues started giving us names immediately as at that time. We were sent for 6 months orientation course on leprosy by then, one Mr. Aggi from Awuda was there as the one in charge. So, in 1986 I was posted to be the Leprosy Superintendent in Yenagoa Local Government in the then Rivers state. That was how I found myself in the Leprosy field. I was posted and I came down to Yenagoa. The only colony that was in existence as at that time, as at 1986 when I came to Yenagoa Local Government was Igbogene leprosy center. That was how I came here and I started the job.

Actually, when I came in to my own state, I registered in my own Local Government being Igbogene. They heard that am working in the leprosy center in Igbogene, there was a lot of stigma attached to me. One, nobody dares comes to that leprosy center in Igbogene for fear of being affected by the disease. So, I was stigmatized by friends and by relations but I thank God that I have knowledge about the spread of the disease and I began to educate them that the way they think is not the way the disease is. With time, they began to understand that one cannot just contract leprosy immediately.

Even those that were patients in Igbogene were stigmatized. There were not allowed to go to the river where others fetched water to bath or wash. So, a lot of things happen with my presence in the community, Igbogene.

One of the remarkable events or experiences while providing this care: One, I discovered that patients that were sent to the center for treatments were not allowed to go back to their communities. Families will come and drop their patients at the center and they will abscond, leaving the person over there at the center. They will never come back to collect their patients even when they are duly discharged. So, the center became a home of leprosy patients because anybody who found his way by bringing their patients down to the center, assumes that that is where the patients should live and not to go back to the community. So, that was one of the events I really know that I experienced when I was doing the job. Patients that were managed and treated were not allowed to go back home. There were kept at the center as if we were their owners. That was one of the major things I experienced.

Then, I also found out that all the patients that were sent as at that time, were deformed with disabilities; rotten bones, in fact, it takes the grace of God because there are people that all the toes are cut off, all the fingers are cut off; they are smelling, you will see maggot coming out from their wound, rotten bones. So, nobody wants them to go back. That was how they dumped all those patients here and I came in and I started attending to them. So, that's one of the things I really solved that time, patients were not allowed to go back home.

They have a major challenge because the public is ignorant about the disease. The public assumes that as far as they are still seeing disabilities and deformities in patients, they are likely to infect others with the disease, even when we have declared them cured. So, they did not allow them to go back to rehabilitate them back into the communities and that is one of the reasons why most of them resulted to going to the main road to and beg for alms because their community rejected them. In fact, it will take the grace of God for our people to understand that it is not the deformities they see in patients that classify one as being infectious in leprosy. It is the ones in their community, in their houses that are untreated that are liable to spread the infection not those ones that are here, that have been treated. They think the *(persons with)* deformities that they are seeing are the ones that are going to transfer the infection. That is, one of the things we needed to give awareness to our community.

So, meanwhile, as I'm talking to you, most patients are not at home because they refuse to rehabilitate them because of the deformities in them. Even when they go to store, people hardly receive money from them because of the deformities in their hands. Even when they sell things, the people living around the community assume that those things they are selling are infected with the disease. So, it is difficult for them to even sell eatable things except things like craft work, weaving, things that maybe they cannot transfer through thin rope, like those things e.g. chairs that they weave with their hands. Those social things are what they can go in but they cannot buy edible things from a leprosy patient. That is one of the social issue we are seeing up till now.

Like, that time, some of the patients that were brought in here were not in their communities, there were driven into the forest. So, we had to locate them in the forest where they were driven to, where they went and built a hut and lived alone, isolated in the bush. We were able to retrieve all those cases as at that time, *(brought them)* down to the center and given the life. So, let the public get an awareness; pursuing a leprosy patient into the forest to go and live, is uncalled for. The stigma attached to leprosy patients as at that time was too high to the extent, a family, a community will gang up together and tell the person you are no longer a member of this community, go and leave in the forest but I just thank God for those people we went and brought from the forest at the end of the day, we treated them, they became cured, some we even employed them in the State Government.

Palemi was an example, yes, he was driven to the forest too. We brought him here and after treatments, we went to the commission and told them that this man can do work, at least, he can do security job. With the deformities, he can't work in the office but he can do security jobs and he was employed and he was on salary until he died. And there is another boy, that boy is from Southern Ijaw Local Government, that boy came in here when he was in the primary school; abandoned by the parent. We trained him here in the primary school, he finished primary school here, I kept him here until he finished his secondary school and when he finished, I had to discuss with the secretary of civil service commission. That time, they gave us preference, when we appeal to issues like this, they gave us automatic preference, so what I wrote and met with the secretary, he said, “bring the boy let us interview him”, the boy was interviewed and he was given a clerical job. As am talking to you now, that boy is a senior clerical officer in the State Government but he was our patient, he has gotten married with children, so, you could still how the job helped.

So, that's one of the things that I know that well, at least, there's joy in me that there were people that were neglected here but we've been able to give them life and that's how the job is supposed to be.

Stories from CROSS RIVER STATE

Leprosy Settlement, Obubra

Rejected by those who should Care

MRS. ADIAH CHRISTIANA

Profile: 56 years, Female, Widow
Place of origin: Obubra, Cross River State.
Diagnosed and Treated for Leprosy from at PTBL Mbembe, Obubra Cross River State

"My mother called on my father to come and check on his daughter but he denied me being his daughter..."

"They don't care to know if I'm alive or dead, they don't even want to know if I'm still suffering the disease, they don't care to buy drugs for me to battle the disease. My child is old enough to begin schooling but no one cares."

The first time I discovered I had leprosy, I had not developed breasts and I was not married.

They came for me and I wasn't aware because I was very tender then but I saw how they killed people in the forest and I asked my mother why those people were killed and she said they suffered a grave illness. Twin babies too were also thrown into the bush. It was when I came of age that I realized that the sufferers of the illness were not meant to be thrown into that forest.

Before I got married, I noticed some bodily changes like, my fingers falling off, adverse change on my face and I went to my mother to tell her what was going on to know whether she had an idea but as I showed her, she started crying and when I asked her further, she told me that I did not know why she was crying because of what I showed her and she said that it was a sign of the very bad disease which the people of the community dispose of any sufferer of such into the forest. I was shocked when she said and reaffirmed it. As time went on, I noticed that I could not feel my legs and hands any longer and I complained to my mother again but she still told me it was that deadly disease.

After marriage, I got pregnant and delivered. But I could not carry my child. At a time, my husband wrapped the child in a cloth and told me he wanted to take me to my mother because he did not see me as one who could survive. He took me back to my mother but when we got there, the people around were suggesting that he took me to the hospital other than dropping me off at my mother's place. He left with the child immediately after dropping me off. My mother called on my father to come and check on his daughter but he denied me being his daughter but my mother said that even though he rejects me, that God will not.

Later, Awasawara, Basawara, Ewa, Sahie, elder Bok, they all helped bring me here. When I came here, I received many drugs, they fed us thrice daily. After some time, I felt better and the doctor discharged me. I went home but it continued which made me return to the hospital for further treatments but the feeding dropped. They began giving us little amount of money monthly to support the feeding but it was also cut off later. Since then, we've been managing ourselves with the little we have.

I myself, go to the farm with my sore legs in order to make sure I and my children see something to eat; we are all suffering here.

Family members and Friends

Nobody takes care of me any longer; not even my family. They don't even border to come and check on their sister or child, they don't care if I'm dead or not, I'm just suffering here. Family members don't have time. And because I'm sick and nobody goes close to a sick one, they don't.

I visit them whenever I leave here. Even when my father was alive and I had some food from this place, I put it in my bag and take it to them but they don't take care of me. They don't care to know if I'm alive or dead, they don't even want to know if I'm still suffering the disease, they don't care to buy drugs for me to battle the disease.

My child is old enough to begin schooling but no one cares.

It's not a matter of having the money or not. Checking up on that person; "let me go and see my sister", "let me go and see how she's doing" is better than money because it is when you go see the person, know how he/she is doing, it is then that you know what the problem really is but if you don't go, you cannot know what the problem really is. Just like the way I am now and you're here, if I don't tell you my problems will you know I have any?

Nigeria today is very different from the past. 20 Naira at that time could get you something comfortable but now, no matter the millions in your account, you can't solve all your problems.

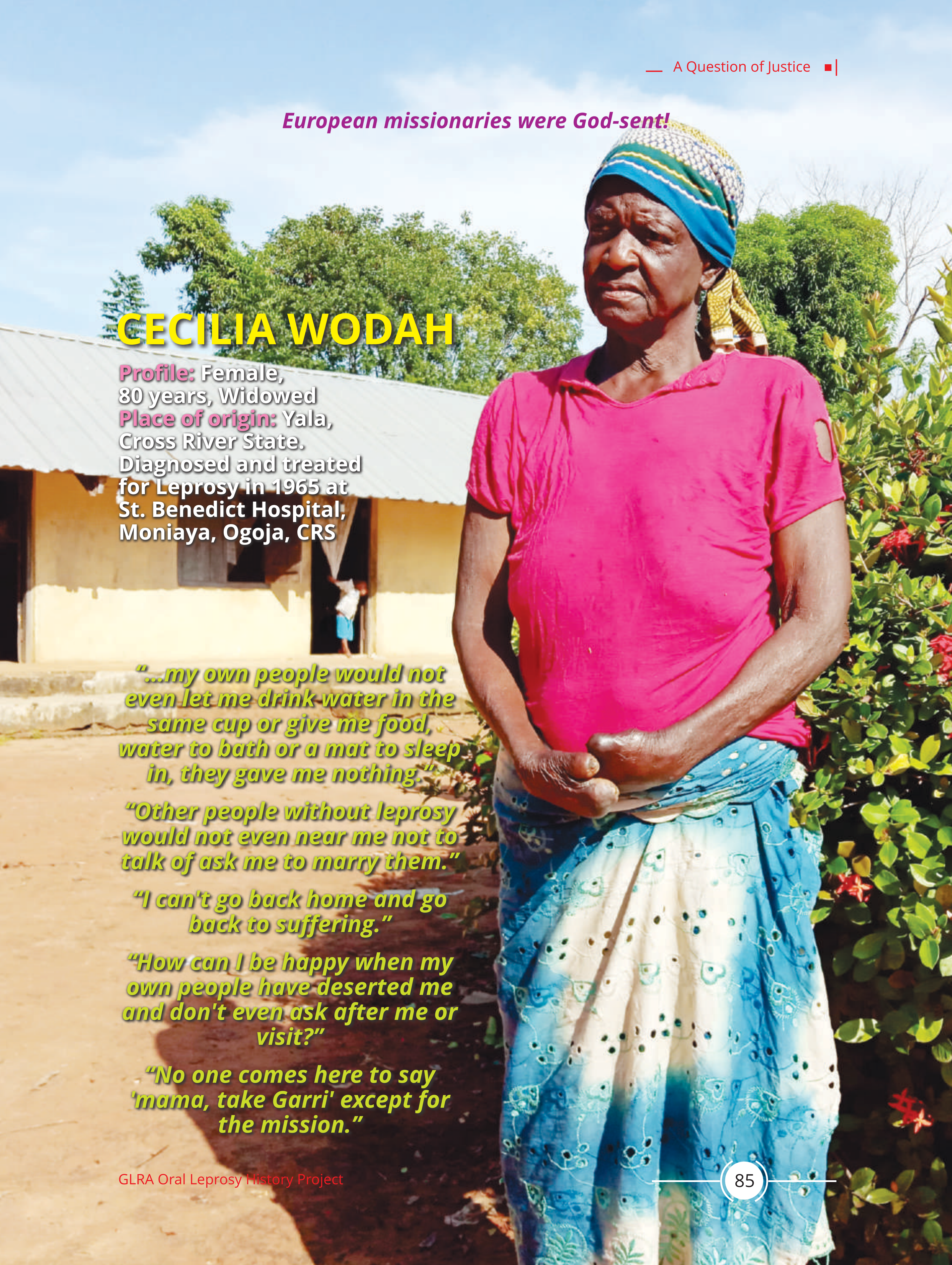
My mother was in tears but she brought me to the hospital and she was the one who took care of me until I recovered and went back home. I never even saw my father till his death while I was ill, it was only my mother who took care of me but she's late now. She really took good care of me; bringing me some things to sustain myself with. Since her death, nobody else has come to see me like she did from my family.

When I was with my friends and relatives, it was only my siblings that came near me, no outsider that knew did come close to me. After I came here, whenever I went home, they welcomed me. They still accepted me even when they knew I had leprosy. Other people don't come to visit me, they don't come to help. When my people visit, that little thing I got from the farm to help myself with, I share with them too so that they see that the person they separated themselves from shared the little she could make out from the bush with them.

My Pains, my regrets

If not for the pains I'm having on the foot where I have wound, I should be farming but anytime I manage to go to the farm, I experience great pains on that foot. If leprosy had not kept me here, I can do any business so long as I can move without disturbance because I can trade; buy and sell items, I can. It really deprived me of things I could do. I am happy because even though I had leprosy, God kept me alive till today. There are some other people who did not suffer the disease but they are not alive today. That even in my ill health, God gave me grace to have children and have life too till today. That is my greatest happiness. It is because of leprosy that my parents never trained me in school if not, I know I'd be sitting in an office now. If not for leprosy, I can engage in any lucrative business and succeed too.

European missionaries were God-sent!



CECILIA WODAH

Profile: Female,
80 years, Widowed
Place of origin: Yala,
Cross River State.
Diagnosed and treated
for Leprosy in 1965 at
St. Benedict Hospital,
Moniaya, Ogoja, CRS

"...my own people would not even let me drink water in the same cup or give me food, water to bath or a mat to sleep in, they gave me nothing."

"Other people without leprosy would not even near me not to talk of ask me to marry them."

"I can't go back home and go back to suffering."

"How can I be happy when my own people have deserted me and don't even ask after me or visit?"

"No one comes here to say 'mama, take Garri' except for the mission."

Discovering Leprosy

When I was small, my father sent me to stay with his sister who was married elsewhere. While I was there, we came from a market at Okoko. While I was sleeping, I felt like I was flung on the floor and something began to scratch me so much. My father's sister woke up and saw me scratching my body and used palm oil to rub my body and the scratch stopped. Less than three days later, on our way to the farm, I found my back already had yellow spots but she kept rubbing palm oil on it. Later, I was carried to Okoko where Dr. Chamber and [Gbagri] were – that time [Gbagri] was still very young. I was examined by the doctor and was told it was leprosy.

Treatment

They wrote a letter with which Dr. Chamber used to transfer me from Okoko to this place. I didn't grow up to suffer but my father sent me to stay with his sister and I got leprosy. That time we took *chamogram* and those other medicines that was charged in a fire before use. We took numerous injections during that time and I was cured of leprosy. They took me home but after a while, the leprosy came back to me and Dr. Chambers said I shouldn't go anywhere again. I've been here twice and have stayed here since the second time.

Discrimination

They found that I had gotten 'bad sickness' and so they didn't allow me go close to the children or even anybody again. My mother saw the discrimination and then brought me here and they built me a house where I have now lived in till date. When my own people would not even let me drink water in the same cup or give me food, water to bath or a mat to sleep in, they gave me nothing. I often slept on a piece of cloth on the ground.

They called it a 'bad sickness'. They didn't want me to infect them. The Europeans, when we were with them here, they were more hospitable to us, they were more at peace with us. But black people . . . *hmmm*. . some of those people that didn't want me to near them, for fear of getting infected with my bad sickness, some of them are dead now but me as 'spoilt' as I am *(putting forth both hands to show her burnt out fingers),* I am here, still alive.

Marriage

My marriage is not a big deal, I got married to a fellow leprosy patient, na we-we (it couldn't have been better than that!).
I gave birth to all my children inside the leprosy settlement here. But he is late now. We're both had leprosy, na we-we – so, it worked out effortlessly. Other people without leprosy would not even near me not to talk of ask me to marry them.

Reuniting with Family after the Biafran War

After the war, we were asked to go back home to our people. But our people, they know we were 'sick people', they didn't let us live with them. That's why we returned to this place. That's why the missionaries said, instead of discharging us from here and we go back home and face suffering, it is better if we stayed here and formed a settlement of our own. They built houses for us, took care of us, fed us, clothed us and cleaned us up. These were Europeans, they came to look after us at least once a week, on Saturdays. I didn't suffer at all during that time, all my needs were being catered for. So, comparing the treatment I got from here and the suffering I got from my own people, why would I want to ever go back? Here, I am fed and being treated. I can't go back home and go back to suffering.

Life after treatment

When I wasn't sick, I was still with my aunt. I helped her fetch firewood, ground *Nyabe,* I did the chores and went on errands. Now that I am sick here, I have found it difficult to even help myself. My husband who used to help, has died and left me here alone. But I still try and help myself and my children with great help from the 'mission'. This sickness made me lazy, I can only do very little. The treatment I got in the past was more caring than what I get now.

Especially since my husband died, I have been striving to take care of my children and myself. The death of my husband is the saddest memory I have. No one takes care of me or asks about me again, except for the 'mission'. If not for the mission, I will die of hunger. I am not even healthy again, yet my people have not come one day to say “let me take this thing and give to my sister”. I have been deserted by even my brother and sister and now I am desolate. This thought often makes me lose sleep. The mission has been very helpful, if not for them, these thoughts would have killed me.

Nothing makes me happy. I am not happy. How can I be happy when my own people have deserted me and don't even ask after me or visit? If not for mission, I will have died. So, what will I do if mission kicks me out? I'll probably die here and mission will bury me here. I have no one. I am saying the truth, so that God will help me. No one comes here to say “mama, take *Garri”* except for the mission.

'I will not discriminate'

Like for my children, if a leprosy patient came to marry them, I will not deny them that chance. I don't know tomorrow, I am not God. The thing is they may have fear that me their mother had leprosy and so they may not bother coming close to my children.

Finding solace when life appears bitter

DONATUS NKOMBE

Profile: 63 years, Male, Separated,
Place of origin: Ishibiri, Ogoja, Cross River.
Diagnosed and Treated for Leprosy in 1965 at St. Benedict Ogoja

"I can't even step my feet on the ground firmly, my wife left me saying she did not want to contract the disease from me."

"Then we enjoyed this place because of the way we were treated but now, we stay up to 6 or 7 months before we receive food items or money. Now, they no longer bring food again, all they send us is pocket money at the end of 3 to 4 months, that's all."

I was about 6 years when I developed leprosy. I noticed the signs on my head and my face. If not for the disease, I could have joined the Biafran army then but I was brought to this place and I have been here till today. I've stayed here for almost 25 years but none of my people have been here to visit because even back at home, anyone with leprosy is considered one without relations because of the deadly nature of the disease. They avoid every contact with us. If not for German Leprosy, we would have been dead and when we die, that is our grave over there; where the priest prays for us and none of our relations will be present because they have rejected us. We have been managing ourselves waiting for any day that death comes knocking so we leave.

Discrimination

At the initial time, they discriminated me. They said I could no longer stay with them and so, they wanted to build a small place for me in the bush before Dr. Agbadula and some other people started moving into communities with a vehicle picking leprosy patients for treatment and when they saw me, they confirmed I had leprosy and took me with them and brought me here where I've been since then till today. None of my people come here to visit only that the missionaries give us some items but no longer do so and that is just how we have been managing since. If I die, take a look at my grave other there.

I have no idea how I developed leprosy, all I know is that its signs started manifesting from here. We call the whites "Okahara" in my language Ishibiri. It was "Okahara" that helped me come here when I was identified as a leper *(use of the terminology "leper" is highly discouraged as it connotes stigmatization)* and have been here till today.

I can't even step my feet on the ground firmly, my wife left me saying she did not want to contract the disease from me. But the doctors said leprosy cannot be contracted through touch or using same items with the person, except cup. There are so many leprosy patients here who have children and when other people see our children, they are like, "are these not the children of those lepers?". We have been rejected by our people, even as I'm talking to you now, whenever I go home, I don't sit with them, I don't mingle.

My father's house was my home but my father is late now, these people you see here are always with me; once I die, they take me to my grave over there.

Marriage

I met my wife here in the hospital. She would come here complaining of food so, I went to make friends with her while having leprosy. She came to the hospital often then and it is when the foreigners were in charge and so, they were giving us garri, rice, beans, and bathing soap. The foreigners have all left now and are no longer here with us. We are left to suffer and wait till anytime, people feel like giving us something to eat. So that period when the whites gave people many things, she came to see me and she liked me. She liked me that period and she stayed with me in this camp for at least 12 or 11 years. I don't know what made her change her mind about me to say that I'm a leper and that I was already old so, she would like to leave.

And I told her to leave if she wanted to and that I will continue to live even after she's gone.

At that time, her mother was still alive and she came to this place and asked her if she wanted to stay here and she agreed but I don't know why she changed her mind to leave after agreeing to marry a leper. I asked her to leave if she wanted to and that I will not force her to stay. You know, they refer to us as lepers *(use of the terminology "leper" is highly discouraged as it connotes stigmatization),* they don't call anybody's name. She said that at that time, she didn't know. Those days she's the one who could talk and answer for me. Then, later she said she was been deceived and she left.

I could not do anything. She was just coming and helping out with some things because no one said anything but when they began revealing, she had the knowledge and said since I'm also getting old, she'll leave me and I just had to ask her to go. She gave me a son, it was the priest that sponsored him all through. She did not want to be infected by leprosy. I think I was up to 20 years ago if not even more. She didn't have leprosy herself.

Nigerian-Biafran Civil War

When the whites came, they said there was treatment here and so, many sufferers in Ogoja; so many people that died and are still alive now, came here and we were together. They really took care of us. War really affected the leprosy settlement camp. They were shooting sporadically. And when they tried to enter here, the whites stopped them and told them the consequence of killing anybody in the Nigerian Government property. And so, the whites relocated us all to a better place for safety and they continued to provide for us there. "Okahara" was around at that time and he asked us to be strong and to fear nothing. I think, Dr. Gbadulak was around then. I think I was up to 20 years old if not even more. Some of the people with leprosy that were treated in the community outside the settlement that I witnessed those days are already dead, even my friend that left not too long ago is also dead. There was a school here for leprosy patients when I came here. Yes, look at the school over there. Everything was fine before the war. People from Ghana, Togo, Cameroun, were all here but as the war broke out, everything and everyone was scattered. The whites took care of the people that remained here while others fled. They then locked us in a safe house.

Changes in the Settlement

Then we enjoyed this place because of the way we were treated but now, we stay up to 6 or 7 months before we receive food items or money. Now, they no longer bring food again, all they send us is pocket money at the end of 3 to 4months, that's all. I have not seen children brought to settlement like it would happen in the past. Nowadays, the children come for treatments and go back home, they are not kept in the settlement anymore but in those days when our relations desert us, once they noticed anyone with leprosy, they advised their children not to go close for fear of contracting the disease. But now, leprosy is not taken as it used to be then. The whites wanted to build a maternity home here but people revolted against it saying they didn't want to have anything to do with lepers. And so, the whites built it over there before the people could agree to visit it. Despite all, the whites still took good care of us; they urged us not to overthink and convinced us that we were better than lepers outside these walls, that we were in God's hands. When we consider what lepers outside face, we know that we are privileged to be where people take care of us; give us food, drugs and still have to thank God too.

I am ready to stay here because I have no family. We have enough yam tubers here; we don't buy, we cultivate; only that some rich people visit us and share yams to us to keep us going. That's how we have been since then till today. Yes, living in the leprosy camp is better than living in the community as a leper. This is because for instance, we eat free; I can sleep here, I can't overthink, I have nothing at home, thieves cannot benefit from me because I have no money, nothing, unless they want to take the "okrika" cloth that I'm being given. Here I do not fear for thieves, not at all. We can sleep in this corridor fearlessly but if we were outside, we would be conscious of the safety of our environments and our children and other things but here, we are afraid of nothing because we have nothing.

Now, a child of 6 years with leprosy in the present day will only come to take treatment and go back home without having to remain in the camp but it was not that way in the past.

Some who come to take drugs and go home now get worse and they're brought here but if it were before, the whites cannot let you go so long as they have confirmed that you suffer leprosy. They'll keep you here and treat you and once they tell you that you have leprosy, when you go back to your people, they'll reject you because they fear leprosy. And so, you just have to remain here. But now, people no longer discriminate between lepers again; they have taken leprosy *(to be as common)* as water. Even people outside struggle to come in here whenever supplies are being distributed but the priest always says he needs only his people who stay here. They have taken our snapshots too and sometimes when I cannot step my feet on the floor, I assist myself with clutches.

Now, I think people have been enlightened because they take leprosy like water unlike before when they don't want to even go close. Sometimes then, if they don't build a house for you in the bush, they drive you out and if you're not lucky to be picked by the whites, you remain wherever they drive you to without hearing from them again but we that were brought here, we enjoy the feeding, they give us soap to bath, we sleep calmly with our radios for those that have and we thank the priest for the day.

Family, Regrets, Joy

As we are now, we are like one family, the people in charge try their best to take care of us even though our relations have deserted us. They provide food, shelter and other amenities for good health for us. I will prefer the settlement camp. While I'm here, I'm not feeling anything; I have no wife, I have nothing. The only thing I do is eat and sleep, I pray to God. Using myself as an instance, my parents died before I discovered leprosy. Since I left home to come here to be honest with you, none of my siblings have come here to see me maybe because I'm no longer human to them. I'd rather remain here than relocate to some luxurious lifestyle because no matter where I leave this very place for, I will still encounter suffering maybe even more and so, it is better I remained here and died. My leg cannot heal completely. They said if the wound should come in contact with sand, the affected part will have to be completely cut off because the bone will be adversely affected. This is why we're not allowed to move out, so that it does not grow worse.

My son left with one of my friends who was a soldier that came to visit me and after considering all factors of survival here, decided to leave with him to save him the suffering he was to encounter if he were to remain with me to this moment. I am very happy my friend took him so that even if I die tomorrow, they'll be less bordered and that is what I want; for nobody to worry much about me but finally, God knows I have a son that even when I die, my son can carry on.

My regret most times is when I wake up and I remember the fact that my people have deserted me because I have leprosy. I have made up my mind that my death will worth less since I'll be buried just right over there. But even in all these, I still hope in God for survival everyday even when we have little or nothing to eat or make use of.

My joy is for the kind of treatment we receive here; groups and individuals come here to visit us, they provide food, drugs, cloths and other necessary things needed for survival and they pray for us too while we also pray for them in return. When I consider this, I'm happy because staying out there, no one will come to you and hand over drugs for leprosy to you but in here, we receive a lot from people of goodwill. They own us, they are our family and I feel comfortable around them and when we die, we would be thrown there. I am a man with less worries; we joke, chat jovially here and are always happy. It cannot be the same when one travels back home and may even lead to an earlier death because one will keep thinking about the good moments here. Personally, I'm happy here because we all are free and tolerative.

We have been here witnessing new set of patients being brought into the camp and when we first came, the people that were already here felt the same way. We belong to the Government and they send us some supplies but at home, nobody looks after us properly. The “Okahara” treated us better those days starting from the quality and quantity of supplies brought for us to share, the motivational back up, prayers too but nowadays, we are treated as though we do not exist.

For instance, Leprosy Day in Enugu was celebrated but here in Ogoja, we were just neglected as though nothing was been commemorated on that day. But when “Okahara” were still around, we celebrated Leprosy Day very interestingly and fun filled. It is worse now than before.

Champion for people affect with leprosy

I have been here for a long time at least since I was little, I can recognize someone with leprosy. Even while we are here, we talk to visitors and let them know that lepers are not to be discriminated because it cannot be contracted through touch. The whites have already built this place for us since we are rejected by even our own family members. They asked us to love ourselves and live in peace.

Pains and gains in leprosy work

ELDER IKPI ABAM

Profile: **Male, married, retired veteran leprosy healthcare worker. Served many years in providing care for leprosy patients from 1977 to 2012. Retired as LGA (District) Tuberculosis and Leprosy Supervisor in Obubra LGA of Cross River State**

"If I knew that I was going to work with leprosy patients, maybe I would have refused the offer, but that was where God sent me to work. After the fear, I developed interest in them."

I am Elder Ikpi Abam, a native of Yakurr LGA of Cross River State.

How I got enrolled to leprosy work

My story started sometime in 1976, after I left school. I was a very good player, a star player. I played football well. That time, Itigidi Memorial Joint Hospital was a major hospital overseeing the area. In 1976 the hospital was about to organize a football match to round up the send-forth ceremony of her retired Medical Superintendent, Dr. S.P. Imoke, the father of the former Governor of the State. The football match was between the hospital team and the Itigidi town team and that was in need of a few hands to help out. That was how one man from my village who was working at the hospital informed them that he has got a good player who he would invite to come and play for them. That was exactly what happened. So, on a Sunday, I had gone to church. They came in after we had gone to church and stayed until after the service. While I was coming back, I didn't know what was happening. The man from my village in the company of his friend was pointing at me, saying, "That is the boy. That is the boy". So, they now invited me and made their mission known to me.

I accepted to go but requested them to discuss with my father for approval. My father asked them what I shall get in return. They promised that they were going to give me employment in the hospital, so that I can be playing with them in the team. That was the agreement.

On the football match day, we played well and defeated the town team. In fact, I really played. That time, I used to play. I played and I really entertained people so much that Dr. Ekoma, who was coming to take over from Dr. Imoke, was impressed.

Unpleasant surprises!

After that time in July, I was invited for interview by the end of November and eventually offered a letter of appointment. But what baffled me was that my expectation to work in Itigidi hospital was disappointed. In the appointment letter, they said I should report at Ngbeke. And before this time, for me I never knew where Ngbeke was. Ngbeke is the place where they had the first leprosy settlement. So, that was where they said we should report. I took that letter to the man. I wanted him to him to explain to me where they said I should report. He replied, at Ngbeke, where you have those buildings, the leprosy patients.

Before that time, I had not seen a leprosy patient and I would say I have not even heard of this disease, leprosy. I have not. So, I told my father and he said, "You will go!. Go and report and see what they have for you". He gave me his bicycle. I rode from Ikori to that place, about 5 kilometers. So, I got there in the morning. Others who were also employed together with me, came around. We met the officers and introduced ourselves. We were informed about our orientation which will last for six months. That was how we started the job. As at that time, they have repatriated all the patients to this area. It was only the administrative block that was there. So, we had the training for six months and were posted out from that place. During the six months' training they took us to this place - Obubra for field work. This was where I saw a leprosy patient for the first time.

My first day to see a leprosy patient – a different bargain

That was my first day to see a 'leper', somebody who's suffering. And that time, leprosy was very serious. They were many in that ward. Life was unpleasant throughout that week, I nearly resigned my appointment. For me, that was how I reacted, because it has never been my mind. So, I went back to the village and complained to my father, “What I saw. I don't think I will be able to work in that place". My father in response asked, “What is there? They are human beings! What is there?” Besides, I went after that very man who introduced me to the hospital team and protested, “What is all this? Our agreement was for me to work at Itigidi. But you're now telling me to come and work with lepers. How?” The man sat me down and told me so many things. He said, “That is that. What do you do?” He told me how many persons have worked there and retired. He mentioned their names to me, even those from our village.

Well, I picked courage. I came back to the place. Almost every week, they will bring us in here. We will go on ward rounds with the doctor and go back. We were doing it until after sometime, I was no longer afraid. I was becoming used to it. That time, it was so difficult to the extent that I can't imagine having a handshake with them. It was that difficult. Over time, I was able to mix with them until I was used to them.

After the six months, we were posted out, I was sent to this very place, Obubra. Others were sent to work to all other places and I was sent to the hospital. The problem was this: my friends would ask me why I choose to work the 'lepers'. It was not an easy experience for those of us who came in here as ordinary people, not having leprosy. Moreover, when we came in, we realized that most of our senior colleagues and staff including our head, the hospital superintendent was previously a leprosy patient.

Difficult moments of discrimination: a question of justice

Yes, it was not easy for us. We passed through so many difficulties. Sometimes when we want to carry out surveys, perhaps we want to go to schools, it was not easy. Even moving about with our vehicle with “Leprosy” inscription was not easy. It was not easy.

In fact, it was not easy. For anyone to even know that you are working with leprosy patients or 'lepers' (as they called them) was a problem. You are rejected of course. Your friends will not want to mix up well with you. Sometimes, together with friends, discriminatory jokes will come when you want to shake them. You will hear, “No, are you are just coming out from the leprosy”. We suffered all those things. That is why when I sit down, I think about it, my conclusion is, “It was God who sent me this place.” That was why I took my time to work, to do this job. I did this job well. That was the time we were having so many patients, over 60 patients on admission.

The whole of this place was filled. A doctor will come from Itigidi and we will do ward rounds from maybe 10:00am up to 3:00pm.

Leprosy stigma declining over the years

People in Obubra don't dread leprosy patients anymore. For us, around this place, there is no problem again oh. Things have greatly improved because of the enlightenment campaigns and health education that have been carried out over the years in this place. That is why the persons affected by leprosy you interviewed were telling you they can now freely go to the market with others to buy or sell their goods.

Well, like I have said, because of the campaign carried out in this place, the fear people had over the sickness, leprosy, started dying off. That is why you can see them come on their own, when they know that well, if somebody has so, so, so. They know where to refer. That is how you see them coming. In Obubra, there are only few areas I will say we still have leprosy. But in Yakurr Local Government, we still have other places where we have not entered. But then, if they see such cases, they still refer them to this place.

So, we were doing that thing until the time Tuberculosis Services came here in 1982 when I was in Health Tech. I attended School of Heath Technology in 1982. That was when TB came in. We started combining TB with leprosy. And that also helped us to go into both areas where we carried out the surveys. So, as we screen for leprosy, we screen for TB.

Family and community life as a leprosy health worker

For my family, there was no problem. When it was time for me to get married, I got my girl. We started on. She has no problem. I have worked here before I got married. She felt comfortable, very comfortable. When brought my family to Apiapum and my son discovered that I work with leprosy patients, he asked me that question: why I choose to work in this place. I used to carry them from Apiapum to go and drop in that school and then after school, I would take them back. So, at times, I would bring them to this place. When they saw all those people, one day he asked me why I choose to work in this place. So, the answer was not farfetched. I told him that that is the work of God. I didn't put up application to work in this place. It's only God who sent me to this place. I can't explain how I found myself here to work in this place. It must be God who sent me to the place. Ordinarily, I didn't apply. Then I narrated the story of how I was invited at Itigidi to go and play. From the football, they offered me this job and sent me to this place.

Regarding friends, we all suffered it. In fact, to go nearer to them was a problem. Once they knew that I was working in the leprosy center, the intimacy soured. I was not only the one who suffered this fate, Almost all of us did. Even as we carry our school surveys, once we land you see them disappearing. Students would disappear. Even the teachers will not be so interested. As soon as they see this our vehicle with that inscription, “Leprosy”, the way they would have received you, they will look down on you.

I can remember a situation where we got to a secondary school. We had sent the letter informing them that we were coming for immunization. But as soon as we landed and they saw this our vehicle, everybody began to run away. The students were running and even their teachers. There was no cooperation and that day, we couldn't work in that school. We didn't because of the way the principal treated us.

But we went back. So, that was why at a time, we introduced a strategy of going with some additional drugs. We used some medicines apart from those of leprosy. The plan was that we would not tell them that we were coming for leprosy. We just wanted to examine everybody. So, if you have any skin disease, will give you drugs, free of charge. We deworm even the children. That one was the one that brought us up. At least, that one helped to remove that stigma. We used to go with drugs like that. When we get there, we give those drugs free of charge. That was how we managed to overcome that rejection.

Most remarkable experience

I look at myself as somebody God destined to work in this place. I don't regret because I really progressed. Because I have said here that I have not known anything concerning leprosy before ever I was employed. ***If I knew that I was going to work with the leprosy patients, maybe that I would have refused the offer, but that was where God sent me to work. After the fear, I developed interest in them.*** I took time to do the work, as far as my ability. I don't regret. Today, I can tell somebody where I work without shame, without fear; where I worked until I retired. I progressed beyond those who started in other jobs before me. I was privileged to be trained at Zaria. I've been there two times. After my Supervisors' training course, I was sent to that place again for POD. I did POD and came back.

I have also been to Ethiopia.

So, I don't regret. This place is a good place. It's only the name. That is why our nurses who are working here, by the time they were posting them, they will say, “No, no, no, no”. But if when anyone comes in here to work and it is time for them to be transferred out, they will go and bribe so they can be kept back.

Legacy fast deteriorating

This is a good place. But that was then!

Not now where nobody has interested in this place anymore. Before now, the government was serious with maintaining this place. Ministry of Health used to send subvention up to 100,000 naira at that time. Ministry of Women Affairs or Social Welfare used to send 80,000 naira and HIV/AIDS programme used to send 150,000 naira. All these former leprosy patients were employed by us then. All these patients, they were many. Some of them are not here, some of them are dead; we used to pay them. At the end of the month, we pay them all stipends they use in helping themselves. See now, the community chief who came in here today just mentioned that the agreement for the occupation of this land has expired since last year. You see, this land (referring to Obubra leprosy centre) was from the highway up there to where you have the stream on the other side, I mean that bridge.

Many years ago, I came in here as a boy and that place was under this hospital, there was no market there. They said there was a primary school there for the “lepers”. If you go this way, there's one you would meet before that village. It was under this hospital. I have seen our laborers work in that place; plant rice there, harvest it for this hospital. The land extends up to the other side. But the church that owns this place is not ready to do anything, maybe because money is not coming out from this place. Nobody wants to take responsibility over the place. The church doesn't want to develop this place. I'm an elder in the church. Maybe they're only interested in the land. That is why you see the community wants to claim back this land.

See, the whole of that place was our place then. See houses! They said they gave them this land for developmental purposes. For over 100 years, the Church have not developed this place. That is why they want to take back our land. The government in Cross River State was supposed to work with the Church. They should call the Church. The Church is the owner of this place. So, the government is supposed to call the attention of the church.

Difficult times for leprosy patients

Leprosy settlement is always at the middle of the bush. It's not always close to a village. Like the one I'm telling you at Ngbeke, what you have there is a farm. It is because of awareness that we carried out in this place that make you see people nowadays. Now, those who don't have leprosy have come and occupied the whole of this place. They can now share this same water with them. But in those days, in our time, this water was mainly for leprosy people. Nobody comes from outside to fetch from them, all because of the fear of the disease.

It has not always easy with them too. Like some of their family members would carry them and come and dump them here and go away. Imagine that someone would carry his own patient, his own brother or sister who is sick to the hospital and will abandon him or her and leave. That was why at a point, we decided that before you bring any patient, you would bring somebody, a supporter, who would be there with him. And the thing was working well with us. It was not always easy for anyone who is a leprosy patient there. His own people will refuse him. Except now that I can see people bring their brother, sister, daughter or little child to the hospital and be able to help the person. It was not like that before. And the introduction of this TB has also helped in a way. Because when you are taken to this place, outsiders will not know whether you are a leprosy or TB patient. The way society fear leprosy is not the same for TB. The way they look at TB, which is even more common and easier to contact is rather simple.

Final words

I think another thing I want to share is this. I don't know whether it is because of economic hardship, the aids that used to come to persons affected by leprosy is no longer coming. In the past, towards the end of the year, we used to see some non-profit organizations come in with donations, material donations. Some would be cash, envelopes would be sent, bags of rice, beans, toiletries, everything. The government too used to send their own. I don't know. That is what I'm saying whether it's because of difficulty. Such things no longer come in for the patients. The commissioner of health was the one who picked interest in this place and was sending so much to this place. I say apart from the government, other people used to come here. The thing is not like that at the moment. Nobody comes to this place again.