Picturing health: a new face for leprosy

Published Online
January 25, 2019
http://dx.doi.org/10.1016/S0140-6736(19)30158-8

It is true that leprosy impairs and society disables. Leprosy is a neglected tropical disease and one of the most stigmatising of diseases. Images of severely disabled patients with leprosy have helped to raise awareness, attract attention, and drive donations. But these pictures are not representative of the disease. Leprosy patients deserve a better image—leprosy needs a new face. Many people with leprosy will not develop severe disease if they access treatment early. Leprosy infection is curable with 6 or 12 month courses of two or three antibiotics depending on the type of leprosy that they develop, provided free to national leprosy programmes by WHO through the Novartis Foundation.

For the New Face of Leprosy Project, we are developing a more positive image of leprosy as a treatable infection, with patients enjoying life and functioning in society. In Ethiopia, we photographed and interviewed patients in Addis Ababa who live around the main leprosy referral hospital, All Africa Leprosy Tuberculosis, Rehabilitation and Training (ALERT) Centre. The moving stories shown here are from patients talking openly, in their own words. Themes that emerged from these interviews included the strength of religious and traditional beliefs when medical problems develop, and the challenge of leaving their rural homes to come to Addis Ababa. Most of the patients we talked to initially had misconceptions, succumbed to rumours, and some even attempted suicide. Many patients had been abandoned by their families and friends. Feelings of isolation, despondency, rejection, as well as stigma and discrimination, contribute to the largely unexplored mental health burden of leprosy. The patients we spoke to emphasised the importance of taking the anti-leprosy drugs correctly, and if necessary steroids for years to treat the immune-mediated reactions. These patients persevered, they re-engaged, and they followed medical advice to not only survive but also thrive. Their shared message to new patients was that of hope. Working, being independent financially, and having a family made many of the interviewees feel accepted, integrated, and able to live on, with happy lives. As the Ethiopian proverb goes, "he who conceals his disease cannot be cured". These photographs are a unique, patient-centred, and positive way to document leprosy. We are expanding this project to other countries and more stories and images from the project will be available online in the future allowing new patients to access these stories.

Alexander Kumar, Saba Lambert, Diana N J Lockwood
School of Population Health and Environmental Sciences, King's College London and Guy's and St Thomas' NHS Foundation Trust, London SE1 1UL, UK (AK); and London School of Hygiene & Tropical Medicine, London WC1E 7HT, UK (SL, DNJL)
www.alexanderkumar.com

AK is a doctor and photographer. SL is a leprosy clinician based in Ethiopia. DNJL is a leprologist. The project was conceived by AK and DNJL. We thank Eden Abate (EA) and Yilma Tesfaye (YT) for assistance in interviews and translation. Interviews by AK, EA, and YT. Words by AK, DNJL, and SL. All photography was performed and self-funded by AK. Other administrative costs (translation and patient transport) were funded by the small grants scheme in public engagement from the London School of Hygiene & Tropical Medicine.

Tulu, merchant of spiritual objects, photograph by Alexander Kumar
"I am Tulu and I am 38 years old. When I first got ill, it was so difficult. I was the only one in my family and community affected by this disease. My face, ears, and arms had many small lumps. I tried various traditional medicines. Then I came to Addis; when I was told it was leprosy I felt so much anger, and so tried to kill myself twice. With medication, I saw great improvement. I and my family feel so much happier, but we went through a lot of stress. I have remarried; my second wife, Messay, had leprosy. We are both treated. I am proud of my successful business. I feel proud to take part in community life at church and at home. I earn enough to also help my family in the rural area."

Berhane, embroiderer, photograph by Alexander Kumar

Berhane was diagnosed with leprosy aged 16 years, when she developed white patches on her skin. "I am Berhane and I am 40 years old. I am married, I work and bring up my children like anyone else. For me this was an easy disease, it did not stop me from achieving all these things. My family, who brought me to Addis Ababa, and my leprosy association group, who have supported me, have been important to me. I would tell newly diagnosed patients not to be scared. Take your treatment carefully and you will be fine. You can have a family, a job, and a normal life."

Michuye, labourer, photograph by Alexander Kumar

"I am Michuye; my leprosy was diagnosed 25 years ago, when I was 14. I did not take my multidrug treatment correctly initially partly because I was following religious fasts. After explanations from the doctors, I understood the need for taking the drugs regularly. Leprosy is not like other diseases. It damages a person so slowly. If you get treatment you can change the course of the disease. At least it does not kill you! The fact that I can do any job makes me feel good. I have beautiful children. I eat, I play, I laugh. To newly diagnosed people, I would say: 'I know this feels hard just now, and that you are scared. But you will get better with treatment and things will be ok'. I think it is important to give hope and encouragement."

Argaw, farmer and student, photograph by Alexander Kumar
"I am Argaw and I am an award-winning farmer in a rural area." Argaw's leprosy was misdiagnosed many times, and his community's conviction that he was being punished by God led him to attempt suicide. He finally made his way to Addis Ababa but found the diagnosis of leprosy difficult to accept, and he interrupted his treatment. Only when he returned with a severe infection in the foot, requiring amputation and needing treatment for reactions, did he complete his course of multidrug treatment. "The thing that I would say is good now is that I have restarted my education and that, thanks to God, I did not commit suicide that night. So much has changed in my life. It has been hard, but I am in a good place."

Sewenet, cotton spinner, photograph by Alexander Kumar

"I am Sewenet and I am a cotton spinner from Gojam. I was 15 years old when I got some lumps on my body, my face, my ears. I made my way to Addis Ababa and was treated here for leprosy. When I got better, I went back to Gojam, married, and had one child. But there were many disagreements about my disease, so I left. My child grew up with my mother, but now she is here close to me. I met my second husband in Addis Ababa. I am happy that I have descendants and that I can work and help my family. I don't believe this is an inherited disease. You should see my beautiful grandchildren."

Shelemew, shoeshiner, photograph by Alexander Kumar

"I am called Shelemew. I am 18 years old. I am affected by leprosy. My mother had leprosy and died from it. A neighbour brought me and another boy to Addis for treatment. I took 1 year of treatment and my face really recovered. But soon I started getting severe pains and ended up being admitted at ALERT hospital. I had all these painful nodules and my hands were so badly affected with the numbness, the pain. I am better now. I have seen many badly affected people managing with daily life that I feel like I can work and live well. I am not less than anyone. Look, gradually I have been getting better and better. I work as a shoeshiner with another friend with leprosy, and we help each other out. I am young, and I plan to do many things. I hope for better times. My hands sometimes don't hold things well, but I still work."

Chekol, taxi driver, photograph by Alexander Kumar

Chekol is 34 years old and works as a taxi driver in Addis Ababa, his birthplace. "My leprosy was diagnosed 6 years ago, whilst I was working in Kuwait. I was put in an isolation ward and deported to Ethiopia. I was emotionally very disturbed by this experience. I would tell newly diagnosed people to be honest with your doctor, even about the difficulties at home, work, society. They can help you deal with these issues, and taking your treatment correctly will help you and give you hope. Do not worry about what others may say to you. I may have been lucky, but my journey since starting my treatment here has been very easy and smooth. Before the year is over, one sees so many changes with the treatment."

Etageg, cotton spinner, photograph by Alexander Kumar
"I am Etageg, born in Gondar. I developed leprosy when I was 10. An uncle brought me to ALERT hospital in Addis Ababa where I was treated, and I have no problems with my hands and feet. I work in a cooperative organising cotton for the spinners. Sometimes I thank the fact that I had leprosy. It was not the worst disease, especially when I compare it to my asthma. I can go live anywhere; no one can see the signs of leprosy in me. The best thing in my life is my daughter. She is at university now, studying law at Gondar. My happiness and pride when I see her are immense. I thank God."

Kebenesh, embroiderer, photograph by Alexander Kumar

"I am Kebenesh. I developed leprosy when I was 6 years old. In my family of 12 siblings, I am the only one affected. This makes me understand that it was a chance disease, a bacteria that affected me. It is not a genetic disease for sure. Because of my disabilities, I received a lot of institutional support for my education, since the age of 16. I learnt skills and now I am independent. I am married and have one girl child. The disease has left some problems in my feet, but I do not see myself as a disabled person. To people that are newly diagnosed with leprosy, I want them to see me as an example, so they can see that they can heal, can learn, work, feed themselves, and be financially independent. They need encouragement to understand that like any other disease, with some care, they can recover."

Love in the time of leprosy: Messay and Tulu, merchants of spiritual objects, photograph by Alexander Kumar

Messay and Tulu are both patients with leprosy who were successfully treated. They fell in love and are now married. "I am Messay. 39 years old. I am the wife of Tulu. We work together as merchants, he sells books and I sell holy candles. I took holy water as treatment for 7 years before I came to ALERT hospital, where the doctors explained things to me and reduced my fears about leprosy. To newly diagnosed people, I would advise them to seek treatment when the first signs of numbness or burning in hands and feet occur. I would tell them not to let any wounds grow bigger. Many people in rural areas lock themselves up or are hidden in their huts because they have smelly wounds and don't know what to do. I would tell people not to hide the ones who are unwell. People affected by leprosy can, after good treatment, work, be independent, marry, and have a family."