

‘I treat it but I don’t know what this disease is’: a qualitative study on noma (cancrum oris) and traditional healing in northwest Nigeria

Elise Farley^{a,b,*}, Hussaina Muhammad Bala^a, Annick Lenglet^{c,d}, Ushma Mehta^e, Nura Abubakar^a, Joseph Samuel^a, Annette de Jong^c, Karla Bil^c, Bukola Oluyide^a, Adolphe Fotso^a, Beverley Stringer^f, Julita Gil Cuesta^g and Emilie Venables^{g,h}

^aMédecins Sans Frontières, Médecins Sans Frontières, Noma Children’s Hospital, Mamarun Nufawa, Sokoto, Nigeria Sokoto, Nigeria;

^bDepartment of Public Health Medicine, University of Cape Town, Anzio Rd, Observatory, Cape Town, South Africa; ^cMédecins Sans Frontières, Plantage Middenlaan 14, 1018 DD, Amsterdam, The Netherlands; ^dDepartment of Medical Microbiology, Radboud University Medical Center, Geert Grooteplein Zuid 10, 6525 GA Nijmegen, The Netherlands; ^eCentre for Infectious Disease Epidemiology and Research, School of Public Health and Family Medicine, University of Cape Town, Anzio Rd, Observatory, Cape Town, South Africa;

^fMédecins Sans Frontières, Lower Ground Floor, Chancery Exchange, 10 Furnival Street, London, UK; ^gMédecins Sans Frontières—Operational Centre Brussels, Medical Department, 68 Rue de Gasperich, 1617, Luxembourg Operational Research Unit (LuxOR);

^hDivision of Social and Behavioural Sciences, School of Public Health and Family Medicine, University of Cape Town, Anzio Road, Observatory, Cape Town, South Africa

*Corresponding author: Tel: +27795601251; E-mail: noma-research@oca.msf.org

Received 12 March 2019; revised 6 May 2019; editorial decision 22 June 2019; accepted 25 June 2019

Background: Noma, a neglected disease mostly affecting children, with a 90% mortality rate if untreated, is an orofacial gangrene that disintegrates the tissues of the face in <1 wk. Noma can become inactive with early stage antibiotic treatment. Traditional healers, known as *mai maganin gargajiya* in Hausa, play an important role in the health system and provide care to noma patients.

Methods: We conducted 12 in-depth interviews with caretakers who were looking after noma patients admitted at the Noma Children’s Hospital and 15 traditional healers in their home villages in Sokoto state, northwest Nigeria. We explored perceptions of noma, relationship dynamics, healthcare practices and intervention opportunities. Interviews were audiorecorded, transcribed and translated. Manual coding and thematic analysis were utilised.

Results: Traditional healers offered specialised forms of care for specific conditions and referral guidance. They viewed the stages of noma as different conditions with individualised remedies and were willing to refer noma patients. Caretakers trusted traditional healers.

Conclusions: Traditional healers could play a crucial role in the early detection of noma and the health-seeking decision-making process of patients. Intervention programmes should include traditional healers through training and referral partnerships. This collaboration could save lives and reduce the severity of noma complications.

Keywords: cancrum oris, noma, operational research, traditional healers, traditional healing

Introduction

Noma (cancrum oris) is a rapidly progressing gangrenous infection of the oral cavity, which mostly affects children aged 2–5 y. If left untreated, it is associated with a reported 90% mortality rate.¹ Those who survive have severe facial disfigurements and multiple physical impairments, including difficulties in eating, seeing and breathing.² Noma manifests in stages categorised

by the World Health Organisation (WHO) as simple gingivitis, acute necrotising gingivitis (accompanied by fetid breath), oedema, gangrene (hard and soft tissue destruction), scarring and sequelae.³ The total destruction of the cheek can take place in less than 1 wk.³ During the early stages of noma, infections can become inactive if treated with antibiotics, wound cleaning and nutritional support, decreasing morbidity and mortality.² In

many cases, however, patients live in remote locations and access to healthcare takes considerable time.

Primary research on noma is limited, and as such, knowledge sharing about the disease is impeded. The most commonly reported risk factors are malnutrition, poverty, immunosuppression, coinfections, poor vaccination coverage, lack of access to quality healthcare, not receiving colostrum at birth and caretakers (also known as caregivers) being someone other than the mother.^{2,4-6} No primary studies on noma prevalence exist, but it is thought to be most prevalent along the noma belt, which stretches from Senegal to Ethiopia.² Cases have recently been reported in other countries, including Laos,⁷ Afghanistan,⁸ the UK⁹ and the USA.¹⁰ The WHO estimate there are 140 000 new noma cases each year.³

The Nigerian Ministry of Health supported by Médecins Sans Frontières (MSF) implements prevention and treatment programmes for noma at the Noma Children's Hospital (NCH) in Sokoto, northwest Nigeria. The programme includes a strong outreach component focusing on finding early stage cases and raising awareness about noma with community members and health workers.

The health system in Nigeria is comprised of three levels: primary (local government), secondary (state government) and tertiary (federal government).¹² These levels of the health system operate in tandem alongside traditional medicine. *Mai maganin gargajiya* (the Hausa name for traditional healers) play an important role in healthcare globally¹³ and in Nigeria, with an estimated 80% of the population exclusively using this form of care.¹⁴ A Nigerian study showed that close to 10% of rural dwellers and 4% of urban dwellers in Nigeria were traditional healers, proportions which are much higher than those trained in biomedicine.¹⁵ Patronage of traditional healing has previously waned due to restrictions and the introduction of biomedicine, but recently there has been an increase in seeking this form of care due to the ability of traditional healers to provide physical, psychological and spiritual care.¹⁶ Traditional healers are said to either reside in the villages within which they serve or to move around from village to village providing care as they go,¹⁷ by utilising remedies including plants and trees,¹⁸⁻²⁰ piercing and cuts²¹ and prayer.²²

As prevention and early detection are the most important strategies in reducing the impact of noma, it is crucial to take into consideration the role that traditional healers play in the pathway to care for noma patients. We interviewed caretakers of noma patients and traditional healers to explore their perceptions of noma, the relationship dynamics between the two, traditional healers' healthcare practices for the different stages of noma and the feasibility of creating referral partnerships with traditional healers. The information generated through this research will be used to guide noma outreach strategies.

Methods

Setting

Interviews with caretakers of noma patients were conducted at NCH and interviews with traditional healers were conducted in their home villages in Sokoto state, northwest Nigeria. From January to December 2018, 110 noma patients were admitted

to NCH, 53 (48.2%) with early stage noma, 50 (45.5%) of whom were female and 58 (52.7%) from Sokoto state. The median age of self-reported onset was 3 y (IQR 1-7 y) and 40 (36.4%) patients had sought care for the noma patient from traditional healers before coming to NCH.

Study design

A descriptive, qualitative study was conducted between April and June 2018. Semistructured interview guides with open-ended questions were used, and the course of the interviews were left open so that any new themes which emerged could be fully explored.

Recruitment and sampling

In-depth interviews were conducted with 12 caretakers (looking after child patients admitted to the NCH at the time of data collection), who were recruited using convenience sampling. The interviews were carried out by HMB, a first language Hausa speaker who was thoroughly trained before data collection commenced and who has experience working with noma patients, accompanied by the Principal Investigator (PI), EF. The researchers interviewed caretakers who were present at NCH during the data collection period. The head matron of NCH invited caretakers to participate in the study. As the caretakers were at NCH for extended periods of times (up to 6 mo), they were known to the head matron. We met with the head matron and requested that she invited caretakers from both rural and urban locations to increase the variety of potential participants. Fifteen traditional healers (people in the community who have taken on the role of providing non-biomedical healthcare and have not received biomedical training) were recruited through purposive sampling. The outreach team at NCH compiled a list of traditional healers working in Sokoto state, where MSF's programme was based (between a 30-min and 3-h drive from NCH). Traditional healers were then contacted from this list by telephone. If they could not be reached by telephone, the research team visited their villages and invited them to participate.

All participants were informed of the aims of the study prior to the interviews taking place. The researchers conducted interviews until data saturation occurred, saturation being the point at which no new information emerged from the interviews.²³

Data collection

Interview guides were developed in English, translated into Hausa by HMB and then back-translated by a further Hausa speaker to ensure accurate translation. Any inconsistencies were rectified and the final version was used for pilot interviews, after which additional adjustments were made and the guides were then finalised. Interviews were conducted in Hausa and audiorecorded in quiet, private locations. During the interviews, photographs of the five different stages of noma were shown to traditional healers to help interviewees discuss their knowledge and healthcare practices for the various stages of the disease.

Interviews lasted approximately 30–45 min. No one else besides the researchers and participants were present during the interviews.

Data analysis

Audiorecorded interviews were transcribed into Hausa and then translated verbatim into English by HMB and checked by EF. Data saturation was discussed between investigators and once this occurred, data collection ended. Transcripts were manually coded by EF. EV and EF read the translated transcripts several times, and then codes that emerged were highlighted. The codes were then discussed within the research team, first between HMB and EF, and then with three other members of the research team (EV, JGC and BS).²⁴ Thematic analysis was undertaken to identify patterns in the data with attributed codes.²⁴

Ethics

The MSF Ethics Review Board (1824), Usmanu Danfodiyo University Teaching Hospital Health Research and Ethics Committee in Nigeria (UDUTH/HREC/2018/No.670) and the Ministry of Health in Sokoto State (SKHREC/039/018) approved the study protocol. The procedures followed were in accordance with the ethical standards of the Helsinki Declaration. Written informed consent for interviews and audiorecordings were obtained in Hausa. For participants who were illiterate, the consent form was read aloud to them and a thumbprint was then requested in place of a signature.

Results

We interviewed 12 caretakers of noma patients and 15 traditional healers. Caretakers were predominantly the mothers of patients (10/12); one was the grandmother of a patient and the other was the father of a patient. The median age of caretakers was 38 y and ranged from 22 to 55 y. Traditional healers were mostly male (13/15). The two female traditional healers were 35 and 40 y of age, and had worked as traditional healers for 2 and 3 y, respectively. The median age of male traditional healers was 55 y, ranging from 35 to 80 y, and they reported practising traditional medicine for a median number of 30 y, ranging from 2 to 50 y.

Three main themes emerged during data analysis: (1) the role and experiences of traditional healers, particularly in the management of noma cases; (2) relationship dynamics between caretakers and traditional healers; and (3) knowledge and perceptions of noma and treatment healthcare practices for the different stages of the disease.

The role and experiences of traditional healers in Sokoto, northwest Nigeria

Traditional healers reported that they played specific roles in the community, were well known and believed that their healing skills were understood and appreciated in the areas where they lived and worked:

Everybody in this village small or big...knows that it is my work (*Traditional Healer 8*).

Even though the traditional healers resided in the communities within which they worked, some were well known in a wider geographical region and reported that patients visited them from hundreds of kilometres away, some even travelling across borders:

Based on my ability, people are coming [from] everywhere [even] all the way [from] Tawa [in Niger]. They are all coming to search for help from me (*TH 15*).

Traditional healers' specialisations

Traditional healers reported learning their craft in different ways, including inheriting the knowledge from family members and others through dreams and spirits:

I inherited [traditional healing knowledge] from my grandfather (*TH 3*).

This craft, I got it from a spirit. In my dreams I am told what [treatments] to get and so I go and get them and then I will mix it (*TH 9*).

Many traditional healers stated that they had specialisations and only treated specific diseases. One traditional healer reported treating an array of diseases, whereas others noted one or two. None of the traditional healers specifically mentioned noma, although some of them mentioned treating elements of it (such as *ciwon daji* [cancer] and *iska* [spirit]):

We have remedies for *gudawa* (dysentery), *shawara* (typhoid) and for *basur* (haemorrhoids) (*TH 1*).

I sell remedies for *ciwon baya* (back pain) and *zufan jiki* (general swelling of the body) (*TH 4*).

Treatment practices

These diseases were reportedly treated by the traditional healers with a variety of methods. Most of the remedies offered were obtained from sources surrounding their villages, such as trees and plants. Remedies included giving patients dried herbs, grinded plants 'to soak' and then to drink, ointments to rub onto the skin and piercing of the skin to create 'bleeding marks'. In conjunction with other aspects of their healing, traditional healers used spiritual beliefs, including reciting the Qur'an to their patients.

Relationship dynamics between caretakers and traditional healers

Caretakers' perceptions about traditional healers

Caretakers of noma patients reported seeking care from a range of health services in the community, including hospitals,

pharmacists (informal care providers who sell medication) and traditional healers:

I prefer going to the hospital because they care most about a person's health (Caretaker 7).

I like going to the pharmacist because you can go very quickly and buy the medication (C 4).

Caretakers had differing perceptions of traditional healing: some said they made use of traditional healers' healthcare services because they were effective or accessible and some because they were affordable:

If we go, we get better (C 9).

Some people prefer visiting traditional healers if they are ill as they will quickly get treatment [in comparison] to [the time it would take at the] hospital (C 10).

I went there [to a traditional healer]. I find it much better, very much better, as there is less cost (C 6).

Other interviewees said that they had heard positive things about the services offered but had not personally visited a traditional healer before. One caretaker said:

My neighbours used to go and they are happy about it and told me to try it but I did not try it (C 1).

Trust and confidence

Caretakers who had visited traditional healers for general health issues noted a positive relationship with them and described the type of care offered as efficient:

When we went he immediately said what it was, he then gathered the remedies and gave them to me. He said 'Do as I say, do it like that'. By His grace when we did it like that [the treatment] worked (C 9).

The same positive relationship was noted by traditional healers:

A lot of people are buying and drinking [our remedies] and feel good about it (TH 1).

Trust in the relationship between caretaker and traditional healer was mentioned by both parties:

I am trusted by people. Honestly, a lot of babies that are weaned that could not stop crying or choked while taking the breast are brought to me and are [treated] successfully (TH 1).

Ah, honestly we trust them because the healer is like our father (C5).

This trust was paired with accountability as partial payments were made upon care provision and the remaining payments were only made after the care provided was seen to be successful:

[We] make a payment agreement that [the caretaker] will not [pay all] now. If I treat and he gets healed after [you can pay me]. If you did not heal, I do not want your money (TH 8).

Knowledge and perceptions of noma and healthcare practices for the disease

Knowledge about noma

Many caretakers and traditional healers referred to noma as *ciwon daji* or *daude*, which, when translated from Hausa to English, refers to a general cancer that can occur anywhere in the body:

We conclude that it was *ciwon daji* (C 2).

Some caretakers believed that noma was the 'disease of *iska*' (spirit) and that it was 'brought by God'. Views differed about the causes of noma, with some caretakers believing that measles 'started' noma in their child. There were also traditional healers who believed that noma was caused by mumps:

This work is that of mumps. Mumps make the teeth have inflammation. This [is] the same as [the] remedy for mumps. If it affects a person it will destroy their mouth and the mouth will smell (TH 12).

Some traditional healers reported never having seen or treated the disease, even when shown photographs of it during interviews:

I never saw it honestly...I have not done a matter like this (TH 2).

I do not know anything about this disease (TH 3).

Noma stages and healthcare options

Caretakers reported seeking care at a variety of biomedical institutions, including pharmacies, community health centres, clinics and hospitals, as well as from traditional healers, before coming to NCH. The pathway to care was at times complex and time-consuming:

So it was the starting point of the disease, we saw that her face was getting chubby and then we went to collect traditional treatment. We were mixing it and giving it to her to drink. We saw the cheek getting bigger so we took her to the hospital where they dressed the wound and closed the affected area. After 2 d he opened it and the area was spoiled and so we took her to [the big town] (C 4).

Before we came here we went to one hospital where he was given three injections. They referred us to the general hospital, and they referred us to a medical centre where we spent 11 d. Someone who works at the other hospital came and saw the disease and asked the medical centre to refer us to Sokoto (C 5).

Some caretakers mentioned delays in accessing care; the main reasons were not having money to pay for transport and problems with finding childcare for their other children.

A variety of symptoms for the different stages of noma were described by caretakers and traditional healers. Many of the caretakers who were interviewed reported the first signs and symptoms of noma as a 'fever', 'skin rash like a single grain of millet' and swelling:

At first her eyes swelled. The following morning everywhere had swollen up; you cannot even see the eye (C 8).

When traditional healers were asked about their knowledge of the different stages of noma, the majority saw them as separate diseases and treated them as such. Healers most often reported treating the earlier stages of noma (gingivitis and oedema) and referring children with the later stages of the disease to other forms of care. One traditional healer noted that '[he] does not know noma disease', but for the swelling stage of the disease he said 'there is remedy for it', and for the necrosis stage he stated he 'does not know' the remedy, showing that noma was not seen as a single disease, but as multiple conditions.

Two commonly reported stages treated were gingivitis and swelling of the cheek. Gingivitis was usually treated with an ointment that was rubbed directly onto the gums:

If the teeth are bleeding, I give a remedy. If a person puts it inside the mouth and [swills] it around the mouth, the [bleeding] will stop (TH 8).

Some traditional healers diagnosed the stage of noma associated with swelling of the cheek as *ciwon daji* or *ciwon iska* and offered care to the patients accordingly. Caretakers also reported being given this diagnosis and relevant remedies:

[We are] taught it is *ciwon daji*. They find a branch of a tree and soak it to drink and to rub. That is what we were taught to do if the cheeks become big (C 2).

I will mix [the bark from three trees locally known as] tsa-da, tamarind and kaiwa and grind them and sieve them to drink in the morning and in the evening. [I use] the *madarar*

tunwahiya (ground herbs), mix them all together and pour them onto the swollen area (TH 9).

Some traditional healers noted uncertainty about the stages of the disease and whether the stages were related, but had treated the swollen cheek stage, which had a known remedy:

I treat it but I do not know what the disease is unless I understand it is swelling. If it is swelling I can understand it and give treatment remedy (TH 3).

Traditional treatment options for a swollen cheek included piercing the cheek with a hot blade (initially placed in a fire) to decrease the swelling:

If the remedy is drunk, it will go down or it will swell up to do piercing or it will burst (TH 8).

Caretakers also reported visiting traditional healers for assistance with piercing the swollen cheek:

I visited...this piercer, the piercing was done, the following morning the [swelling] did not stop we came here [NCH] (C 10).

Traditional healers did not commonly report seeing patients in the necrosis stage of the disease, and as such, this stage was not widely known, although some were able to recognise it. One traditional healer described this stage as 'burnt meat'.

Caretakers reported being offered various remedies from traditional healers when visiting them with a child later diagnosed at NCH as having noma. The remedies offered included 'ground herbs or tree branches...for drinking, rubbing and bathing' and 'to be mixed with pap (a type of porridge staple made from maize, sorghum or millet) to drink'.

Caretakers reported mixed efficacy of these remedies:

Last year when he was sick I took him [to the traditional healer] so this year when it came back I thought it is the same with the last one and I took him there, then I collected that remedy and it did not work so I took him to hospital (C 6).

I collected [the remedy] but I did not see any improvement (C 7).

Knowledge transfer and referrals

Traditional healers reported utilising referral to hospitals and doctors for unknown ailments, or conditions they felt would be best treated elsewhere.

For the [diseases I] cannot [treat], I will send them to a doctor who can treat them (TH 5).

[I]f I see that [the disease] is much and beyond me and I cannot do the work I will refer him to the hospital. If it is too much [for me] I can only send a person to hospital (TH 9).

Referring to all stages of noma treatment, one traditional healer stated that, 'For that disease, it is a doctor that gives help'. Other traditional healers reported not knowing where to refer noma patients.

One caretaker reported being referred to NCH by a traditional healer, who stated, 'This disease is beyond my power but some kids are taken to Sokoto [NCH]'.

And some traditional healers reported that now that they knew about NCH, they would begin to refer any noma cases:

As from today that we started the relationship, your issue [noma] is not a playing one as from today if I hear a person having it if I know your place I will take him (TH 13).

When asked whether they would be interested in attending a training course on noma, which would involve learning about the different stages of the disease, some traditional healers noted they were too old to travel, but most said they would be willing to attend and were enthusiastic about learning more about noma.

Discussion

Traditional healers play a role in the health system of north-west Nigeria; our findings showed that they are trustworthy, accessible, affordable care providers who offer specialised forms of care for specific conditions and offer guidance on referral options. Traditional healers viewed the stages of noma as different conditions with individualised remedies rather than as one disease, which is similar to the biomedical approach in that each stage of noma has a specific treatment protocol.³ Traditional healers reported referring people to other providers when they were unable to treat a specific condition, and the majority stated that they would be willing to refer noma patients to NCH and attend a training course on the disease.

There is no other literature looking at how traditional healers diagnose and treat noma, making comparisons with other findings challenging, with only one study suggesting that qualitative research methodologies are useful in understanding craniofacial conditions such as noma.²⁵ The naming of noma as *ciwon daji*, which loosely translates to cancer in English, is also of interest, as this is similar to a biomedical name for the disease that is frequently used, *canrum oris*, meaning mouth cancer.²⁶

A third of caretakers at NCH visited traditional healers before coming to NCH. Our study corroborates other research findings which show that traditional healers are the first point of care for many people, especially those living in rural areas with little access to biomedical health facilities,²⁷ and that the first line of treatment for 60% of children living in Nigeria who have a high fever from malaria would be traditional medicine.²⁸ The pluralistic nature of the Nigerian health system, where biomedical and traditional care are offered together in a dynamic system, is not unique to this setting and has been seen in other contexts, including Ghana,²⁹ Nepal¹⁸ and South Africa.³⁰

Our study showed that caretakers trusted traditional healing methods and that care was sought from traditional

healers due to the belief in its quality, as also seen in a study from Cameroon.²¹ Treatments offered by the traditional healers in our study, such as ointments and piercings/bleeding marks, were similar to those offered by healers in other studies,^{21,31} as were the diversity of the diseases treated.^{19,20,32-34}

Due to the rapid evolution of noma,² it is imperative that patients are detected early and receive the appropriate treatment (antibiotics, wound cleaning and nutritional support) during the reversible stages of the disease. Some traditional healers reported recognising and treating the earlier stages of noma, and this, along with the fact that caretakers reported seeking care at traditional healers first, reinforces the importance of ensuring that traditional healers are able to detect cases of noma early and refer them to the appropriate health-care facilities. Not many traditional healers reported treating the later stages of the disease, possibly indicating that caretakers seek care elsewhere for these stages, or that, due to the rapid progression of the disease, the patients die before seeking care.

Partnering with traditional healers in order to set up robust referral networks for diseases has been implemented in a variety of settings.^{22,35,36} A South African study noted that referrals by traditional healers were affected by the attitudes, perceived subjective norms and perceived behavioural controls as influences on behaviour, which would need to be studied at a more in-depth level in our setting.³⁷

The willingness of traditional healers to be a part of referral networks and take part in a training course, caretakers' positive views of traditional healing and their geographical proximity to patients provides a unique opportunity to build such partnerships. This could increase the frequency with which noma patients are detected at a community level and the speed with which they are referred, thus leading to efficient access to treatment in the crucial early, reversible stages of the disease. Future studies on the effectiveness and efficiency of referrals are needed as well as research assessing biomedical healthcare worker knowledge on noma as this could greatly impact the effectiveness of referral partnerships.

Study limitations include interviewing the caretakers of patients already accessing biomedical care, which raises a potential social desirability bias as there could have been a reluctance to offer a wide range of opinions about traditional healers,³⁸ and not locating traditional healers who had provided care for patients in the later stages of noma.

Conclusion

Our research has identified several different actors involved along the pathway to care of noma patients, including traditional healers, who need to be included in intervention activities. These findings show that traditional healers would be willing to attend training on the disease and be a part of referral partnerships for noma patients. This collaboration could expedite care provision from the community level, which would ultimately save lives and reduce the severity of the complications associated with noma.

Authors' contributions: EF contributed a substantial amount to conceptualisation of the project, including protocol development, and also to data collection, data analysis and writing up of the results in conjunction with the coauthors. HMB contributed a substantial amount to data collection, data transcription and translation, and also to data analysis and writing up of the results. AL and EV provided supervision for all aspects of the project. AL, JGC and EV contributed to conceptualisation of the project, protocol development, formulation of the analysis plan, interpretation of data, writing up of the results and manuscript content. UM, AdJ, KB, BO, AF and BS contributed to conceptualisation of the project, as well as reviewing the writing up of the results and offering advice on manuscript content. NA and JS contributed to data collection during the project, as well as reviewing the writing up of the results and offering advice on manuscript content. All authors provided final approval of the version to be published and agree to be accountable for all aspects of the work.

Acknowledgements: We are extremely grateful to the traditional healers and caretakers who agreed to be a part of this study. Their shared insights and knowledge have been invaluable in helping us to better understand noma. We also acknowledge the staff at the Nigerian MSF Mission and the Noma Children's Hospital for assisting in logistical arrangements for data collection, providing useful information and providing care to all of the noma patients interviewed in this study. Finally, we thank Mr Laden from the Sokoto Ministry of Health and Dr Tanua from the Usmanu Danfodiyo University Teaching Hospital, Sokoto, for ensuring that the highest ethical standards were maintained during the study.

This research was conducted through the Structured Operational Research and Training Initiative (SORT IT), a global partnership led by the Special Programme for Research and Training in Tropical Diseases at WHO (WHO/TDR). The model is based on a course developed jointly by the International Union Against Tuberculosis and Lung Disease (The Union) and Médecins Sans Frontières (MSF/Doctors Without Borders). The specific SORT IT programme that resulted in this publication was managed by MSF.

Funding: This research received no specific grant from any funding agency in the public, commercial and not-for-profit sectors. MSF staff carried out the research as part of their routine roles.

Competing interests: The authors declare no conflicts of interest.

Ethical approval: The MSF Ethics Review Board (1824), Usmanu Danfodiyo University Teaching Hospital Health Research and Ethics Committee in Nigeria (UDUTH/HREC/2018/No.670) and the Ministry of Health in Sokoto State (SKHREC/039/018) approved the study protocol.

Availability of data and materials: MSF has a managed access system for data sharing that respects MSF's legal and ethical obligations to its patients to collect, manage and protect their data responsibly. Ethical risks include, but are not limited to, the nature of MSF operations and target populations being such that data collected often involves highly sensitive data. The dataset supporting the conclusions of this article is available on request in accordance with MSF's data sharing policy (available at: <http://fieldresearch.msf.org/msf/handle/10144/306501>). Requests for access to data should be made to data.sharing@msf.org.

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