

Model of care, Noma Children's Hospital, northwest Nigeria

Shafi'u Isah¹, Mohana Amirtharajah², Elise Farley^{1,3}, Adeniyi Semiyu Adetunji¹, Joseph Samuel^{1,3}, Bukola Oluyide³, Karla Bil², Muhammad Shoaib³, Nura Abubakar^{1,3}, Annette de Jong², Monique Pereboom², Annick Lenglet^{2,4} and Mark Sherlock²

¹ Noma Children's Hospital, Sokoto, Nigeria

² Médecins Sans Frontières, Amsterdam, Netherlands

³ Médecins Sans Frontières, Sokoto, Nigeria

⁴ Department of Medical Microbiology, Radboud University Medical Centre, Nijmegen, The Netherlands

Summary

The Nigerian Ministry of Health has been offering care for noma patients for many years at the Noma Children's Hospital (NCH) in Sokoto, northwest Nigeria, and Médecins Sans Frontières has supported these initiatives since 2014. The comprehensive model of care consists of four main components: acute care, care for noma sequelae, integrated hospital-based services and community-based services. The model of care is based on the limited evidence available for prevention and treatment of noma and follows WHO's protocols for acute patients and best practice guidelines for the surgical treatment of noma survivors. The model is updated continually as new evidence becomes available, including evidence generated through the operational research studies performed at NCH. By describing the model of care, we wish to share the lessons learned with other actors working in the noma and neglected tropical disease sphere in the hope of guiding programme development.

keywords cancrum oris, model of care, Nigeria, noma

Sustainable Development Goals: Good Health and Well-being; Reduced inequalities; Clean Water and Sanitation

Introduction

Noma, also known as cancrum oris, is a gangrenous infection of the oral cavity which causes rapid, widespread orofacial destruction [1]. The disease progresses through several acute stages increasing in severity, during which the reported mortality rate for untreated patients is 90% [1]. WHO classifies these early stages as Stage 0: simple gingivitis, Stage 1: acute necrotising gingivitis, Stage 2: oedema, Stage 3: gangrene and Stage 4: scarring [1]. Treatment in these early acute stages with antibiotics, wound debridement and nutritional support greatly reduces mortality and morbidity [2]. The infection can then become inactive with or without treatment and moves to Stage 5 noma: sequelae [1], where patients are frequently left with debilitating sequelae [1] including difficulties eating, seeing and breathing, all of which contribute towards stigmatisation and social isolation [2]. Once noma becomes inactive, extensive reconstructive surgery can be utilised to improve function and aesthetics [3–5]. Multiple studies have identified acute malnutrition, unsafe drinking water, poor sanitation, poor oral hygiene practices, limited access to quality health care including

vaccinations [1,2,6–8] and comorbidities such as measles [9,10] and human immunodeficiency virus (HIV) [11–20] as risk factors for the development of noma. Due to the multiple aspects involved in the progression of noma, health programming to combat this disease needs to combine preventive methods (improving oral health care, increasing vaccination coverage and addressing food security and malnutrition), early recognition and treatment measures (through community-based detection and healthcare facility treatment) and surgical care for noma survivors.

Noma cases are frequently reported in Nigeria [8,9,21–26]. In northwest Nigeria in 2018, 3300 out of every 100 000 children in the 0–15 year age group were estimated to have any stage of noma at the time of the survey [27]. For the past 21 years, the Nigerian Ministry of Health has run a specialised programme for the treatment of noma at The Noma Children's Hospital (NCH) in Sokoto State in the northwest of the country. Médecins Sans Frontières (MSF) has supported noma initiatives at the hospital since 2014. Together, MSF and the Ministry of Health have created a comprehensive model of care for noma that

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encompasses acute care, care for noma sequelae, integrated hospital-based services and community-based services. We wish to share the lessons learned in the development of this model with other actors working in the noma and neglected tropical disease sphere in the hope of guiding programme development. Most of the literature around noma programming focuses solely on surgical reconstruction and its aftercare. To our knowledge, this manuscript is the first to describe the comprehensive nature of care that is required for effective noma treatment. We believe that outlining this model of care will underscore the feasibility of this type of comprehensive programming and will be of interest to both ministries of health and non-governmental organisations involved in the management of noma.

Methods

Data included in this manuscript come from routinely collected data, institutional knowledge and programme reports. As the different services began operating at different times, the date ranges for the data reported differ. A descriptive analysis was completed on a range of variables from the routinely collected data. Categorical variables are reported as frequencies and percentages.

Continuous variables are summarised using means and standard deviations if normally distributed and medians and interquartile ranges if not normally distributed. Institutional knowledge was gathered, and common themes were grouped together.

This research fulfilled the exemption criteria set by the MSF Ethical Review Board (ERB) for a posteriori analyses of routinely collected clinical data and thus did not require MSF ERB review. It was conducted with permission from the Medical Director of the MSF Operational Centre Amsterdam.

Noma Children's Hospital model of care

The model of care at the NCH consists of four main components: intensive care for patients with acute noma, continuous care for patients with noma sequelae, integrated hospital-based services and community-based services (Figure 1). These components are discussed in more detail below. The model is based on the limited evidence available for noma and as new evidence becomes available (some of this generated through our own operational research), the model is updated.

From 1 January 2014 to 31 December 2019, 496 noma patients were admitted to the NCH. The median age of patients upon admission was 6 years (interquartile

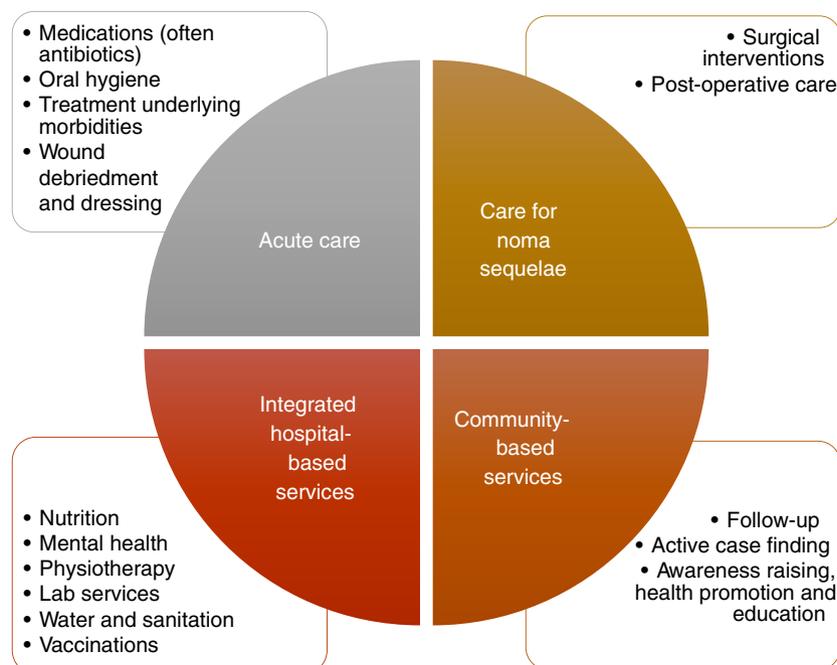


Figure 1 Model of care Noma Children's Hospital, Nigeria.

S. Isah *et al.* **Model of care for noma patients in Nigeria****Table 1** Volume of care provided at Noma Children's Hospital under the existing model of care

Demographic characteristics 1 Jan 2014–31 Dec 2019	N = 496 admissions	% of admissions
Median age (yrs) of patient upon admission (IQR)	492	Median 6 (IQR 3, 23)
Sex		
Female	230	46.4%
Male	266	53.6%
State		
Sokoto	271	54.6%
Kebbi	91	18.4%
Other	225	27.0%
Clinical diagnosis upon admission		
Noma acute (with active infection)	209	42.1%
Noma sequelae (no active infection)	287	57.9%
Surgical procedures 1 Jan 2014–31 Dec 2019	N = 527 procedures performed	% of all procedures performed (N = 527)
Deltpectoral flap	130	24.7%
Release of Trismus	65	12.3%
Lip/Commissuroplasty	58	11.0%
Estlander flap	44	8.3%
Forehead flap (medial and lateral)	40	7.6%
Nasal Reconstruction	38	7.2%
Cheek rotation flap	37	7.0%
Division and inset of flap	27	5.1%
Abbe flap	21	4.0%
Fan flap	14	2.7%
Tooth extraction	10	1.9%
Submental Island flap	7	1.3%
Eyelid reconstruction	7	1.3%
Temporoparietal fascia flap	6	1.1%
Visor flap	5	0.9%
Pedicled Radial Forearm flap	1	0.2%
Nutritional support 1 January 2017 to 31 December 2019	N = 126	% recovered
Admissions	126	NA
Recovered	109	86.5%
Mental health support 1 January 2017 to 31 December 2019		
Total number of individual sessions	1262	NA
Total number of individual psycho education sessions	641	NA
Group Discussion/Counsel Sessions	161	NA
Total number of group psycho education sessions	581	NA
Total participants (group and individual)	27233	NA
Physiotherapy 1 January 2018 to 31 December 2019		
Patients assessed	222	NA
Assessments	726	NA
Outreach 1 September 2017 until 31 December 2019		
Local government areas visited	304	NA
Villages visited	877	NA
Number to be traced	124	NA
Patients traced (% of no. to be traced)	99	79.8%
Outcome of tracing	N = 99	% of those traced

Table 1 (Continued)

Agreed to come back to hospital	71	71.7%
Refused to go back to hospital	12	12.1%
Lost to follow-up	9	9.1%
Moved away from the area of residence	4	4.0%
Died	3	3.0%
Reported reason for loss to follow-up	N = 71	% of those with a reported reason
Work commitments	30	42.3%
Patient recovered	19	26.8%
Carer not available	9	12.7%
Transport problem	7	9.9%
Clinic experience	2	2.8%
Treatment not effective	1	1.4%
Other	3	4.2%
Surveillance/active case-finding		
Number of children screened	4370	NA
Number noma identified through screenings	155	NA
Number of other noma cases identified (not through screenings)	109	NA
Health promotion-Community residents		
Number of sessions	711	NA
Number of target individuals that attended	12093	NA
Number of brochures/flyers distributed	3918	NA
Number of phone calls received	1700	NA
Health promotion-Community/religious and other leaders		
Number of sessions	341	NA
Number of target individuals that attended	7008	NA
Number of brochures/flyers distributed	1937	NA
Number of phone calls received	745	NA
Health promotion-Health facility workers/clients		
Number of sessions	37	NA
Number of target individuals that attended	272	NA
Number of brochures/flyers distributed	205	NA
Number of phone calls received	154	NA

range (IQR) 3, 23 years) and 271 (46.4%) were from Sokoto State. Of the total patients admitted, 287 (57.9%) were diagnosed as having sequelae of noma (Table 1).

Acute care

During the acute phase of the infection, the focus of treatment is on stabilisation of the patient, minimising the risk of mortality, limiting the damage caused by the infection and promoting infection inactivity. The acute phase treatments at the NCH follow the WHO guidelines and reports of successful treatment from numerous other noma endemic regions [1,10,11,23,28–33]. Care includes the timely administration of medications such as broad-spectrum antibiotics, wound

debridement and dressing changes, promotion of healthy oral hygiene practices and treatment of underlying comorbidities [1]. There is no cost to patients for in-hospital medical care, medications or food. Transport costs for noma patients are reimbursed. An adult caretaker stays with paediatric patients for the duration of their hospital stay.

Vaccination

Noma cases are frequently reported in conjunction with comorbidities [19,25,34–37], specifically measles [8,25,36]. These comorbidities are treated at the hospital. Vaccines are provided where needed due to the low vaccination levels in this context [38,39]. Vaccination information for patients prior to admission at the

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hospital from 1 January 2014 to 31 December 2019 was available for all 496 patients; this information is self-reported or (where possible) taken from a vaccination card upon admission. A low proportion ($n = 70$, 14%) of the patients was vaccinated against measles and multiple other vaccine preventable conditions (Figure 2).

Care for noma sequelae

Noma survivors often require extensive reconstructive surgery to correct the structural and functional defects [40]. Physical sequelae can include displacement of the teeth and intense scarring and bony fusion between the maxilla and mandible [2,3,29,40–42]. Sequelae around daily functioning may include difficulty eating, seeing, talking and breathing [40,42,43]. Trismus (a restriction in mouth opening) is one of the most disabling sequelae [5] and can lead to complications such as aspiration, malnutrition, poor oral hygiene, speech deficits, a compromised airway and pain [44].

The clinical manifestation of each noma case is unique, and, as such, the surgical procedures used to treat each noma case differ [4,45–51]. Reported surgical techniques include pedicled supraclavicular flaps for the treatment of large unilateral facial defects [48]; myocutaneous submental artery flaps, bony and/or soft tissue trismus releases [29], forehead flaps for nasal reconstructions [29] and lower lid ectropion release [29].

Four times a year, an MSF team comprising four to six health professionals including plastic and maxillofacial

surgeons, anaesthetists and a nurse join their colleagues at the NCH to perform a series of surgical interventions. Approximately 20 patients undergo surgical reconstruction over a period of two weeks. Of the 496 patients admitted to the NCH from 1 January 2014 to 31 December 2019, 267 had surgeries, undergoing 528 procedures. The median number of procedures was one (IQR 1, 3), and the median duration of surgery was 60 min (IQR 50, 105 min). The most commonly performed procedure was the Deltopectoral flap ($n = 130$, 24.7% of all procedures performed) (Table 1).

Integrated hospital-based services

During the intervening periods between the surgical interventions, a team (doctors, nurses, mental health professionals, nutritional therapists and a physiotherapist) provide integrated services for all hospitalised patients. In addition, there is a laboratory providing microbiology and haematology services and a robust infection–prevention control programme with a water and sanitation component.

Nutritional support

As malnutrition is a widely reported risk factor for the development of noma [8,24–26,34,36], there is a dedicated team at the hospital who monitor patients' nutritional status and, when required, provide additional nutritional support. Nutritional support is primarily given orally, but enteric feeding is also offered if needed. This

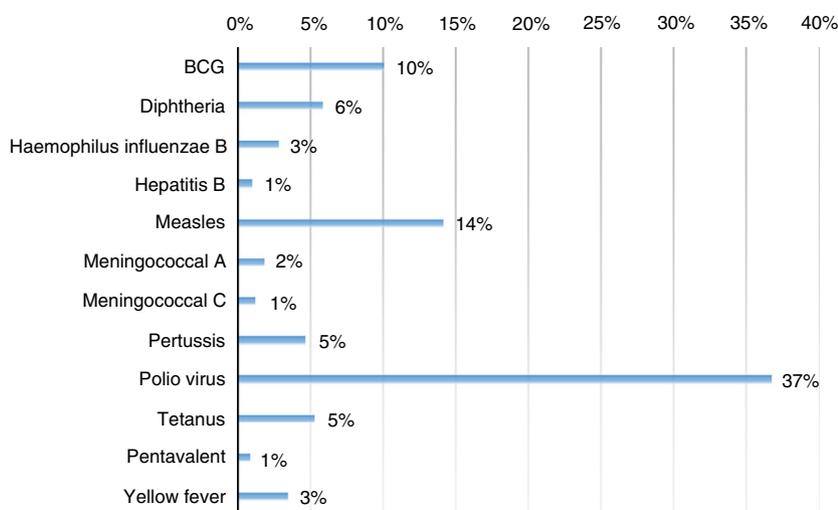


Figure 2 Proportion of cases presenting at the Noma Children's Hospital self-reported being vaccinated against listed diseases ($N = 496$).

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support improves the immune status of patients with acute noma and facilitates post-operative healing [37,52–54]. From 1 January 2017 to 31 December 2019, 126 patients were treated for malnutrition by the team (Table 1).

Mental health

Noma often leads to stigmatisation and resultant social isolation of the patients and their family members [2]. As such, the management of noma patients invariably requires social and psychological support. This support is provided by a dedicated mental health team, which offers individual counselling for patients and caretakers along with group sessions. The team also provides education about noma and the services available at the hospital, psychological preparation for reconstructive surgery and preparation for patients to return to their communities upon discharge. From 1 January 2017 to 31 December 2019, 27 233 individuals took part in the mental health support sessions (patients and caretakers attended multiple sessions while at the hospital) (Table 1).

Physiotherapy

Physiotherapy is an essential part of noma treatment, especially to prevent or minimise the occurrence of trismus [45]. Physiotherapy can lead to improvements in eating, chewing and speaking [55]. Since 2017, one full-time physiotherapist assesses each new patient and has regular consultations with patients who require physiotherapy while at the hospital. The physiotherapist works extensively with patients with trismus before discharge and provides instructions for post-operative activities to be carried out at home by the patients. These patients are then assessed at various intervals after discharge when they return to the hospital, and the physiotherapy care plan is adjusted according to each individual's needs. From 1 January 2018 to 31 December 2019, the physiotherapist assessed 222 patients (Table 1).

Infection prevention and control

NCH has a dedicated Hospital Infection Prevention and Control committee, which consists of the heads of department, chief medical director and MSF team members. The committee's role is to ensure a high standard hygiene practice in the hospital. Key components of the committee's work include supervision of the water and sanitation activities and supervising hand hygiene of staff

at the hospital. A dedicated water and sanitation team at the hospital is responsible for medical waste management, sanitation, vector control and water supply. The team ensures the provision of clean drinking water, clean facilities for cooking food and adequate sanitation facilities for all patients and caretakers. This team maintains the sanitation of the wards and operating suites.

Laboratory

The onsite laboratory runs all necessary tests on new admissions, supports blood transfusions where indicated, as well as carrying out testing of samples for antimicrobial resistance. Tests available in the laboratory include HIV, hepatitis B and C, complete blood counts, haemoglobin counts, white blood cell counts, malaria testing and stool and urine examination. The laboratory facility assists in gaining timely information to guide patient care.

Community-based services

Alongside the hospital-based programmes, there is a strong community-based component run by a dedicated outreach team. The aims of these outreach activities are to create referral pathways, raise awareness, reduce stigma and promote behaviours that counteract the main risk factors for noma. From 1 September 2017 until 31 December 2019, the outreach team visited 877 villages and conducted various activities (Table 1).

Follow-up of prior patients

The outreach team follow-up with patients who were previously cared for at the NCH, assessing patients' outcomes after surgical treatment and tracing patients who had been lost to follow-up. From 1 January 2018 to 31 December 2019, 99 patients who were previously lost to follow-up were traced and 71.7% ($n = 71$) of these agreed to come back to the hospital (Table 1).

Screening

While conducting village visits, the outreach team actively screens children under the age of five years for any stage of noma. From 1 September 2017 and 31 December 2019, 4,370 children were screened and 155 noma cases were found. If Stage 0 (simple gingivitis) and Stage 1 (acute necrotising gingivitis) cases were found, patient caretakers were informed of the best oral health measures to follow. If Stage 2 to Stage 5 (oedema, gangrene, scarring and sequelae) were found, the urgency for

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seeking timely care was explained to the caretaker, and they were requested to come to the hospital with their child immediately or as soon as possible. If the caretaker and child were not able to come to the hospital that day, the outreach team scheduled a date suitable for them to be collected and brought to the hospital.

Awareness raising

The outreach team runs awareness-raising activities that include community discussions, networking and trainings. The target groups for these efforts are community members, community leaders, traditional healers and biomedical healthcare workers. The initiatives focus on improving the understanding of noma (including the early signs and treatment options), prevention strategies and reducing stigma associated with the disease. In addition, the team uses radio and flier-centred mass media campaigns. These mediums were chosen based on advice from team members well versed in the local context who suggested that these methods were the most appropriate for this setting. Between 1 September 2017 and 31 December 2019, 711 awareness-raising sessions were held with community residents, 341 with community and religious leaders and 37 with healthcare workers (Table 1). The team received 2599 phone calls from attendees (Table 1).

Community engagement

The messaging used by the outreach team during health promotion, awareness-raising and education activities focuses on promoting behaviours that counteract the main risk factors for noma. These include improving nutritional status, infant feeding, oral health practices and promoting vaccinations. One novel concept incorporated into the outreach programme is the use of storytelling during the outreach team's awareness-raising efforts. The Story of Change is a participative and dynamic intervention [56]. A story about a fictional boy with noma was created based on the findings of qualitative interviews conducted with hospital staff, patients, caretakers, village heads, imams and traditional healers [56]. The story was utilised during community awareness raising to encourage dialogue with community members and to teach people about the disease [56]. As the approach is centred around the lived experiences of community members, it is hypothesised that they recognise their words, beliefs and experiences in the story and, as such, can be expected to retell the story in their own social networks and communities [56]. During the piloting of this approach, 40 villages were visited and

community members were told the co-created story. In the three months after the implementation of this intervention, 67% of noma patients presenting at the hospital reported that they had learned about the hospital through verbal information shared by relatives, neighbour's or friends [56].

Strengths and weaknesses of the model

The main strengths of our model are the comprehensive nature of the care provided to the patients. Many other treatment programmes focus only on the surgical reconstruction of the sequelae, despite the fact that noma is preventable and its progression can be arrested with early-stage treatment. In our model, patients are not only provided with surgical care for Stage 5 noma, but we also perform activities to support noma prevention, treat early stages and provide psychosocial support. These aspects are crucial for noma care provision.

One weakness of the model is the reliance on international surgical teams to provide care for patients with sequelae. To address this deficiency, we have created a roadmap to building extra capacity within the country by mentorship and support of Nigerian surgeons and anaesthetists by experienced international staff. In March 2021, the first solely Nigerian Ministry of Health team provided surgical care for patients with the remote support of international specialists. In the future, through a combination of remote and in-person mentorship and coaching, we seek to have all reconstructive interventions performed by experienced Nigerian staff while also continuing to train new surgeons and anaesthetists to build local surgical capacity.

A further weakness is that most patients arrive at the hospital in the later stages of disease (58%); this limits the ability for the team to provide treatment in the early reversible stages of the disease. This factor indicates the need for a concerted effort to improve diagnosis in the early stages, make referral mechanisms more efficient and encourage a change in health-seeking behaviours to allow for the identification of cases in the earlier stages. The team is addressing this by conducting wide-scale community and healthcare worker training.

A final weakness of this model is its sustainability. As with the surgical component, we are seeking ways to reduce dependence on both international staff and MSF supply and funding by actively seeking partnerships with other organisations, working with the Nigerian Ministry of Health and advocating for noma to be included in the WHO list of Neglected Tropical Diseases, potentially creating new revenues of funding.

Improving the model of care- operational research

An additional limitation of the project is the sparse amount of robust evidence there is to use for programme planning. In order to improve the model of care, we established an operational research programme that seeks to fill some of these gaps in knowledge. We created a noma research committee comprised of local and national staff, researchers and clinicians, and MSF and Ministry of Health staff. In this committee, we discuss potential research topics to be funded in the coming year. Ideas for research frequently arise from clinical and outreach staff working at the NCH. The noma research committee has employed both qualitative and quantitative methods to examine the biopsychosocial features of noma, its epidemiology in northwest Nigeria and treatment practices for the disease [7,27,57–59]. Published studies include a case-control study assessing the risk factors for diagnosed noma [7]; two qualitative studies examining the names and beliefs about noma [57] and traditional healers experiences of noma [58]; a case series of patients surgically treated at the NCH [59]; and a cross-sectional prevalence survey [27]. Findings from these studies are incorporated into the messaging used by the outreach team and care provided at the hospital. One of these studies [58] illuminated the need for an improved follow-up system, which was subsequently implemented. This has formed the basis of the ongoing prospective outcomes study, which will be completed in 2021. In addition, several studies are currently in the planning stages based on ongoing needs identified within the model of care. These include a cross-sectional study assessing healthcare workers knowledge, attitudes and perceptions of noma; a study assessing the outcomes of patients first admitted to the NCH with pre-sequelae noma; an evaluation of the impact of physiotherapy on trismus in the acute stages of noma and finally a burden of disease study with paediatric admissions at another MSF supported hospital in the region.

There are limits to the number and scope of studies that can be carried out in this setting, and there are several gaps in knowledge that still need to be filled. Some of the main areas of focus for further research should be enumerating the global burden and distribution of disease (specifically incidence), describing the true mortality rate of noma, elucidating its pathogenic cause(s) and exploring the role of different comorbidities (specifically measles and HIV) in the development of noma.

Conclusions

The NCH model of care is based on the limited evidence available. The model incorporates the WHO treatment

protocols for acute patients, best practice surgical management for treatment of noma sequelae, a wide range of tailor made integrated services available to all patients at the hospital, along with a robust outreach programme that utilises novel context-specific approaches. Our model of care is similar to others in that it is person-centred and relies on the engagement of different community actors [60–65]. These models have been successful in their target populations as they encourage relationships between patients, caretakers, healthcare workers, community leaders and community members. For noma, these partnerships can have positive implications by improving the efficiency of referrals.

This summary of our model of care is descriptive in nature, and the data presented are thus limited in terms of offering evidence of the effectiveness of these interventions. Further research is needed to assess the efficacy of the varying programme components so that more evidence will become available upon which to base future models of care.

This manuscript is the first to describe the comprehensive nature of care that is required for effective noma treatment, from community engagement to prevention to care of noma sequelae. Noma programming should focus on providing integrated evidence-based care to noma patients paired with a strong focus on prevention through community-based initiatives.

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Corresponding Author Annick Lenglet, Médecins Sans Frontières, Amsterdam, Netherlands.
E-mail: Annick.Lenglet@amsterdam.msf.org