Perspective Piece

Facing Africa: Describing Noma in Ethiopia

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Abstract. Noma affects the most marginalized communities in the world, beginning as oral ulceration and rapidly progressing to orofacial gangrene. With a mortality rate estimated to be as high as 90% and with very few able to access treatment in its active phase, very little is understood about the disease. This retrospective review of patients treated by Facing Africa for deformity and functional impairment secondary to noma between May 2015 and 2019 highlights some of the difficulties encountered by those afflicted. Eighty new patients with historical noma defects were identified and were seen over the course of nine surgical missions, with notes providing valuable geographical, socioeconomic, and psychosocial information. The mean self-reported age of onset was 5 years and 8 months, with a median time of 18 years from onset to accessing treatment. Before intervention, 65% covered their face in public, 59% reported difficulty eating, 81% were unhappy with their appearance, and 71% experienced bullying. We aimed at emphasizing the significant burden, both psychologically and physically of noma, demonstrating the disparity between recent decades of progress in the well-being of Ethiopians in general and the access to health care and mental health support for some of those most in need.

INTRODUCTION

Aptly described as the face of poverty, noma rapidly progresses from oral ulceration to orofacial gangrene (Figure 1).^{1–5} An opportunistic infection with a name derived from the Greek term meaning “to devour,” the disease aggressively spreads through the hard and soft tissues. With a mortality rate thought to be as high as 90%⁶ and with very few able to access treatment in its active phase, very little is understood about the disease. Most commonly affecting children younger than six years,^{6–8} the WHO estimates a worldwide incidence of 140,000 new cases a year.⁹ Predominantly reported in sub-Saharan countries in a belt running from Mauritania to Ethiopia, the incidence is highest in West Africa.^{7,10,11}

Risk factors can broadly be held under the umbrella of poverty. However, specific factors identified from affected populations highlight viral coinfection, poor oral hygiene, the low coverage of immunizations, malnutrition, poor sanitation, and lack of access to clean water alongside an increasing incidence in those affected by the HIV and AIDS pandemic.^{4,7,9,12–16}

What turns the preceding oral ulceration or necrotizing ulcerative gingivitis into noma is yet undefined, although it is probably due to a combined pathological oral flora in the presence of a child with limited physiological resources and impaired immunity secondary to poor nutrition and concurrent disease. *Fusobacterium necrophorum* and *Prevotella intermedia* are purported microbiological isolates.^{3,10,17–19} Sub-Saharan Africa, in keeping with the rest of the world, sees faltering growth most frequently noted before the third year of life, with some infants predisposed following intrauterine growth restriction.²⁰ As a result, it is unlikely to be a coincidence that the average age of onset of noma is analogous

with the timing of the linear phase of growth retardation and often affects those most profoundly stunted.^{8,12,21}

Treatment for the acute phase of the disease includes addressing the underlying malnutrition, provision of oral antibiotics, and good oral hygiene.^{6,8} For those who survive, predicted to be numbering 770,000 people worldwide,⁴ the functional, psychological, and aesthetic sequelae are significant. With the majority of reported work on noma centered in West Africa, we hope to provide a more rounded picture by describing our experience treating those who have been affected in Ethiopia. Focusing on quantifying the burden of disease, we aimed at providing more insights into quality of life, social circumstances, and living standards experienced by those who endure the stigma of noma long after the initial infection.

MATERIALS AND METHODS

A retrospective review of patients who presented for treatment by the nongovernmental organization (NGO) Facing Africa for deformity and functional impairment secondary to noma between May 2015 and May 2019 was undertaken. Only those with historical noma presenting for the first time were included. Analysis of each new patient pro forma provided geographical, socioeconomic, and psychosocial information. The questionnaire was structured to form part of the clinical history and examination and although unvalidated, was designed by Facing Africa to cover common complaints arising secondary to noma (see Supplemental Data for an example of the care pathway documents). Histories were taken largely with the aid of Ethiopian nurses but also occasionally with nonclinical staff employed by Facing Africa. When vast cultural diversity is coupled with the range of more than 80 languages and 200 dialects spoken within Ethiopia, there can be difficulties in communication, and this resulted in some incomplete data sets. Clinical photographs enabled classification of the defects to describe the pattern of disease.^{11,22}

Enumeration areas from the 2007 Census by the Ethiopian Central Statistics Agency were used as the basis to ascertain

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FIGURE 1. A 3-year-old girl with acute noma; this image encapsulates why the term “the face of poverty” is so fitting. The destructive and aggressive nature of the disease is clearly seen alongside the hallmarks of protein energy malnutrition. This figure appears in color at www.ajtmh.org.

the nature of living environments.²³ Comparisons of water, sanitation, and hygiene alongside other socioeconomic and health indicators such as household size and the keeping of livestock were made with national statistics collated from the World Bank and the WHO to provide context.^{23–26} Mean and SD are given for normally distributed variables and median and interquartile ranges (IQR) for abnormally distributed variables.

RESULTS

As summarized in Table 1, we identified 80 patients who presented over the course of nine surgical missions. Thirty-eight patients were male and 42 female. The mean reported age of onset was available for 37 patients (46.3%) and was found to be 5.6 years (SD 3.6); for those of whom the exact age was not given, it was noted that the disease had started in “childhood.” The median age at presentation was 25 years

(IQR, 19–37), with the median time taken to access treatment being 18 years (IQR, 11–35). The number of patients presented from the regions of Ethiopia is shown in Figure 2.

Socially, two-thirds (65.8%) came from rural environments, with a mean household size of 7.38 (SD 2.48). Eleven patients were from refugee camps on the Somali and Sudanese borders (Dolo Ado and Gambella). Forty-eight patients (61.5%) had an improved water source as defined by the WHO,²⁵ and half of all patients kept livestock, with 21 patients (27.6%) coexisting with animals inside their house.

The median BMI was 18.2 (IQR 17–20) for the 67 patients older than 19. For the nine who were younger, all had a BMI that put them in the third percentile in the WHO growth standards.²⁷ Blood-borne illnesses were screened for in 68 patients; 5 (7.4%) were HIV positive, and one (1.5%) had hepatitis B. Only 10 patients (12.5%) believed they had received immunizations with 27 (33.8%) stating they had not received any and 43 (53.8%) unsure of their vaccination history. No patients had a vaccination card.

Functionally, 45 (59.2%) patients reported difficulty eating and 27 (36.0%) reported difficulties in communication. Psychologically, 12 (15.4%) of patients did not feel comfortable going out in public and 51 (65.4%) covered their faces when outside (excluding those for religious reasons). Fifty-five (70.5%) patients had experienced bullying regarding their appearance, and only 15 (19.2%) were happy with how they looked. Seventeen patients (21.3%) had sought traditional healing methods. Of these, 15 had endured burning or the use of hot instruments with two sustaining chemical injuries. It is unclear if this treatment was sought during active infection or as remedy for the lasting deformity.

The pattern of disease was described for 78 patients where complete data were available. Using the classification originally described by Marck et al.,¹¹ the routine involvement of the inner and outer lining of the cheek and at least a small portion of the upper lip is highlighted. Thirty patients (38.5%) had an interincisal opening of ≤ 20 mm, and 16 (20.5%) had complete ankylosis, while 13 cases (16.6%) involved the infraorbital rim or lower lid. Montandon’s classification^{22,28} of noma defects has been adopted by the WHO, and the distribution of our cases is shown in Figure 3.

DISCUSSION

The most insightful aspect of this study was the gateway into each patient’s quality of life. It is not just the aesthetic and functional side of disease that reconstructive surgery aims to address, but with mental well-being and a feeling of belonging being of at most importance. It is clear that the long-lasting sequelae have such detrimental effects that further work is required to understand how we can improve outcomes both surgically and more holistically in this cohort.

Global indicators of health were unsurprising considering the nature of disease. The mean self-reported age of onset is consistent with previous publications, as is the increased prevalence of HIV relative to the population (7.5% in comparison to 1.1%).²⁵ A median BMI of only 18.2 is indicative of malnutrition in the cohort. Although clear vaccination histories were unavailable for most patients, it can be extrapolated that the rate decreases well below the 70–80% coverage for all vaccines currently found in Ethiopia and even further below the Global Vaccine Action Plan targets of 90%.²⁹ This is

TABLE 1
Summary of results

Demographic									
Number of patients	Male:Female	Self-reported age of onset (years)		Age at presentation (years)		Time taken to access treatment			
80	19:21	Mean 5.6	SD 3.6	Median 25	IQR 19–37	Median 18	IQR 11–35		
Socioeconomic									
Living environment		Household size		Water source*		Live with livestock			
Rural 50 (66%)	Urban 26 (33%)	Mean 7.38	SD 2.48	Improved 48 (62%)	Unimproved 30 (38%)	Outside home 17 (22%)	Inside home 21 (28%)		
Health									
BMI†		HIV +	Hepatitis B	Hepatitis C		Immunization status			
Median 18.2	IQR 17–20	5 (7%)	1 (1%)	0 (0%)	Yes (any) 10 (13%)	No 27 (34%)	Unsure 43 (54%)		
Psychological and functional implications									
Feel unable to go out in public	Cover the face in public‡	Report difficulty eating	Report difficulty communicating			Have experienced bullying because of appearance	Happy with their appearance		
12 (15%)	51 (65%)	45 (59%)	27 (36%)			55 (71%)	15 (19%)		
Pattern of disease									
Nose	Outer lining	Inner lining	Trismus	Upper lip	Lower lip	Montandon classification, number of cases (%)			
Median score§						I	II	III	IV
1	2	2	2	2	1	23 (29)	16 (21)	10 (13)	29 (37)
Number of cases with region affected (%)									
42 (54)	65 (83)	65 (83)	66 (85)	66 (85)	60 (77)				

IQR = interquartile range.

* Improved drinking water sources are defined as those that are likely to be protected from outside contamination and from fecal matter, in particular.²⁶

† Including only those older than 19 years.

‡ Excluding those who cover their face for religious reasons.

§ As described by Marck et al.¹¹

FIGURE 2. Geographical distribution across Ethiopia, by region, of noma cases seen by Facing Africa between May 2015 and May 2019. This figure appears in color at www.ajtmh.org.

FIGURE 3. Pattern of disease distribution, as classified by Montandon, of cases seen by Facing Africa between May 2015 and May 2019. This figure appears in color at www.ajtmh.org.

important as, in contrast to West African populations where HIV has a higher prevalence, the predisposing viral coinfection for noma in Ethiopia is more likely to be measles.

Socioeconomic information provided insights into the current living conditions of these patients. The mean household size of 7.38 is higher than the national mean for those in the poorest 40% (6.82), and this fits with other previously published data.^{8,24,30,31} A rural preponderance is typical of Ethiopia. Similarly, the number with access to improved water sources among patients was in keeping with the WHO estimates (57.3%).²⁶ Living in close proximity to livestock has previously been suggested to be a risk factor for noma.^{8,32} In a country with a high dependency on agriculture, 90% of rural

households and 48% of small-town area households are live-stock holders.²³ However, this patient group was less likely to own animals than the average, and a recent case-control study in northwest Nigeria also failed to demonstrate this link.¹³

Because of the time that has elapsed following primary noma infection in our cohort, it is difficult to interpret some of the aforementioned data in relation to the disease itself. Instead, it provides a more holistic picture of the patients who have survived noma and how they have continued to live their lives.

Figure 2 demonstrates the geographical distribution of cases presenting to Facing Africa. However, there are myriad ways that patients hear of the NGO, whether it is through our own outreach, word of mouth, advertising, or referrals from other organizations. Similarly, there are many barriers to access such as conflict and potential loss of earnings. Indeed, a proportion of the disease in the most remote, deprived, and conflicted areas will be unreported both in general and in this study. As a result, there is inherent selection bias.

Our data show that patients are significantly challenged by the psychosocial impacts of their disease. The majority in our cohort were found to have significant functional deficit and dissatisfaction with their own appearance. The time from the start of the disease to accessing treatment was prolonged in this group and reflects the poor access to specialist health care in the region. Exposure to traditional medicines often involves hot irons, caustic agents, or even battery acid applied either to the face or abdomen and increases the burden of disease.³³

The pattern of defects demonstrated in this group is similar to the recent series by Pittet et al.³⁴ Most commonly, they are laterally based, with the majority being classified as Type I or IV. These cases can be surgically challenging to manage, often with significant ankylosis and the required scar excision leaving an even larger defect than initially appears. Over time, treatment has evolved considerably as initial treatments predominantly focused on local or pedicled delto-pectoral, latissimus dorsi, or supraclavicular island flaps.^{11,28,35} It still remains true that local flaps are generally used where possible, conferring excellent

FIGURE 4. A 59-year-old woman who previously had noma underwent reconstruction of the defect with a radial forearm free flap. This figure appears in color at www.ajtmh.org.

tissue match, reliability, and reduced morbidity. Certainly, Facing Africa has also found the submental island flap particularly useful in the reconstruction of noma. Despite this, large pedicled flaps are now generally discarded in favor of free tissue transfer, which have been shown to be safe and reliable even in resource-poor developing countries (Figure 4).^{36,37}

CONCLUSION

Ethiopia has experienced remarkable progress over the last two decades, with the average household seeing improvements in health, education, and living standards in comparison to the turn of the millennium. However, despite this, poverty is still rife and consumption distributions show that the poorest are becoming even poorer.^{24,38} It is this small subset where noma is most prevalent, and the inequality is not easily overcome.

Noma will continue to affect those with the least, representing a preventable loss of life and devastating those who survive both functionally and psychologically. Although it is difficult to remedy the economic situation in Africa and its resolution is unlikely to be aided by the Western stimulus, we can continue to provide help to those afflicted by this disease.³⁹ Although the treatment of noma provides a challenge logistically, surgically, and anesthetically, it is important to aim for the highest possible standards.^{11,40} This study shows the need to introduce validated patient-reported outcome measures centering around quality of life, a move that we would encourage to be adopted by the governments, health partnerships, and NGOs, treating noma across Africa.

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