

Geneva Health Forum 2018 Workshop: Noma a Neglected Disease in the Digital Age – Old Difficulties, New Tools?

Introduction

Noma (*cancrum oris*) is a non-contagious disease occurring predominantly in undernourished children aged 1-7, living in extreme poverty conditions in developing countries in Africa, Asia and South America. Noma evolves through different stages: it begins with an intraoral lesion which is followed by an oedema of the corresponding facial region. The oedematous region becomes rapidly necrotic and spreads to produce extensive and irreversible destruction of the soft and bony facial tissue. Noma leads to death in up to 90 per cent of cases. Survivors face aesthetic and functional sequelae (facial deformity, impairment in breathing, swallowing, speaking, vision and sometimes definitive mouth closure), stigmatisation, and discrimination across a wide range of human rights. If diagnosed in the earliest stages and treated adequately (oral hygiene, nutritious interventions and mild antibiotics) mortality can decrease to 10 per cent and the evolution of the disease can be arrested. By addressing the associated risk factors, malnutrition, debilitating concomitant diseases and poor oral hygiene, noma could be prevented altogether.

As with many other diseases already prioritised under the Neglected Tropical Diseases (NTDs) designation of the World Health Organization (WHO), data on the incidence and prevalence of noma is poor. This situation represents one of the main obstacles in raising awareness about the disease, its prevention, early diagnosis and treatment. During three working sessions, participants in the Geneva Health Forum 2018 Workshop on Noma discussed three specific questions related to data on noma and the transversal question of how a human rights approach shapes the answer to these.

1. What difficulties are encountered in gathering data on noma?

Inadequate surveillance and subsequent under-reporting of noma result in a skewed global burden of this disease. Several factors interact to bring about this situation, including:

- a) The **characteristics and evolution of noma** itself – The starting intraoral lesion of noma (ulcerous gingivitis) is insidious and therefore it is often not noticed by parents or recognized by medical personnel. The subsequent evolution of noma is very rapid – the disease can reach its terminal phase in the extremely short time span of two weeks since the onset. Due to this fulminant progression and the high mortality rate, numerous cases remain undetected, untreated and unreported.
- b) **Extreme poverty** of the affected children and their family – Noma exists where extreme poverty conditions prevail. For these communities, many inhabiting **remote areas**, adequate health care facilities are often inaccessible due to financial, geographical or cultural reasons. The large majority will seek the help of traditional practitioners who do not have the knowledge to identify and treat noma.
- c) **Lack of awareness and training of medical personnel** – Even when treatment in a conventional health care centre is sought, the medical staff are generally not trained to recognize the disease – noma is not taught in medical schools and is not part of medical protocols. Traditional healers and health care personnel will therefore often misdiagnose noma and contribute to the delay in adequate treatment with severe consequences. These cases of noma will not be captured by statistics as noma.
- d) **Social stigma** - Due to the lack of appropriate information about noma in the general population, this disease tends to be perceived as a curse, as a shame on the family or the wider community. The social stigma attached to noma pushes families to sometimes hide away or isolate their children with animals, instead of seeking access to adequate health care. The majority of these isolated children will die without any diagnosis, treatment and reporting. Provided they survive, they are not included in any statistics on the disease.
- e) The **intersectional vulnerability of children & governmental ignorance** – As children, as poor children, as children with extensive deformities and functional sequelae due to noma, these individuals are in a particularly vulnerable situation marred by multiple discrimination. In turn, this situation restricts their voice and ability to demand the attention of governmental authorities. Some states have shown themselves reluctant to acknowledge that noma exists within their borders, despite evidence to the contrary.

2. What (new) digital tools could be developed to gather data on noma?

Epidemiological studies on case series reporting on risk factors of noma date back to the 1950s and 1970s. In the 1990s, the WHO has recorded cases of noma in 23 countries and conducted prevalence

surveys in Niger, Guinea and Senegal. In 1994, the WHO conducted a **Delphi-type consultation** where they reached a consensus regarding the mortality and the percentage of survivors who seek medical help. They defined the mortality of noma to be 90% and the rate of referral 10%. Finally, taking into account all the previous WHO studies (published or not), the World Health Report of 1998 notes that annually some 100,000 children aged 1 to 7 contract noma in sub-Saharan Africa, whereas the global incidence is 140,000 cases per year. The prevalence of survivors is 770,000 worldwide. A 2013 Disability-Adjusted Life Year (**DALY**) calculation for noma, relying on the WHO estimates of incidence and mortality, disability weight of cleft lip/palate and life expectancy taken from the WHO Global Burden of Disease 2010 Study, has resulted in a burden of 1,073,079 years lost due to premature mortality in the population and disability for people living with the health condition or its consequences. This DALY is comparable or exceeds that of many other neglected tropical diseases.

There are three types of tools (including digital) that could be used, depending on context, to improve the data on noma:

a) Enhancing collaboration among care professionals

- A Delphi consultation on prevalence and incidence (less expensive, but limited)
- Focused epidemiological surveys in randomly selected regions with retrospective mortality survey

b) Collecting data when patients access health care facilities

- Prevalence surveys realized in specialised health centres
- Retrospective estimation of incidence (fresh noma) based on existing hospitals and NGOs' recordings
- Surveillance based on health centre with digital tools
- Including noma in already existing digital tools (e.g., MSF E-care based on IMCI)
- Adding indicators of noma in primary care procedures
- Make noma (and indicators of noma) notifiable (requires commitment from countries)
- Adopting software aimed to facilitate that information collected in primary health centres reaches the central level (already used in different African countries for other diseases)

c) Working directly with communities

- Improve medical education of care-workers, traditional practitioners, and the wider population
- "Amnesty Decoders", an innovative platform for volunteers around the world who use their computers or phones to help researchers sift through data ("micro-tasking").

What emerged from our exchange during the workshop is that the viability of the above-enumerated tools, have advantages and disadvantages. Their viability will depend upon language skills, literacy and access to technology, levels of education, data sharing willingness and in general political will. Existing digital tools can be used or new ones developed; in some very remote areas the use of classical tools such as posters or pictures combined with social media has been successfully used to recognise noma and refer patients to medical centres.

3. How can new data on noma be used for prevention and treatment?

A strong consensus emerged among the participants in the workshop that the **formal inclusion of noma on the WHO list of NTDs** would raise awareness about this disease, and ultimately contribute to its prevention and treatment. It has been emphasised that many other diseases have been prioritised in the absence of perfect data, and that the current relative opacity of data in relation to noma cannot fully explain the lack of interest the disease receives from relevant national and international fora. In addition to the recognition of noma as a WHO NTD, employing the tools identified above to gather new data or interpret existing data on noma will greatly assist governmental authorities at national and local levels and international organizations to acknowledge the existence of noma and set priorities for its prevention and treatment.

Transversal question: How does a human rights approach shape the above questions?

International human rights law which binds states through treaties and international custom stipulates the rights to life, to health, to food, to water and sanitation, to education, to work and the prohibition of discrimination. A 2012 Study of the United Nations Human Rights Council Advisory Committee has found that noma occurs because of violations of some of these rights *and* contracting the disease has as consequence violations of these rights. In particular, the prohibition on discrimination would require states to gather and facilitate the gathering of data on noma, and to use such data to implement targeted prevention and treatment measures. The Human Rights Council recommended that states acknowledge and address this disease which affects the most vulnerable members of society, children, by including it on the WHO list of NTDs.