NOMA: A neglected disease!

By GESNOMA, Winds of Hope, Sentinelles, and Médecins sans Frontières

A boy having undergone rehabilitative surgery during the surgical camp, organised in collaboration between HUG (Hôpitaux Universitaires Genevois) and Sentinelles, in Ouagadougou, Burkina Faso, 2013.

Mylène Zizzo, 2013

NOMA (cancrum oris and fusospirochetal gangrene or Necrotising Ulcerative Stomatitis), disfigures children rapidly, if they survive. It is one of the most devastating and disfiguring human diseases worldwide and was designated a health priority by the WHO in 1994 (1). NOMA is still a neglected disease, and there is not much known about its causes, prevention and optimal treatment. Fortunately, with simple interventions, NOMA can be addressed and contained and people with NOMA can be cared for. Thus, this disease deserves more attention from healthcare workers, nutritionists, researchers and policy-makers. In this article, we explain NOMA, explore the relationship between NOMA and nutrition and suggest how health workers in nutrition programmes can be involved in its identification and management. Two posters are included with the print edition of *Field Exchange*, one for an outpatient and one for an inpatient consulting room setting, in both English and French.

What is NOMA?

NOMA is a gangrene in the orofacial area. The course of the disease is very aggressive and fast. It starts as a gingivitis that develops into a gingival ulcer and/or necrotising gingivitis, spreading rapidly throughout the tissues of the mouth and face. The infection can result in necrosis of tissue and bone in the face which, combined with sepsis, is fatal in most patients. NOMA not only disfigures the patient but also causes dysfunction in eating and speaking, resulting in malnutrition and social isolation (2). If NOMA is untreated, 70-90% of patients will die.

The incidence of NOMA among children is estimated at 140,000 per year and the prevalence at 770,000 cases worldwide (2, 3). Lower estimates are 100,000 children per year who are affected by NOMA, of whom 20,000 survive (www.nonoma.org). However these figures are likely gross underestimates; NOMA is underreported since it occurs in remote areas, people are not eager to let the world know there is a disfigured member of the family, and the disease progresses rapidly to death. Most cases of NOMA (80%) occur in countries in the SAHEL belt, such as Chad, Nigeria, Niger, but also in Asia and South America. In the past, NOMA occurred in Europe too, where it was associated with poverty and the presence of other infectious diseases such as measles or tuberculosis.

The precise causes of NOMA are unknown, but the disease is thought to be related to immune dysfunction. Reduced immune function is in turn associated with poverty, the presence of other diseases (measles, malaria, pneumonia and HIV/AIDS (4)), malnutrition (5), poor hygiene and sanitation (no clean water, contact with animal waste), as well as lack of primary health care and health promoting activities like vaccination. Lack of oral hygiene is also a risk factor for NOMA; one of the early stages of NOMA is gingivitis and other infections in the mouth.

Treatment of NOMA

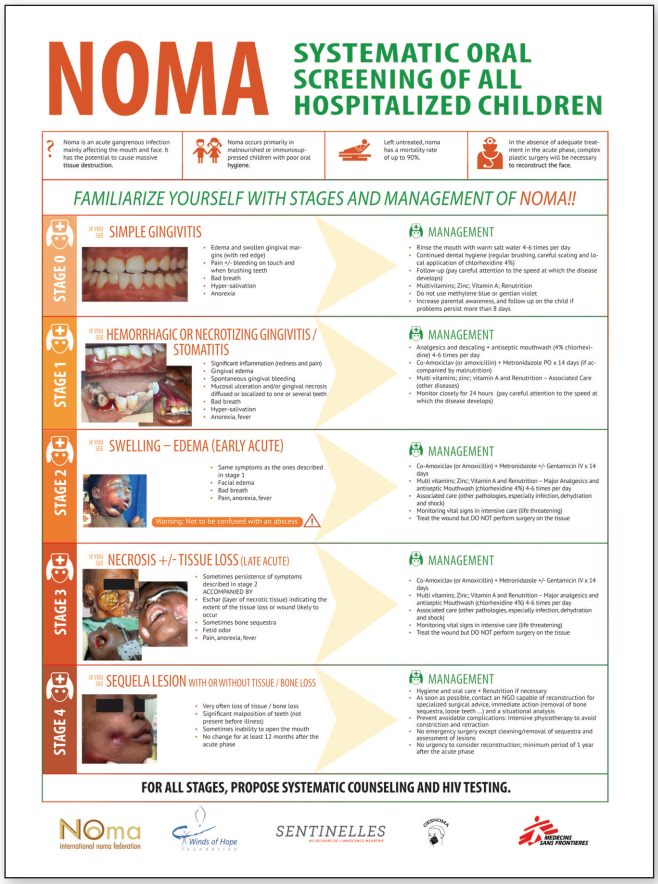
The early stages, such as simple gingivitis, should be treated with mouth washes of salted water and general oral hygiene. A complicated gingivitis (with necrosis, spontaneous gingival bleeding and pain) requires professional dental hygiene and follow up (if available). If dental hygiene and follow up cannot be achieved, antibiotics are needed. When there is a necrotising gingivitis/stomatitis with oedema of the corresponding facial region, antibiotics are mandatory. The later stages should be managed by an intense antibiotic regime in order to stop the spread of the infection and to avoid the deadly complications (such as septicaemia). Once the infection is over, and depending on the localisation of the NOMA, physiotherapy aimed to avoid complete trismus (jaws constriction) must be started for those patients developing this complication. In many cases, specialist reconstructive surgery is needed and can only be planned once the scarring process is over and no earlier than one year after the acute NOMA. Treatment to improve function, counselling and actions to maintain dignity of the patient must always be present from the beginning of the lesion.

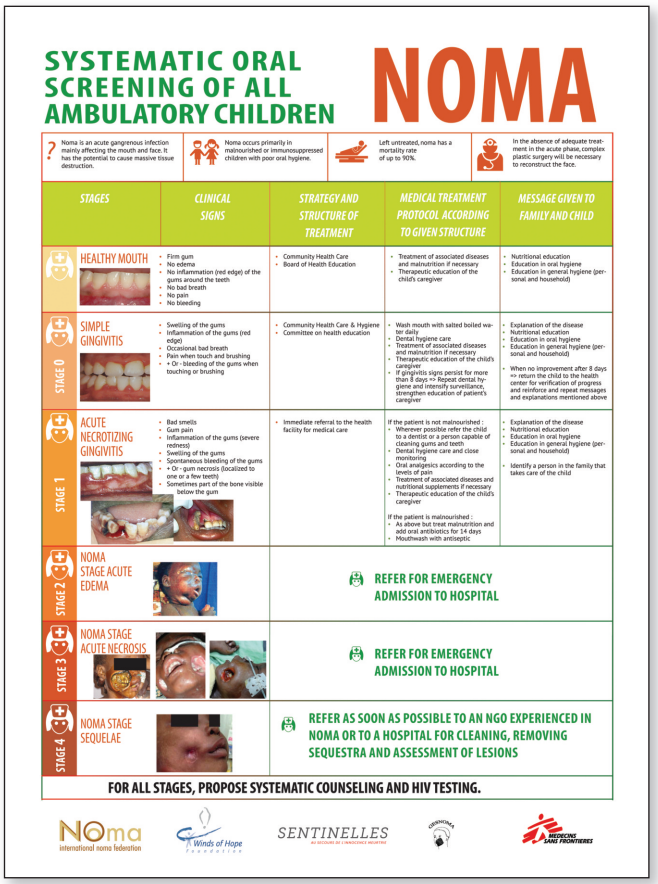
Simple gingivitis can be treated in an ambulatory therapeutic feeding centre (ATFC), the clinic and at home by rinsing with salted water for 14 days. In inpatient settings, such as an inpatient therapeutic feeding centre (ITFC) or hospital, mouth washes with 0.5% Betadine 4 times per day for 5 days (maximum) can also be used. Then, application of a solution consisting of 2 parts 1.4% bicarbonates at to 1 part nystatine 4 times per day for at least 10 days, or possibly over the total duration of the hospitalisation, can be applied with the aid of a compress rolled up on a tongue compressor (the caregiver can be taught to do this). In the case of necrotising gingivitis, the above local treatment should be completed with antibiotics (amoxicillin-clavulanate combination or amoxicillin plus metronidazole).

The treatment should be complemented by active nutrition support (e.g. supplementation with lipid nutrition supplements (LNS) or therapeutic foods where severely mal-

Screening for gingivitis:

- Gums: redness, pain, bleeding
- Hyper salivation, drooling
- Bad breath
- Anorexia
- Gingival ulceration
- Facial swelling / oedema.
- Dry necrosis, loss of tissue, possible bone sequestrum





nourished), treatment of any other existing infections, and updating of vaccination status. Prompt recognition of the early stage of NOMA (gingivitis) and treatment at this stage can prevent subsequent tissue destruction and disfigurement. This implies early recognition and active screening for NOMA.

Malnutrition and NOMA

Malnutrition (moderate and severe) is the most important risk factor for NOMA (5). Therefore prevention of malnutrition (along with treating underlying diseases, improving vaccination coverage and HIV testing) is an important step in the prevention of NOMA. This means that all moderately or severely malnourished individuals should be screened for signs of gingivitis. In addition, every patient in inpatient and outpatient nutrition treatment centres should be screened for gingivitis (simple and severe) and other mouth abnormalities. Once the NOMA infection is treated, many patients still have severe lesions in the mouth and face that can hamper eating, chewing, swallowing, talking, and sometimes even vision or breathing. Good nutritional support and guidance, with possible physiotherapy, can help to return to an acceptable nutritional status. Prior to any surgery, the lesion must no longer be active and the patient should be well nourished; close monitoring of their nutrient status and supplementary feeding is often necessary before surgery can be performed.

Active screening in feeding programme

Feeding programmes treating moderate and severe malnutrition have a concentration of children at risk for NOMA and are therefore excellent places to target these children; they can play an important role in controlling NOMA in an area.

Activities to include in a feeding centre are:

- Systematic screening of patients on admission for gingivitis
- Nutritional rehabilitation
- Vaccination
- Systematic HIV counselling and testing
- Screening of siblings and mothers,
- Improvement of water quality, sanitation and hygiene
- Education of patients and caretakers on mouth hygiene and NOMA
- Reporting of cases of NOMA in the village by caretakers
- Referral of NOMA patients to specialised institutes (where available)

Accessing guidance and support

Sentinelles, Winds of Hope, GESNOMA (all members of the International NoNoma Federation) and Médecins Sans Frontières (MSF) have created a working group to collaboratively develop several kinds of support:

- Posters for the consultation room in French and English for inpatient (hospital, ITFC) and outpatient facilities (outpatient medical clinic and outpatient/ambulatory therapeutic feeding centres (ATFC)) (included *Field Exchange 53*)
- Guidelines on treatment of NOMA
- Support to specialised centers for surgery
- Background information
- Guidelines on management of moderate and severe acute malnutrition
- Research

Nonoma (FR): www.nonoma.org
Winds of hope (EN, FR, GE): www.windsofhope.org
Sentinelles (FR, EN): www.sentinelles.org

Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example. UN General Assembly. 24th February 2012. Human Rights Council Nineteenth session Agenda item 5. www.righttofood.org/wp-content/uploads/ 2012/09/A-HRC-19-73.pdf
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