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Framing Noma: Human Rights and Neglected Tropical Diseases As Paths for Advocacy

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Abstract

Noma is a gangrenous disease that affects around 140,000 young children each year. The disease has an estimated mortality rate of up to 90%. This chapter examines framings of noma that have been prominent over the last four decades: the medicalised and humanitarian frames, as well as the human rights and neglected tropical disease frames. The analytical focus is on the framers (who?), the purpose of the faming (why?), and the outcome sought or accomplished (what?) in respect to the identified frames. The chapter's aim is to illustrate how the neglected tropical disease and human rights frames have, and could be, leveraged to enhance advocacy and generate policy change at international level and on the ground to tackle noma and support survivors.

1. Introduction

Search the internet for 'noma' and information about the world's best restaurant located in Copenhagen, Denmark will likely be returned first. Also sharing this name is a little-known disease that affects people living in conditions of extreme poverty across Africa, Asia, and Latin America.[1] Noma, the disease, is a devastating gangrenous condition that starts inside the mouth and is estimated to affect around 140,000 individuals every year.[2] It is both preventable and, when diagnosed early in young children, highly treatable.[3] When noma develops undetected, however, the disease spreads very quickly to the structures surrounding the mouth. This may lead to the destruction of the skin, muscle, and bone of the person's face.[4] The untreated mortality rate for noma, last reported by the World Health Organization (WHO) in 1998 and still used today, estimates that up to 90% of children do not survive the full onset of this disease.[5]

Surviving children carry the experience of noma on their faces for a lifetime. People affected by the disease are known to encounter social isolation, stigmatization, and discrimination, as well as difficulties with speaking, eating, and seeing.[6] It is thought that there may be as many as 770,000 people living with these long-lasting sequelae.[7] Given noma's strong association with malnutrition and extreme poverty, as well as the isolation many survivors may

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experience, it is likely that current epidemiological understandings of the disease underestimate the reality of noma today.[8]

We are not the first authors to contrast the accessibility of information about a restaurant with the (in)accessibility of information on a malnutrition-related disease.[9] Indeed, a noma survivor and advocate has recently started his presentation on the disease by referencing the famous Danish restaurant.[10] Making this connection is one way of communicating – or 'framing' – the depths of noma's neglect to specific audiences. The contrast also serves as an illustration of the focus of this chapter itself: the examination of noma's framing in health, humanitarian, and human rights circles.

The aim of this chapter is to evaluate two of the most recent framings of noma – as a human rights issue and as a neglected tropical disease (NTD) – and to consider how these frames have, and could be, leveraged to enhance advocacy and generate policy change at international level and on the ground to tackle noma and support survivors. We posit that developing awareness of the purpose and perception of these frames – whilst also continuing existing inquiries into noma's epidemiology, prevention, and treatment – is essential in lifting the veil of neglect that has long encircled noma globally and in many national contexts.

This chapter reports the findings of a research project that combined desk-based and empirical research to examine noma's framing as a human rights issue and as an NTD.[11] A narrative review of the literature on social and political theories of framing served to structure a series of key informant interviews. Twenty medical, humanitarian, and human rights practitioners from inter- and non-governmental organisations were purposively sampled for their expertise on noma to participate in 'elite' interviews. With the consent of our participants, these interviews were recorded, transcribed, and thematically analysed. In reporting the contributions of our participants, we honour the requests of both those who requested full anonymity as well as those individuals who preferred to be identified in the research outputs.

Structurally, the chapter is divided into four parts. Pursuant to this introduction, the second part draws on an interdisciplinary literature to define framing and identify its possible purposes as a means of communication. Using the findings of this review, we then configure our examination of existing research, expertise, and outputs on noma. The third part examines 'frames' of noma that have been variously prominent over the last four decades: the medicalised and humanitarian frames, as well as the human rights and NTD frames. Our focus is on the 'who' (the framers), the 'why' (the purpose of the faming), and the 'what' (the outcome sought and/or accomplished) in respect to the identified frames. The penultimate section of the article, draws together the findings of the narrative literature review with those of the key informant interviews to reflect on the significance of the intermingling of the discussed frames for enhancing future advocacy efforts on noma. The conclusion reflects on the NTD and human rights frames' compatibility and complementarity.

2. What is (in) a frame?

Framing theory departs from the premise that an issue or topic may be 'viewed from a variety of perspectives'.[12] Frames animate this process, as rhetorical devices created and advanced

by actors with the intention to communicate specific understandings of an issue and to target the generation of specific responses. Media outlets, national governments, social movements, and transnational advocacy networks have all been framers – '*the who'* in our three-part analysis – that sought to utilise framing processes for a variety of reasons – '*the why'*.[13] Some actors design and deploy frames to 'mobilise adherents and constituents' for a particular cause or to 'demobilise antagonists'.[14] Other framers, such as activist groups, seek to construct 'shared understandings of the world… that [then] legitimate and motivate collective action'.[15] As will be discussed in the following sections, when this perspective is applied to the noma agenda, it is possible to discern the influence of the professional identity of the frame-*r* on the purpose and outcome of the frame-*ing*.

Scholars underscore the versatility of framing as an advocacy tool. For Jorgensen and Steier, a frame is a means of advancing 'one possible view' on an issue, while Merry notes the utility of frames as tools for 'packaging and presenting ideas'.[16] When read together, these definitions highlight that a frame is not comprised of an issue in and of itself, but refers to different features of a given substantive issue. As such, the practice of framing involves a 'selection' of particular features of the issue at hand and the highlighting of their 'salience' with the aim of prompting specific reactions from target audiences.[17]

That the same issue can be communicated in different ways to different audiences and for different reasons is a cornerstone of both the theory and practice of framing. Keck and Sikkink provide one illustration of this in their analysis of land-use rights in the Amazon rainforest. The authors observe that the rights in question, 'took on an entirely different character and gained quite different allies when viewed in a deforestation frame than in either social justice or regional development frames'.[18] It is clear that multiple framings of the same issue can co-exist, either simultaneously or over an extended period of time. There may be tensions between these frames, or stakeholders may leverage differences in the focus of the frames to stimulate and influence action. This process is, however, predicated upon framers being able to formulate an issue in such a way that speaks to the interests of the intended audience. As Snow and Benford summarise, 'the potency of a frame depends on its relevance to the targeted population'.[19] Thus, the greater degree of relevancy, the more likely a frame will affect discursive and material changes – 'the what' or outcome in this chapter's analysis. As the following section discusses, in the context of the noma agenda there is some evidence of the former – with narrative changes emerging – and, with the progression of the NTD campaign, we consider it likely that material changes will come to greater fruition over the course of the next decade.

3. Frames of noma in operation

Attention now turns to consider the frames of noma that continue to operate both locally, in affected states, and internationally, across health, humanitarian and human rights fora. In doing so, the analytical focus is on the framers (who), their aim (why), and the outcomes of the framing process (what). Because of the limited literature on noma, this section of the article is necessarily supported by reflections on both our own and our research participants' experiences. At this stage, it is necessary to disclose the authors' positionality – Cismas has been involved in noma's framing as a human rights concern since 2009 and in all subsequent efforts to support noma's inclusion on the WHO list of NTDs,[20] while Trotter has been a

principal researcher on one of the most recent major interdisciplinary research projects on noma.[21] In undertaking our examination of noma's framing in this article, we will therefore engage with our own work reflexively, and thus necessarily critically.

3.1 The 'traditional' frames: medicalised and humanitarian frames

Noma's framing as both a medicalised and humanitarian issue has since the early 1990s directed how various stakeholders identified and acted on the disease. Practice has closely intertwined these frames, which have been drawn together by the specific medical, social, and economic circumstances that are thought to give rise to noma.[22] This is reflected in the assemblage of approaches required to prevent and treat the disease. As one interview participant observed, noma sits a bit in-between emergency-medical and humanitarian-development interventions.[23]

The medicalised and humanitarian frames were brought into being – not coincidentally – by charities, medical and humanitarian actors. Two evolutive characteristics relating to both the purpose and outcome of these frames are of relevance to our discussion: the locality and scope of interventions.

Non-governmental organisations with a charitable and/or medical character, such as Sentinelles, the Dutch Noma Foundation, Facing Africa, Hilfsaktion Noma e.V., and Winds of Hope engaged in humanitarian- and medicalised-based framings of noma with the specific purpose of raising funds in the Global North to resource surgical 'missions' to sub-Saharan Africa. These organisations primarily delivered surgical interventions in areas where noma was known to occur, and some temporary relocated individuals to European hospitals for treatment.[24] The importance of this work should not be underestimated: treatment was offered to people at all five stages of noma. Another important strand of work focused on noma's etiology, which despite efforts remains to this day unknown.[25]

In time, the locality and scope of interventions took a different, and we would argue, more sustainable meaning. The focus of the movement – which by mid-2000s also included Health Frontier Laos, Médecins Sans Frontières (MSF), and other members of the NoNoma Federation – shifted to incorporate capacity building of local actors and the prevention of noma as central features. Efforts to build local medical (including surgical) knowledge and structures have led, for example, to the establishment of noma health centers in Burkina Faso and Niger[26] and to the creation of the first specialist hospital for noma patients in Sokoto, Nigeria.[27] Medical professionals spoke about the social determinants and consequences of noma – in particular, poverty and malnutrition.[28] Awareness-raising campaigns were developed targeting healthcare professionals and traditional healers working in communities across a dozen countries in Africa.[29] For example, brochures were developed and circulated by WHO's Regional Office for Africa (WHO AFRO) to depict and explain the stages of noma.

It is not surprising that in the thirty years since the emergence of these frames an evolution has occurred in their purpose and outcomes. The medicalised-humanitarian frame has not remained temporally or spatially rigid. This fluidity is characteristic of framing in practice.[30] Benford and Snow observe that once in circulation, frames are in a continuous process of being, 'constituted, contested, reproduced, transformed and/or replaced'.[31]

In the case of noma, one example of this is evident in the changing practices around the provision of specialist reconstructive surgery for children who had developed, and survived, the latter stages of the disease. Where previously people were brought to Europe to undergo reconstructive treatment, normative practice has moved toward a more localised model, with specialist medical care facilities established in several sub-Saharan African states. This has enabled individuals to undergo reconstructive treatment in-county, often accompanied by their families as they move through surgical and rehabilitation pathways at clinics staffed by both local and Global North surgeons. The benefits of doing so are clear: aftercare takes place in relatively familiar, accessible environments, more local staff receive specialised training and participate in care provision, and the scope of the care provided is expanded and benefits many more people at risk or affected by noma.[32] A related example is the recognition of the agency of local actors. In Nigeria, the Noma Children's Hospital – set up by the Nigerian Ministry of Health in Sokoto and supported by MSF since 2014 – regards community-based services as a central pillar of its model of care. In addition to local health workers, leaders and members of community are seen as vital for noma's prevention and treatment in a more sustainable manner.[33] Similarly, an evaluation report of the WHO Africa Regional Programme on Noma Control notes that 'with the support of Hilfsaktion… the programme trained 5000 health workers (doctors, nurses, midwives, community health workers and medical assistants) in 10 countries to be able to carry out preventive and management actions'.[34]

Put differently, a shift in focus has evidently begun, engendering, or accepting, local ownership of the processes aimed to prevent and treat noma. Finally, then, and without seeking to take away from the importance of charity-led work – indeed, in the past, often surgical missions sponsored by charities and staffed by Global North doctors were the only avenue to medical intervention for many who experienced noma in the Global South – it is important to observe that the discourse had, on occasion, signalled a 'white saviour' trope. This approach is problematic both morally, as well as from the point of view of sustainability of interventions.[35]

3.2 Noma's more recent framings: human rights and NTDs

The human rights and neglected tropical disease framings of noma have emerged in the last fifteen years. These frames are, therefore, comparatively recent occurrences and the process of their development is ongoing. As there is very little research that directly examines these frames of noma, the following discussions are both pro- and retrospective, recognising the trajectory of current advocacy whilst also reflecting on our own and our research participants' experiences with these framing processes.

The analysis of the human rights and neglected tropical disease frames of noma must begin with one of their earliest iterations: the 2012 Human Rights Council Advisory Committee (HRCAC) *Study on severe malnutrition and childhood diseases with children affected by noma as an example* (hereafter, HRCAC Study).[36] The HRCAC is formed of independent experts who are mandated to provide research-based advice to the United Nations (UN) Human Rights Council, the main intergovernmental UN body tasked with the protection of human rights. In the HRCAC Study, noma was for the first time presented as a cause and effect of human rights violations, with the Committee *also* going on to request that the WHO recognise noma as a neglected tropical disease.[37]

The Committee was not, however, the first mechanism of the UN to underscore the links between the human rights and neglected tropical disease frames more generally. In 2007, Paul Hunt, the then Special Rapporteur for the right to health stated that 'neglected diseases are both a cause and consequence of human rights violations'.[38] This association is often mutually reinforcing, for as Hunt goes on to observe, 'failure to respect certain rights increases the vulnerability of individuals… to neglected diseases [and] people affected by neglected diseases are vulnerable to violations of their human rights'.[39] Whilst we recognise both this intermingling of the two frames, and that undertaken by the HRCAC, for the cogency of the analysis, this section will first consider noma's communication as a human rights concern, and then as a neglected tropical disease.

Which human rights frame, with what purpose, and what outcomes?

In formulating the human rights frame of noma, the HRCAC Study described the disease as, 'the most brutal face of poverty and malnutrition in children… thus giv[ing] rise to some of the worst violations of the rights of child'.[40] As is characteristic of a violations-based approach to human rights framing, the Study goes on to recognise governments of both affected and donor states as the principal duty-bearers for acting against the prevalence of noma and addressing discrimination experienced by survivors.[41] The identification of these actors as bearers of legal obligations, as well as the evocative language used to emphasise accountability, aligns the Study with 'naming and shaming' practices often employed in human rights campaigns.[42] These practices are typically carried out by non-governmental organisations seeking to identify and denounce perpetrators of violations with the aim of establishing accountability, ensuring redress for victims and survivors, and preventing further abuse.[43]

Why then did the HRCAC pursue this *specific* approach? Among our research participants, the rationale underpinning the HRCAC's decision to adopt a rights-based – and specifically a violations-based – framing of noma was undisputed. Indeed, this framing was perceived to be intuitive – not just because of the professional identity of the framer, a body working on human rights, but because of the nature and circumstances of the disease itself. As one interviewee noted, the majority of noma cases seen today are 'children who are born into these basic human rights violations'.[44] The individuals developing noma are those whose rights to adequate food, sanitation and health are not realised, and who, in their large majority, will have their right to life itself violated.[45] Another interview participant specifically urged due consideration of the right to life of people affected by noma:

> …it's important we don't forget that everyone has a right to live. [Noma] is not only a disease, not only malnutrition, but it's a matter of life itself… somehow you see not only the life of a child [but] you also see their death. You see what you never see in someone. You see the skull, you see the bones, and you see the potential death of the person.[46]

As this interview excerpt so vividly demonstrates, a significant moral impetus continues to animate the noma agenda, cutting across the medicalised, humanitarian, and human rights frames. Indeed, according to the author of the HRCAC Study, who is also one of the co-authors

of this article, the Committee sought to use a human rights violations-based framing of noma to leverage the moral authority embodied by the wider human rights agenda. Yet, the HRCAC's overarching goal was, as Cismas notes:

> To speak to the consciousness of governments and, importantly, that of the WHO. We [the HRCAC] wanted to see them taking action on the ground, *not because it was the charitable thing to do but because they have human rights obligations under international treaty and customary law to do so*. We wanted to see accountability.[47]

If the PANEL (Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality) principles are taken to embody the human rights approach, the HRCAC concentrated on legality – anchoring action and policies on noma in legal rights – and accountability – monitoring of states' activity on noma and providing remedy when that activity fall short. Specifically, the HRCAC was preoccupied with how both legality and accountability were being frustrated by the restricted locality and limited thematic scope of noma-related activities.

In the early 2000s, following a decision of the Regional Consultative Committee, the noma program was transferred from WHO headquarters in Geneva to WHO AFRO – specifically to the oral health department.[48] Stakeholders expressed concerns, reported in the HRCAC Study, that this relocation would likely serve to institutionally invisibilise people at risk or affected by noma who lived *outside* the African continent.[49] Recent scholarship continues to emphasize that noma's prevalence remains underexplored in Latin America, Asia, and specifically the Indian subcontinent.[50]

A human rights frame, then, connects the absence of monitoring and institutional attention paid to noma in these regions with the human rights violations that individuals living in these areas and affected by the disease are *likely* to experience.[51] The likelihood is not theoretical, if we argue by analogy with the lived experiences of those in sub-Saharan Africa affected by noma,[52] and based on the limited evidence from existing studies focusing on Asia.[53] As such, a whole range of human rights are at stake, certainly the right to health, but also the rights to food, water and sanitation, housing, education, to life, freedom of expression, the right of children with disabilities to a full and decent life, and the overarching right to equality and non-discrimination.[54] Human rights framing also points to the fact that states, as primary duty-bearers under international human rights law, are failing these individuals.

As such, the HRCAC aim was to widen the geographical scope of interventions beyond sub-Saharan Africa and the thematic focus beyond medicalised interventions to include considerations of the lived experiences of rights-holders – whether at risk or survivors of noma – and of the obligations states have towards these individuals. Adopting such an expansive approach would, therefore, enable stakeholders to address noma through the lens of structural power imbalances that manifest themselves in poverty and discriminatory patters, and thus connect the disease with broader agendas that seek to tackle these –the human rights movement evidently, but also, at the time, the Millennium Development Goals.[55]

The examination of whether noma's framing as a human rights concern has materialised into concrete outcomes must recognise that its two objectives – acknowledgment by states of their human rights obligations in respect to individuals at risk of noma and survivors as *rights-holders*, and the global institutionalisation of noma's prevention and treatment – were undoubtedly ambitious. They require significant, almost paradigmatic shifts in the way that stakeholders think and act on noma. As we look back over the decade since the HRCAC study was published, it is perhaps unsurprising that the objectives of the human rights frame cannot be said to have been fully achieved in either state practice or institutionalisation processes. Yet, there are three significant advances that should be noted.

The HRCAC's focus on legality has been echoed by some scholarly works – interestingly published in medical journals[56] – research projects[57] and WHO publications.[58] These portray individuals affected by noma as rights-holders, often emphasising their victimhood, that is holders of rights that have been violated. The WHO AFRO's Step by Step Guide to Develop National Action Plans for Noma Prevention and Control in Priority Countries presents a more complex understanding of noma survivors than was seen before. The guide includes the objective of 'reintegration of noma survivors and their families into society', centring lived experiences, as well as seeking to ensure reintegration in educational institutions and workplaces, and to facilitate small business opportunities and partnerships with community groups and development initiatives.[59] Finally and crucially, authorities are encouraged to seek noma survivors' input in noma prevention and control activities, including by enlisting them as community health workers.[60] This indeed reflects a fuller understanding of the human rights approach, one that engenders the empowerment and participation of those whose rights are affected by noma in policy processes that directly concerns them.

In terms of accountability efforts, the Human Rights Council acknowledged in a 2012 resolution the work conducted by the HRCAC on noma, and explicitly encouraged states to implement the *Human Rights Principles and Guidelines to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by noma*.[61] This instrument had been developed by the Committee and annexed to its 2012 Study as an embodiment of a human rights approach to tackling noma and addressing discrimination against survivors. Subsequently, UN treaty bodies had taken up noma in their periodic country reviews.[62] The Committee on Economic, Social and Cultural Rights (CESCR) and the Committee on the Rights of the Child (CRC) – the treaty bodies tasked with monitoring state parties' compliance with the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Convention on the Rights of the Child (CRC) respectively – have asked Burkina Faso, Ethiopia and Eritrea to report on the prevalence of noma in their populations.[63]

Have states embraced noma's human rights framing? In response to the above-mentioned UN treaty bodies' review, a marked contrast is evident, with Eritrea on the one hand, and Burkina Faso and Ethiopia on the other. Eritria denied the very existence of noma within its borders.[64] Ethiopia and Burkina Faso, however, engaged constructively with the CRC and the CECSR, respectively.[65] The latter explained how it partnered with non-governmental organisations and the WHO in the 'fight against noma', what progress it has made, and interestingly that it 'advocated the inclusion of noma in the list of neglected tropical diseases'.[66]

Whilst no general conclusion can be drawn from these few examples of state practice as to whether states assume their human rights obligations in respect to individuals experiencing noma, one observation is in order. States that have engaged with humanitarian organisations or charities – as did both Burkina Faso and Ethiopia – and had worked with the WHO to develop noma programs – the case of the former – are more likely to not deny the existence of the disease, and thus not seek to further invisbilise survivors. In turn this may place them in a better position to see the utility of and assume a human rights approach to noma.

Nigeria's practice provides further evidence for the above observation: steps taken to address noma could be interpreted and presented as an indicator of a state's progress toward the realization of international human rights obligations. Various Nigerian state actors in collaboration with intergovernmental and non-governmental partners have taken active roles in shaping multi- and cross-scalar action on noma. Nigeria is one of several African states to have established national action plans in collaboration with the WHO, and the disease has been incorporated into the curriculum of medical schools.[67] It has also sought to develop public awareness of the disease through an annual 'National Noma Day'.[68] During the third commemoration of the day in 2019, the federal government declared its commitment to eliminating the disease in Nigeria by 2030.[69] This in-country action has been undertaken alongside interventions in the international health agenda: with the support of MSF, the Nigerian Ministry of Health has taken the lead on preparing the dossier of evidence for submission to the WHO Strategic Advisory Group calling for noma to be recognised as an NTD. Full circle then, at a side-event presentation during the COP26 summit held in autumn 2021, a representative of the Nigerian delegation noted that the human rights to food, health and education are vulnerabilised when a person develops noma.[70] These actions of Nigeria, which have occurred at different scales and in different fora serve to demonstrate that when states takes steps to address noma, they are less likely to be adverse to applying a human rights approach to noma – a discussion to which we shall return in the next section of this chapter.

Finally, then, the above-mentioned dossier of evidence, which has been submitted to the WHO in January 2023, cites human rights obligations as one of the justificatory grounds for the inclusion of noma in the WHO list of NTDs.[71]

NTD as noma's self-evident frame and framers, yet with what outcome?

As several interview participants observed, the rationale of communicating noma as an NTD is evident: noma meets each of the four criteria of a neglected tropical disease. The disease:

1. predominantly affects people living in conditions of poverty, and causes important morbidity and mortality in these populations, therefore justifying a global response;
2. affects people living in tropical and subtropical areas;
3. is immediately amenable to broad control;
4. and has been neglected in the field of research.[72]

Noma's inclusion on the formal WHO list of NTDs would, therefore, be a recognition of fact. It would also be the logical and purposeful step to pursue, with the derivation of a range of benefits immediately clear. Drawing in part on the trajectories of other neglected diseases formally recognised by the WHO, interview participants noted that the visibility, awareness,

and funding of noma in the international health agenda would likely increase.[73] NTDs have, as one interviewee noted, become 'an established brand' which attach certain commitments from inter-, national and corporate actors in the global health community.[74] Gaining the WHO's recognition of noma as an NTD would, then, 'carry a lot of weight', according to another participant.[75] This would be a highly positive development, likely amplifying awareness within the global health community, expanding attention and political commitment in national health policy, and increasing funding for in-field programming.

Despite noma's framing as an NTD being self-evident, as noted above, at the time of writing, its inclusion on the WHO NTD list remains an objective to be formally reached. Indeed, as two experts in the field describe it, noma remains a 'neglected-neglected tropical disease'.[76]

What can explain this? There may have been a number of possible factors at work. First, the HRCAC Study – which, recall, recommended noma's inclusion on the WHO NTD list – did not have its intended *immediate* impact. While some states had shown an interest, the buy-in had not been cultivated due to lack of human and financial resources. The hope was that a multi-stakeholder, cross-regional coalition would emerge that championed noma's formal listing as a WHO NTD. Whilst this did not materialise immediately in the years after the HRCAC's report publication, MSF had taken up work on noma in Sokoto, Nigeria. This led to more systematic attention being paid to noma within the organisation: a large, influential humanitarian actor had thus entered the noma advocacy stage.

Second, there was a resistance to declaring noma an NTD from some WHO member states (important voluntary contributors to the organisation's budget) and from within the WHO itself. We understand this to have occurred in a context of insufficient resources and capacity that the WHO Department of Control of Neglected Tropical Diseases was facing (and indeed continues to face to this day).[77] Jean Ziegler, former member of the HRCAC, wrote of a high-level meeting with a Swiss public health official:

> [they] refused to present any resolution on noma to the World Health Assembly, [arguing that] 'there are already far too many diseases on the checklist'. WHO's representatives in the field are already overwhelmed. They hardly know what to do next. Adding another disease to the list – don't even think about it.[78]

Thus, the NTD framing of noma had to contend with a counter-framing: the competition between diseases for human and foremost financial resources. It is unlikely that the institutional challenges that were described by Ziegler nearly a decade ago have been resolved. However, the inclusion of snakebite envenoming on the NTD list in 2017 continues to give reason for optimism.[79]

Third, noma fell prey to the vicious circle of imperfect data. Data on noma's incidence and prevalence dates to the 1990s and is objectively imperfect. As to the circle: when advocates had previously raised noma's inclusion in the WHO NTDs list, advocations were rebutted as 'premature' given lack of data systematically evidencing the disease's impact on populations. More data and more recent data, it was argued, was needed to prove the necessity of noma being listed as an NTD. As to the viciousness of the circle: NTDs by their very definition *will* have imperfect data because they are neglected by research. To gain better data noma will

have to not be neglected by researchers. This very point was brought home in the dossier of evidence in support of noma's addition to the WHO NTD list.[80]

Who then are noma's NTD framers? The NTD frame blends humanitarian and medical approaches to diseases which, in the case of noma, tare he fields where the majority of actors are working to provide immediate and long-term interventions. Whilst the process of *framing* noma as an NTD may have been initiated by the HRCAC in 2012, the intervening years have seen medical experts and humanitarian practitioners take up the agenda, ground it in empirical evidence, and launch strategic advocacy efforts. In 2017, an interdisciplinary, multi-actor advocacy task force was established, and a few meetings were held at MSF's headquarters in Geneva with, among others, representatives of Sentinelles, GESNOMA, and MSF – some of the individuals present had been involved in the successful snakebite dossier.

Some four years later, MSF launched an official campaign for noma's recognition as an NTD, appointed a researcher to draft the dossier of evidence, and a journalist and award-winning documentary filmmaker as campaign manager. Notably, whilst run by MSF, the campaign has become paradigmatic in its inclusion of a range of stakeholders: from medical experts, humanitarians, charities who had long worked on noma, human rights practitioners, and to, most importantly, noma survivors themselves.[81]

The progression of the campaign over the last three years offers the most concrete indication yet that noma's position in the international health agenda may be about to change. One key moment was the World Health Assembly's approval of a landmark oral health resolution in May 2021 that proposed exploring noma's inclusion in the next cycle of the NTD roadmap.[82] Another crucial event is marked by the submission of the dossier of evidence by Nigeria and 30 cross-regional co-sponsoring states. 2023 is likely to be a year to watch for noma.

It would not be amiss to ask: what changed in the past decade? The epidemiological data on noma has seen little progress[83] – yet, advocates seem, and rightly so, to have broken the vicious circle of imperfect data we discussed earlier. Noma remains as deadly *and* can be cured as inexpensively if treated in the early stages – again, advocates appear to have had greater success in persuading states and WHO structures of this fact. This may have assuaged some concerns in particular of those who resisted noma's inclusion on the WHO list due to (legitimate) concerns relating to limited human and financial resources. The conclusion appears inescapable: what changed and enabled the progress in noma advocacy that we currently witness has less to do with the disease itself and more to do with its framers. Nigeria, the largest country in Africa by population size and GDP is leading the campaign for noma's listing. MSF, one of the most important and influential humanitarian organisations has provided support, expertise, and resources to develop the dossier of evidence and the advocacy campaign – in doing so, it has built bridges between decades of work of noma medical experts, of charities and organisations, and human rights professionals and sought to centre the voices of noma survivors.

4. Two inter-related reflections for future advocacy

Whilst it is not yet possible to identify a definitive outcome, the above discussions combine to suggest that the NTD frame is currently seen as the most effective way to further noma's

position in the international health agenda. The inclusion of noma in the WHO NTD list, however, will not be a silver bullet for the eradication of noma and the realisation of the human rights of people who experience and survive the disease. Funding, research, integration in existing mechanisms, new policies, continued political will, changing of mindsets will all be needed. Drawing on the above analysis, a thematic literature review and the responses of our interview participants, we offer two reflections for future advocacy practice on noma.

4.1 Prioritising the NTD frame, while retaining elements of other frames

We posit that when the status of NTD is formally conferred upon noma by the WHO, core elements of the medicalised, humanitarian, and human rights frames must be retained and incorporated within the roadmap process. Over the last forty years of their operation, the actors engaged in these frames have developed unparalleled knowledge of noma: of its causes and its risk factors, of the treatment of people who have developed noma and their follow-up, of the surveillance of cases and the planning of effective medical as well as socio-economic interventions. They have also funded such work (almost) at the exclusion of state and corporate funding. Further utilizing and scaling up these evidence bases will be crucial to develop the global institutionalisation of preventative action and treatment of noma.

The rights-based nature of our own work leads us to advocate in particular for incorporation of the human rights perspective going forward. Doing so will be vital in ensuring that people affected by noma take up positions at the forefront of the agenda, that their lived experiences inform planning and programming at every level – in other words that the empowerment and participation principles become reality. Working to incorporate these principles into practice may, in time, come to guard against over-medicalisation, understood here as application of exclusively or predominately medical knowledge to social problems.[84] Over-medicalisation is likely to have a tunnel-vision effect: looking at noma through medical lenses *only* will focus on its prevention and treatment through medical means *only*, ignoring the structural power imbalances that give rise to noma in the first place and that fuel patterns of discrimination.

Edificatory are the comments in reference to leprosy made by Alice Cruz, the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. Leprosy, an NTD formally recognised by the WHO, and noma share similar social consequences for the people they affect.[85] Cruz notes, 'we cannot separate the discrimination attached [to this disease] from social and economic justice and inequality'.[86] This means that, when programming, actors must look beyond health-related stigma, which is far too often understood by non- and intergovernmental organisations as stigma and discrimination that is restricted to person-to-person interactions.[87] Instead the wider structures of power that condition the social realities of people with NTDs must be acknowledged and addressed. The alternative is to 'somehow justif[y] [stigmatisation] as being sort of a natural consequence' of NTDs.[88] On this account then, it is the health conditions that are thought to catalyse the 'social disqualification' of individual people or populations.[89]

This has, to a certain extent, been documented by research into the lived realities of people who have developed noma. A doctoral thesis surveyed two hundred people living with sequelae of noma in Niger. Nearly half of those interviewed had encountered instances of discrimination, and over thirty percent had experienced some form of social exclusion.[90] Another, more recent example sees Kagoné et al. discuss a series of interviews carried out with noma survivors, healthcare professionals and opinion leaders in Burkina Faso. One individual, who had received medical treatment for noma, spoke of their experiences: 'when you are the only one in the village with this disease, you become the village pariah. The stigma drives you crazy and you suffer an unbearable ordeal'.[91] As this interview excerpt directly, and crucially, exemplifies, a person's development of noma is not *just* a medical issue. It is, therefore, necessary to recognize and account for the 'wider power relations that shape the micro dynamics' of stigma that are experienced by people in their day-to-day lives.[92] We move to follow Cruz in submitting that the human rights agenda may be uniquely placed to expand work on the disease:

> [t]hat is why it is important to have these diseases recognized in the human rights arena… [because] you can call for other types of intervention… that attach a cross-sectoral governance mentality.[93]

Widening the scope and focus of interventions on noma through the human rights frame would, we posit, place people, and their rights, at the centre of policy and programming. We recognise, however, that doing so may require a significant reorientation in the practice of non- and intergovernmental organisations both in the field of NTDs and in that of human rights.

4.2 Retaining a human rights frame, but reflexively refocusing it and educating stakeholders

Earlier in this chapter, we discussed the broad-based agreement amongst our interviewees that noma was a human rights issue. This consensus was, however, complicated when we asked our interview participants to consider the effect of the human rights frame in states where noma is known or thought to occur. When responding to this question, the majority of participants leant on a violations-based framing to then express concerns over the perceived repercussions of this. A participant commented that, 'it's not pleasant [for governments]… to hear that there are violations of human rights in their country',[94] while a second suggested that, 'it would be like shaming and blaming people who are [decision-makers] in affected countries'.[95] There may, therefore, be political connotations of engaging with the human rights frame – or at least in its violation-based form – as one participant hypothesised. If a humanitarian organisation were to adopt this framing, this may mean that: [the organisation] would have to denounce [noma] as a violation of the right to food, and by extension [the organisation] would have to denounce the activities of the state.[96] Doing so in states where the human rights agenda is contentious may result in outcomes that range from the restriction of access for non-governmental organisations to constraining institutional surveillance of cases.[97]

There are three relevant aspects that we wish to highlight in relation to these concerns. First, the tension between a (violation-based) human rights approach and (especially emergency) humanitarian action is not a novel phenomenon, and it certainly does not only concern noma.

For example, humanitarian bodies such as the UN High Commissioner for Refugees have, historically, resisted calls to embrace a human rights approach for fear of being perceived as politicised and thus compromising its ability to gain humanitarian access to refugees, internally displaced people and other persons of concern to its mandate.[98] This position, of course, has been replaced by a recognition of the complementarity of the human rights and refugee law frameworks, their respective missions, and the importance of context-sensitivity. Returning to noma, perhaps no better evidence exists as to the compatibility between the human rights and humanitarian frame that the example provided by state practice. Indeed, as noted earlier, states that are open to working on noma with humanitarian organisations are less likely to shy away from human rights discourses.
The lesson to be learnt by human rights practitioners is that they will have to engage more constructively with humanitarians explaining the synergies between the human rights approach and the medicalised and humanitarian framings of noma.

Second, whilst analysing the answers provided by our interviewees, we observed that often it is not a human rights approach to noma that raises concern, but a particular discourse that associates noma with poverty, and poverty with shame. For example, one participant noted: 'noma is a shameful disease in one sense… a synonym of poverty in many ways… It would be difficult to admit that your population is suffering from noma'.[99]

The 2012 HRCAC Study had indeed explained the corelation between poverty and noma. Whilst adopting discourse often employed by medical doctors and charities working on noma, the Study was insufficiently reflexive and sensitive to the connotations it evoked for affected states, and foremost for individuals experiencing noma. Its intention had been to break the stigma attached to poverty by moving states toward preventing and treating the disease, addressing discrimination experienced by those affected by noma, and power imbalances that give rise to poverty; yet, it may have reinforced the perception of stigma by using such expression as 'noma, the face of poverty'. It is hoped that a participatory approach, that centres the voices of noma survivors, not only in programming and implementation of noma policies, but also in research and fundraising activities, will avoid such errors. To cite Fidel Strub and Mulikat Okanlawon, who set up the Elysium Noma Survivors Association 'Noma is often referred as the 'Face of Poverty'. We think it more like the face of neglect instead'.[100]

Third, it is important to emphasise that 'naming and shaming' approaches are not the only human rights framings. Entman notes that framers may expect to impart common responses across audiences, yet, in reality, the frames they construct are 'not likely to have a universal effect on all'.[101] Thus, a more positive, progress-based human rights framing may be the more appropriate focus for certain states, such as those already addressing noma or those that are willing to engage in such activities. We believe that such a framing is already evident and yields results, as illustrated by the UN treaty bodies' review processes of Burkina Faso and Ethiopia.

This is not to say that the violations-based frame should be set aside. Rather, both forms of rights-based framing retain utility. As our earlier discussion of the UN treaty body system sought to evince, adopting a violations approach has been beneficial in ensuring that human rights mechanisms *themselves* are attentive to noma. There are signs that this frame has begun to also be embedded institutionally within the WHO – guidance and training material

recently published by WHO AFRO have incorporated human rights language when discussing the experiences of people who have developed noma and the need to address discrimination.[102] In contrast, framing action on noma as progress on human rights obligations may function more prospectively, perhaps furthering state buy-in to case surveillance, as well as education and awareness-raising initiatives. It is, then, more a question of deployment of these different iterations of the human rights frame.

Several of our participants suggested that connecting noma with the Sustainable Development Goals (SDGs) may, perhaps, bring the disease under the remit of a different international framework of indicators.[103] Whilst not without their own challenges,[104] the broad scope of the SDGs and the constructive, collaborative dialogues that underpin them may serve to reorientate the current human rights framing of state action on noma toward the notion of progress. As one interview participant noted, doing so will rhetorically present the governments of affected states, 'as leaders in the fight against noma and, therefore, in achieving [some of] the SDGs'.[105]

5. Conclusion: advocating for frame compatibility due to their complementarity

At the conclusion of this article, we posit that that developing the relationship between the human rights and NTD framings of noma is the way forward for advocacy and action. Noma, after all, exists at the intersections of health and nourishment, of individualised medical interventions and wider, deeply political systems. Recognising this interconnectedness in practice requires, as one interview participant remarked, stakeholders to remain attentive to the fact that, for noma, the 'underlying problem is not medical'.[106] This is of course relatively straightforward to write: the reality of doing so is, we recognise, incredibly complex, and the first steps may have to be medical ones. Put differently, the human rights and NTD frames of noma need to find ways to become increasingly compatible because their individual success lies in their complementarity. Not only is it possible for these two overarching framings of noma to coexist, but we move to suggest that translation of this coexistence into policy and action will be necessary to the long-term advancement of the agenda. Doing so will go some way toward recognising that, as Cruz incisively observed in interview, it is no longer possible to, 'separate what is medical from the social, the economic, the cultural, and the political'.[107]

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11 This chapter is one output of a wider research project, 'Noma - The Neglected Disease: An Interdisciplinary Exploration of Its Realities, Burden, and Framing' (The Noma Project) <https://thenomaproject.org/>. The project, which ran from 2019 to 2022, received generous support through research grants and donations provided by public and private institutions. We gratefully acknowledge the Swiss Network for International Studies, Hilfsaktion Noma e.V., the Service de la Solidarité Internationale (SSI) of the Republic and Canton of Geneva, Noma-Hilfe-Schweiz and the Winds of Hope Foundation. The fieldwork reported in this paper received full ethical approval, from the University of York's Economics, Law, Management, Politics and Sociology Ethics Committee in November 2019.

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