

**Review Article** 

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# **Impact of Erroneous Belief on Timely Health Care-Seeking Practices Among Noma (Facial Gangrene) Survivors in Ethiopia**

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# Abstract

**Background:** Noma is a gangrenous disease that primarily affects young children in extremely poor regions of Africa, Asia, and Latin America. Noma has one of the highest mortality rates, estimated at 90%. Noma begins in the oral cavity and it spreads rapidly and destroys bone, muscle, and skin in the orofacial anatomy. The full onset of Noma is preventable and inexpensive to treat at its early stage. However, a significant number of Noma cases do not receive treatment until it is either too late to save their face or, more commonly, their life. With the recommendation to further investigate the beliefs and perceptions of Noma patients to understand their behavior in seeking medical care, the focus in this situation should remain on understanding the underlying causes. This study examined the main reasons Noma survivors initially had for delaying medical care and that eventually motivated them to seek it.

**Methods:** To achieve the objective of the study, a structured and scheduled qualitative interview was used. A total of 46 Noma cases from different geographic areas in Ethiopia were interviewed in March 2023 to describe the main factors that prevent them from seeking timely medical care and ultimately lead them to seek it. The study participants were asked to indicate their main reason for not seeking medical care soon enough. Then they were asked why they finally decided to pursue medical care. MAXQDA software was used to carry out the data management and analysis of the survey.

**Results:** Inaccessibility to nearby health facilities, economic constraints, lack of awareness, social stigma and isolation, unpleasant self-conscious emotion, preference for traditional healers, fatalism, and the practice of divination were mentioned by most of the Noma survivors (65.2%) participating in the survey as hindering factors in not seeking medical help early enough. On the other hand, a single factor, i.e., an erroneous spiritual belief such as the view that the disease is a curse and the related perception that the condition cannot be cured, was reported by 34.8% of the study participants as a major factor influencing their decisions. In general, erroneous spiritual belief (34.8%), the practice of divination (15.2%), and the preference for traditional healers (10.9%) were found to be the leading factors for not seeking medical care among adult Noma survivors in Ethiopia. On the other hand, the role of social workers in exploring Noma cases and referring them to health services was rated as excellent.

**Conclusion:** In order to develop appropriate education, screening, treatment, and care and support models that promote better engagement of Noma survivors, these underlying beliefs must be specifically considered. Policymakers and healthcare professionals must consider these cultural and spiritual aspects when developing culturally appropriate models of care

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and support. Ensuring cultural safety, addressing systemic barriers, and achieving technical and scientific excellence are critical to ensuring that Noma sufferers access health care and benefit from timely treatment options. In this case, the engagement of social workers would be of paramount importance. Therefore, any policy aimed at reducing the burden of disease on disadvantaged societies should consider the involvement of social workers. As such, the results of this study can provide vital insight for policymakers and health care providers involved in the delivery of Noma-related services in Ethiopia.

**Keywords:** Care-Seeking Practices; Gangrenous disease; Health care providers; Noma

## Introduction

Orofacial gangrene, known as Noma, dates back to ancient times [1,2]. Carel Baten first described Noma as a clinical entity in 1595, and Cornelis van de Voorde first used the term "Noma" to describe this orofacial gangrene in 1680, replacing the then-common term "water cancer [3]." Noma is generally understood to be a pathology that begins with a gum ulcer and destroys part of the face within a few days [4]. Since the Middle Ages, Noma has mostly been found only in "developing" countries, particularly in sub-Saharan Africa, Asia, and Latin America. Children between the ages of 2 and 6 years, who are already suffering from severe chronic malnutrition and other comorbidities, are most at risk [5]. The disease is notorious for its high mortality rate, which the WHO estimates to be between 80 and 90 percent in the acute phase [6]. Those who have survived Noma continue to suffer from aesthetic and functional after-effects that are a source of pain, disability, and stigma. Other social impacts include fear of the disease spreading and the widespread belief that Noma is the result of a spell or curse placed on the child or their family [7]. Because Noma is most prevalent in areas of high poverty, the financial burden of treatment (e.g., surgery and housing) is well beyond the financial means of households [8,9]. Recent literature has called for WHO to classify Noma as a neglected tropical disease [10]. Noma is incorrectly thought to be a disease that affects only sub-Saharan African countries [11,12]. Although Noma still occurs in Asia, the earliest descriptions of the disease suggest that it also occurs in Europe and North America [5,13]. However, recent research suggests that Noma is still alive and widespread in Asia [14]. Socioeconomic factors such as low standard of living, extreme poverty, poor sanitation and proximity to livestock, oral conditions such as poor oral hygiene and the presence of some forms of gingivitis, systemic conditions such as severe malnutrition, incapacitating diseases, malaria, tuberculosis, HIV infection or other immunosuppressive conditions (leukemia and other blood dyscrasias), and other factors such as low birth rates are all predisposing factors for Noma [15-17]. According to recent epidemiological data, between 30,000 and 40,000 people worldwide contract Noma each year, with 75% of these cases occurring in sub-Saharan Africa (the Noma belt) [18]. Although Hippocrates provided the first descriptions of Noma, the first dissertation on the disease was published in 1848, and the first Medline article appeared in 1852 [1,19], little is known about the disease, and it has only been studied in recent years [20]. Chronologically, research on Noma has been sparse, with only one article appearing in Medline in 1901 and another in the same database in 1960. It seems that the year 2000 marks the turning point. The number of published articles increased significantly from 14 in 2003 to 34 in 2020 [10]. Yet, Noma, also called cancrum oris, is a disease of extreme poverty that is widely neglected [21]. Therefore, there is still much to learn about Noma, as most patients live in remote areas and the disease often goes unreported and undiagnosed [22]. On the contrary, several researchers have focused, studied, and reported on the surgical outcomes, associated psychosocial morbidity, etiology, epidemiology, risk factors, and sequelae of Noma [4,13,14,18]. However, only a few have attempted to study and describe the perceptions of this disease from societal, economic, spiritual, infrastructure, and cultural perspectives [23,24]. For example, the lack of health facilities in neglected areas where Noma is highly prevalent has been cited as a potential problem for treating Noma cases. However, this argument is partly due to logical thinking [6,9,16]. In addition, there are a limited number of studies in the current literature that provide first-hand accounts of the reasons that prevent Noma survivors from seeking timely medical care [25]. This study was initiated to address this knowledge gap by interviewing Noma survivors in Ethiopia. Thus, the study primarily aimed to investigate the main reasons for masking Noma patients' decision not to seek medical help in a timely manner. The study also examined how they came to seek medical care, albeit late in the process. The researcher expects that the results of this study will serve as the basis for future intervention and prevention efforts.

#### **Methods**

A structured and scheduled qualitative interview was used to explore the reasons that initially prevented adult noma cases in Ethiopia from seeking medical help and that eventually motivated them to seek it. The structured questionnaire consisted of demographic data and two questions relevant to answering the research question. The demographic data obtained from their medical records retrieved in January 2023 for the purpose of a retrospective study was filled in by the researcher in February 2023. Thereafter, in March 2023, study participants were asked to confirm the accuracy of the demographic data and to answer questions designed to

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explore the reasons that initially prevented them from seeking medical care and that eventually motivated them to seek it. The interviews were taken place by telephone.

#### **Inclusion criteria**

The inclusion criteria were that the subject was a volunteer who was an adult ( $\geq 18$  years of age) and had an onset of the disease when younger than 10 years of age.

#### **Studied population**

The study participants included in this survey were recruited based on demographic and clinical data obtained from a retrospective study conducted in February 2023 by the same author [13]. The retrospective study included 182 medical records of Noma cases that were admitted to three major Noma treatment centers between 2004 and 2023 with the aim of describing the epidemiology of the condition in Ethiopia. According to the study, 88.6% (n=109) of the 123 medical records indicating the time of onset of the disease documented that the disease first appeared between the ages of 1 and 10 years; only 7.1% of the total medical records examined indicated that they had sought medical care at the same age category as the disease first appeared (i.e., between the ages of 1 and 10 years). 32.4% of them sought health care for the first time between the ages of 11 and 20 years, while 60.5% of them did seek health care for the first time between the ages of 21 and 70 years. Why do patients seek health care very late after the onset of the disease? Or what caused them to seek health care late after the onset of the disease? The present study aimed to investigate the main reasons why Noma cases in Ethiopia were compelled to seek health care long after the onset of the disease.

#### Data collection and analysis

A structured questionnaire was used to collect the needed data for analysis. MAXQDA software was used to manage and analyze the surveyed data. In the current study, 46 adult Noma cases were interviewed to disclose the main reasons that initially prevented them from seeking medical care and that eventually motivated them to seek it.

#### **Ethical consideration**

Before participating in the study, all participants gave their written informed consent. Each potential participant was provided with the necessary information about the objectives of the study, the procedures, the expected benefits and risks, and any potential embarrassment to which they might be exposed. In addition, participants were informed of their right to refuse to participate in the study or to withdraw their consent at any time without consequences. Strict confidentiality rules were observed. Interviews took place in appropriate locations where respondents could be assured that their privacy and confidentiality would be maintained. All raw data were kept confidential and accessible only to the researcher. Published results and reports related to this study cannot be used to identify specific individuals. Ethical approval was granted by the Addis Ababa Health Bureau Institutional Review Board (IRB) Ethics Committee in Ethiopia (No. A/A/H/B/2116/227).

## Findings

A total of 52 volunteer Noma cases ( $\geq$  18 years of age) with disease onset under the age of 10 years who could be reached by telephone were initially asked to participate in the current survey. However, 6 declined. Therefore, the responses

| Responses  | Interpretation                        | The number of Noma survivors responded | Proportion by<br>percent |
|--|---------------------------------------|--|--------------------------|
| I didn't dare go out in public because I had a bad face.   | Unpleasant self-conscious emotion     | 3                                      | 0.065                    |
| There was no healthcare facility nearby.   | Lack of nearby health service         | 2                                      | 0.044                    |
| I was isolated and stigmatized because of that, I couldn't get medical care.   | Social stigma and isolation           | 3                                      | 0.065                    |
| I didn't know if anything could be done about the disease by going to a health center.   | Lack of awareness                     | 3                                      | 0.065                    |
| I had no money to pay for a doctor's consultation.   | Economic constraint                   | 3                                      | 0.065                    |
| I prefer traditional healers to modern medicine.   | Preference for traditional<br>healers | 5                                      | 0.109                    |
| I constantly believed that the disease would kill me tomorrow if not today.  | Fatalism                              | 4                                      | 0.087                    |
| I believed in divination and was convinced that I could cure the disease with it.  | Practice of divination                | 7                                      | 0.152                    |
| I thought the disease was a curse from God because I had sinned,<br>so I was convinced that the condition was unmanageable for<br>humankind. | Erroneous spiritual belief            | 16                                     | 0.348                    |
| Total  | -                                     | 46                                     | 1                        |

 Table 1: Reasons indicated by Noma survivors for not seeking medical care promptly.

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and demographics of 46 Noma survivors were included in the survey analysis. The ages of the study participants ranged from 32 to 67 years. Twenty-seven of them were female, while the remaining 19 were male. Of these, 80.4% (n=37), 13% (n=6), and 6.5% (n=3) were followers of Orthodox, Muslim, and Protestant Christianity, respectively. Participants were asked to indicate the main reasons that prevented them from seeking medical help immediately after the onset of the disease and that eventually led them to seek it, albeit too late. Accordingly, the study identified 10 factors influencing Noma survivors' decision to seek timely medical care. The factors are related to the economic, social, psychological, and spiritual aspects of Noma survivors. In general, it was found that erroneous spiritual beliefs (34.8%), involvement in divination (15.2%), and preference for traditional healers (10.9%) were the three main reasons why Noma cases did not seek medical help (Table 1). Of the total 28 Noma survivors who reported the above three factors as reasons for not seeking medical care, 89.3% (14 in the misbelief category, 7 in the group that practiced divination, and 4 in the group that preferred traditional healers) were followers of Orthodox Christianity, while the rest were Muslims.

On the other hand, a significant majority of study participants (84.8%) described the influence of social workers as a driving force for seeking medical care long after the onset of the disease. They reported that social workers recruited, educated, and convinced them to seek medical care. Although delayed, calls from local radio and television media (n=4) and recommendations from patients (word of mouth) who had already received treatment (n=3) were cited as other factors in seeking medical help.

## Discussion

Patients' beliefs have been reported to influence how they use various healthcare services; the case of Noma is no different [26]. Noma, a Latinized version of a typical Greek word, is a metaphor for the ongoing process of a forest fire [2]. This metaphor has conceptual similarities to the rapid progression of the disease with the Hausa word ciwon iska, which is an indigenous Hausa term for Noma in West and Central Africa [27]. Although cases of Noma were documented over a thousand years ago, we still do not know much about it in the twenty-first century. The name Noma is derived from the Greek word "nomē," which means "to devour." [1]. Noma primarily affects children under the age of 10 in areas of extreme poverty, such as parts of Africa and Asia, but researchers are not sure why children are particularly at risk [9,20]. Srour contends that Noma is a biological indicator of extreme poverty. In most cases, these children are born in places where neither their birth nor death has ever been officially recorded [15]. The last estimate by the World Health Organization (WHO) was in 1998: 140,000 new cases per year [11]. Nothing has changed since then.

However, it is undeniable that Noma is deadly; according to the WHO, 90% of patients die without receiving treatment [5].

In the early stages, Noma can be successfully treated with common, readily available antibiotics. Accordingly, patients can be easily treated in any basic healthcare system with knowledge of Noma [28]. The problem is that Noma occurs in areas that do not have access to this basic care. The hospitals that can diagnose and treat Noma are often far away for patients in remote communities. Sometimes they don't even exist [23]. Unfortunately, by the time parents realize that their infected child needs medical attention, it may already be too late [23]. Few patients actually receive timely treatment. Of course, it is possible to save the lives of these patients if they are treated quickly with common antibiotics that are available everywhere [29]. The few Noma cases who survive are left with this dysfunction and disfigurement. They may have great difficulty speaking, breathing, and eating [13]. Those who survive usually need multiple surgeries to restore the bones and tissues in their face [29-32]. But not all Noma survivors get medical help, or they don't get it fast enough for various reasons [33,34]. The results of the current study, which analyzed responses from 46 adult Noma cases, revealed 10 different reasons. Accordingly, the most commonly reported reasons for waiting too long to seek medical care among the Noma survivors in Ethiopia were erroneous spiritual beliefs, such as misperception of the cause of illness, e.g., a curse, and the practice of divination. This perception is similar to patients' understanding of the disease among Noma survivors in Burkina Faso [25]. Noma cases involved in this study said: "We felt helpless, we didn't understand. We don't know anything about this disease, we didn't receive any information about it. We felt that it was simply down to God."

The general feeling of helplessness (fatalism) and pessimism about Noma as a "killer" were other reasons for reluctance to seek medical help. Some believed that they would die of the disease tomorrow if not today. A study by Kagoné et al. [25] reported the Noma patients' societal, psychological, and spiritual experiences associated with the disease.

Other factors that led to delaying the attempt to seek medical treatment for too long were stigmatization, isolation, shame associated with a disfigured face, financial constraints, difficulty in accessing medical facilities, and preference for traditional healers. The findings of this study are consistent with the social constructivist approach [35], which describes how cultural factors, spiritual beliefs, social interactions, and relationships influence beliefs and understandings of an illness, which in turn impact the use of medical care. The findings of the study by Kagoné et al. [25] also revealed that most Noma patients experience discrimination and stigma

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in Burkina Faso. Noma survivors were pointed at, mocked, and insulted by friends and even by the family members who are supposed to protect them. For example, one study participant who was involved in their study was reported to say the following: "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." Similarly, another Noma case said: "I have found it tough because since my nose split, even being allowed to be among other people has been impossible. [...] Even within my own family, if there is a gathering of family members, I wouldn't take part." On the other hand, this study found that the role of social workers in recruitment, health education, and convincing Noma cases to seek healthcare facilities was remarkable. Some 84.8% of the Noma cases who participated in the current study were eventually able to seek health care thanks to the great efforts of social workers (community health). Similarly, several research papers have shown the significant role of social workers (Community Health) in disease prevention and control programs [36,37]. In general, the current study provides information directly from the source (the horses' mouths). It is therefore critical for reducing the pervasiveness of misperceptions of spirituality and other socio-cultural challenges while improving economic, educational, and health systems in underserved areas where Noma is prevalent.

## Conclusions

Analysis of this study revealed a variety of erroneous spiritual and cultural beliefs among adult Noma patients in Ethiopia. These were found to impact patient healthseeking behaviors, which could have important implications for Noma case outcomes. Therefore, it is not only essential to improve the level of poverty and the overall healthcare system in the country in the long term but also it is critical to develop and implement community awareness programs as early as possible to convince Noma patients to seek medical help as early as possible. Furthermore, in Noma cases where misguided spiritual and cultural beliefs prevail, it is vital to provide holistic, psychosocial care in addition to medical and surgical interventions. On the other hand, the crucial role of social workers (community health) in improving the health and well-being of Noma cases, and thus of families and communities living in neglected areas, should be recognized and taken into account when designing disease control interventions at the national and international levels.

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Volume 5 • Issue 2 | 231

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