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Influencing Factors for Social Acceptance of Noma (Cancrum Oris) Patients in Niger: A Hospital-Based Cross-Sectional Study

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Abstract

Background: Noma, mostly identified in malnourished young children in the world's low-income countries, causes severe orofacial disfigurement and significant mortality and morbidity. The majority of noma patients surviving with aesthetical effects are exposed to stigmatization and social rejection. Studies focusing on the socio-psychological impact of noma survivors have rarely been done. Our study aimed to identify the differences in social acceptance/rejection and the influencing factors associated with social acceptance in noma patients. **Methods:** A cross-sectional study was conducted at the NGO-Sentinelles (Niger) reception center on patients with noma from Zinder, Maradi, and Tahoua regions between 9th May 2017 and 2nd June 2017. The survey was conducted through a face-to-face interview on patients admitted to the center and those discharged from the centre after the treatment. The interview questionnaire comprised 45 questions (Cronbach's alpha coefficient = 0.812) with pathological information, sociodemographic characteristics, and socio-psychological qualitative information. **Findings:** We recorded 50 noma patients (43 from Zinder and 7 from Maradi and Tahoua). The younger patients (1 - 5 years old), noma patients who stayed in school during follow-up treatment, patients who were referred by a health structure, patients enrolled into the centre in a short time (<30 days), and patients in the acute phase of noma had a significantly high social acceptance rate with 60.0%, 82.9%, 60.0%, 57.1% and 94.3% respectively; whereas single adults and cheek

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lesion site had the highest social rejection rate when compared to their corresponding factors with 60.0% and 86.7% respectively. There were significant differences in victims' perception of noma [χ^2 = 45.536, (P < 0.001)] and acceptance of their new faces [P = 0.023], between the social acceptance and social rejection rate, therefore all patients who accepted their new faces felt social acceptance. Social acceptance was significantly highly correlated with pathological history (admission method, phase of noma, care, and treatment received at center) with r_s ranging from 0.609 to 0.810, moderately correlated with patient's sociodemographic characteristics (age, marital status, and region) with r_s ranging from 0.381 to 0.474. Lowly correlated with clinical evolution after treatment (r_s = 0.293). Logistic regression results showed that the likelihood of social acceptance increased when the patient's age was young (≤15 years), their marital status was minor, they were enrolled at the school before noma appearance, they were referred to the centre after diagnosis, the admission time to the centre was short (≤30 days), acute phase of noma, and care received at the centre was non-surgery. The location of the lesion on the cheek was a risk factor for social acceptance, indicating cheek lesions from noma increased the likelihood of social rejection in our study. **Conclusion:** The sociodemographic characteristics, pathological history, and psychological aspects of noma patients were correlated and were found to be important factors influencing their social acceptance/rejection rate.

Keywords

Noma, After-Effects, Socio-Psychological Factors, Social Acceptance/Rejection, Social Reintegration

1. Introduction

Noma, commonly known as cancrum oris, is a gangrenous stomatitis that causes severe end-destruction of the face and is associated with significant mortality and morbidity [1]. World Health Organization has estimated 770,000 people living with noma [2]. The global incidence rate of noma has been estimated to 140,000 new cases yearly, with a mortality rate as high as 90% [3] [4] [5] [6]. Noma mostly affects young children (between 1 and 6 years old) in low-income countries, especially in the most impoverished remote areas, where birth and death records are unavailable [3] [7]. Only 15% of children survive the acute phase of noma, and its disease burden is calculated to be a loss of 1 - 10 million [4] [5] [8].

Noma cases have recently been reported in China, the United Kingdom, the United States, Afghanistan, and Laos [5] [9] [10] [11] [12]. Most noma prevalence has been reported in sub-Saharan Africa, in the so-called "noma belt", a region from Senegal to Ethiopia, including central Africa, such as Niger and Nigeria [3] [13] [14]. From the results of a systematic review, at least 23 countries with noma cases were identified, with most of the cases in the noma belt coun-

tries in West Africa [13]. In Niger, the prevalence of noma was 1.34% for children aged 1 - 6 [15], with the annual incidence rate estimated at 7 - 14 cases per 10,000 children aged 0 - 6 years [5], which was higher than the incidence of the whole sub-Saharan region (5.1 per 100,000) [16].

Treating noma at an acute phase of its progression mainly improves the patient's general condition and quality of life. However, treatment of noma sometimes becomes a problem because both traditional healers and primary healthcare workers fail to recognize it on time, resulting in thousands of children dying or surviving at the cost of functional sequelae and aesthetical defects [17] [18]. Majority of the survivors present with facial deformities and trismus or ankylosis of the mandible, ensuing in eating problems, oral incontinence, teeth loss or displacement, speech difficulties, fetid breath or halitosis as well as social isolation, which are also contributors to their stigmatization [1] [3] [18]. Overall, the literature showed the progress made in knowledge and prevention of the disease but also highlights two major gaps that identified a lack of accurate and up-to-date epidemiological data on noma and a lack of understanding of the experiences of persons at risk and survivors of noma. Regarding this latter point, although the stigma and discrimination experienced by survivors of noma are recognized as having an enormous burden on the survivors themselves and their communities, there is little or no knowledge of the experiences of survivors and communities. Due to this stigmatization, these survivors often cannot attend schools, socialize, marry, or find employment [19]. They face social rejection from the surrounding population, community, and society, hence finding it difficult to be accepted back into society. It is therefore important for these survivors to, at all costs, find a common way of social life and be reintegrated into society in order to be able to forget the nightmares they previously experienced.

The psychological impact of surviving noma can be easily understood, but it has rarely been studied [20]. Most studies on noma disease/patients focused on the epidemiology, pathogenesis, etiological aspect or microbiology and treatment [10] [13] [14]. There is no report to clarify the differences in social acceptance/rejection in noma patients. The influencing factors associated with social acceptance/rejection in noma patients are also still unclear. Very often, noma survivors face discrimination and stigma in the communities. This study highlighted a lack of information and knowledge about noma and factors impacting the acceptance of these patients in society, even in populations that are already facing this disease. However, medical treatment, surgical operations, and reintegration lead to patient satisfaction, and these remain one of the coping strategies used to tackle stigma and discrimination. The outcomes set out in this article are aimed firstly at stepping up research into the psychosocial impacts of noma and secondly at considering these impacts in world programs plans against the disease. Therefore, in this study, we aimed to identify the differences in social acceptance/rejection from sociodemographic characteristics, pathological history, and psychological aspects of noma patients. Further, we explored the influencing factors related to social acceptance in noma patients.

2. Methods

2.1. Participants and Settings

The study was conducted at the non-government organization (NGO)-Sentinelles reception centre located in Zinder city, where generally all noma patients, from the whole country are referred for individualized, free, and qualified follow-up. The recruitment areas of patients were the Zinder region and rural parts of the Maradi and Tahoua regions (Figure 1). These three regions of the country represent the high incidence and prevalence area. However, the limitation of the research framework did not influence the selected sample and its representativeness. The victims already treated and released from the center outside these three regions were excluded. The Sentinelles reception centre was established in 1992 in Niger and was the first and largest non-government organization of care, social monitoring, and support in humanitarian aid, documentary making, and awareness in the fight against noma. The NGO-Sentinelles reception center receives noma patients, offers medical care, plans an international plastic surgery campaign, does the medical follow-up after surgery, and installs the reintegration program for noma patients.

The sample size was estimated by the total number of patients present at the centre, added to the number of patients visited by the Sentinelles teams at their own localities for follow-up and social reintegration during the research period. Finally, a period of 30 days was estimated to cover almost all victims in our study area. This research time is relative to the time needed for the program to survey patients at the centre and make home visits to the entire study population.

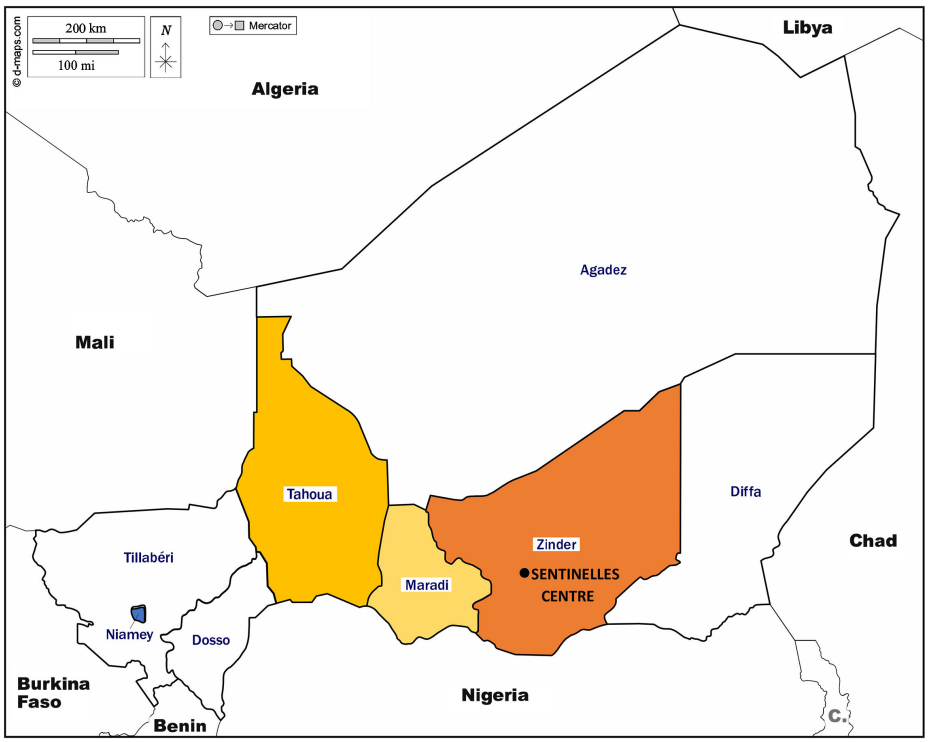

Figure 1. Map of Niger showing the 3 study regions.

All cases who have suffered from noma, with an acute phase or a sequelae phase of noma, that have been recorded and admitted by the NGO-Sentinelles for medical and/or surgical treatment in the centre of Zinder and the victims who underwent the Sentinelles foundation treatment but returned home and still in the program of follow-up for social reintegration were included in this study. The study also included opinions from family or entourages comprising representatives of public authorities, neighbors, teachers, or healthcare professionals who have an idea about the disease and its consequences.

The victims located outside the study location area, who or their guardians did not agree to attend the study or whose entourages ignored the noma disease history, and who were not in the visit program of our study period were excluded from our research. The victims treated and released from the Sentinelles foundation program were also excluded. Since noma and orofacial cleft may share some similarities in clinical presentation, and both are in the Sentinelles foundation program, cases of the latter were excluded based on the research topic. In the end, 50 noma patients were enrolled in our study.

2.2. Data Collection

We conducted a cross-sectional study from 9th May 2017 to 2nd June 2017 in NGO-Sentinelles reception centre, where we met all patients currently admitted to the center and underwent the care process. The research team also did a daily home visit of patients who returned and lived with their families in the urban and rural locations of Zinder region and some parts of the rural area of Maradi and Tahoua regions during the study period for an extensive coverage of the study sample (**Figure 1**). In order to achieve a total sample size, the research team solicited and was given the time necessary to cover the total number of patients being followed at the time of the research. This was a qualitative study in the form of semi-structured interviews. The interview guide was developed in conjunction with the team members of the research. It was then tested and adjusted through pilot interviews with Sentinelles members before the start of data collection. The focus group members were composed of patients with acute noma. The ones who survived-acute phase (noma survivors), victims of noma sequelae, the socio-medical assistants of the Sentinelles centre, and members of the victim's household (parents/gardens/teachers…) whose viewpoints were very important for participants severely sick or suffering from speech problems; usually young children, animators, and research authors. Participants' pathological information was obtained from stored records and documents of patients in the centre. The sociodemographic characteristics and socio-psychological qualitative information were obtained using a self-made dedicated questionnaire designed for the study comprising 45 questions (Cronbach's alpha coefficient = 0.812). If the participants could answer the questions independently, we got the answers directly by interview; otherwise, we got the answers from parents or entourages, especially for children less than 6 years old.

A focus group discussion was created with concerned members:

- Patients who have been victims of noma disease, admitted and treated by the NGO Sentinelles against the disease, some of them have done surgery and/or follow up after surgery.
- The socio-medical assistants of the centre specialize in anthropology with a background in social sciences and public health, come from the same area, have years of professional experience in the field, and speak the local language (Hausa).
- Members of the victim's household (parents or guardians), opinion entourages, and leaders who had an idea about the disease and its consequences were later selected on rational grounds rather than on a random basis due to their role and influence on the victim or community.
- And research authors.

A semi-structured interview guide was used for each type of participant. The interviews were conducted in Hausa language and French. The length of the interviews was between 45 and 60 minutes.

The key informant interviews were conducted in a setting that minimizes the researcher's influence and encourages the interviewee to discuss noma disease and their role in the project.

During a focus group, a measuring instrument with a scale of five levels ranging from non-satisfaction to full satisfaction was established to assess each participant's psychometric satisfaction level. This evaluation allowed us to rank three types of satisfaction (victims not socially reintegrated, victims in the process of reintegration, and victims socially reintegrated).

Content of the interview:

Firstly, we;

- Thanked the participants for agreeing to participate in this research and introduced all the participants.
- Created a relaxed atmosphere; offered the participants something to drink.
- Made sure the group participants have been informed about the study and consented to participate.

Finally, we get into the main topic

- We told the group "*I* (*We*) *would like to talk to you about your experience in noma disease as victims*', *your knowledge about this disease*, *and the impact it has had on your social and professional or student life*. *We would like to hear your stories*, *what you think about the disease*, *what works well for treatment and the challenges you face*, *and your real feelings on different points of our survey questionnaire*? *This discussion will contribute to a better understanding of how people living with noma experience the disease*. *The interview will take approximately 45 - 60 minutes*, *and anyone in the group can decide to leave if they no longer want to contribute at any time without any consequences*."

NOTE: Fill in the questionnaire survey sheet step by step after taking a photo of the after-effects of noma on the patient, followed by a family photo to relax the atmosphere.

2.3. Study Variables

The patient's sociodemographic characteristics, such as sex, age, marital status, education level, region, community type, ethnicity, nutritional status, oral hygiene, and school aspect were obtained through our questionnaire. Nutritional status had two categories: normal and abnormal; where we defined a child with a body mass index (BMI) ≥ 18 without a sign of kwashiorkor or doldrums as normal and a child with a BMI < 18 with the sign of kwashiorkor or doldrums as abnormal. For children under 4 years of age, the measurement of the mid-upper arm circumference (MUAC) and the cranial perimeter (head circumference) was used. The ratio MUAC/head circumference ≥ 0.31 reflected a normal nutritional condition, and the ratio < 0.31 indicated an abnormal nutritional condition. Oral hygiene has three categories. In our study, we defined clean teeth, pink and healthy gums without halitosis, bleeding and bad breath as good oral hygiene; clean teeth, affected gums with or without halitosis, bleeding and bad breath as passable oral hygiene and unclean teeth; affected gum with halitosis, bleeding and bad breath as bad oral hygiene. The participants' pathological information, such as admission mode and time, phase of noma, location of the lesion, care and treatment received at the center, and clinical evolution after treatment, were retrieved from the medical records of the centre. Socio-psychological aspects include entourages' perception (Ignorance or Superstition/Spell/Curse), victims' perception (Acceptance or Guilt/Isolation or Feeling of social rejection), other discriminations to survivors (Yes or No), acceptance of the new face of victims (Yes or No) and the impact of noma on the victims in the community (social acceptance or social rejection) were obtained using our open-ended questionnaire through the interview. During a focus group, a measuring instrument with a scale of five levels ranging from non-satisfaction to full satisfaction was established to assess the level of psychometric satisfaction of each participant; this evaluation allowed us to rank three types of satisfaction (victims not socially reintegrated, the victim in the process of reintegration and victims socially reintegrated). The theoretical and operational definition of each variable, including the detail of the questionnaire, score interpretation, and psychometric property, was set up. In this study, we defined the impact of noma on the victims in the community as our dependent variable.

2.4. Statistical Analysis

Data obtained from the study were analyzed using Statistical Package for Social Sciences (SPSS) version 23.0 (IBM Corp Armonk, NY, USA). Descriptive statistics such as frequencies were explored for categorical variables as appropriate. Differences between categorical variables were determined using the Chi-square

test or Fisher's exact test when the expected values were less than 1. The relationships between categorical variables were determined using the Spearman correlation test. Univariate analysis with Logistic regression was conducted to identify factors associated with the dependent variable (social acceptance or social rejection) on the total study sample, where the number of noma cases was too small to allow for multivariable analysis. The variables were described using odds ratio (OR) and 95% confidence interval (CI). All of the statistics were 2-tailed tests, and the significance value of all statistical tests was set as 5% (α = 0.05). A P-value of ≤0.05 was considered statistically significant.

3. Results

The results of the impacts of noma on the patients in the community (social acceptance/rejection) based on sociodemographic characteristics are shown in Table 1. Fifty patients who had noma (with or without complications of the disease) were recorded from the NGO-Sentinelles reception center during our research period. Forty-three were located in Zinder region, with 11 cases admitted in the healthcare department of the center and 7 patients in Maradi and Tahoua rural areas. We were unable to reach more villages where we may find more noma patient cases that were eligible for inclusion in the study due to logistical reasons and research time limitations. The respondents for the age range 1 - 5 years were mostly the children's mothers. All the patients interviewed had a clear history of the disease and were recorded by the agents of the NGO-Sentinelles. The ages of the patients range from 18 months to 42 years with a mean of 3 year, and majority of them, 24 (48.0%) were aged 1 - 5 years, and 33 (64.0%) were females. Acceptance can be defined by the simple fact that the disease has had no impact on the victim's social life within the community, and rejection can be summarized by a situation leading to socio-psychological suffering through acts or words such as being pointed at, mocked, insulted, and often repudiated by the community, friends, and even family members who are supposed to protect them in addition to the physical suffering caused by the sequelae of the disease. There were no significant differences in matching variables (sex, education level, community type, ethnicity, nutritional status, and oral hygiene) between the rate of social acceptance and social rejection in noma patients. There was a significant difference in age groups between social acceptance and social rejection rates in noma patients. Patients with larger age (>15) had the lowest social acceptance rate (8.6%) when compared to all other age groups. The results indicated that the younger the noma patients, the higher their social acceptance rate is (Table 1). Compared to other marital statuses, minor patients had the highest rate of social acceptance (85.7%), and single adults had the highest social rejection (60.0%). The Zinder area has a maximum rate of social acceptance (97.1%) as compared to other areas in our survey. Noma patients who enrolled in school after the noma diagnosis and have been in a follow-up program had a higher social acceptance rate (82.9%) than those who enrolled before the noma diagnosis, and the ones did not been under a follow-up program (Table 1).

Table 1. The impacts of noma on the victims in the community (social acceptance/rejection) based on sociodemographic characteristics (n, %).

Variables of all patients	Social acceptance	Social rejection	χ^2	P-value
Sex				
Male	14 (40.0)	4 (26.7)	0.810	0.368
Female	21 (60.0)	11 (73.3)		
Age group (in years)				
1 - 5	21 (60.0)	3 (20.0)	7.282	0.026
6 - 15	11 (31.4)	8 (53.3)		
>15	3 (8.6)	4 (26.7)		
Marital status				
Minor	30 (85.7)	5 (33.3)	15.703	<0.001
Single adult	3 (8.6)	9 (60.0)		
Married adult	2 (5.7)	1 (6.7)		
Education level				
None	14 (40.0)	3 (20.0)	2.256	0.324
Primary	16 (45.7)	8 (53.3)		
Secondary and high school	5 (14.3)	4 (26.7)		
Region				
Zinder	34 (97.1)	9 (60.0)	9.144$^{\Delta}$	0.001
Maradi and Tahoua	1 (2.9)	6 (40.0)		
Community type				
Rural community	20 (57.1)	11 (73.3)	1.168	0.280
Urban community	15 (42.9)	4 (26.7)		
Ethnicity				
Haoussa	29 (82.9)	10 (66.7)	0.799$^{\Delta}$	0.371
Others	6 (17.10)	5 (33.3)		
Nutritional status				
Normal	32 (91.4)	14 (93.3)	0.052	0.820
Abnormal	3 (8.6)	1 (6.7)		
Oral hygiene				
Good	16 (45.7)	10 (66.7)	3.500	0.174
Passable	13 (37.1)	5 (33.3)		
Bad	6 (17.1)	0 (0.0)		

Continued

School aspect				
Enrolled in school before noma diagnosis	6 (17.1)	3 (20.0)	16.803	<0.001
Enrolled in school after noma sequelae	0 (0.0)	6 (40.0)		
Enrolled in school after noma during noma follow-up treatment	29 (82.9)	6 (40.0)		

[Δ]Continuity correction of Chi-square.

The results of the impacts of noma on the patients in the community (social acceptance/rejection) based on pathological history are shown in Table 2. The analysis found no significant differences in social acceptance and rejection rates between the two clinical evolutions after treatment (Table 2). As expected, there were significant differences in matching variables such as the admission mode and time to the centre, phase of noma, location of the lesions, as well as care and treatment received at the centre between the social acceptance and social rejection rate. A health structure referred 24 patients (48.0%) to the centre after noma diagnosis, 16 (32.0%) patients came to the centre by themselves, 10 (20.0%) patients were transferred to the centre by Sentinelles agents. Compared to other admission methods, patients who were referred by a health structure had the highest rate of social acceptance (60.0%). Only 7 (14.0%) patients went to the centre after 1 year of developing the disease, and 22 (44.0%) patients went to the centre within one month. The result indicated that the shorter the time of the patients enrolled in the centre, the higher the rate of social acceptance they felt. In this study, 35 (70.0%) patients were in the acute phase of noma as compared to the sequelae phase, and they had a significantly higher social acceptance rate (94.3%). There were 26 (52.0%), 9 (18.0%), 5 (10.0%), and 10 (20.0%) patients who had cheek, lip, chin, and eyelid/nose lesions, respectively. Among all lesion sites, cheek lesions had a significantly higher social rejection rate (86.7%). Of the 15 cases that developed noma sequelae, one patient with fresh lesions located to the cheek, lips, and chin was interviewed at the centre (Figure 2). At the center, only 8 (16.0%) patients took surgical care. The patients who had surgical care had the lowest social acceptance rate (2.9%) in our survey. Here, we presented four patients who had recently received surgical treatment and were in the process of returning to live in their homes/communities (Figure 3).

The results of the impact of noma on the patients in the community (social acceptance/rejection) based on socio-psychological aspects are shown in Table 3. There were no significant differences in entourages' perception of noma and other discrimination against victims between social acceptance and social rejection rates (Table 3). There were significant differences in victims' perception of noma and acceptance of new faces between the social acceptance and social rejection rates (Table 3). Thirty-eight entourages (76.0%) had no knowledge about noma, and 12 (24.0%) entourages thought noma was a spell or a curse to patients. All patients who accepted their new faces felt social acceptance (Table 3).

Table 2. The impacts of noma on the victims in the community (social acceptance/rejection) based on pathological history.

Variables of noma patients	Social acceptance	Social rejection	χ^2	P-value
Admission mode				
Referred by a health structure after diagnosis	21 (60.0)	3 (20.0)	14.470	0.002
Come to the center by themselves	10 (27.6)	6 (40.0)		
Identified and transferred to the center by Sentinelles agents	4 (11.4)	6 (40.0)		
Admission time (in days)				
10 - 30	20 (57.1)	2 (13.3)	15.038	0.002
31 - 90	12 (34.3)	6 (40.0)		
91 - 365	2 (5.7)	1 (6.7)		
>365	1 (2.9)	6 (40.0)		
Phase of Noma				
Acute phase	**33 (94.3)**	**2 (13.3)**	**29.025$^{\Delta}$**	**< 0.001**
Sequelae phase	**2 (5.7)**	**13 (86.7)**		
Location of lesion				
Cheek	13 (37.1)	13 (86.7)	11.005	0.012
Lip	8 (22.9)	1 (6.7)		
Chin	4 (11.4)	1 (6.7)		
Eyelid and nose	10 (28.6)	0 (0.0)		
Care and treatment received at the center				
Nutritional corrections	18 (51.4)	2 (13.3)	27.738	< 0.001
Oral/nursing care	13 (37.1)	0 (0.0)		
Medicated care	3 (8.6)	6 (40.0)		
Surgery	1 (2.9)	7 (46.7)		
Clinical evolution after treatment				
Healing without sequelae	34 (97.1)	12 (80.0)	2.187$^{\Delta}$	0.139
Healing with minor or major sequelae	1 (2.9)	3 (20.0)		

$^{\Delta}$Continuity correction of Chi-square test.

Table 3. The impacts of noma on the victims in the community (social acceptance/rejection) based on socio-psychological aspects (n, %).

Variables	Social acceptance	Social rejection	χ^2 (P-value)
Entourages' perception of noma			
Ignorance	25 (71.4)	13 (86.7)	1.337
Superstition/Spell/Curse	10 (28.6)	2 (13.3)	(0.248)

Continued

Victims' perception of noma			
Acceptance	26 (74.3)	0 (0.0)	45.536
Guilt/isolation	8 (22.9)	0 (0.0)	(<0.001)
Feeling of social rejection	1 (2.9)	15 (100.0)	
Other discrimination to victims			
Yes	15 (42.9)	8 (53.3)	0.464
No	20 (57.1)	7 (46.7)	(0.496)
Acceptance of new face			
Yes	35 (100.0)	12 (80.0)	
No	0 (0.0)	3 (20.0)	(0.023)$^{\Delta}$

$^{\Delta}$Fisher' s exact Test.

Figure 2. An example of noma lesions. A 13-year-old-boy from a small village located about 670 kilometers from Zinder, presented a more advanced noma stage showing a well-defined loss of cutaneomyomucous substance of the lower and upper left hemi-lips, left the commissural region and left cheek with loss and exhibition of teeth leaving a hole.

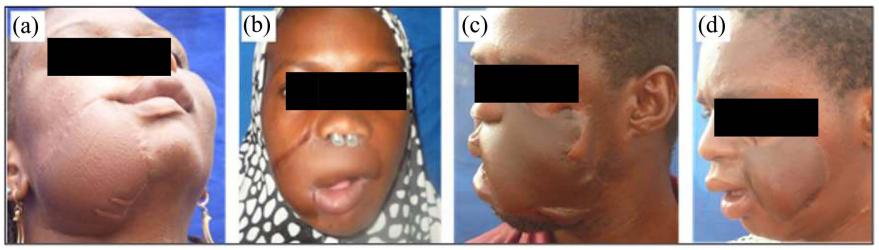

Figure 3. Examples of noma victims after plastic reconstruction surgery by micro anastomosis free flap. (a) 31-year-old-woman living in koukouzouk village, to Poyé-Dabagui (Bouza) located about 480 kilometers from Zinder, who did reconstruction surgery after the loss of cutaneomyomucous substance of the right cheek, a lower right hemi-lips and right commissural region. (b) 26-year-old-girl living in karakara/Commune rural of Alla-Kayi (Bouza) located about 500 kilometers from Zinder, who did reconstruction surgery after the loss of cutaneomyomucous substance of the upper lip, right commissural region, and right cheek. (c) 31-year-old-man living in the noma center of the capital city (Niamey), located about 900 kilometers from Zinder, who did reconstruction surgery after the loss of cutaneomyomucous substance of the upper and lower left hemi-lips, left the commissural region and left cheek. (d) 20-year-old girl living in Guidan-Baroau (Malbaza), located about 460 kilometers, did reconstruction surgery after the loss of cutaneomyomucous substance in her left cheek.

The results of the correlation among sociodemographic characteristics, pathological history, and socio-psychological aspects in noma patients are shown in Table 4. Socio-psychological aspects included 5 parts: entourages' perception of the noma, victims' perception of noma, other discriminations to victims, acceptance of the new face of victims, and impact of noma on the victims in the community (social acceptance or social rejection). From the results, we found that the entourages' perception of noma and other discriminations to victims had no significant correlation with all sociodemographic characteristics and pathological history in noma patients; however, they were highly related to each other with the absolute value of correlation coefficient 0.515. The two socio-psychological aspects (victims' perception of noma and social acceptance/rejection) were significantly moderately correlated with the patient's sociodemographic characteristics (age group, marital status, and region), ranging from rs 0.381 to 0.474. In addition, they were highly correlated with pathological history such as admission method, phase of noma, care, and treatment received at the center, with r_s ranging from 0.589 to 0.810, moderately correlated with the location of the lesion (r_s = 0.490 and 0.443, respectively), and lowly correlated with clinical evolution after treatment. Social acceptance was lowly correlated with patient's school aspect (r_s = −0.298). Acceptance of new faces was lowly correlated with the marital status of noma patients, admission method, phase of noma, and care and treatment received at the center (Table 4). The correlation between victims' perception of noma and the impact of disease on the victim (social acceptance/rejection) was high (0.850). The correlation between acceptance of the new face of patient and social acceptance/rejection was medium (0.386) (Table 4). The results indicated that the more chance the patients accepted their new face, the more likely they got social acceptance. Here we reported a successful example of one noma victim. She left school after being discriminated against by the school community because of her horrible destruction of facial tissues (Figure 4(a)). After receiving treatment in Switzerland (Figure 4(b) and Figure 4(c)), she was delighted with her new face, decided to return to school, and realized her dream of becoming a nurse. In 2017 she was in high school nursing (Figure 4(d)).

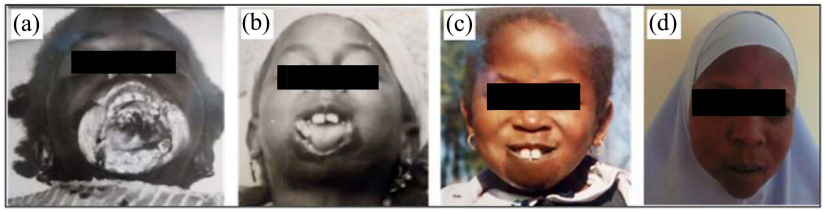

Figure 4. A young girl living in Danou, a village about 140 kilometers from Zinder. (a) Presented a gangrenous tissue with loss of cutaneomyomucous substances affecting the whole lower lips, the two commissural regions, and the left cheek with loss of tissue and tooth, leaving a hole with mandible exhibition. (b) Results of the first surgeries. (c) After several surgeries, results of the last surgery in Switzerland with Lausanne Sentinelles healthcare workers. (d) Picture of victim in May 2017 (28 years old in 2018), and was working towards becoming a nurse in Zinder city.

Table 4. The correlation among sociodemographic characteristics, pathological history, and socio-psychological aspects in noma patients (r_s, P-value, n = 50).

	Entourages' perception of noma	Victims' perception of noma	Other discrimination against victims	Acceptance of new face	Social acceptance/rejection
Sex	0.129 (0.373)	0.064 (0.661)	−0.023 (0.872)	0.014 (0.923)	0.127 (0.378)
Age group	−0.004 (0.980)	0.406 (0.003)	−0.099 (0.494)	0.246 (0.085)	0.381 (0.006)
Marital status	−0.049 (0.738)	0.440 (0.001)	−0.106 (0.465)	0.349 (0.013)	0.490 (<0.001)
Education level	0.122 (0.400)	0.251 (0.079)	−0.224 (0.118)	−0.054 (0.710)	0.220 (0.124)
Region	0.199 (0.165)	0.464 (0.001)	−0.215 (0.135)	0.131 (0.365)	0.474 (0.001)
Community type	0.139 (0.336)	−0.246 (0.086)	−0.104 (0.472)	−0.198 (0.169)	−0.153 (0.289)
Ethnicity	0.054 (0.709)	0.161 (0.263)	0.094 (0.514)	0.061 (0.675)	0.157 (0.275)
Nutritional status	0.007 (0.962)	0.084 (0.560)	0.124 (0.390)	−0.075 (0.607)	−0.032 (0.824)
Oral hygiene	0.281 (0.048)	−0.149 (0.303)	−0.074 (0.609)	0.052 (0.721)	−0.235 (0.100)
School aspect	−0.111 (0.444)	0.237 (0.097)	−0.174 (0.226)	0.181 (0.208)	0.298 (0.035)
Admission method	−0.007 (0.962)	0.631 (<0.001)	−0.118 (0.416)	0.346 (0.014)	0.628 (<0.001)
Phase of noma	−0.061 (0.672)	0.713 (<0.001)	−0.184 (0.201)	0.386 (0.006)	0.810 (<0.001)
Location of lesion	−0.128 (0.374)	−0.490 (<0.001)	0.130 (0.369)	−0.228 (0.111)	−0.443 (0.001)
Care received at the center	0.073 (0.614)	0.589 (<0.001)	−0.128 (0.374)	0.334 (0.018)	0.609 (<0.001)
Clinical evolution after management	0.003 (0.981)	0.317 (0.025)	−0.163 (0.259)	0.230 (0.109)	0.293 (0.039)
Entourages' perception of noma	-	−0.125 (0.386)	−0.515 (<0.001)	−0.142 (0.325)	−0.164 (0.257)
Victims' perception of noma	−0.125 (0.386)	-	−0.074 (0.612)	0.328 (0.020)	0.850 (<0.001)
Other discrimination against victims	−0.515 (<0.001)	−0.074 (0.612)	-	−0.105 (0.469)	−0.096 (0.506)
Acceptance of new face	−0.142 (0.325)	0.328 (0.020)	−0.105 (0.469)	-	0.386 (0.006)
Social acceptance/rejection	−0.164 (0.257)	0.850 (<0.001)	−0.096 (0.506)	0.386 (0.006)	-

The results of influencing factors of social acceptance are shown in Table 5. All categories of sociodemographic characteristics and pathological history variables were organized as 2 different parts. Age group was divided as ≤15 and >15, marital status was divided as minor and adult (including single and married adults), educational level was divided as no and yes (including primary, secondary, and high school education), oral hygiene was divided as good and not-good (including passable and bad oral hygiene). The school aspect was divided as before noma and after noma (including enrolled school after noma sequelae or noma follow-up treatment). The admission mode was divided as referred by health structure and others (including coming to the center by himself or transfer by Sentinelles agents), admission time was divided as ≤30 days and >30 days, location of the lesion was divided as cheek and others (including lip, chin, eyelid, and nose lesion), and care and treatment received at the center

Table 5. The results of influence factors of social acceptance in noma patients.

Variables	B	S. E.	Wals	df	P	OR	95% CI of OR
Sex (Male *vs* Female)	0.606	0.678	0.799	1	0.371	1.833	0.485 - 6.927
Age group (≤15 *vs* >15)	1.627	0.773	4.438	1	0.035	5.091	1.120 - 23.142
Marital status (Minor *vs* Adult)	2.485	0.730	11.578	1	0.001	12.000	2.868 - 50.212
Education level (No *vs* Yes)	0.894	0.737	1.471	1	0.225	2.444	0.576 - 10.365
Region (Zinder *vs* others)	1.220	0.677	3.246	1	0.072	3.389	0.898 - 12.782
Ethnicity (Haoussa *vs* others)	0.200	0.491	0.167	1	0.683	1.222	0.467 - 3.196
Nutritional status (Normal *vs* Abnormal)	−0.272	1.198	0.051	1	0.820	0.762	0.073 - 7.979
Oral Hygiene (Good *vs* not good)	−0.929	0.540	2.959	1	0.085	0.395	0.137 - 1.138
School aspect (Before noma *vs* After noma)	1.430	0.692	4.275	1	0.039	4.178	1.077 - 16.202
Admission mode (Health structure *vs* others)	1.792	0.732	5.993	1	0.014	6.000	1.429 - 25.186
Admission time (≤30 days *vs* >30 days)	2.159	0.833	6.724	1	0.010	8.667	1.694 - 44.335
Phase of noma (Acute *vs* Sequalae)	1.890	1.052	19.740	1	<0.001	6.619	1.637 - 8.476
Location of lesion (Cheek vs others)	−2.398	0.836	8.222	1	0.004	0.091	0.018 - 0.468
Care and treatment received at center (Non-surgery *vs* Surgery)	3.393	1.139	8.873	1	0.003	29.750	3.191 - 57.323
Clinical evolution after treatment (Without sequelae *vs* With sequelae)	2.140	1.203	3.167	1	0.075	8.500	0.805 - 89.746

were divided as non-surgery (including nutritional corrections, oral/nursing care, medicated care) and surgery. For the analysis, we defined social acceptance as our successful event. For sociodemographic characteristics, the unadjusted analysis suggested that the likelihood of social acceptance increased when young (≤15 years), marital status was minor, and patients were enrolled at the school before noma appearance. For pathology aspects, the unadjusted analysis suggested that the likelihood of social acceptance increased when the patients were referred to the centre after diagnosis, the admission time to the centre was short (≤30 days), the acute phase of noma, and care received at the centre was non-surgery. The location of the lesion on the cheek was a risk factor for social acceptance, indicating cheek lesions from noma increased the likelihood of social rejection in our study. Patients whose clinical evolution after treatment were without sequelae had a high likelihood of considerable social acceptance compared to the patients with sequelae (Table 5).

4. Discussion

Our findings consider sociodemographic and clinical features that potentially affected psychological aspects in noma survivors.

Our results also provided new insight into understanding the influencing factors for psychological effects in noma patients. Factors influencing the social ac-

ceptance identified in noma patients included age group, marital status, school aspect, admission mode, admission time, phase of noma, location of the lesion, as well as care and treatment received at the centre (**Table 5**).

An uneven distribution of age was apparent in our study population. The age of the patients ranged from 18 months to 42 years, and 48.0% of noma patients were aged 1 - 5, which was similar to other studies [3] [18] [21]. The age of the onset of noma was related to the weaning time, substitute food status, income status of a family, nutritional status, oral hygiene, and immunological defenses of children [22] [23] [24]. The noma victims aged 1 - 5 had the highest social acceptance (**Table 1**), and the younger the victims, the higher their social acceptance rate. The age group of victims as well had a mid-association with their perception of noma (r_s = 0.406) and social acceptance (r_s = 0.381, **Table 4**). The reason for higher social acceptance of younger-aged children is unclear. The positive effect of young aged children on the psychological aspects of noma victims may be related to several facets. Firstly, younger children (<3 years old) spend less time outside their family environment, and their families offer unconditional social acceptance to them. At higher ages, they had to be out throughout the day, either going to school or accompanying their friends, and they were more emotionally sensitive to discrimination or social rejection. Secondly, toddlers may be too young to be aware of their condition. Social rejection, such as discrimination, might increase in school age, and it is achieved paramount in adolescence [25]. Adolescents have been found to experience more negative psychosocial consequences than younger children. Thirdly, the noma victims felt social rejection that may result from the victims' expectation of society's reaction to them rather than their practical experience in society [26] [27] [28] [29].

In our result, all the 15 patients who thought noma was a disease to be rejected by society felt social rejection in the survey (**Table 3**). The results were similar to other studies, which reported that people with disfigurement which results from Moebius syndrome, head and neck cancer, and facial lipoatrophy were likely to believe that society did not accept them, even without actual objective experience to support their thoughts [27]-[32]. As a result, especially among adolescents and children, they fail to develop the necessary social skills to integrate into society, which leads to isolation from the community when they are grown-up [28].

Negative self-perception of noma victim's maybe a possible contributory factor for social rejection. The study showed that single adults felt the highest social rejection rate (60.0%) (**Table 1**), and marital status had mid-association with victims' perception of noma, acceptance of new faces, and social acceptance (**Table 4**). All the results indicated that victims, especially single adults, developed a negative self-perception. Some researchers have reported that individuals with disfigurement due to a certain disease felt less attractive than their counterparts without it. They became socially stigmatized due to their physical appearance, and as such, they developed low self-esteem, thereby feeling more so-

cial rejection from others than their colleagues [27] [32] [33] [34].

Moreover, other people also often associated facial disfigurement with a deficiency, disorder, or disease and showed unsolicited attention or avoidance towards these victims. As positive feedback, victims with facial disfigurement felt more social stigma, stayed far away from people, isolated themselves from the community, and finally lost societal acceptance. Socio-psychological aspects of the entourage were another contributory factor for social acceptance/rejection. Entourages included families and friends around noma victims, who might show discrimination against them.

Our study showed a significant difference in victims enrolled in school before and after being victims of noma between social acceptance and social rejection. 82.9% of victims were accepted by entourages after treatment and returned to school; however, 40% of victims were rejected from school or entourages after noma sequelae (**Table 1**).

Discrimination against noma victims came because of several reasons. Ignorance of noma knowledge was one of the reasons. There were 38 (76.0%) entourages who had no or little knowledge about noma disease (**Table 3**), and a negative mid-correlation ($r_s = -0.515$) between other discrimination to victims and entourages' perception of noma, which meant that the more the entourage knew about the noma, the easier for them to accept the noma victims (**Table 4**). Lack of knowledge and understanding about the causes of noma or disfigurement due to the noma led to negative mental associations and assumptions. These results were similar to a previous study by Bogart [30]. Superstition existing in the 'noma belt' region was another reason for the discrimination of noma victims. These underdeveloped countries have a high incidence of noma, and most people do not have access to education, information, and health. People pay less attention to oral diseases until sequelae appear. Entourages thought noma was a spell and/or a curse for noma patients and looked at noma victims as evils. As a result, entourages discriminated noma victims and isolated them. We noted that 5 patients (10%) came to the center after social rejection (**Table 2**). Those victims felt discrimination from others and forced themselves to seek help from a professional institution. Honestly, entourages played a double-edged sword function in noma patients. They became responsible for the stigmatization and played an important role in psychological construction. Previous studies have shown that a strong friendship or parental support helps the victims with disfigurement feel more comfortable about their appearance and helps individuals become more resilient, raising their self-esteem [28] [29] [31] [35]. In fact, resilience was the intrinsic motivation of people with disfigurement, and it made victims with disfigurement due to noma disease strong to continue with their daily lives.

Pathological history of noma victims was found to be the third contributory factor for social acceptance/rejection. The admission mode, admission time, phase of noma, lesion location, care, and treatment at the centre were all influencing factors for social acceptance in noma victims. Except for the location

of the lesion, other variables showed a high positive association with social acceptance (Table 4 and Table 5). In this study, 35 (70.0%) patients were in the acute phase of noma compared to the sequelae phase, and they had a significantly higher social acceptance rate (Table 2). There were 52.0% of patients who suffered cheek lesions, which was higher than 32% and 48% by Pittet and Feller, respectively [36] [37]. Cheek impairment exposed the victims to several forms of uncomfortable mutilations that can affect their social, aesthetic, and professional quality of life, leading to them being non-members of the community. Overall, individuals with disfigurements may have three reaction modes: 1) being ready to accept their situation or acceptance of their new face, 2) hiding their disfigurement to avoid eliciting negative reactions from other people, and 3) undergoing plastic surgery to lessen the severity of their appearance [27] [38].

In our study, 47 patients (94.0%) accepted their new face (Table 3), indicating they wanted to begin a new life. Then, 15 patients had sequelae, and only 8 patients took surgical care (Table 2). There were two reasons for the low surgical care rate. One reason was the usage of traditional therapy in Niger. In the Southeast area of Niger, conventional therapy was the first gesture for most diseases, including noma. We found out that 68% of patients go through traditional medicine before attending a health centre (results were not shown here). Traditional treatment delayed noma patients' management and exposed more patients to complications such as sepsis or death because powders or potions applied to the wounds triggered more infection and spread lesions. Even in that situation, some victims still depended on traditional treatment rather than modern medical treatment. At no time during our interviews, we received testimony from a participant who had received awareness of the disease from traditional healers. Another reason was that the victims were isolated from society and did not know how to seek professional help. During the survey, we found 14% of noma patients were admitted to the centre beyond 365 days (Table 2), indicating the difficulties the victims experienced in finding professional help. Professional help was found to be very critical in treating noma patients. It provided clinical treatment and other training programs, such as social skills development [27] [32]. With the help of professional institutions, noma victims could have a channel wherein they were understood, accepted, and their social interaction with others improved. Therefore, it also emerged that there was a lack of knowledge about the support services available and an association of visible differences with mental and physical disability.

5. Strengths and Limitations

This study has a number of strengths. Notably, this is the first study to specifically investigate psychological experiences in noma patients with or without sequelae using standardized documents of high validity. The results will help raise awareness among the society of the need for greater involvement in supporting community members surrounding noma survivors. Similarly, increased aware-

ness of the disease among the population will improve early detection and ensure an appropriate treatment in order to reduce avoidable patient death, facial sequelae, and related social discrimination. Secondly, the response rate is high enough to conclude since the NGO-Sentinelles centre received noma patients from the whole country. However, some limitations are noted. Firstly, it is possible that some noma patients were not included in the survey. Due to logistical and research time limitations, we could not reach more villages where we may find noma patient cases that were eligible for inclusion in the study. Secondly, the psychological aspect was assessed through questionnaires. Thus, any comparison among noma victims should be interpreted with caution. Thirdly, it is possible that some results did not reach statistical significance due to the small sample size. In addition, some complex statistical models cannot be used to analyze the data because of the small sample size. Fourthly, the feeling of social rejection in younger children might not have had the same meaning as in older children. Finally, this study did not investigate the impact of stigma experiences on psychosocial development and quality of life, which should be the target for future studies.

Abbreviations

NGO: Non-governmental organization; BMI: Body mass index; MUAC: measurement of the mid-upper arm circumference; χ^2 = chi-square statistic test; P: P-value; r_s: The Spearman's Rank Correlation Coefficient; OR: Odds ratio; CI: Confidence Interval; α: Significance value; n: sample size; B: Unstandardized beta coefficients; S.E: Standard error; Wals: Weighted-average least squares; df: degrees of freedom.

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Ethics Approval

The scientific committee of the University of Abdou Moumouni authorized the study by the Research Authorization (S1) (000263/UAM/FSS/SP), and it has been approved by the scientific committee (S2).

The NGO-Sentinelles provided the ethics approval letter (S3) (S4). A collaboration agreement with the officials of NGO-Sentinelles to perform this study was made after a meeting with coordinators in both Switzerland and Niger. After the collaboration agreement was signed with the institution in charge of the participants involved in our study, which is the Sentinelles, a schedule was drawn up which identified and listed the victims of noma who were able to participate in the research. For reasons of understanding and consent, the latter were invited to participate in an organized interview, which brought together officials of the institution, socio-psychological assistants, and participants (minors accompanied by parents or guardians). After participant's counseling, detailing information on the research question and the reasons for such an initiative, as well as explaining the contents of the questionnaire materials that were to be used for the study, informed consent from the participants was obtained. Each participant wishing to participate in the research was required to sign into the list of participants and be included in the schedule, and those who did not covet to participate were free to withdraw.

During our field visits, we also established the information form which we discussed with each participant in order to obtain informed consent from each. This consent was obtained orally because most of these victims were illiterate, with most of them being able to get an education during reintegration. Since they came from disadvantaged remote rural areas, a written form was of no interest for proper understanding to them. Consents form and collected data of questionnaire survey (S5) were coded and conserved separately in a safe place by authors and Sentinelles representation both in Niger and Swiss, accessible only to the research team. Confidentiality was strictly observed. The interviews took place in convenient locations where participants could be reassured that their privacy and confidentiality will be maintained and no individuals can be identified in the results distributed or in the reports related to this study.

Contributors

AHI, NGO-Sentinelles Zinder Staff were involved in the field visits; data collection and site study monitoring.

AHI, GY, KAKO, SJH had the responsibility for the overall study design, management, conduct, data analysis, and writing of the paper.

AHI, GY, KAKO, E-OHI, MDD, ASI, EM were involved in the interpretation, synthesis, revision, correcting, and reforming the paper.

GY, SJH were responsible for the statistical analysis.

Sentinelles foundation (Lausanne representation) conceived the ethics approval letter, organized site study monitoring, and provided the logistic throughout the study period.

All authors received and approved the final version.

Conflicts of Interest

We declare that we have no conflicts of interest.

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