

Psychosocial, Functional and Aesthetic-Related Patients' Reported Outcomes Measures (PROMS) after Orofacial Reconstructive Surgery among Noma Cases in Ethiopia

Heron Gezahegn Gebretsadik*

Department of Global Health and Bioethics, School of Global Health and Bioethics, Euclid University, Brusubi, Gambia

ABSTRACT

Noma is facial gangrene that can disfigure the facial appearance severely. Patients with severe facial disfigurement are certainly prone to psychosocial and functional morbidity. Although conventional facial reconstructions can positively affect such morbidity, these procedures are often inadequate for more severe facial defects. In this cross-sectional study, the functional, psychosocial, and aesthetic-related patients' reported outcomes were measured among surgically treated noma cases in Ethiopia. Forty-five patients who underwent orofacial reconstructive surgery between 2015 and 2022 were involved in the study. The Face Questionnaire (FACE-Q) and the Derriford Appearance Scale (DAS59) scores were modified and used to assess the PROMs among the Noma cases. The data analysis revealed slight improvements in aesthetic (Likert's score=1.9), psychosocial (Likert's score=2.3), and functional (Likert's score=2.4) domains after an average of 4 years following the surgery. Generally, the confidence level in appearance after surgery was low, whereas distress and depression remained high. The findings of this study suggest the necessity of providing an interdisciplinary surgical approach to treat noma. Furthermore, physical and psychological rehabilitation programs need to be provided to the patients after surgical interventions.

Keywords: Speech; Mouth opening; Distress; Depression; Confidence; Face questionnaire

Abbreviations: PROMs: Patients' Reported Outcomes Measures; FACE-Q: Face Questionnaire; DAS: Derriford Appearance Scale; ANUG: Acute Necrotizing Ulcerative Gingivitis

INTRODUCTION

Noma is a rapidly progressive, polymicrobial, opportunistic, gangrenous infection of the mouth, most likely caused by certain kinds of buruli bacterial flora that switch to pathogenic when the host is immunocompromised [1]. Alternatively known as stomatitis gangrenosa or cancrum oris, the etiology of Noma is infectious, yet unclear as regards the exact causative microorganism [2]. Several potential pathogens were found in abundance in the sites of Noma, which include *Prevotella melaninogenica*, *Corynebacterium pyogenes*, *Fusobacterium nucleatum*, *Bacteroides fragilis*, *Bacillus cereus*, *Prevotella intermedia*, and *Fusobacterium necrophorum* [3]. Microbial analysis in the early 20th century revealed the presence of spirilliform and fusiform

microorganisms in biopsy samples taken from the transitional zone between gangrenous and healthy tissues [4]. Later studies reported that *Fusobacterium necrophorum*, a predominant animal pathogen, is the most common microorganism isolated from the disease sites in Nigerian children [5]. Since then, scientists suggested that *Fusobacterium necrophorum* could be a trigger organism for Noma [6]. This microorganism produces various toxins and has been associated with necrotizing infections in animals, and it may contaminate livestock and potentially infect children [2].

In many cases, the disease begins to develop from Acute Necrotizing Ulcerative Gingivitis (ANUG) [7,8]. ANUG is a non-contagious anaerobic infection associated with the proliferation

Correspondence to: Heron Gezahegn Gebretsadik, Department of Global Health and Bioethics, School of Global Health & Bioethics, Euclid University, Brusubi, Gambia, E-mail: gezahegn.heron@gmail.com

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of *Borrelia vincentii* and fusiform bacteria [9]. The disease continues as gangrenous stomatitis and gingival ulcer. It spreads to adjacent hard and soft tissues by disrupting anatomical barriers within a few days, causing lysis and necrosis of bones and muscles of the orofacial region [10]. It disfigures the cheek (maxilla and mandible), the lips, the floor of the mouth, the head and neck, the infra-orbital, and the nose. In most instances, the lesion (wound) area is well-defined (cone-shaped), with unilateral, yellowish, and blackish necrosis and foul-smelling purulent discharge [11,12]. Fetid odor, significant pain, fever, malaise, tachycardia, increased respiratory rate, anemia, leucocytosis, and regional lymphadenopathy are typical [13]. Additional lesions also may occur in distant sites, such as the scalp, neck, ear, shoulders, chest, perineum, and vulva [14].

The disease is associated with very high functional and psychosocial morbidity and mortality (especially from septicemia, intracranial infection, and pneumonia) [15-17]. Most survivors present with prominent facial deformities, trismus or ankylosis of the temporomandibular joint and extensive muscle and skin contracture, which leads to difficulty in opening and closing the mouth, thereby, trouble in chewing and swallowing, oral incontinence, breathing, and speech difficulties [18-20]. The problems in chewing and swallowing can also further exacerbate or cause malnutrition, and many young patients show significant growth stunting [21]. At a later stage, the lesions and contractures often lead to growth disturbance and result in further facial disfigurement and functional impairment. Even after modern and sophisticated interventions (particularly reconstructive and plastic surgeries), the outcome is less than complete recovery, and, understandably, psychosocial impacts on the patients remain substantial [22]. As a result, patients are not only severely disfigured but also rejected by family and society [23]. However, these longer-term effects, particularly psychosocial ones, have rarely been studied [24]. Perhaps, due to its primary occurrence in young children living in remote areas of the least developed countries with inadequate health systems and its rapid progression rate and high case fatality, today, Noma is a poorly studied disease, and even the cause of the condition remains idiopathic [25,26]. This study investigated the psychosocial, functional (ability to open mouth, masticate, and speech), and aesthetic outcomes among noma patients who underwent orofacial reconstructive surgery in Ethiopia.

MATERIALS AND METHODS

Research design

A cross-sectional survey of patients who underwent orofacial reconstruction surgery in Ethiopia was conducted to assess improvements in quality of life after the surgery. The prime aim of the study was to investigate the functional, psychosocial, and aesthetic-related PROMs after Orofacial reconstructive surgery among Noma Cases in Ethiopia. FACE-Q and the DAS59 based questionnaire were used to assess the PROMs among the cases. Patients answered 26 questions on a 5-point Likert scale measuring PROMs from functional, aesthetic, and psychosocial perspectives. The primary outcome measures were PROMs from functional, aesthetic, and psychosocial perspectives.

Sample and setting

The study was conducted in Addis Ababa, the capital city of Ethiopia. Patients who underwent Orofacial reconstructive surgery in Yekatit 12 Hospital, Facing Africa Ethiopia, and Harar Project between 2015 and 2020 were involved in the study.

Instruments

The functional, psychosocial, and aesthetic domains of the FACE-Q were used to collect the needed data for analysis. The FACE-Q was modified to incorporate essential demographic data. The FACE-Q scale was developed according to international guidelines for patient-reported outcome instrument development.

The demographic section of the FACE-Q contained the name, gender, age, physical address, telephone address, and year of operation of the patients. Furthermore, this section included information on the time of onset of Noma and the patient's reasons for seeking treatment. The questionnaires' functional, psychosocial, and aesthetic domain sections consisted of 4, 14, and 8 questions, respectively. The questions were drafted based on Likert's score and coined around the core objectives of the study. Each domain is composed of multiple independently functioning scales. The 5-point Likert scale was used to scale the responses of the surveyed study participants. Each response corresponded to a sentiment level with specific numerical values. The variety of scales provided flexibility to choose the subset of scales best suited to measure the outcomes of interest in the study. The researcher verified the validity of the questionnaires before applying them to collect the final data for analysis.

Data analysis

SPSS (Statistical Package for Social Sciences) software used to analyse the collected data. Furthermore, a numerical analysis of the Likert's scale was conducted to derive a numerical value (domain sentiment score) that quantifies and describes the cumulative response of the study participants in each studied domain. Items sentiment scores were calculated for each question in the questionnaire before calculating the corresponding domain sentiment scores. The sentiment levels' numerical values range from 1 to 5. In this case, "not at all", "slightly", "moderately", "very much", and "completely" have 1,2,3,4,5 numerical values, respectively.

Steps of Likert's data analysis

Step 1: The item sentiment score was calculated for each question in the questionnaire. First, the numerical value of each sentiment level was multiplied by the number of the corresponding respondents for the given item/question. Then, the sum of these findings was divided by the total number of study participants involved in the study to calculate each item's sentiment score.

Step 2: The domain sentiment score was calculated for each domain. Two alternative methods were used to calculate each

domain's sentiment score. The first method was similar to the above approach used to calculate item sentiment scores. In fact, in this case, the numerical value of each sentiment level was multiplied by the total number of the corresponding responses for the given item/question. Then, the sum of these findings was divided by the total number of responses for the entire corresponding domain. In the second method, the sum of the item sentiment scores was divided by the total number of items/questions in each questionnaire to calculate the domain sentiment score for the corresponding domain. In other words, the domain sentiment score was the mean of the item sentiment scores. Notably, decimals were rounded down or up to the closest whole number to comply with the 5-point Likert's score and better describe the findings. To round the decimal numbers to the nearest whole number, the researcher first checked the tenth digit, which is the digit to the immediate right of the decimal point. When this digit was found to be equal to or more than 5, the given number was rounded up, and the given number was rounded down when it was less than 5.

RESULTS

A total of 45 eligible, volunteer, and accessible patients who underwent orofacial reconstructive surgery in Yekatit 12 Hospital, Facing Africa Ethiopia, and Harar Project between 2015 and 2020 were involved in the study. Of these, 28 (62.2%) and 17 (37.8%) were females and males, ranging from 19 to 54 years. After data analysis, the study participants reported slight improvements in aesthetic (Likert's score of 1.9), psychosocial

(Likert's score of 2.3), and functional (Likert's score of 2.4) domains after an average of 4 years following the surgery. Furthermore, the level of confidence in appearance after surgery was low, while distress and depression were still high. The study's overall findings are discussed around the prime goals of the study as follows.

PROMs findings on functional domain

As Table 1 shows, a total of 4 items/questions were provided to answer by each study participant involved in the study. The participants (n=54) were asked if their ability to speak, open mouths, masticate, and breathe improved after the surgical intervention. The interview aimed to assess the PROMs related to the functional domain. Accordingly, 94 Likert's scale-based responses (52%) were recorded. The anticipated total Linkert scale-based responses were 180. The remaining 86 responses (48%) were found to be not Likert's scale-based (i.e., participants reported no problem with speech (19 responses), mouth opening (10 responses), mastication (16 responses), and breathing (41 responses), even before the surgery. In general, the item sentiment levels for the ability to speak (Likert's score=2.2) and breath (Likert's score=2.0) were reported to be improved slightly after the surgery. At the same time, the item sentiment levels for the ability of mouth opening (Likert's score=2.5) and mastication (Likert's score=2.5) were improved moderately. The overall functional domain sentiment level was calculated to be Likert's score of 2.4, signaling a slight improvement across the board of functions after the surgery.

Items/ Questions (n=4)	The 5-point Likert's scale/Sentiment levels with corresponding numerical values					Not applicable I did not have the problem	Total number of positive responses	Items/ Questions sentiment levels
	Not at all-1	Slightly-2	Moderately-3	Very much-4	Completely-5			
Is the quality of your speech improved after the surgery?	4	13	8	1	-	19	26	58/26=2.2, Slightly
Is your ability to open your mouth improved after the surgery?	3	15	14	3	-	10	35	87/35=2.5, Moderately
Is your ability to masticate improved after the surgery?	-	17	9	3	-	16	29	73/29=2.5, Moderately
Does your breathing ability improve after the surgery?	1	2	1	-	-	41	4	8/4=2.0, Slightly
Domain sentiment level	8	47	32	7	0	86	94	226/94=2.4, Slightly

Table 1: Summary of findings on the functional domain.

PROMs findings related to the aesthetic domain

A total of 8 items/questions were used to investigate the PROMs associated with the aesthetic domain. All the 360 responses were under the category of Likert's sentiment levels, as shown in Table 2. The study participants did not feel like they were more attractive (Likert's score=2.5) and lovable (Likert's score=2.5) after the surgical intervention. The study participants' convenience (Likert's score=2.5) to talk with others about their

features was not improved after the surgery. The relative extent of distress when the study participants looked at themselves in a mirror and when people stared at them improved slightly after the surgery. The study participants' general facial appearance, social acceptance, and overall confidence about how they look after the surgery were also improved slightly. The aesthetic domain sentiment level among the study participants was found to be Likert's score of 1.8, which indicates a slight improvement.

Items/ Questions (n=8)	The 5-point Likert's scale/Sentiment levels with corresponding numerical values					Not applicable I did not have the problem	Total number of positive responses	Items/ Questions sentiment levels
	Not at all-1	Slightly-2	Moderately-3	Very much-4	Completely-5			
Does your appearance improve after the surgery?	6	19	15	5	-	-	45	109/45=2.4, Slightly
Do you feel attractive after the surgery?	36	6	3	-	-	-	45	57/45=1.3, Not at all
Do you feel lovable after the surgery?	31	9	5	-	-	-	45	64/45=1.4, Not at all
Do you feel, in general, more confident about how you look after the surgery?	27	11	6	1	-	-	45	71/45=1.6, Slightly
Do you feel less distress when people stare at you after the surgery?	10	26	5	4	-	-	45	93/45=2.1, Slightly
Do you feel less distress when you look at yourself in a mirror after the surgery?	12	10	17	6	-	-	45	107/45=2.4, Slightly
Do you feel more comfortable when people ask about your feature after the surgery?	34	5	5	1	-	-	45	63/45=1.3, Not at all
Do you feel socially accepted after the surgery?	12	18	8	7	-	-	45	100/45=2.2, Slightly
Domain sentiment level	162	104	69	25	0	0	360	664/45*8=1.8, Slightly

Table 2: Summary of findings on the aesthetic domain.

PROMs findings related to the psychosocial domain

In this section, the PROMs related to the psychosocial domain were assessed by asking the study participants 14 questions (items sentiment levels)-seven questions each for the psychology and social perspectives, as shown in Table 3. The psychosocial

domain sentiment level among the study participants was found to be a Likert's score of 2.3, which indicates a slight improvement. The slight, not at all, and moderate sentiment levels constituted 43%, 14%, and 43% of the total study participants' responses in the psychosocial domain, respectively.

Items/ Questions (n=14)	The 5-point Likert's scale/Sentiment levels with corresponding numerical values					Not applicable I did not have the problem	Total number of positive responses	Items sentiment levels
	Not at all-1	Slightly-2	Moderately-3	Very much-4	Completely-5			
If your social/ public participation was limited, did it improve after the surgery?	5	18	15	7	-	-	45	114/45=2.5, moderately
If it was the case, does bullying decrease after the surgery?	8	17	9	11	-	-	45	113/45=2.5, moderately
If your personal relationship was impaired, did it improve after the surgery?	11	24	4	6	-	-	45	95/45=2.1, Slightly
Do you have more friends after the surgery?	34	8	3	-	-	-	45	59/45=1.3, not at all
If you were stigmatized/ discriminated against, does it improve after the surgery?	7	10	18	10	-	-	45	121/45=2.7, moderately
If people make fun of your way of speaking, does it improve after the surgery?	3	3	14	4	-	21	45	67/24=2.8, moderately
Would people decrease staring at you after the surgery if it was the case?	9	5	15	13	3	-	45	131/45=2.9, moderately
If you were ashamed of your look, does it improve after the surgery?	8	10	16	11	-	-	45	120/45=2.7, moderately
If it was the case, do you	14	18	13	-	-	-	45	89/45=2.0, Slightly

feel like you are no more inferior after the surgery?								
If it was the case, do you feel less freak/anomalous after the surgery?	17	28	11	-	-	-		106/45=2.4, Slightly
Do you feel comfortable when people look at you after the surgery?	31	8	6	-	-	-	45	65/45=1.4, not at all
Does your frustration (because of your look) meeting people decrease after the surgery?	16	21	8	-	-		45	82/45=1.8, Slightly
Does your frustration of suffering from bullying decrease after the surgery?	12	22	7	4	-	-	45	93/45=2.1, Slightly
Do you decrease isolating yourself because of your look?	21	10	9	5	-		45	88/45=2.0, Slightly
Domain sentiment level	196	202	148	71	3	21	630	1373/630=2.18, Slightly

Table 3: Summary of findings on the psychosocial domain.

DISCUSSION

According to reports, face plays a pivotal role in an individual's self-concept and path to psychological recovery [27,28]. Facial appearance and self-concept are reportedly more closely intertwined among people with congenital or acquired facial disfigurement compared to the general population [29]. This indicates the profound psychosocial implications of facial disfigurement in people with facial deformity. People with facial disfigurement reportedly suffer from various psychosocial problems, including poor self-esteem, reduced quality of life, and altered body image [30,31]. Negative self-perception and impaired social interaction are the most common psychosocial problems associated with facial disfigurements [32]. At the same time, low self-confidence and a negative self-image are reported to be the most persistent facial disfigurement-induced psychosocial burdens. Patients with facial disfigurements also

commonly present with social anxiety, fear of negative social evaluation, and social avoidance [33]. A study that assessed the psychological implications of cleft lip among children disclosed a high risk of developing anxiety, general unhappiness, low self-confidence, and self-doubt in interpersonal relationships [34]. Moreover, another alarming psychosocial study revealed a double suicide rate among Danish adults with clefts compared to the control unaffected group [35].

Furthermore, people with facial disfigurement are reported to have trouble making new friends and keeping relationships long. Thus, facial disfigurement can impede social interaction [36]. On the other hand, mocking, staring, commenting, asking unsolicited questions about the disfigurement, and exhibiting avoidant or negative behavior are the most common reactions people with facial disfigurements receive from family members and peers [37,38]. These negative connotations are the primary

causes of persons' preoccupation-induced self-isolating behaviors that weaken the affected people's available social support network. According to a report, if not intervened, the facial disfigurement-induced psychosocial crisis might also lead to substance abuse and changes in income or occupational status [39].

Different research works have revealed the positive effects of facial reconstructive surgery on self-concept. According to studies, improvements in measures of personality adjustment, such as psychosis or neurosis, as well as improvements in self-concept, self-identity, self-esteem, and self-conflict, were seen among patients who underwent corrective facial surgery for various facial disfigurements [40-44]. In another research work that assessed the psychological outcomes of orthognathic surgery among patients with dentofacial abnormalities, the research team witnessed the overwhelming desire of the patients to improve their facial appearance [40]. In this regard, elder patients treated with cleft lip repair reported experiencing a restored sense of personal identity after the corrective surgery [45]. Similarly, orthognathic surgery yielded consistent improvements in patient quality of life through restoration of physical facial identity [40,46,47]. The findings of this study also comply with these arguments. For example, though few, study participants reported near-complete restoration of facial appearance and functional activities such as speech and mastication after the surgical intervention. A few others also reported major improvement in psychosocial morbidity after the surgery.

On the contrary, surgical intervention may result in postsurgical facial disfigurement among patients who receive surgery to treat head or neck malignancies, eventually leading to a damaged self-concept [28]. General dissatisfaction, limited improvement in function, and unhappiness with appearances are also reported to be major complaints among patients who undergo facial reconstructive surgery [48,49]. Likewise, this study revealed PROMs of slight improvements in aesthetic (Likert's score of 1.9, psychosocial (Likert's score of 2.3, and functional (Likert's score of 2.4 domains after an average of 4 years following the surgery. Considerable number of study participants were not happy with how they look after the surgical intervention.

In another case, patients may struggle with adapting to their new appearance even after receiving effective facial surgery [47]. In this regard, a research work described temporary depression and loss of self-esteem among surgically (Orthognathic treated patients as they adapt to their new facial appearance [50]. These psychological alterations may last up to two years after the surgery [51]. In these cases, a robust support system that can ease the challenge must be initiated following the surgical intervention [27].

CONCLUSION

A large subset of surgically treated patients involved in this study experienced major psychosocial and functional problems after treatment. The findings of this study also disclosed that complete reconstruction of Noma-induced midfacial defects and restoring the psychosocial makeup of patients to normal through conventional corrective surgery is challenging. Therefore, conventional orofacial reconstructive surgery should be

supported with other corrective surgical procedures such as skin grafts, local flaps, distant pedicled flaps, and free flaps. Furthermore, the postoperative care menu for surgically treated Noma cases should include social reintegration and psychological and physical rehabilitation programs.

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