Mental health status and associated factors prevailing among the patients having orofacial clefts in Bangladesh: A mixed method study



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Abstract

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Background: Patients with craniofacial anomalies endure various psychological distress. This study assessed the mental health status and related factors among the patients with cleft lip and/or palate in Bangladesh.

Methods: This case-control study was conducted at the Department of Orthodontics, Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh, over a four-year period. Treated and untreated patients were recruited. A validated Depression Anxiety Stress Scale 21(DASS-21) questionnaire was used to determine the depression, anxiety and stress levels. In-depth and key informants' interviews included 16 and 7 participants, respectively. Participants were taken purposively from Bangabandhu Sheikh Medical University, Dhaka, Bangladesh; Sheikh Hasina National Institute of Burn and Plastic Surgery, Dhaka, Bangladesh, and Bangladesh Specialised Hospital, Dhaka, Bangladesh.

Results: Among the 105 cleft patients, 55 were treated, and 50 were untreated. The overall (Median and interquartile range) depression rate was 2 (0-6) versus 28 (24-32), anxiety 4 (0-6) versus 16 (12-18), and stress 6 (4–8) versus 20 (16–24) in treated and untreated groups (P<0.01). Untreated patients had significant association of poor mental health status (depression, anxiety, and stress), female gender (anxiety), postgraduate education (anxiety), Peri-urban/rural living areas (depression, and anxiety). Qualitative evidences supported these study findings.

Conclusion: Treated patients with cleft lip and/or palate have a better mental health status compared to those remained untreated.

Key messages

Patients with cleft lip or palate who received partial or complete treatment exhibited lower levels of depression, anxiety, and stress compared to those who did not receive any treatment. Females and individuals with higher educational attainment experienced higher levels of anxiety than males. Furthermore, patients from peri-urban and rural regions reported greater levels of depression and anxiety.

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Introduction

Oral clefts, also known as cleft lip and/or palate (CL/P), are frequent congenital disabilities. Birth abnormalities affect approximately 0.45 in 1,000 live births globally [1]. Seventy percent of newborns with CL/P have an isolated phenotype and do not have any other severe structural problems [2].

Persons with CL/P experience difficulties with eating, hearing, breathing, and speaking, and some of these also have psychological effects. The affected person reported more behavioral problems, depression, anxiety, low self-esteem and poor interpersonal skills than the unaffected people [3].

The knowledge provided by the numerous research studies conducted on various aspects of cleft lip and palate is inadequate. Cleft lip palate individuals are predicted by studies to suffer from some psychosocial functioning issues, yet little is known regarding how severe and long-lasting such problems might affect [4]. A range of physiological and sociocultural factors influence psychosocial disorders among individuals with any kind of facial abnormalities. It seems that being physically attractive is a positive attribute at every stage of life [5].

The current study assessed the mental health status among the adult treated and untreated groups of CL/P patients in Bangladesh and factors related to these issues. Data were collected from three tertiary-level hospitals located in Dhaka City, Bangladesh.

Methods

Study design and settings

This case-control study was conducted by the Department of Orthodontics at Bangabandhu Sheikh Medical University (BSMMU) for four years, 2021-2024. Samples were collected from the Department of Orthodontics of BSMMU, Sheikh Hasina National Institute of Burn and Plastic Surgery, Bangladesh and Bangladesh Specialised Hospital, Dhaka, Bangladesh. The World Health Organization's Study on Global Ageing and Adult Health (SAGE) provided the sociodemographic questions [6]. Mental health statuses of the participants were assessed by validated Bangla version of Depression Anxiety Stress Scale 21 questionnaire [7]. The reliability of the tool has been reported in terms of Cronbach's alpha. We utilised data from a qualitative study, which included key informant interviews (KII) and in-depth interviews (IDI), to support the findings of the quantitative study.

Participants

Fifty-five treated and 50 untreated adult patients, aged 15 to 30, with CL/P, were selected using purposive sampling methods, considering the inclusion and exclusion criteria. Patients with medically handicapping conditions and unwilling to participate in the study were excluded. IDIs were carried out with 16 adult treated and untreated cleft lip and cleft palate patients. KIIs were conducted with 7 key informants who were connected to the cleft care services. The interview sessions were continued until the last saturation point was reached to achieve sufficient data.

Key variables ascertainment

The data collection was initiated after a pilot study involving 15 patients. Pretesting of the qualitative interview guidelines was carried out.

Cleft lip and cleft palate

An opening or split in the upper lip that results from an unborn baby's developing facial tissues unable to close fully is called a cleft lip. An opening in the roof of the mouth known as a cleft palate develops when tissue fails to fuse during fetal development [8].

SAGE

The demographic information of SAGE, including age, sex, residence (rural or urban), marital status, level of education, and socioeconomic variables, was collected from the HDSS (Health and Demographic Surveillance System) surveillance data and verified during the interview [6].

DASS-21

It's a shorter form of the DASS-42, a self-report instrument designed for assessing negative emotional states like stress, anxiety, and depression. The Bangla version of the DASS-21 questionnaire was employed in this study to determine the participants' mental health statuses [7]. The DASS assesses the three related states of stress, anxiety, and depression, and then evaluates them clinically. There are 21 questions on

To indicate how much each statement applied to them over the previous week, the patient is asked to read each statement and circle a number 0, 1, 2, or 3, which indicates how much the statement applied to them over the past week. There are no correct or incorrect responses [7]. The rating scale is as follows:

- 0 Did not apply to me at all.
- 1 Applied to me to some degree, or some of the time.
- 2 Applied to me to a considerable degree or a good part of time.
- 3 Applied to me very much or most of the time.

Depression

Depressive disorder is characterised by a persistently low mood, loss of enjoyment, or disinterest in activities [9].

Anxiety

These emotions are frequently accompanied by physical tension. Anxiety disorders disrupt everyday routines and can negatively impact a person's social, familial, academic, and professional lives [9].

Stress

A feeling of anxiety or tension brought on by a challenging circumstance is known as stress. It is a normal human reaction to confront obstacles and dangers in life [10].

Ethical considerations

Ethical clearance to conduct the study was obtained from the Institutional Review Board of BSMMU. Informed written consent was obtained from each participant, explaining the purposes of the study, goals, minimal risks, and benefits. A separate identification number was given to each patient to

maintain confidentiality. Participation in the survey was voluntary, and participants had the complete right to withdraw from the study at any time without affecting their regular treatment procedures.

Statistical analysis

Data were analysed using SPSS, version 20.0. The characteristics of the study participants were expressed as percentages. The dependent variables were depression, anxiety, and stress. Fisher's exact tests assessed the distribution of depression, anxiety, and stress levels. The DASS-21 scale assessed the average score of depression, anxiety, and stress. Cronbach's alpha assessed the reliability of the test. We have conducted Kruskal-Wallis tests to check the association of depression, anxiety, and stress indicators with the characteristics of the individuals. As the three key outcome variables were categorised, we conducted logistic regression models to understand the factors influencing depression, anxiety, and stress levels.

For the IDIs and KIIs, interview sessions were scheduled and conducted with each participant, continuing until a sufficient amount of data was collected. After recording, immediate transcription was carried out. After that, the coding of transcribed data was completed, and themes were identified. Finally, data were analysed by thematic analysis procedures.

Results

a. Quantitative study findings

Out of 105 study participants, 55 were from the treated group and 50 from the untreated group. The highest proportion of patients was 25 years and above in the treated group and up to 24 years in the untreated group. The percentages of female patients in the treated and untreated groups were 38.2% and 44.0%, respectively, and those of male patients were 61.8% and 56.0%, respectively. The percentage of unmarried patients in the untreated group was 80.0. In the untreated group, 72.0% of the participants were

Table 1 Characteristics of treated and untreated patients with cleft lip and/or palate, n (%)

Characteristics	Total (n=105)	Treated (n=55)	Untreated (n=50)	Р
Age (years)				
≤24	52 (49.5)	14 (25.5)	38 (76.0)	<0.01
≥25	53 (50.5)	41 (74.5)	12 (24.0)	
Sex				
Female	43 (41.0)	21 (38.2)	22 (44.0)	0.55
Male	62 (59.0)	34 (61.8)	28 (56.0)	
Marital status				
Unmarried	73 (69.5)	33 (60.0)	40 (80.0)	0.03
Married/divorced/widowed	32 (30.5)	22 (40.0)	10 (20.0)	
Education				
Up to secondary school	51 (48.6)	13 (23.6)	38 (76.0)	<0.01
College completed and above	54 (51.4)	42 (76.4)	12 (24.0)	
Occupation				
Student/unemployed	72 (68.6)	36 (65.5)	36 (72.0)	0.34
Employed	33 (31.4)	19 (34.5)	14 (28.0)	
Living area				
Urban	67 (63.8)	36 (65.5)	31 (62.0)	0.83
Peri-urban/rural	38 (36.2)	19 (34.5)	19 (38.0)	

students, and in the treated group, this proportion was 65.5%. Most of the patients had completed college or higher education. Most of the patients in both groups were from urban areas (Table 1).

The depression, anxiety, and stress score were significantly lower among the treated patients compared to that of untreated. Untreated patients found significant association of mental health status' (depression, anxiety, stress), male gender (anxiety), postgraduate (anxiety), peri urban/rural living areas (depression, anxiety) (Table 2).

Multivariable logistic regression model for assessing the association of depression, Anxiety, and Stress score of DASS 21 items with treatment status of cleft patients after adjusting with other covariates. Depression was found to be significantly higher, by 11 times, among the untreated patients compared to the treated patients. Those who were divorced or widowed had higher depression levels compared to those who were married. Those who had completed secondary education were significantly more depressed compared to the patients who had up to the primary level of education. Patients living in urban areas had significantly higher depression scores by 3.2 times than those living in rural/peri-urban areas (Table 3).

The findings from the second model on anxiety showed that untreated patients had significantly higher anxiety levels, 6.4 times higher compared to the treated. Females had 2.1 times higher anxiety, which was statistically significant, compared to males. Patients who had postgraduate level education had significantly more anxiety compared to the patients having up to secondary level of education.

The findings from the third model on stress showed that untreated patients experienced significantly more stress than treated patients, a 3.2-fold increase. Patients in higher education had a significantly higher level of stress compared to patients at the secondary level. Other socioeconomic factors did not have a significant influence on stress levels. Patients living in urban areas had significantly higher stress levels, 3.2 times higher than those living in rural or peri-urban areas. A significant association (P<0.01) of depression, anxiety, and stress with untreated CL/P patients was observed when the multiple logistic regression was done, adjusting for covariates (Table 4).

b. Qualitative study findings

Saturation for the qualitative IDIs was reached with 16 participants, comprising 8 participants who were treated and 8 participants who were untreated. Out of them, 50% were male and 50% were female in each group. KIs included 7 participants from 3 organisations.

Eating difficulties

Some patients shared their experiences of difficulty in incising foods with their teeth. As one mentioned, "My cleft makes it difficult for me to chew or swallow hard things like fish bones, meat, or medication like tablets. I usually prefer syrup over tablets when I suffer from a fever or cold type symptoms."

Table 2 Median (interquartile range) score of depression, anxiety, and stress scale of DASS 21 by characteristics of the treated and untreated patients with cleft lip and/or palate

Characteristics	Depression	Depression		Anxiety		Stress	
	Treated (n=55)	Untreated (n=50)	Treated (n=55)	Untreated (n=50)	Treated (n=55)	Untreated (n=50)	
Overall	2 (0-6)	28 (24-32)b	4 (0-6)	16 (12-18)b	6 (4-8)	20 (16-24)b	
Age group (years)							
≤24	1 (0-8)	29 (26-34)b	3 (0-4)	17 (14-18) ^b	6 (4-8)	20 (16 -26)b	
≥25	2 (0-6)	25 (17-27)	4 (2-6)	11 (8-14)	6 (4-8)	18 (15-19)	
Gender							
Female	4 (0-10)	32 (24-35)	4 (2-6)	18 (15-20) ^a	6 (4-8)	20 (16 -26)	
Male	0 (0-2)	26 (24–28)	0 (0-4)	12 (10-14)	4 (4-8)	18 (16–22)	
Marital status							
Unmarried	2 (0-2)	28 (24-32	4 (0-4)	16 (12-18)	6 (4-8)	20 (18-22)	
Married/divorced/widowed	2 (0-6)	28 (24-34)	4 (2-6)	15 (10-18)	5 (4-8)	16 (14-18)	
Education							
Up to secondary school	6 (2-8)	29 (24-34)b	4 (2-6)	16 (12-18) ^b	6 (4-8)	18 (16-24)b	
College completed or above	1 (0-4)	26 (18-28)	4 (0-6)	14 (9-17)	6 (4-8)	20 (18-23)	
Occupation							
Student/unemployed	2 (0-9)	29 (25-34)	4 (2-6)	17 (18-13)	6 (4-8)	20 (17-25)	
Employed	0 (0-2)	26 (20-28)	4 (0-4)	12 (14-8)	4 (4-8)	18 (16-20)	
Living areas							
Urban	0 (0-2)	26 (20- 30)b	2 (0-4)	14 (10-18)	4 (4-8)	20 (18-26)	
Peri-urban/ rural	8 (4-16)	32 (26-36)	4 (4-6)	18 (14–20)	8 (4-8)	16 (16-24)	

^aP<0.05; ^bP<0.01 obtained by Kruskal-Wallis test

Speaking difficulties

Speech difficulty is one of the most problematic issues for these patients. Due to the nasal voice associated with their speaking issues, they frequently face mockery from their classmates when communicating. A patient mentioned, "Since I can't speak clearly, I used to suppress myself a lot." I keep myself sit down. I always apprehend whether everyone will understand me or not. I might have to repeat it again. I should remain silent."

There were also a few patients who believed that it was a God-given issue, beyond their control. They desire to resolve these issues by becoming self-reliant through education.

Table 3 Odds ratio (95% confidence interval) for treatment status obtained by multiple logistic regression analyses for depression, anxiety, and stress^a using three separate models adjusted for covariates, n=105

Characteristics	n (%)	Depression	Anxiety	Stress
Patients type				
Treated	55 (52.3)	Reference	Reference	Reference
Untreated	50 (47.6)	11.0 (6.1-19.9)°	6.4 (4.4-9.3)°	3.2 (2.6-3.9)c
Age group (years)				
≤24	52 (49.5)	Reference	Reference	Reference
≥25	53 (50.4)	1.6 (0.8-3.1)	1.1 (0.8-1.6)	0.8 (0.6-1.1)
Gender				
Male	43 (40.9)	-	Reference	-
Female	62 (59.0)	-	2.1 (1.5-2.9)°	-
Marital status				
Unmarried	73 (69.5)	Reference	-	Reference
Married/ divorced/widowed	32 (30.5)	0.67 (0.4-1.1)	-	0.9 (0.7-1.2)
Education				
Up to secondary school	51 (48.6)	Reference	Reference	Reference
University/college completed	34 (32.4)	0.7 (0.4-1.2)	0.9 (0.7-1.3)	0.9 (0.7-1.2)
Postgraduate	20 (19.0)	0.9 (0.4-2.0)	1.5 (1.0-2.4)b	1.1 (0.9-1.5)
Living area				
Urban	67 (63.8)	Reference	Reference	-
Peri-urban/rural	24 (36.1)	3.2 (1.8-5.6) ^c	1.4 (1.1-1.9)°	-

aDetermined using DASS-21 items scale; bP<0.05; cP<0.01

Orthodontic problems

Another common difficulty reported by patients was orthodontic issues. Practically all patients feel depressed about their outward attractiveness and aesthetic beauty.

One of the participants mentioned, "One thing I often hear is, 'Hey! Your teeth are crooked; when will you address this issue? "

Stigma related to health conditions

Emotional experiences

The patients' feelings about their facial anomaly were found to be uneasiness, sadness, shock, confusion, and guilt, and over time, they tried to adapt to it in their way.

According to a participant, "People often ask me about the abnormality of my appearance; I try to explain it to them normally." It's true that I feel a lot of pain inside and become upset with the thought of why this has happened to me and feel bad about myself."

Reactions from family, friends or the public

The majority of respondents reported having experienced some form of cruelty from friends, neighbors, family members, or relatives.

One of the patients mentioned, "My grandparents and relatives, teased me as disabled and commented that I became more handicapped looking after having my cleft surgeries and not able to hear properly. They never realise these make me sad."

Another patient shared her experience as, "People not only imitated my way of speaking, they also try to make the shape of my lip by altering their lip position."

Anxiety for the future, especially marriage

Though the majority of the patients were concerned about their future self-esteem and self-image, the primary concern of female patients was marriage. When the issue of marriage arises, the issue of appearance also comes into play. Demanding dowry from the bride's side is very common, as they are often considered to be esthetically compromised.

Table 4 Distribution of depression, anxiety, and stress scale by treated and untreated cleft patients, n (%)

Level of sub-scales (range)	Total (n=105)	Treated (n=55)	Untreated (n=50)	Р
Depression				
Normal (0-9)	44 (42.4)	45 (81.8)	1 (2.0)	<0.01
Mild (10-13)	4 (4.2)	3 (5.5)	1 (2.0)	
Moderate (14–20)	11 (10.5)	7 (12.7)	8 (16.0)	
Severe (21–27)	12 (11.5)	0 (-)	12 (24.0)	
Extremely severe (28+)	28 (26.8)	0 (-)	28 (56.0)	
Anxiety				
Normal (0-7)	54 (49.0)	50 (90.9)	4 (8.0)	<0.01
Mild (8–9)	8 (15.3)	4 (7.3)	4 (8.0)	
Moderate (10–14)	17 (33.5)	1 (1.8)	16 (32.0)	
Severe (15–19)	17 (34.0)	0 (-)	17 (34.0)	
Extremely severe (20+)	9 (18.0)	0 (-)	9 (18.0)	
Stress				
Normal (0-14)	60 (57.3)	54 (98.2)	6 (12.0)	<0.01
Mild (15–18)	19 (18.1)	1 (1.8)	18 (36.0)	
Moderate (19–25)	15 (14.3)	0 (-)	15 (30.0)	
Severe (26–33)	10 (9.7)	0 (-)	10 (20.0)	
Extremely severe (34+)	9 (8.6)	0 (-)	9 (18.0)	

A patient stated, "When my relatives discuss my marriage issue, they advise me that you have to sacrifice than others because you have a problem."

Key informants' experiences related to the patients' mental health status

According to most KIs, mental health status largely varies according to the patient's health conditions, severity of the clefts, socioeconomic status, social and cultural norms, beliefs and level of education. They found the most frequent causes for the lower mental health were the scheduled treatment process, lack of treatment facilities in the peripheral areas, lack of awareness and proper information regarding the available treatment options, social classes, lack of financial support, travel costs, lack of information and health system responsiveness.

A KI from the speech therapy department of BSMMU stated that "There might be some prejudices among patients from the upper class of our society, who believe that spending more money will provide them with better services, and vice versa."

One KI stated that one of the participants shared her mother's griefs by mentioning that, "My relatives often tell my mother that, this is a God gifted condition and you will commit sin by altering this condition of your child. Leave it as it is, and keep faith in your destiny."

People from higher societal levels tend to exhibit relatively high mental strength and believe that these events are actually things that happen by God to test people and that everything is going according to God's plan, as one KI stated.

A common experience was shared by all KIs that female patients experience more worries and anxieties about their conditions and face more sociocultural difficulties compared to the males. Almost all patients who seek treatment believe that undergoing functional and cosmetic treatments will enable them to achieve an attractive look, ultimately enhancing their overall quality of life.

Discussion

Physical attractiveness plays a significant role in social settings, such as developing relationships at various stages of life. Within the current study, a considerable difference was found between the treated and untreated patients. Overall mean depression, anxiety, and stress scores were lower among the treated patients compared to the untreated patients using DASS 21, which is a validated tool. However, since the tool was not previously used among these groups, the validity of the tools was checked by CA. Depression among the patients was significantly related to gender, marital status, education, occupation and family income. Anxiety among patients with cleft lip was significantly associated with sex, marital status and occupation. Stress was significantly related to treatment status and education level. A study conducted among the Chinese CL/P patients found that the difference in proportions of depression groups was statistically significant between the CL/P group and control group. This study also found that CL/P patients suffered from severe depression [11].

The first model of regression analysis found that depression was significantly higher by 23.5 points among the untreated patients compared to the treated patients. Compared to the unmarried patients, depression was lower among the married patients by 3.5 points; however, it was significant at a 10% level of significance. Patients who had secondary incomplete education at university/college and postgraduate level of education had significantly more anxiety compared to the patients having up to primary level education. Unemployed patients had significantly higher depression scores by 6 points compared to the students. Compared to the patients living in the urban areas, patients in the peri-urban areas had significantly higher depression scores by 4.7 points.

From the qualitative IDIs, a similar scenario was also observed, where a respondent mentioned that despite having a cleft child, she did not face any comments from neighbors or relatives, as they live in a place like Dhaka city, where nobody seems to care about such issues. One of the KIs from the Sheikh Hasina National Burn and Plastic Surgery Institute, Bangladesh, mentioned that patients usually visit there, ranging from day laborers to upper-class society, and the majority of patients are from the lower and middle classes. Therefore, their physical and mental health status also varies accordingly.

The findings from the second model of regression on anxiety showed that untreated patients had significantly higher anxiety levels by 12.1 points compared to the treated patients. Females had significantly higher anxiety compared to males. In general, females' depression, anxiety and stress levels were at the extreme severe level as compared to their male counterparts. The tremendous social pressure these patients face from society makes them vulnerable [12]. From our qualitative findings, it was also evident that the primary concern and anxiety among the female patients were regarding their marriage. The KIs of every organisation shared a common experience: female patients experience more worries and anxieties about their conditions and face more socio-cultural difficulties compared to male patients.

The findings from the third model of the regression analysis showed that untreated patients experienced significantly more stress than treated patients, by 15.5 points. Patients with higher education had significantly higher levels of stress compared to those who completed primary education or less.

A cultural meta-analysis by Kathleen Hutchinson reported that people with cleft lip and palate have less psychological development than people without it, regardless of age, gender, or culture [13].

The majority of respondents often experienced cruelty from friends, neighbors, family members or relatives. One KI from the Orthodontics Department of BSMMU stated that patients' social status, level of education, and presence of stigmas have profound impacts on their mental health status and treatment-seeking behaviors.

From our qualitative IDIs, it was also found that teasing was a strong predictor of lower psychosocial functioning and was more common among people with cleft lip and/or palate. Almost all patients who seek treatment believe that undergoing functional and cosmetic treatments will result in an attractive appearance, ultimately enhancing their overall social status, self-esteem, and physical and emotional wellbeing, as stated by the KIs.

This study will help generate evidence-based information regarding the mental health status of adult CL/P patients with associated factors by using the standard tools. Although the findings from this study cannot support the study conclusion regarding actual causal relationships, as it was based on cross-sectional data, they can be useful for establishing preliminary evidence of a causal relationship.

Conclusion

This study found a lower mental health status among the untreated CL/P patients compared to the treated group. A multifaceted approach is needed, including addressing psychological challenges, promoting positive self-esteem, and ensuring access to comprehensive medical and psychological support, as well as family support. Future studies would need to investigate causal effects using a causal effect research design.

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Author contributions

Conception or design of the work; or the acquisition, analysis, or interpretation of data for the work: TR. Drafting the work or reviewing it critically for important intellectual content: TR, FH, GSH. Final approval of the version to be published: GSH, FH, TR. Accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: GSH, FH, TR.

Conflict of interest

We do not have any conflict of interest.

Data availability statement

We confirm that the data supporting the findings of the study will be shared upon reasonable request.

Supplementary file

None

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