

RESEARCH ARTICLE

Barriers in accessing treatments for cleft lip and cleft palate in Bangladesh

Tanzila Rafique¹ | Rakia Ishra² | Sharlin Akter³ | Shahriar Mohd Shams¹

Gazi Shamim Hassan¹



¹Department of Orthodontics, Bangladesh Medical University, Dhaka, Bangladesh

²Department of Public Health, American International University, Dhaka, Bangladesh

³Department of Public Health and Informatics, Bangladesh Medical University, Dhaka, Bangladesh

Abstract

Background: Cleft lip and cleft palate are common congenital craniofacial anomalies requiring timely multidisciplinary care, yet access to treatment remains limited in many low- and middle-income settings due to social and structural barriers.

Methods: This study employed a mixed-method services study purposively selected 105 treated and untreated adult patients with a craniofacial anomaly. Data were collected from September 2019 to June 2023. Socio-demographic data were collected utilizing the world health Study on global AGEing and adult health (SAGE) survey. A questionnaire was used to assess the socio-cultural, economic, and healthcare barriers including stigmas. The qualitative component included in-depth interviews with 16 patients and 7 key informants involved in cleft services. Samples were obtained from the Department of Orthodontics, Faculty of Dentistry at Bangladesh Medical University, National Institute of Burn and Plastic Surgery, and Bangladesh Specialised Hospital, Dhaka, Bangladesh.

Results: Fear of unnecessary tests (67.6%), inability to visit the doctor regularly (65.7%), long waiting times (62.0%) and fear of not getting treatment from the same physician (61%) were the most commonly reported barriers. Social and familial stigma (70.3%) and financial hardships (50.6%) were the commonly found socio-cultural and socio-economic barriers. The major personal factors for receiving healthcare were work responsibilities and transportation (96.2% each) and fear for personal safety (53.3%). The qualitative findings support the above results.

Conclusion: Perceived fear of caring out undergoing unnecessary investigation by the patients, socio-cultural stigma, economic constraints, and health system limitations continue to hinder access to cleft lip and palate treatment in Bangladesh. Overcoming these barriers is therefore essential to promote equitable access and improve health outcomes for affected individuals.

Key messages

One of the most common sociocultural barriers was the stigma from family and society, particularly the blaming of mothers for these issues. Longer treatment durations, employment responsibilities, financial problems, transportation difficulties, long waiting times at hospitals or doctors' surgeries, concerns about unnecessary tests recommended by medical professionals, and worries about safety while out in the street were also prevalent. Additionally, women were more vulnerable to marriage-related issues at the social level.

Correspondence

Tanzila Rafique
tanzila_rafique@bsmmu.edu.bd

Publication history

Received: 3 Dec 2025

Accepted: 21 Mar 2026

Published online: 28 Mar 2026

Responsible editor

M Mostafa Zaman
0000-0002-1736-1342

Reviewers

F: Ahsan Aziz Sarkar
0000-0002-8800-8669

I: Hridi
0000-0002-7708-0614

Keywords

cleft lip, cleft palate, barrier, access to treatment, stigma

Funding

Funded by Bangabandhu Sheikh Mujib Medical University (Memo No. BSMU/2020/6600(41), Dated 21 June 2020).

Ethical approval

Approved by Institutional Review Board of Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh (Memo No. BSMU/2018/3022, Dated 12 Mar 2018).

Trial registration number

Not applicable

Declaration

This article partially encompasses PhD thesis of Dr. Tanzila Rafique

© The Author(s) 2026; all rights reserved.

Published by Bangladesh Medical University (former Bangabandhu Sheikh Mujib Medical University).

Introduction

Cleft lip and/or palate (CL/P) are the most common orofacial birth defects, occurring in 1 in 600 live births worldwide [1]. In Bangladesh, CL/P affects approximately 1 in 500-600 children, with an estimated 5,000 babies born with these conditions annually [2]. There are approximately 300,000 patients with unrepaired facial clefts, often from underprivileged families, and only a handful of qualified surgeons to treat them. A lot of patients cannot afford or access essential surgeries related to cleft conditions because of financial limitations, a lack of available surgeons, and stigmas. Significant psycho social impacts, such as social isolation, rejection from education and employment, and negative perceptions, are prompted by the stigma related to clefts in poor and middle-income countries (LMICs) [3]. Certain traits that differentiate the affected are culture, gender, race, socioeconomic status, age, sexual orientation, body image, and health [4]. Stigma against individuals with certain diseases impedes access to diagnosis, treatment, and positive health outcomes, leading to feelings of despair and shame that hinder care-seeking [5]. Systematic reviews summarising the psychosocial effects of cleft from high-income countries have previously been published, but there is a relative paucity of cleft treatment data in central and western Asia [6]. Regional and socioeconomic disparities also exist, and those from the Middle East and South Asia face more challenges [7]. Some research conducted in middle- and lower-income areas explained why different cultural ideas developed in each setting. This study examined the barriers to treatment for CL/P among Bangladeshi patients visiting a tertiary-level hospital.

Methods

Study design and settings

This cross-sectional study was conducted at Department of Orthodontics at Bangladesh Medical University from September 2019 to June 2023. Data were collected from three tertiary centres in Dhaka, Bangladesh Medical University, National Burn and Plastic Surgery Institute, and Bangladesh Specialised Hospital. These locations were chosen because they offer access to a wide range of patients and have expert cleft care, modern reconstructive facilities, significant patient flow, and extensive urban-peri-urban-rural. World Health Organization's world health Study on global AGEing and adult health (SAGE) survey was used to the socio-demographic data [8]. A questionnaire was used to assess the perceived barriers reported by the patients in accessing health care services. This section included seven questions, employing a 5-point Likert scale from "No" (1) to "Most" (5) [9]. Both an interviewer-administered questionnaire and a semi-structured interview were carried out to assess the socio-cultural, socio-

economic barriers and personal factors related to access to healthcare services [10]. Matching and stratification were done during the study design. The questionnaire's viability was tested in a pilot study involving 15 patients. Key informant interviews (KIIs) and in-depth interviews (IDIs) were conducted to obtain qualitative data. The qualitative interview guides were pretested and adjusted as necessary.

Participants

A total of 105 adult patients with CL/P were recruited using purposive sampling based on specific characteristics relevant to the study's objectives. The selection was intentional and strategic. The researcher employed their expertise to identify and select individuals most likely to provide valuable data. Patients with medically handicapped conditions or those unwilling to participate in the study were excluded. IDIs were conducted with 16 adult patients who had undergone treatment and those untreated for cleft lip and palate. KIIs were conducted with 11 key informants involved in cleft care services, including teaching faculty, orthodontists, speech therapists, cleft nurses, and project coordinators.

Key variables ascertainment

Cleft lip and cleft palate

A cleft lip is a gap or division in the upper lip caused by the inability to develop the facial tissues of an unborn baby to completely close. A cleft palate occurs when there is an opening in the roof of the mouth due to the failure of tissue to join during fetal development [11].

Barrier

Our participants experienced various levels of socio-cultural and socio-economic factors, certain personal factors and different self-perceived obstacles and challenges while seeking health care. Barriers to health care access are any physical, financial, social, or structural obstacles that restrict, delay, or prevent individuals from obtaining necessary medical services, evidence-based care, or health information [12].

Stigma

The negative attitudes or false beliefs associated with these specific traits, circumstances, or health symptoms were assessed among the participants. Stigma refers to a negative view, belief, or attitude towards an individual or group because of specific traits or characteristics, leading to discrimination and social disapproval [13].

Social stigma

Social stigmas within the participants were found as they were negatively discriminated against as normal due to their physical unattractiveness. According to the World Health Organization, social stigma involves negative associations between a person and a group sharing specific traits associated with a disease [14].

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

Characteristics		Total (n=105)	Treated (n=55)	Untreated (n=50)
Age group	Up to 24 years	52 (49.5)	14 (25.5)	38 (76.0)
	25 years and above	53 (50.5)	41 (74.5)	12 (24.0)
Sex	Female	43 (41.0)	21 (38.2)	22 (44.0)
	Male	62 (59.0)	34 (61.8)	28 (56.0)
Marital status	Unmarried	73 (69.5)	33 (60.0)	40 (80.0)
	Married/ divorce/ widow	32 (30.5)	22 (40.0)	10 (20.0)
Education	Up to secondary school	51 (48.6)	13 (23.6)	38 (76.0)
	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)
	Employed	33 (31.4)	19 (34.5)	14 (28.0)
Living area	Urban	67 (63.8)	36 (65.5)	31 (62.0)
	Rural	38 (36.2)	19 (34.5)	19 (38.0)

IDs and KIIs

For the IDs and KIIs, interview sessions were scheduled and conducted with each participant. The sessions continued until theoretical saturation was reached and sufficient data were collected. Empathetic neutrality was maintained throughout the procedures. Member checks were performed to verify the accuracy and credibility of the findings. Interviews were audio-recorded. Immediately after recording, transcription was done.

Ethical considerations

Ethical clearance to carry out the study was obtained from the IRB of Bangladesh Medical University. 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 study was voluntary, and participants had the right to withdraw at any time without affecting their regular treatment procedures.

Statistical analysis

Quantitative data were analysed using SPSS for Windows, Version 20.0. Characteristics of treated and untreated patients were expressed as percentages. The patient-perceived barriers related to treatments and

healthcare providers were expressed in numbers and percentages. The distribution of patient-perceived barriers across age categories, sex, cultural and socioeconomic factors, and personal factors affecting access to care and services was illustrated using bar diagrams. The perceived barriers from moderate to most were considered meaningful barriers. The transcribed data were coded, and themes were developed. Finally, data interpretation and concept development were carried out using thematic analysis. The emerging themes and subthemes were presented in tables with example quotes.

Results

Quantitative findings

Of the 105 study participants, 55 were in the treated group and 50 in the untreated group. Half of them were 25 years 59% were men, 69.5% were married, half had college level education, 68.6% were unemployed and 63.8% were from urban area (Table 1).

Participants' responses regarding obstacles to treatment and healthcare providers were according to five Likert scale responses (Table 2). Ninety-nine per cent (95% confidence interval, 97.1%–100.0%) experienced meaningful (moderate to most) treatment or provider-related barriers. The most common barriers included fear of unnecessary tests (67.6%), inability to visit the doctor regularly (65.7%), and fear of not receiving treatment from the same physician (61%). Other notable barriers were fear of being diagnosed with a complex illness (59.0%) and delays in treatment at the chamber (55.2%). A perceived lack of sincerity among physicians was reported by 2.9% of participants.

We observed a tendency for the barriers to cluster among participants. More than 16% of people had six or more barriers. However, there were hardly any perceivable differences between age (Figure 1) and sex groups (Figure 2) in barrier clustering.

Our assessment on socio-cultural, socio-economic barriers found that 70.3% of the patients faced stigmatization from both family members and the general public, suggesting that negative attitudes were prevalent regarding the illness, followed by financial problems (50.6%), blaming the mother about illness

Table 2 Patient perceived barriers related to the treatments and healthcare providers (n=105)

Barriers	Number (%)					
	No	Little	Moderate	Much	Most	Meaningful barriers ^a
Able to visit doctor regularly	7 (6.7)	29 (27.6)	58 (55.2)	5 (4.8)	6 (5.7)	69 (65.7)
Get treatment from same doctor	30 (28.6)	11 (10.5)	53 (50.5)	5 (4.8)	6 (5.7)	64 (61.0)
Get treatment without delay at chamber	17 (16.2)	20 (19.1)	54 (51.4)	4 (3.8)	–	58 (55.2)
Able to bear treatment expenditure	17 (16.2)	28 (26.7)	54 (51.4)	1 (1.0)	6 (4.8)	61 (58.1)
Fear of unnecessary tests prescribed	8 (7.6)	27 (25.7)	57 (54.3)	8 (7.6)	6 (4.8)	71 (67.6)
Fear of diagnosed with complex illness	16 (14.3)	28 (26.7)	54 (51.4)	3 (2.9)	5 (4.8)	62 (59.0)
Doctor is not sincere	96 (91.4)	6 (5.7)	2 (1.9)	1 (1.0)	–	3 (2.9)

^aModerate to most categories

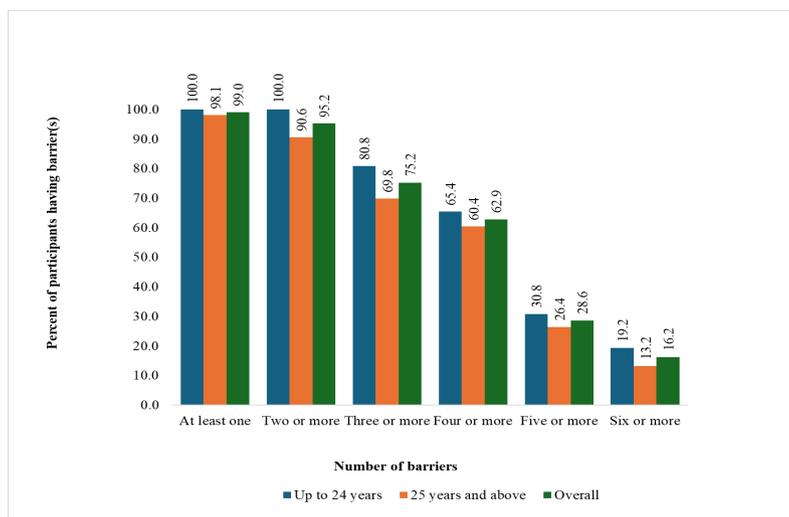


Figure 1 Distribution of patient perceived barriers according to age categories (n=105)

and misconceptions about a cure (40.7%), and (28.6%) religious belief about treatment (Figure 3). Additional factors at the individual's level in accessing healthcare services were work loss due to regular follow-ups (96.2%), a lack of transportation (96.2%), fear of street safety (53.3%), and responsibility for caring for someone else at home (26.7%).

IDIs

Findings of the IDIs and KIIs are summarised in Table 3. The thematic areas were as follows:

Stigmas and beliefs about cleft

The most common belief among our community members was that this type of cleft occurs when a pregnant woman cuts something with a knife during a solar eclipse. One patient explained, "My family members believe that my mother cut something with scissors or 'Boti' (a traditional Bangladeshi kitchen tool for cutting vegetables, fish, and meat) during the

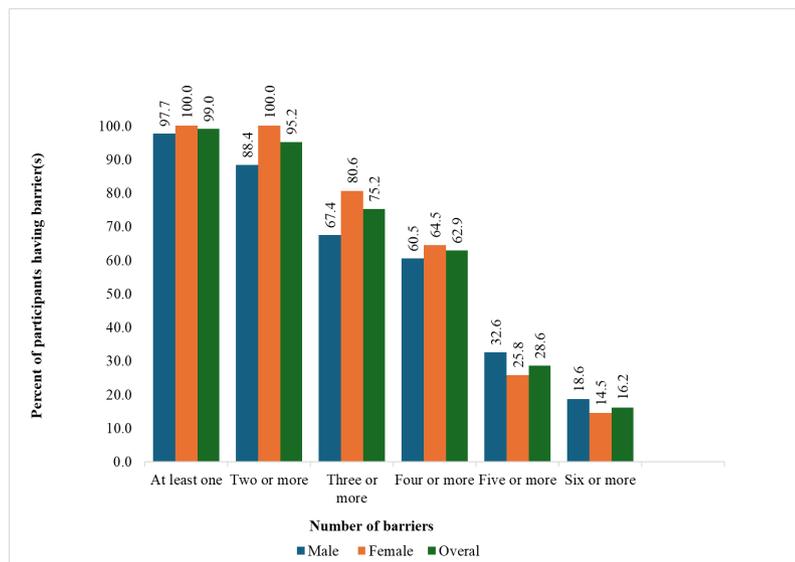


Figure 2 Distribution of patient perceived barriers according to sex (n=105)

lunar eclipse when she was pregnant." A few participants linked the CL/P condition to curses and evil spirits. One patient also shared that some people in her community did not consider her a human being after her birth. According to her, "They said that it was a curse and people asked to kill me by burying me." Besides several misconceptions, some participants firmly believed that the occurrence of clefts was God's will.

Barriers related to the decision-making for seeking treatment

Almost all decisions regarding cleft surgery were made by the family, although the mother's role was more significant in most cases. When it came to orthodontic treatment, decisions were made through family discussions, with the main concerns being the girls' prospects for a better life and marriage. Most respondents did not face any obstacles when deciding to undergo treatment, although a few encountered situations where they were forbidden or discouraged from doing so. One patient mentioned, "My relatives tell me that this is God gifted, and you will commit sin by altering this."

Lack of awareness and proper information

Lack of awareness, available healthcare options, and proper information were identified as major barriers to accessing treatment, especially for those living in remote areas. One participant mentioned, "General people like us don't have enough knowledge regarding these treatments. We faced issues due to insufficient information and communication gaps despite spending a lot of money." Another participant stated that, although I was a medical student, I did not know much about cleft treatments. More awareness needs to be raised at all levels.

Longer treatment time

Almost all participants reported that orthodontic treatment takes too long and faced obstacles in continuing the scheduled process, including increased travel expenses. As one participant mentioned, "Regular visits are somewhat troublesome as this involves the travel costs combined with orthodontic treatment costs."

Lack of financial support

Most respondents were from lower-middle or middle-class families; therefore, they faced financial difficulties during certain aspects of their treatments. One participant stated, "The cosmetic treatments are not affordable for our socioeconomic status." Another mentioned, "It is very expensive for my family. I still don't have my own income sources and depend on my father's income."

Health system responsiveness

A few respondents shared their experiences at the doctor's office. One of them mentioned, "In fact, the doctor didn't even give us 10 minutes for a check-up! A lot of people were there; the doctor didn't even speak well."

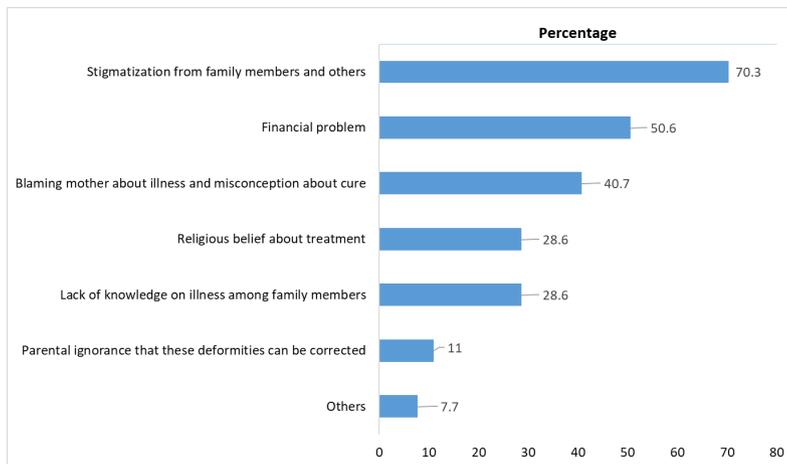


Figure 3 Socio-cultural and economic barriers to access healthcare services

KIIs

1. Experience related to the delivery of services

Service providers from different institutions shared that many patients belonged to the lower and middle classes and lived in remote areas. There is a high level of information gap about cleft treatment, including treatment unavailability, lack of standard treatment protocols, and the necessity of speech therapy centres for cleft patients. As one of the KIIs said, "Many patients come for treatments at the age of 15-16 years and express regret for not knowing earlier about the services." They also shared that the time-consuming procedures involved in speech therapy and orthodontic treatments often lead to their dropout before the completion of the treatments. As one KI said, "Patients initially show a lot of interest in receiving treatment, but when they face difficulties like the long distance of the hospital from the locality, travel expenses, and time-related aspects of the procedures, they discontinue the treatment. Some prejudices also exist among patients toward people from the upper class, believing that spending more money provides them with better services."

2. Limitations in existing services

The KIIs reported that, despite the presence of some well-structured facilities in Dhaka city, those who require orthodontic care, speech therapy, and other treatments face problems with the services. One KI mentioned, "Sometimes, we also face problems due to the overflow of patients. In some instances, patients leave without receiving any care." In addition, the KIIs report the lack of manpower, a shortage of resources, including equipment, the lengthy official demand and supply procedures, scheduled treatment, and space problems as barriers to service delivery.

3. Key informants' experience regarding the role of existing stigmas as barriers

All KIIs believe that a person's treatment-seeking behaviours vary according to the social and cultural norms, beliefs, stigmas, and level of education. One KI explained a cleft patient's mother's sorrow by saying, "Her relatives try to convince her that it is a God-gifted

problem, and it would be wrong if she goes against the will of God! They asked her to leave it as it is and keep faith in destiny."

Discussion

Barriers related to CL/P profoundly affect individuals and their families, leading to social rejection and difficulties accessing healthcare and education. Our quantitative study found that almost all the participants faced more than one barrier related to their treatments and healthcare providers. Fear of undergoing unnecessary tests advised by physicians, the costs of these tests, and the inability to visit a doctor regularly were found to be major barriers. Scheduling difficulties in receiving treatment from the same doctors, as well as prolonged waiting room time, were also found. A study conducted at the eleven different governmental health care centres across Saudi Arabia reported that sometimes/often, not receiving the required medical care was due to scheduling difficulties, prolonged waiting room time, and transportation difficulties [15]. A study found that a lack of hospitals providing the surgery in their areas was perceived by patients barrier [16]. Although one of the main obstacles among our study participants was the fear of having unwanted tests recommended by the doctor, this kind of patient perception might also apply to other medical conditions also which needs further exploration.

Cultural factors are inherently involved in shaping maternal reactions to childbirth, and our analysis of barriers on socio-cultural, socio-economic factors found stigmatisations from family members and blaming mothers for illness as major barriers. Social stigma varies according to context and is influenced by cultural views on the cleft. In developing countries where prenatal care is less advanced, a CL/P is usually unpredictable, and families have more faith in religion and folklore than in medical explanations to explain the deformity. Such faiths include the causation of clefts as sins from a past life, witchcraft, God's will, and engaging in behaviour associated with causal power. Responses to physical deformities are influenced significantly by beliefs and attitudes and have a profound impact on the affected individual and his/her family [17] and myths that CL/P occurred when mothers observed the eclipse during pregnancy [18].

While assessing personal factors, our quantitative study found transportation problems and work responsibilities as major barriers. A represented the diverse regions of the Arab Gulf, North Africa, and South Asia, who found traveled long distances for care and missed appointments due to work commitments were major barriers [19]. Similar findings were also found from our qualitative IDIs and KIIs, where cultural norms, beliefs, stigmas, especially blaming mothers for these problems, lack of financial support, and limited caregivers' awareness and knowledge were reported as barriers. Reaching care was also

Table 3 Five major and 12 sub-themes according to in-depth interviews

Major themes	Subthemes	Description/ example quotes
Theme 1: Health and treatment-related information	1. Difficulty in eating	"My cleft makes it difficult for me to chew or swallow hard things like fish bones, meat, or medication in tablet form. I usually take syrup rather than tablets when I have a fever or cold-related symptoms."
	2. Cleft surgery	"I had a total of 5 surgeries under a surgical team that came from Japan. Among them, I underwent three operations up to third grade."
	3. Difficulty in speaking	"When I speak, the air is expelled through my nose, which means I have a nasal voice, which makes it a little difficult to speak normally. When I go to do something in front of people, I feel a little hesitant about whether they will understand me or not."
	4. Orthodontic problems	"One of the things I often heard was, "Hey, your teeth are crooked, when will you treat them."
Theme 2: Experiences related to the stigma and health conditions	1. Emotional experiences friends, or the public	"People often ask me about the abnormality of my appearance. It's true that I feel a lot of pain inside, and I also feel depressed when I'm alone, but I always try to handle situations normally. I feel upset thinking about why this has happened to me!"
	2. Reactions from family	"My neighbours, relatives, even my cousins bullied me... I am fed up with hearing all these...people commented negatively while I was receiving treatments...they also comment negatively when I'm discontinuing all those..."
	3. Anxiety for the future	"When my relatives discuss my marriage issue, they advise me that I have to sacrifice more than others because I have a problem."
	4. Beliefs about the causes of clefts	"People blamed my mother for the clefts, saying that she cut something using a knife during an eclipse, and that was the main reason behind the development of my problems."
Theme 3: Factors related to the decision-making for seeking treatment	-	"People in my community said, it is a gift from God, it should be preserved as such, and there is no need for treatment."
Theme 4: Barriers to treatment seeking	1. Lack of awareness and proper information	"We had more issues with insufficient information and communication in spite of spending a lot of money."
	2. Scheduled treatment process	"Regular visits for the orthodontic treatment at an interval of 21 days are somewhat troublesome for me. The travel and orthodontic treatment costs are so expensive considering my socioeconomic status."
	3. Lack of financial support	Though treatment may be free at Government Medical hospitals, the medicine, accommodation, and food still matter. Because we don't have any relatives to stay with in Dhaka, everything becomes a challenge for us."
	4. Health system responsiveness	"In fact, the doctor didn't even give us 10 minutes; a lot of people were there; the doctor didn't even speak well, mostly."
Theme 5: Opinion regarding the treatment strategies and existing facilities	-	"I am satisfied with the treatment, but I think that even as a medical student, I did not know much about cleft palate treatment, so how will general people get the information about this. That means we need to raise more awareness about this."

impeded by prolonged treatment duration, long distances and inadequate transportation options. A qualitative study conducted across six operation smile-supported hospitals in low- and middle-income countries found barriers such as limited caregiver awareness, cultural beliefs, long distances, poor road infrastructure, and inadequate transportation options [20]. While others named mothers for several potential causes of the defect or abnormal conditions [21].

Certain barriers encountered at various levels and the treatment-related challenges faced by adult CL/P patients have not been the focus of any previous research in Bangladesh. The selection of study participants through purposive sampling enabled the inclusion of cleft patients based on specific characteristics or criteria relevant to the study's objectives. As it was a cross-sectional study, causal relationships cannot be established, but this research

may help address the multifactorial challenges that cause delays in timely treatments, which can lead to lifelong consequences for patients in low- and middle-income countries. This approach also allows researchers to identify, analyse, and mitigate these obstacles—ranging from lack of awareness to economic constraints—thus improving access to care and supporting comprehensive treatment planning.

Conclusion

The barriers related to CL/P pose significant challenges for affected individuals and their families, requiring public health care providers to intervene by educating society about the natural causes and straightforward management of these conditions, thereby substantially increasing opportunities for patients.

Acknowledgements

We are grateful to the study subjects for their cooperation and active participation, which helped achieve the desired outcomes. We are in debt to the authorities, employees and staff of the department of Orthodontics, faculty of Dentistry of Bangabandhu Sheikh Medical University, Sheikh Hasina National Institute of Burn and Plastic Surgery and Bangladesh Specialised Hospital, Dhaka, Bangladesh, for their sincere and whole-hearted cooperation.

Author contributions

Concept or design of the work; or the acquisition, analysis, or interpretation of data for the work: TR, RI, SA, SMS. *Drafting the work or reviewing it critically for important intellectual content:* TR, RI, SMS, SA, GSH. *Final approval of the version to be published:* TR, RI, SA, SMS, GSH. *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:* TR, RI, SA, SMS, GSH.

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.

AI disclosure

None

Supplementary file

None

References

- Salari N, Darvishi N, Heydari M, Bokaei S, Darvishi F, Mohammadi M. Global prevalence of cleft palate, cleft lip and cleft palate and lip: A comprehensive systematic review and meta-analysis. *J Stomatol Oral Maxillofac Surg.* 2022 Apr;123(2):110-120. doi: <https://doi.org/10.1016/j.iormas.2021.05.008>
- Cleft Bangladesh. Available at: <https://www.cleftbangladesh.org/patient-information/about-cleft/overview.html>. [Accessed on 24 Mar 2026]
- Chung KY, Sorouri K, Wang L, Suryavanshi T, Fisher D. The Impact of Social Stigma for Children with Cleft Lip and/or Palate in Low-resource Areas: A Systematic Review. *Plast Reconstr Surg Glob Open.* 2019; 7(10):2487. doi: [10.1097/GOX.0000000000002487](https://doi.org/10.1097/GOX.0000000000002487)
- Al-Namankany A, Alhubaishi A. Effects of cleft lip and palate on children's psychological health: A systematic review. *J Taibah Univ Med Sci.* 2018; 13(4):311-318. doi: [10.1016/j.jtumed.2018.04.007](https://doi.org/10.1016/j.jtumed.2018.04.007)
- Hunt O T, Burden D, Hepper p, Johnston T. The psychosocial effects of cleft lip and palate: A systematic review. *The European Journal of Orthodontics.* 2005; 27(3):274-285. doi: [10.1093/ejo/cji004](https://doi.org/10.1093/ejo/cji004)
- Wilson W L, Chai K C. Cleft craniofacial care in Asia—a narrative review. *Frontiers of Oral and Maxillofacial Medicine (FOMM).* 2024; 6: 1-9. Available at: <https://fomm.amegroups.org/article/view/76133/html>. [Accessed on 24 Mar 2026]
- Rabah SM, Sabbagh HJ, AlZabin A, Almajed E, Albrahim R, Aldawish R, Alyahiwi L, Alshabnan R, Helal NM, Khan MA, Yousaf MA, Refahee SM, Koraitim MM, Kasem Albadani MS, Khader YS, Al Halasa TK, Al-Batayneh OB, Albatayneh MA. Parental knowledge and barriers to cleft lip and palate care: a cross-cultural study from the Middle East and South Asia. *Front Public Health.* 2026 Jan 9;13:1691553. doi: [10.3389/fpubh.2025.1691553](https://doi.org/10.3389/fpubh.2025.1691553)
- Kowal P, Chatterji S, Naidoo N, Biritwum R, Fan W, Lopez Ridaura R, Maximova T, Arokiasamy P, Phaswana-Mafuya N, Williams S, Snodgrass JJ, Minicuci N, D'Este C, Peltzer K, Boerma JT; SAGE Collaborators. Data resource profile: the World Health Organization Study on global AGEing and adult health (SAGE). *Int J Epidemiol.* 2012 Dec;41(6):1639-1649. doi: [10.1093/ije/dys210](https://doi.org/10.1093/ije/dys210)
- Khogeer L, Helal N, Basri O, Madani S, Basri A, El-Houseiny AA. Instrument Development and Validation to Assess Care Barriers for Patients in Saudi Arabia with Oral Clefts. *Int J Environ Res Public Health.* 2021 Mar 25;18(7):3399. doi: [10.3390/ijerph18073399](https://doi.org/10.3390/ijerph18073399)
- Adeyemo, Wasiu L; James, Olutayo; Butali, Azeze1. Cleft lip and palate: Parental experiences of stigma, discrimination, and social/structural inequalities. *Annals of Maxillofacial Surgery,* 2016; 6(2):195-203. doi: [10.4103/2231-0746.200336](https://doi.org/10.4103/2231-0746.200336)
- Scott C. Litin, M.D. Mayo Clinic Family Health Book, Fifth Edition, [New York] : Time Inc. Home, 2018. Available at: <https://www.amazon.com/Mayo-Clinic-Family-Health-Book/dp/1945564024>. [Accessed on 24 Mar 2026]
- Nachiappan N, Mackinnon S, Ndayizeye JP, Greenfield G, Hargreaves D. Barriers to accessing health care among young people in 30 low-middle income countries. *Health Sci Rep.* 2022 Jul 20;5(4):e733. doi: [10.1002/hsr2.733](https://doi.org/10.1002/hsr2.733)
- Chopra KK, Arora VK. Covid-19 and social stigma: Role of scientific community. *Indian J Tuberc.* 2020 Jul;67(3):284-285. doi: [10.1016/j.ijtb.2020.07.012](https://doi.org/10.1016/j.ijtb.2020.07.012)
- Bruns DP, Kraguljac NV, Bruns TR. COVID-19: Facts, Cultural Considerations, and Risk of Stigmatization. *J Transcult Nurs.* 2020 Jul;31(4):326-332. doi: [10.1177/1043659620917724](https://doi.org/10.1177/1043659620917724)
- Almazrou SH, Alfaihi SI, Alfaihi SH, Hakami LE, Al-Aqeel SA. Barriers to and Facilitators of Adherence to Clinical Practice Guidelines in the Middle East and North Africa Region: A Systematic Review. *Healthcare (Basel).* 2020; 8(4):564. doi: [10.3390/healthcare8040564](https://doi.org/10.3390/healthcare8040564)
- Citron I, Neto JB, Costa E, Lima C, Ise A, Menezes C, Roa L, Saluja S, Staffa SJ, da Silva Freitas R, de Andrade Sá AJ, Rocha F, Collares MV, Alonso N. Patient-perceived barriers to surgical treatment of cleft lip and palate in Brazil: A multi-region study. *J Plast Reconstr Aesthet Surg.* 2022 Jul;75(7):2375-2386. doi: [10.1016/j.jbpts.2022.02.009](https://doi.org/10.1016/j.jbpts.2022.02.009)
- Balaji SM. Burden of Orofacial Clefting in India. *A Global Burden of Disease Approach.* *Ann Maxillofac Surg.* 2018; 8(1):91-100. doi: [10.4103/ams.ams.196.17](https://doi.org/10.4103/ams.ams.196.17)
- Turlapati S, Krishna S, Deepak KU, Kanagaraja B, Gayathri KA, Jahagirdar D. A Cross-Sectional Study: Are Myths on Cleft Lip and Palate Still Prevalent? *Cureus.* 2021 Nov 14;13(11):e19579. doi: [10.7759/cureus.19579](https://doi.org/10.7759/cureus.19579)
- Rabah SM, Sabbagh HJ, AlZabin A, Almajed E, Albrahim R, Aldawish R, Alyahiwi L, Alshabnan R, Helal NM, Khan MA, Yousaf MA, Refahee SM, Koraitim MM, Kasem Albadani MS, Khader YS, Al Halasa TK, Al-Batayneh OB, Albatayneh MA. Parental knowledge and barriers to cleft lip and palate care: a cross-cultural study from the Middle East and South Asia. *Front Public Health.* 2026 Jan 9;13:1691553. doi: [10.3389/fpubh.2025.1691553](https://doi.org/10.3389/fpubh.2025.1691553)
- Mukanahayo E, Umugwaneza O, Mukundwa PN, Sheferaw ED, Riviello R, Dukundane A, Murithi G, Ntiringanya F, Alayande B. Barriers and delays in access to cleft surgery among children with cleft deformities in Rwanda: a qualitative study. *BMJ Open.* 2026; 16(1):112929. doi: [10.1136/bmjopen-2025-112929](https://doi.org/10.1136/bmjopen-2025-112929)
- Nguyen VT, Jagomägi T, Van TN. Maternal Experiences of Having a Child with a Cleft. *J Otol Rhinol.* 2018; 7(3). doi: [10.4172/2324-8785.1000343](https://doi.org/10.4172/2324-8785.1000343)