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Families' experiences regarding cleft lip and palate management in Egypt: A cross sectional study

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Abstract

Objective: To report the experiences of parents for cleft lip and palate children throughout their treatment journey. Additionally, to identify the presence or absence or organized healthcare services for the cleft lip and palate patients in terms of parents' awareness about the condition and its management, as well as the presence of medical referrals between the specialists. Moreover, to highlight the obstacles that could be faced by the patients along the treatment journey.

Design: Cross-sectional survey.

Setting: The Department of Orthodontics, Faculty of Dentistry, Cairo University and Abouelreish Children Hospital, Cairo University, Egypt.

Participants: 125 Parents for Egyptian patients with unilateral or bilateral complete cleft lip and palate, with age > or = 6 years old were included in the study.

Intervention: The parents were asked to fill a questionnaire that was designed to gather information regarding the the mentioned objectives.

Results: 92% of the parents reported that they couldn't afford the treatment procedures that were needed throughout their children's' timeline. 95% of the families didn't know the meaning of a specialized cleft center and 98.4% said that their children haven't been referred to a cleft center before. 71% of the families reported that they don't know the interdisciplinary treatment team-based approach for management of cleft lip and palate patients. 47% of the included sample reported that they weren't guided with medical referrals between the different medical specialists.

Conclusion: The overall parents' experiences are complex and reflect that cleft care require a lot of improvement in our country to meet the parents' expectations.

Parents' knowledge regarding cleft care is considered deficient.

Parents reported the unmet need for an organized medical referral system, clear roadmap of treatment, further financial and social support as well as more awareness about the condition and the phases of treatment.

Keywords: Cleft lip, cleft palate, cleft lip and palate, congenital anomalies, Orofacial cleft, interdisciplinary treatment, healthcare services

Abbreviation: CLP: Cleft lip and palate

Introduction

Congenital anomalies or birth defects are structural or functional abnormalities which develop prenatally and are present to deal with from birth. They mark one of the major challenges to all practitioners starting from accurate diagnosis to proper treatment ^[1]. Without any doubt, birth defects impose a great challenge to the patients and their families as well ^[2].

Congenital anomalies could be classified according to their medical, social, and esthetic consequences into major and minor congenital anomalies ^[1]. Major congenital malformations lead to significant impairment in the neonatal period and require extensive treatment.

Oro-facial clefts are considered of the major, complex congenital anomalies that impacts the physical health, in addition to the psychological, and social well-being of afflicted individuals as well as their suffering families ^[1]. We can picturize orofacial clefts as deformities that could be seen, heard and felt.

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The key behind the proper management of oro-facial clefts lies in the presence of collaborative teamwork which includes various medical and non-medical specialists.

Since 1943, the American Cleft Palate Craniofacial Association has been emphasizing the importance of this team-oriented approach throughout managing cleft patients [3]. Another major difficulty could be the long treatment journey that awaits any cleft patient which extends from the initial diagnosis till adulthood passing through a lot of surgical and nonsurgical procedures. Indeed, this requires a well-defined and organized roadmap that encompasses all the treatment stages in- order to provide a satisfactory treatment outcome without missing any important stop throughout that journey.

Taking a sight at the treatment approach that is being implemented in our developing country concerning the cleft lip and palate patients reveals that the literature is insufficient regarding reporting the treatment protocols that are being followed. Patients experiences throughout their long journey remain unrevealed. As healthcare providers, we can obviously feel some gaps in the field of cleft care, however there's no evidence that highlights the obstacles that could be faced in this aspect. These gaps could be claimed to be due to the absence of the communication or referrals among specialists, insufficient medical training, perhaps the incomplete knowledge of some healthcare workers, and maybe the lapse of deficient clarification and explanation to the families regarding how this condition should be managed leading to their lack of awareness. Subsequently, evidence is needed to identify the real obstacles that could be facing the healthcare providers and the cleft patients.

Research work in the field of cleft care should be directed to report the CLP treatment approach that is being followed in our country, this could be achieved through exploring the actual experiences lived by the parents, hoping to highlight the key challenges faced by the patients along their journey. The intention behind this work is to mark the gap between the patients' expectations and reality regarding the quality of cleftcare in Egypt.

Objectives

1. Identify the presence or absence or organized healthcare services for the CLP patients in terms of parents' awareness about the condition and its management, as well as the presence of medical referrals between the specialists.
2. Reporting the patients/parents' experiences throughout their treatment journey.
3. Highlight the obstacles that could be faced by the patients along the treatment journey

Materials and Methods

This study was designed as an observational, cross-sectional, questionnaire-based, descriptive study. The study proposal was reviewed and approved by the Research Ethics Committees of the Faculty of Dentistry, Cairo University, Egypt. It took place in the Department of Orthodontics, Faculty of Dentistry, Cairo university and Abouelreish Children Hospital, Cairo University. 125 Parents for Egyptian patients with unilateral or bilateral complete cleft lip and palate, with age $>$ or $=$ 6 years old were asked to fill a

questionnaire that was designed to gather information regarding the the mentioned objectives.

Questionnaire Design

Three main domains were covered in the parents' questionnaire including: Demographic data, General knowledge, and Healthcare service organisation. (Fig 3 and 4) The first section of the questionnaire aimed to gather demographic data of the CLP patients through their participating parents including gender, date of birth, governorate, cleft phenotype, educational background, and socioeconomic level.

The second section aimed to assess the general knowledge of the parents regarding the interdisciplinary treatment approach that should be followed with their CLP children and if they've been referred to a cleft center before.

The third section of the questionnaire aimed to assess the organization of healthcare services in terms of medical referrals and presence, or absence of CLP team-based treatment approach were assessed.

Moreover, the level of satisfaction of the parents with the level of healthcare services, and the treatment outcomes were questioned. Lastly, the parents were asked if they wanted to change something in their past journey what would it be?

Administering the Questionnaire

Parents' responses were recorded through interviews with the principal investigators. The reponses were recorded via SurveyMonkey website which allowed for easier analysis and interpretation of data.

Results

Demographic Data

- Names and telephone numbers were recorded optionally
- Date of birth:

The sample included parents for patients with age range 6-29 years old.

Classification

41.8% of the participants had a child born with bilateral complete cleft lip and palate, while 58.2% had a child born with unilateral complete cleft lip and palate. (Fig 1).

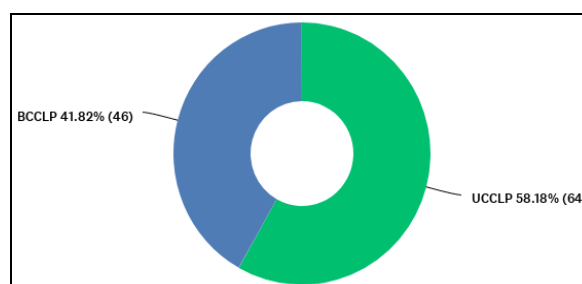


Fig 1: Cleft phenotypes of the included patients

Geographic Distribution

34.4% of the sample were families from Giza governorate, 20.8% were from Cairo governorate. The rest of the families presented from governorates all over Egypt. (Fig 2)

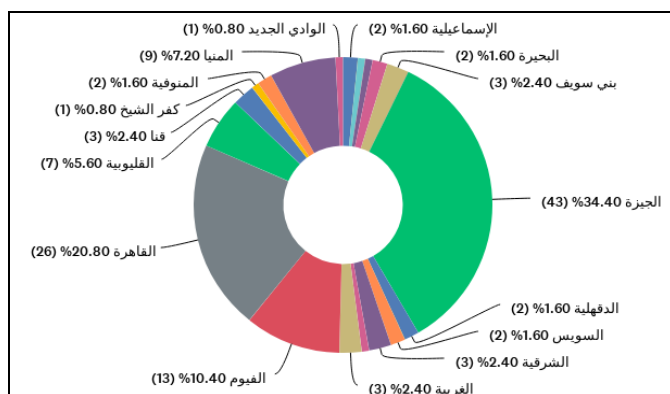


Fig 2: Geographic Distribution of the included sample

Socio-economic Background

92% of the parents reported that they couldn't afford the surgical/non-surgical procedures that were needed throughout their children's timeline.

73% of the families reported that they have received financial support in this aspect from governmental and non-governmental organizations.

The educational background of the included sample was variable. (Table 2)

General Knowledge

- 95% of the families didn't know the meaning of a specialized cleft-craniofacial anomalies center and 98% said that their children haven't been referred in such a center before.
- 71% of the families reported that they don't know the interdisciplinary treatment team-based approach for management of CLP patients, while 87% couldn't identify any of the specialists who should participate in such team.
- 77% couldn't know the role of the orthodontist in CLP management though 43% reported that their children have been previously referred for orthodontic treatment.
- 88% of the families couldn't identify the medical specialists that their children might need to be referred to. (Table 3)

Healthcare Services Organization

- 98.4% of the families reported that they haven't been referred before to a cleft center. (Table 4)
- Prenatal diagnosis was reported in 6.5% of the sample only. (Table 5)
- In the aspect of education and awareness, 91% of the families said that they weren't provided with any educational instructions or information manuals to help them deal properly with such condition. (Table 6)
- 47% of the included sample reported that they weren't guided with medical referrals between the different medical specialists.
- Referrals to the orthodontists were the most common (43%) followed by referrals to the plastic surgeons (17%).
- The most common timing for orthodontic referrals is reported to be around 6-9 years. (Table 7)
- Parents seem to be dissatisfied with the level of healthcare services that are being offered for their children in our country; on a 5-point Likert scale 24% rated their satisfaction level as 1, 32.8% gave it a rating of 2, 28.8% rated it as 3, 8.8% rated 4, and 5.6% rated it as 5.

- Parents seemed to be dissatisfied with the treatment results of their children; on a 5-point Likert scale 28.2% rated their satisfaction level as 1, 29.8% gave it a rating of 2, 24.2% rated it as 3, 11.3% rated 4, and 6.5% rated it as 5. (Table 8)
- Bullying is a common social problem that affects the children with CLP as reported by 78% of the participants. (Table 9)
- All families hoped for the presence of a clear road map of treatment and an awareness plan since the early stages of diagnosis. Also, they demanded more financial and social support, in addition to the presence of medical referrals. (Table 10)

Discussion

The interdisciplinary team-based approach of treatment is the key behind successful cleft lip and palate management.³ The cascade of treatment shouldn't be interrupted at any timepoint to guarantee optimal treatment outcomes^[4]. The results of this study provide insight into the lived experiences by parents of children older than years born with unilateral or bilateral complete cleft lip and palate. The low socioeconomic level of the families was reflected through their responses as they couldn't afford the surgical/non-surgical procedures that were needed throughout their children's timeline. Previous studies have revealed that the socioeconomic status could highly impact the access to cleft care^[5].

In the present study the educational background of the included sample was variable, and it couldn't be correlated with the lack of knowledge of the families towards the proper management of cleft lip and palate patients.

The absence of basic knowledge was clearly reflected through the parents' responses regarding the meaning of specialized cleft-craniofacial anomalies centers or the concept of interdisciplinary treatment approach for management of cleft lip and palate cases. Additionally, the majority couldn't identify any of the specialists that their children might need to be referred to.

Moreover, their knowledge was revealed to be deficient regarding comprehending the objectives of orthodontic treatment to their children even if they have performed it previously, this could signify that families aren't provided with enough explanation and clarification about the objectives behind the treatment. Parallel studies in other countries reported the parents' limited knowledge towards orthodontic care^[6].

The absence of the medical referrals among the various specialists was noted in many cases,

Referrals to the orthodontists are the most common (43%) followed by referrals to the plastic surgeons (17%) this can reflect that cleft care in Egypt could be based on surgical interventions and orthodontic treatment only.

The most common timing for orthodontic referrals is around 6-9 years as reported by the parents.

In the aspect of education and awareness, 91% of the families said that they weren't provided with any educational instructions or information manuals to help them deal properly with such condition.

Prenatal diagnosis of clefts was rare in the included sample. This reflects the limited scope of prenatal diagnosis of such a condition in our country which leads to the absence of early organized plans of treatment as well as the lack of psychological adaptation of the families. This was revealed through the parents' interviews, "His mother and grandmother lost their consciousness when they saw the baby, nobody told

us where we should go” father of a 10-year-old boy with unilateral CLP, Egypt).

Parents seem to be dissatisfied with the level of healthcare services that are being offered for their children in our country, in addition to their dissatisfaction with the treatment results of their children. This could signify that cleft care in Egypt requires a lot of improvement.

Bullying was reported to be a common social problem that affects the children with CLP in our country as reported by 78% of the participant. This could be attributed to the lack of social awareness regarding the condition and the overall compromised treatment outcomes that renders the affected individuals different among their peers. Other researchers have reported that bullying presents a common daily obstacle that cleft patients might face due to their facial difference [7].

The families hoped for the presence of a clear road map of treatment and an awareness plan since the early stages of diagnosis. Also, they demanded more financial and social

support, in addition to the presence of medical referrals. “I’d seek any chance to see my son improving through treatment, if we have to go from one place to another, knock on doors and spend all the money that we have, we’d do so, but I really wished if we were provided with any awareness or support from the beginning” (mother of a 16-year-old boy with unilateral CLP, Egypt).

Table 1: Overview of research methodology for this study

Research purpose	Descriptive
Research strategy	Survey
Data collecting technique	Questionnaire
Procedure to administer questionnaire	Structured interview
Designing questionnaire	Developing new questionnaire
Types of questions	5 point Likert scale – close ended questions

Parents for Cleft Lip and Plate Children Questionnaire				
Demographic Data				
Name:	DOB:	Cleft type: UCCLP/BCCLP	Geographic distribution:	
Question		Yes	No	
1. Were you able to afford all the financial costs of the surgical/non-surgical procedures throughout the treatment journey?				
2. If yes, have you received any governmental/non-governmental funds?				
Question	I'm Uneducated	Primary Education	Secondary Education	Higher Education
3. Which level of education have you received?				
General Knowledge				
Question		Yes	No	
4. Do you know what a craniofacial anomalies center is?				
5. Do you know about cleft lip and palate patients' treatment team approach?				
6. Do you know what the role of the orthodontist in such a team is?				
7. Do you know which medical specialties does your child need to be referred to?				
Healthcare Services Organization				
8. Have you ever been referred to any cleft center? (Please specify)				
9. Was your child diagnosed prenatally?				
10. Which specialists had your child been referred to previously?				
<ul style="list-style-type: none"> ○ Dentist ○ Pediatric dentist ○ Pediatrician ○ Orthodontist ○ Oral and maxillofacial surgeon ○ Prosthodontist ○ Otolaryngologist ○ Plastic surgeon ○ Speech therapist ○ Psychiatrist ○ Psychologist ○ Social worker 				

Fig 3: Questionnaire design

Parents for Cleft Lip and Plate Children Questionnaire											
<input type="radio"/> All of the above <input type="radio"/> Others											
Question	Just after birth	1 month after birth	3 months after birth	1 year after birth	6-9 years	12 years	After 13 years	My child wasn't referred			
11. When was your child referred to an orthodontist?											
Question							1	2	3	4	5
12. From your perspective to what extent are you satisfied with the level of healthcare services provided to CLP patients in Egypt? On a 5-point Likert scale (1= very dissatisfied, 5= very satisfied)											
13. From your perspective to what extent are you satisfied with your child's treatment results? On a 5-point Likert scale (1= very dissatisfied, 5= very satisfied)											
Question					Yes	No	I don't know				
14. Does your child experience bullying?											
15. If you wanted to change something in your child's treatment journey, what would it be?											
More awareness	Less waiting time	Financial support	Social support	Presence of medical referrals	Presence of a clear roadmap	All of these					

Fig 4: Questionnaire design

Table 2: Families' Socioeconomic background

Question			Yes	No	
1.	Were you able to afford all the financial costs of the surgical/ non-surgical procedures throughout the treatment journey?		8%	92%	
2.	If yes, have you received any governmental/non-governmental funds?		73%	27%	
	Question	I'm Uneducated	Primary Education	Secondary Education	Higher Education
3.	Which level of education have you received?	30%	19%	34%	17%

Table 3: General knowledge of the parents towards cleft care

Question	Yes	No
1. Do you know what a craniofacial anomalies center is?	5%	95%
2. Do you know about cleft lip and palate patients' treatment team approach?	29%	71%
3. Do you know what the role of the orthodontist in such a team is?	23%	77%
4. Do you know which medical specialties does your child need to be referred to?	12%	88%

Table 4: Cleft centers that the patients were referred to before

Question	Yes	No
1. Have you ever been referred to any cleft center? (Please specify) The following answer was recorded: ▪ Innovinity Center	1.6%	98.4%

Table 5: % of families who discovered the condition prenatally.

Question	Yes	No
1. Was your child diagnosed prenatally?	6.5%	93.5%

Table 6: Timing of orthodontic referrals as reported by the parents.

Question	Yes	No
1. Were you provided with any educational instructions or information manuals to help you deal properly with your child?	9%	91%

Table 7: Timing of orthodontic referrals as reported by the parents.

Question	Just after birth	1 month after birth	3 months after birth	1 year after birth	6-9 years	12 years	After 13 years	My child wasn't referred
When was your child referred to an orthodontist?	11%	4%	1%	2.4%	25%	12%	9%	40%

Table 8: Parents' satisfaction levels

Question	1	2	3	4	5
1. From your perspective to what extent are you satisfied with the level of healthcare services provided to CLP patients in Egypt? On a 5-point Likert scale (1= very dissatisfied, 5= very satisfied)	24%	32.8%	28.8%	8.8%	5.6%
2. From your perspective to what extent are you satisfied with your child's treatment results? On a 5-point Likert scale (1= very dissatisfied, 5= very satisfied)	28.2%	29.8%	24.2%	11.3%	6.5%

Table 9: % of CLP children who experience bullying as reported by their parents.

Question	Yes	No	I don't know
2. Does your child experience bullying?	78%	14%	8%

Table 10: Improvements that the parents wished for along their journey

1. If you wanted to change something in your child's treatment journey, what would it be?						
More awareness	Less waiting time	Financial support	Social support	Presence of medical referrals	Presence of a clear roadmap	All of these
21.6%	19%	7.5%	16.5%	21.6%	20%	73%

Conclusion

- The treatment procedures seem to be unaffordable by the CLP patients' families which reflects the low socioeconomic status of CLP patients in Egypt.
- No correlation could be established between the educational background of the families and their knowledge regarding the interdisciplinary treatment approach for cleft care.
- Parents' knowledge regarding cleft care is considered deficient.
- Parents reported the unmet need for an organized medical referral system, clear roadmap of treatment, further financial and social support as well as more awareness about the condition and the phases of treatment.

Recommendation

- Patients' awareness plans should be initiated and implemented among the public hospitals to combat their concerns.
- Centralizing cleft care to a limited number of prominent tertiary healthcare facilities across Egypt would help in standardizing a treatment protocol for managing CLP patients.
- A registry is highly needed in Egypt to maintain the patients records and lay a foundation for future research in this field.

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Not available

Conflict of Interest

Not available

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Not available

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