



# The quality of life after cleft lip and palate surgery

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## Abstract

**Background and aims.** Labio-maxillo-palatal clefts represent one of the most common congenital malformations, which manifests through aesthetic, functional and psycho-social alterations. The long course of multidisciplinary treatments represent a psycho-emotional and financial burden for both the patient and his family, being an important factor in the complex management of these patients.

The study aims to assess the quality of life of parents of children with clefts and the psychosocial impact on the family and society.

**Methods.** The study included 40 subjects who met the inclusion criteria for this study. Following patient informed consent and the approval of the ethics committee, the data were collected by applying the quality-of-life evaluation questionnaire. The evaluation was performed using the Likert scale (1 - not at all to 5 - very satisfactory), and the data were statistically processed.

**Results.** Most of the questionnaires were completed by the mother, who accompanied the child to the regular check-up; 58% of parents believe that their social life is not affected by having a child with a cleft, and 83% say that interfamilial relationships have not been affected. Most parents consider that the postoperative result was very good, which led to improved psycho-social integration of the child.

**Conclusions.** The study confirmed an acceptable quality of life for the children's parents, which was not influenced by the family presence of a child with a cleft. At the same time, the excessive care of the parents for the child with the cleft was confirmed. The postoperative improvement of the aesthetic aspect led to a much better psycho-emotional integration of the child in the society.

**Keywords:** cleft lip, cleft palate, quality of life, oro-facial deformities

## Introduction

Cleft lip and palate (CLP) represents one of the most common congenital malformations with a prevalence of 1/1000 in European population. Oro-facial clefts (OFCs) can be associated with several syndromes, but it can also occur as non-syndromic, being divided into cleft lip, cleft lip and palate or isolated cleft palate [1]. Manifesting during development, this abnormality affects not only the aesthetics of the face, but also functions such as hearing,

phonation, mastication, deglutition, and ventilation.

Giving birth to a child with cleft lip/palate (CL/P) may induce in parents a range of emotions including sadness, shock, anxiety, grief, guilt, or resentment, all of which could affect the family's well-being. Parents must be able to cope with their emotions, deal with the situation, and restructure their lives to suit the requirements of their affected child [2,3].

CL/P treatment is a multidisciplinary process that begins at

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birth and continues through adolescence and adulthood. Surgical reconstruction of OFCs is a treatment routinely performed by maxillofacial surgeons and involves the repair of the lip when the child is around 4-6 months old and the repair of the palate anytime between 8 to 14 months of age [4,5]. The follow-up requires frequent clinic visits to manage health issues such as mid-facial growth deficiency, hearing difficulties, ear infections, speech impairment, dental anomalies and alveolar bone defects [6,7]. The long course of multidisciplinary treatments represents a psycho-emotional and financial burden for both the patient and his family, often with an impact on social relationships and coping.

The study aims to assess the quality of life of a group of parents of children with CL/P and the psychosocial impact on the child and their family.

### Methods

The study compared the quality of life in parents of children with CL/P before and after surgical procedures in a retrospective study.

The research was carried out at the Department of Maxillofacial Surgery and Implantology of Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania, from August 2020 until September 2021.

Ethical approval for this study was obtained from the Ethical Committee (number 205/05.06.2020) from Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania.

The Questionnaire for the evaluation of quality of life of parents of CL/P patients [8] was adapted and translated into Romanian for the parents of the patients who presented to the maxillofacial surgery department for the follow-up examination. Before each participant was enrolled in the trial, the parents provided written informed consent. Prior to this, each parent or guardian was given extensive information and explanations about the study. During the permission procedure, parents were also encouraged to address questions and get clarifications. Each parent was informed of their right to withdraw at any time during the trial without being mistreated or denied treatment.

The inclusion criteria for the subjects enrolled in the study were: parents of patients diagnosed with CL/P and treated in our department, non-syndromic patients, as well as written informed consent signed by each parent who participated.

The exclusion criteria were as follows: parents of patients without CL/P or parents of patients with CL/P who have not had surgery and have not received full treatment and follow-up in our department, syndromic patients or patients who refused to take part on our study.

The questions consisted of simple statements and were evaluated with the Likert scale where 1 corresponds to “fully disagree” or “not true at all”, 2 represents “disagree in most aspects” or “not true in most aspects”, 3 represents

“undecided”, 4 is “agreement in most aspects” and 5 corresponds to “fully agree”.

The questionnaire included 24 items related to five dimensions which were evaluated pre- and postoperatively. The domains comprised: the financial impact, the social relationships, the impact on the child from the parent’s point of view, the impact on coping and the impact on family relationships.

The data was processed with Microsoft Excel version 16.54 and is presented in the tables below. Other descriptive data were employed as needed. The paired t-test was used to compare the mean pre- and postoperative total scores. The pre- and postoperative mean scores on the questionnaire’s five domains were also compared. For all comparisons, the level of statistical significance was set at  $p < 0.05$ .

### Results

The study enrolled the mothers of 40 children with OFCs who met the inclusion criteria and agreed to participate.

The most common type of OFC in our study was the unilateral cleft lip and palate representing 37.5%, followed by bilateral cleft lip and/palate with 32.5% and unilateral cleft lip only (15%).

The descriptive statistics shown in table I represents the sex distribution according to cleft type. Of these, 22 were females and 18 were males, with a female-to-male ratio of 1.2:1.

### Demographics of the included patients

**Table I.** Sex distribution according to cleft type.

Type of cleft	N patients 40 (100%)	Male 18 (45%)	Female 22 (55%)
bilateral cleft lip	1 (2.5%)	0 (0%)	1 (2.5%)
unilateral cleft lip	6 (15%)	4 (10%)	2 (5%)
palate	5 (12.5%)	2 (5%)	3 (7.5%)
cleft lip/palate bilateral	13 (32.5%)	5 (12.5%)	8 (20%)
cleft lip/palate unilateral	15 (37.5%)	7 (17.5%)	8 (20%)

The mean age of the patients with cleft lip and/palate is shown in table II. The mean age of all the patients is 13.38 years. In case of the unilateral cleft lip the mean age was 10.38 years with the minimum of 1 and the maximum of 16. For cleft palate only (CPO) the mean age value was 9.20 years. Regarding the bilateral cleft lip and/palate, the mean age was 12.54, ranging from a minimum 3 to maximum 20 years. The greatest mean value was for the bilateral cleft lip and/palate with 16.33 years and a minimum of 6 and a maximum of 26 years.

**Table II.** The mean age (in years) of the subjects according to cleft type.

Type	N patients 40 (100%)	Age of patients	
		Mean $\pm$ SD (95%IC) 13.48 $\pm$ 5.74 years	Minimum–maximum 1-26 years
Bilateral cleft lip	1 (2,5%)	20	20
Unilateral cleft lip	6 (15%)	10.83 $\pm$ 5.56 (4.99-16.67)	1-16
Palate	5 (12.5%)	9.20 $\pm$ 3.96 (4.28-14.12)	4-5
Cleft lip/palate bilateral	13 (32.5%)	12.54 $\pm$ 4.92 (9.56-15.52)	3-20
Bilateral cleft lip/palate	15 (37.5%)	16.33 $\pm$ 5.79 (13.13-19.54)	6-26

**Table III.** The mean age values for the parents of patients with clefts according to cleft type.

Type of cleft	N patients 40 (100%)	Age of parents	
		Mean $\pm$ SD (95%IC) 42.80 $\pm$ 8.20 years	Minimum–Maximum 25-60 years
Bilateral cleft lip	1 (2,5%)	42	42
Unilateral cleft lip	6 (15%)	44.64 $\pm$ 4.59 (39.85-49.48)	39-51
Palate	5 (12.5%)	39.20 $\pm$ 3.96 (34.28-44.12)	35-45
Cleft lip/palate bilateral	13 (32.5%)	41 $\pm$ 9 (35.64-46.52)	25-55
Bilateral cleft lip/palate	15 (37.5%)	44.07 $\pm$ 9.37 (38.87-49.26)	28-60

**Table IV.** Comparison of the mean quality of life before and after surgery in each domain.

Question category	Evaluation of score answer Mean $\pm$ SD		p
	Surgical preoperative	Surgical postoperative	
Impact on the child	2.76 $\pm$ 1	4.47 $\pm$ 0.64	0.001
Impact on coping	2.30 $\pm$ 0.77	4.67 $\pm$ 0.51	0.001
Social impact	2.40 $\pm$ 1.44	3.13 $\pm$ 0.85	0.006
Financial impact	2.55 $\pm$ 1,13	3.60 $\pm$ 0.90	0.001
Impact on family relationships	2.47 $\pm$ 0.77	3.40 $\pm$ 1.10	0.001

The mean values for the parents' age included in the study as described in table III was 42 years, with a minimum of 25 and a maximum of 60 years. The oldest group according to the mean value of the age of parents was 44.64, belonging to the group of unilateral cleft lip patients and followed by the group of bilateral CL/P patients with 44.07.

The youngest parents had a mean value of 39 years, in the group of cleft palate only (CP) patients.

#### Quality of life questionnaire

After the score answer was evaluated pre-surgery and post-surgery for each question domain, a paired t-test was applied to try to answer a null hypothesis: There was no significant statistical difference between preoperative and postoperative questionnaire score in CL/P patients. The statistical significance threshold was chosen for a  $p < 0.05$ . As seen in table IV, all categories including the impact on the child, the impact on coping, the financial impact, the

impact on family relationships and the social aspect had a statistically significant modification ( $p < 0.05$ ) of the score.

We have also tested the null hypothesis that there is no statistically significant difference between the number of children affected before the surgery and after the surgery. Regarding this a paired t-test was applied and the summary of the results can be seen in table V. The value of p for significance was chosen  $p < 0.05$ . After the mean value was calculated for each category, the total number of affected children was calculated and the before and after surgery count was compared. There is a statistically significant difference between the count of CL/P patients with a value over the mean for each category.

The results of the correlation index regarding the age of the parents and the preoperative and postoperative questionnaire score are presented in table VI and table VII. The correlation was analyzed using the regression model (Anova) and the intensity with the Pearson coefficient and Spearman respectively ( $p < 0.05$ ).

**Table V.** Comparison of the mean quality of life before and after surgery in each domain.

Type of question	Affected surgical preoperative N (%)	Affected surgical postoperative N (%)	p
Impact on the child	25 (62.50%)	39 (97.50%)	0.001
Impact on coping	13 (32.50%)	40 (100%)	0.001
Social impact	15 (37.50%)	27 (67.50%)	0.001
Financial impact	21 (52.50%)	35 (87.50)	0.001
Impact on family relationships	18 (45%)	40 (100%)	0.001

**Table VI.** Correlation between the age of the parents and the preoperative questionnaire score.

The preoperative questionnaire score	Correlation index with the age of the parents	p
Impact on the child	0.200	0.215
Impact on coping	-0.102	0.532
Social impact	0.046	0.779
Financial impact	-0.035	0.831
Impact on family relationships	0.081	0.619

**Table VII.** Correlation between the age of the parents and the questionnaire score postoperatively.

Parents postoperative score	Correlation index with the age of the parents	p
Impact on the child	0.021	0.898
Impact on coping	0.112	0.491
Social impact	-0.117	0.473
Financial impact	0.038	0.818
Impact on family relationships	-0.002	0.989

## Discussion

In this study the most frequent type of CL/P was the bilateral cleft lip/palate (37.5%) followed by the cleft lip/bilateral palate (32.5%) and by the isolated palate cleft (12.5%). The findings are not in accordance with other studies. The variation maybe due to the schedule modification of the cleft patient profile during the COVID-19 pandemic that is addressing to our clinic.

Caring for a child with CL/P can have a negative impact on parents and caregivers' quality of life [8]. It is estimated that afflicted families will need to make social and personal adjustments before beginning treatment [9]. CL/P has been proven to affect family functioning and lower quality of life in school-aged children and their parents [10].

Most of the limited studies on the quality of life of families with children with cleft lip/palate focused on the impact of OFC on the family, rather than the effect of surgical intervention on QoL [10]. The current study examines the impact of surgical intervention on the quality of life of CLP patients' families and caregivers.

There is a statistically significant different shown by

the data (Table IV), evidencing that the mean scores of all domains of the quality-of-life questionnaire improve after surgery ( $p < 0.05$ ). There is also a statistically significant difference in the number, not just the score, as seen in table 5, regarding the improved scores after surgery.

There is no correlation between the age of the parents and postoperative questionnaire score and postoperative score for a  $p < 0.05$  as seen in Tables VI and VII. The age of the parents does not seem to influence the perceived quality of life before and after surgery.

The mean preoperative total QoL score as well as the proportion of families whose QoL was affected preoperatively were both high in the current study, demonstrating that families/caregivers of children with OFC had a lower quality of life. The findings imply that caring for a child with a cleft lip or palate might negatively affect the family's quality of life. The domains with the greatest impact were coping, the impact on the child and the financial aspect.

Specifically, impacts were most evident on the dimensions of coping and personal impact [11]. Parents of children with CL/P reported a lower effect on QoL

than parents of children with only a cleft lip or palate, according to prior research [10]. In our study, the domains most affected were coping, impact on the child and social relationships. This is understandable considering that many children with CL/P have a less attractive facial appearance or speech than their peers. A high incidence of teasing over facial appearance is reported among those with CL/P [12].

All of the needs of long-term interdisciplinary treatments and the facial differences expose CL/P patients and their families to a range of additional life stresses from infancy through adulthood, which may affect the families' psychosocial and economic well-being. Furthermore, the family structure and functions may differ from those of healthy infant families [9,13,14].

In some cases, the mother is abandoned by her husband, family, and friends. This might explain why the areas of social relationships and sibling relationships are the most affected. Caring for a child with OFC often involves frequent hospital visits, with associated loss of work hours, out of pocket financing of health care services, and often loss of job due to frequent time away. All these reasons might explain why our study found such a high level of financial effect.

In the early stages of CL/P, surgery is a crucial determinant impacting QoL [15]. Repair of the cleft was indicated as an essential issue in OFC care by both mothers and fathers in previous research of 175 sets of parents [12]. Parents expressed their anticipation of 'everything being fine' following surgery, which was considered as a remedy to the cleft [12]. Operation is sometimes a cause of anxiety for parents, particularly as the surgery date approaches [16]. Timing of the treatment, duration and rehabilitation, side effects, the necessary care, if extra tissue was required for the repair, procedures employed, surgical results, and discomfort have all been cited as concerns [17].

In the current study, the mean total QoL score after surgery was found to be significantly higher than before surgery, indicating that surgical intervention greatly improved the parents' quality of life. The effects of surgery on coping, impact on the child, and social domain were the most noticeable. Although the impact reflected by the questionnaire responses is not correlated with the parents' age, in preoperative and postoperative time, the significant improvement in parent quality of life following surgery may be attributed to the improvement of the facial appearance, but also due to the moderation of the financial and psycho-emotional burden that comes with caring for children with malformation.

After receiving the diagnosis, both mothers and fathers ranked cleft correction as a top priority, according to a previous study [12]. Families with children with bilateral cleft lip reported the greatest total effect before surgery, whereas families with children with isolated cleft palate reported the greatest impact after surgery.

Cleft palates are operated at a later age than cleft

lips, therefore the stress of extended clinic consultations, as well as the complications of cleft palate collapse and additional operations, may have the greatest impact on families with solitary cleft palates. In addition, in isolated cleft palate situations, the necessity for speech therapy visits may add to the stress of parents.

Caring for a child with OFC was found to bring a significant financial burden on the family in international studies. According to a previous American study [18], the average home health expense per child with OFC was 45 times greater than the average home health expenditure per child without cleft. It was also shown that the average cost per child with OFC was \$22,642, compared to \$3,900 for a child who was not afflicted [19].

According to these studies, there is a three-fold greater average expenditure for a child with cleft palate or cleft lip and cleft palate than for one with cleft lip alone. A review on the current economic elements of CL/P therapy observed that treatment expenses might be as high as \$30,000 per patient on a fee-for-service basis, without counting indirect costs like travel, lost earnings, and additional childcare [19].

The most noticeable effect of CL/P is a change in look, with many parents hoping that the changes in appearance will improve their child's quality of life. The bonding connection between parent and child might be affected by changes in appearance as a result of OFC. Early attachment is said to be a reciprocal process that relies on the reactions of the baby's primary caregiver [12].

The coping domain has the greatest difference between mean values of the questionnaire score, followed by the impact on the child from the parents' perspective and the financial domain. Other studies also stated a negative influence on the financial aspect before surgery and on the child's psychosocial integration.

When compared to parents of children without clefts, parents of children with clefts have indicated that their children had more psychosocial and behavioral issues [12]. According to other research, children with CL/P see their parents as having more negative sentiments and being more worried [12].

In the attempt to better understand how a family adjusts to having a child with CL/P, elements of coping and adjustment have been studied [3]. In our study, surgical intervention had only a favorable impact on the families of children born with unilateral cleft lip. Families with children born with bilateral cleft lip and cleft lip/palate claimed that their coping abilities had deteriorated after surgery, but families with children born with isolated cleft palate reported no change in their coping abilities.

This conclusion is consistent with Kramer et al. [9], who found that coping issues were more prevalent in families of children with cleft lip (whether unilateral or bilateral) than in families of children with CL/P or isolated cleft palate. This conclusion might be explained

by the child's physical appearance being affected more severely by bilateral cleft lip and cleft lip/palate, or by the parents' using avoidant rather than problem-solving coping mechanisms [16]. The importance of social support, as well as perceived support from professionals involved in the child's care, has been recognized as helpful in the coping process [3].

Support from friends and family has been associated with less suffering, better adjustment, and less negative family effect, presumably because social support fosters emotions of belonging, self-esteem, and a positive attitude.

### Conclusions

The current study, with its limitations, presents the improvement of the quality of life of the CL/P patients and parents/caregivers following surgery. The burden of treatment of the CL/P patients is perceived differently, depending on the severity of the cleft and improvements can be achieved after the surgical phase. Further research should be undertaken regarding the quality of life of patients and caregivers of CL/P patients to include other types of treatment such as speech therapy, orthodontic treatment, as well as procedures to further enhance the knowledge and the possibility to help the patients.

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