

Chapter

Quality of Life in Adolescents with Cleft Lip and Palate

Latifa Elmouden, Fatima Zahra Elgasmi and Lahcen Ousehal

Abstract

The cleft lip and palate (CLP) is the second most common congenital anomaly in the world; therefore, understanding the quality of life in children and adolescents with this malformation is extremely important. The study of the quality of life in this population is based on how the patient feels about his condition and how it affects his general well-being depending on the problems he may encounter concerning bone growth, phonation, speaking, facial appearance, and social relationship. As part of a descriptive survey, the aim was to assess and study the quality of life of patients with labio-palatal clefts operated and undergoing medical management, as well as the quality of life perceived by their parents to evaluate the family impact of this dysmorphia. According to the studies, teenagers had the lowest quality of life rates in the items: physical appearance and self-esteem, so the psychological support for patients and their families with multidisciplinary treatment that meets standards, are the keys to improving the quality of life of this category of patients.

Keywords: quality of life, adolescents, cleft lip and palate, self-esteem, parents

1. Introduction

Cleft lip and cleft palate are facial anomalies and are the most common congenital anomalies that affect the orofacial region and remain a significant public health burden [1].

Orofacial clefts (CL/P) commonly affect the lip, alveolar ridge, and hard and soft palates. Problems associated with these anomalies are dental problems, malocclusion, nasal deformity, feeding, and ear and speech difficulties [2].

Thus, any difference in those structures is noticeable and may cause some difficulties in the relationship field. In fact, the face is the front by which every human being is presented and communicates with others.

In the book “bec-du-lievre” (“harelip”): Clinical Forms-Surgery (1938) of Victor Veau, the presence of a cleft lip is stated by the absence of contacts between the external muscles and the inner verge [3]. This has the effect of destabilizing the anatomy of the nose (deformation of the alar cartilages, the nasal septum, and triangular cartilages).

Such deformation causes in humans a change in its well-being, autonomy, own world, expectations, and social insertion, which are parts of the concept of “quality of life” (QoL).

The quality of life (QoL) is a complex multidimensional and subjective concept in permanent evolution. The study of QoL can be an instrument of evaluation of the daily impact of an individual with CL or CLP operated. It is an integral part of the evaluation of results as well as the satisfaction of the surgeon and that of the patient [4].

The issue of QoL is attracting increasing interest from many researchers. It is a concept that groups together different areas of life and is strongly subject to individual experiences [5].

The QoL of a patient with a cranio-facial deformity is already influenced at birth by the impact of the disease on the newborn, the parents, and the family. The birth of a child with a cleft lip and palate raises controversial feelings among parents especially the mother. The relationship with the child is dominated by the notion of “who,” which cannot be separated from “what we are.” The abnormal child is not only the beloved child but also an unknown stranger. Once the diagnosis has been made, the child’s removal can occur but also ownership [6].

The QoL of individuals with cranio-facial diseases is challenged throughout life, given the conditions themselves and the treatments needed to be done. In other words, age and time the frameworks in which optimal care and quality of life must coordinate perfectly. These children with CLP experience a number of psychosocial risks, including medical appointments and assessments, surgery, feeding difficulties, appearance differences, as well as the possibility of need for early special treatment, such as phonotherapy.

This otherness and especially the differences in appearance often involve varying degrees of facial scars, and dentition variations, such as missing teeth, limitation of speech, and language [7–9].

Several studies have described the psychological and social burden in children with CLP and reported that these patients have significantly more behavioral problems, as well as more symptoms of depression, and are less satisfied with their facial appearance.

In addition, the new concept of health proposes to measure the oral health of people in relation to general health and psychosocial well-being [7].

The judgment of the functional and esthetic results of surgery has always been traditionally performed by clinicians (surgeons, speech therapists, and orthodontists).

Quality of life brings together a number of distinct branches (appearance, speech, facial growth, and psychosocial interaction). In addition, the importance lies in how these different areas could change from the period of childish development to adulthood. As a result, a questionnaire for the cleft lip and palate population could be able to address areas of importance and be aware of any changes in quality of life aspects as the child matures [4].

There are very few studies that illustrate how patients feel after surgery and how they assess their quality of life [10].

To adequately measure the quality of life of patients with cleft lip and palate, an instrument showing the clinically significant scientific findings reported by the patient that specifically addresses quality of life issues in patients with cleft lip and palate is required. These are questionnaires that quantify QoL and/or other significant outcome variables (e.g., satisfaction, symptoms, and function) from the patient’s point of view. The lack of a tool specific to this population with orofacial clefts has been identified as a major research gap that should be filled.

The objective of our study was to assess the quality of life of patients operated by a cleft lip or cleft lip and palate as well as the perception of quality of life of the

patients perceived by their parents through a quality of life scale adapted to the age of the patients.

2. Patients and methods

2.1 Patients

This study is a monocentric cross-sectional descriptive analytical survey on a sample of 40 adolescents (25 boys and 15 girls) aged between 12 and 16 (average age of 12.53 ± 1.65 years) operated with a cleft lip (CL) ($n = 12$) or cleft lip and palate (CLP) ($n = 28$) and their parents.

Patients operated on for cleft palate only were excluded from the sample.

The survey was conducted at the “Opération Smile” center in Casablanca (Morocco) among patients with a cleft lip and palate treated at the center over a period of 4 months, and only one interviewer was responsible for data collection.

2.2 The questionnaire

The questionnaire used in the study is the VSP-A (Vécu et Santé Perçue de l'Adolescent), it is a self-administered French indicator of health-related quality of life that has been developed from the perspective of healthy and sick adolescents aged 11–17.

For adolescents, nine areas were explored:

- relations with parents,
- self-esteem,
- energy and vitality,
- relationships with friends,
- leisure and activities,
- psychological well-being,
- physical well-being,
- school labor and relations with teachers, and
- relationship with the nursing staff,

Each response was rated from 1 to 5. The points were distributed as follows: 1 point for the answer that corresponded to “ill-being,” 5 points for “well-being” with all the intermediate nuances. The “no answer” and “unconcerned” questions were not included in the questionnaire administered to adolescents and therefore do not correspond to any rating.

The questions corresponding to the same field were distributed throughout the questionnaire in order to limit the response bias. The questions were in the form of multiple choice answers. Five responses were received possible: never, not at all/ rarely, a little/sometimes, moderately/often, much /always, and a lot.

In the questionnaires given to “parents,” in addition to the previous items, a sixth proposal appeared: not concerned.

2.3 Statistical analysis

The statistical data for this study were captured, analyzed, and compared using the Microsoft Excel 2010 software; and the Spss software, Version 23.0. Armonk, NY: IBM Corp.

A test-retest was performed for a sample of 10 patients that was randomly selected to see if the questions were well assimilated by the patients. The intra-class correlation coefficient (ICC) with a 4-week interval between the two measurements with alpha level of significance $\alpha = 5\%$ (corresponds to a 95% confidence). $P < 0.05$ value was considered significant.

3. Results

In order to verify the validity of the questionnaire and the reproducibility of the responses of the adolescents interviewed, we conducted a test/retest with 10 adolescents who were asked after 1 month of the first interview, giving answers, for the most part, equivalent to the first answers and therefore insignificant differences ($p = 0.21$) and, therefore, we can conclude that the questionnaire was well assimilated by the patients (**Table 1**).

Our results show that the overall quality of life index for adolescents with CLP is 59.61, while the index for parents of patients is 60.58 (**Table 2**). The quality of life perceived by parents is therefore close to that of their children (**Figure 1**). This was confirmed by the linear regression curve (**Figure 2**).

Parents overestimated their children's quality of life in terms of family relationships, self-esteem, education, and physical and psychological well-being. However, adolescents slightly overestimate their quality of life compared to their parents in terms of activity and leisure and relationships with friends.

The relationship with medical and nursing staff has yielded the best results for both parents and adolescents. More than 60% of adolescents reported a better quality of life in their relationships with friends, sharing their secrets and problems and expressing themselves freely.

Domains	Average test score	Average retest score	P-value	Significance
Family relationship	59.2	58.1	0.21	NS
Friends relationship	58.7	60.2	0.54	NS
Vitality	62.3	61.4	0.43	NS
Self-esteem	55.1	57.2	0.24	NS
Psychological well-being	56.7	58.4	0.19	NS
Physical well-being	47.3	48.5	0.42	NS
School labor and relationship with teachers	59.1	60.2	0.53	NS
Leisure and activities	62.1	61.7	0.67	NS
Relationship with the nursing staff	69.3	71.4	0.12	NS
Global Index	58.86	59.67	0.46	NS

Table 1.
Results of the test/retest patients.

Domains	Average quality of life score according to adolescent patients	Average score of adolescents' quality of life according to parents
Family relationship	60.2	65.4
Friends relationship	59.6	62.1
Vitality	61.3	58.2
Self-esteem	54.6	59.6
Psychological well-being	53.2	58.6
Physical well-being	45.2	55.4
School labor and relationship with teachers	57.4	60.1
Leisure and activities	62.4	60.2
Relationship with the nursing staff	70.2	69.3
Global Index	59.61	60.98

Table 2.
Average quality of life of adolescents and the quality of life perceived by their parents.

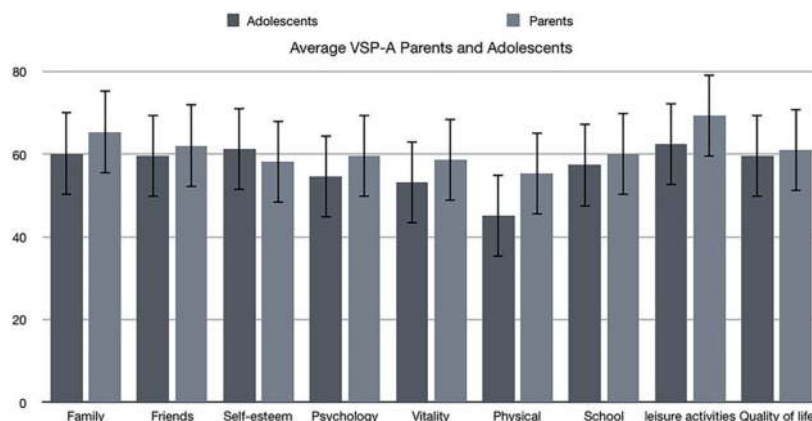


Figure 1.
Diagram of the averages of VSP-A parents and adolescents.

According to our results, between 32.5 and 42.5% of adolescents had self-confidence. Fifty percent of adolescents lacked vitality and energy, and 50% of adolescents often went out to play with their friends; 72.5% were understood and reassured by their friends.

About 47.5% of adolescents were satisfied with their academic performance, while 15% thought they were very well understood by their parents about their schooling. About 67.5% are complexed by their physical appearance.

Psychologically, only 2.5% of adolescents are self-confident with 47.5% tending to take life on the bright side.

The relationship with medical and nursing staff showed that 70% of adolescents found that they were understood, reassured, and respected by medical staff.

As far as parents of sick children are concerned, only 30% found that their children were too worried.

Fifteen percent of parents noticed signs of depression in their children, and 35% found that they were not at all revolted or shocked by what was happening

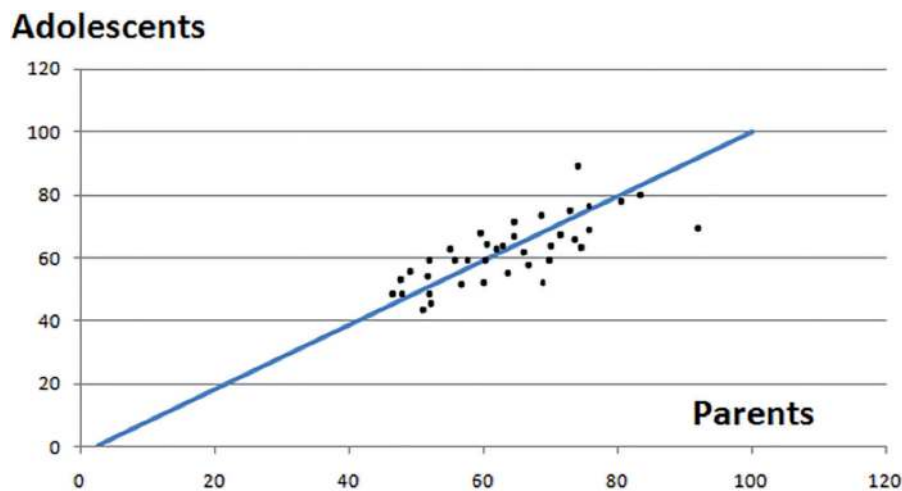


Figure 2.
Linear regression, overall quality of life index.

around them. Sixty percent of parents noted that their children were optimistic and confident about their future; only 10% thought that their children were extremely happy and satisfied with their lives.

With regard to the education component for adolescents, parents with an average of 31% were satisfied with their children's schooling and relationship with their children's teachers. Fifty-five percent of parents noted that their children were not at all complexed by their physical appearance.

On average, 45% of parents reported that their children lacked energy and vitality; 65% of parents reported that their children tended to take life on the right side; and 70% thought their children thought that everything was fine around them.

4. Discussion

4.1 Quality of life instrument evaluation

Our study was based on the administration of two questionnaires, VSP-A "Vécu et Santé Perçue par l'Adolescent" "Experienced and Perceived Health by the Adolescent" one for adolescents with CLP and the other for their parents.

These questionnaires were considered reliable by a test/retest with the first 10 patients interviewed. The questionnaire we used is in French [4].

Quality of life is defined by the World Health Organization (WHO) as "perception of people in terms of their situation in life, in the cultural context, and in values with whom they live according to their objectives, expectations, models, and concerns" [11].

When an individual is accepted into society, the sense of well-being or good quality of life is easier to achieve [12]. The overall quality of life index for adolescents with CLP was 59.61 and that of the parents of the children of was 60.58, which shows that the perceived quality of life is almost superimposable between parents/children.

Recent studies show that reports of children on OHRQoL are reliable and valid. Instruments developed to measure the quality of life of children must also assess the impact of these problems on the quality of life of the family, as they are inseparable factors [13–16].

4.2 Psychological aspect of quality of life perception

The analysis of the quality of life in CL/CLP remains a difficult exercise. Family dynamics, education, and professional factors influence the social development and rehabilitation of these patients [17].

Psychological problems, such as loss of self-esteem and difficulties in social interaction, are also encountered in patients with cleft lip or palate [8, 18–20].

In our study, the quality of life perceived by parents was close to that of their children, which was confirmed by the linear regression curves (**Figure 2**).

The literature on quality of life in cases of facial malformation (congenital or acquired) is disparate. The quality of life index is considered in the majority of cases to be equal to and, in some cases, lower than that of a control population.

François-Fiquet et al. [4], in his study, found that patients' quality of life was estimated by patients at an average of 65.1/100. This overall quality of life index was comparable ($P = 0.66$) to that of the control population. The perceived quality of life of patients by their parents was quite close to the quality of life described by patients (66.5/100).

In our study, and during adolescence, problems of attractiveness, peer acceptance, and identity formation are particularly acute in populations and patients in general. With CLP, the results show that 67.5% of patients surveyed are complexed by their physical appearance.

Turner et al. [21] conducted a study in England that showed that a negative reaction from foreigners, real or perceived, can damage our own image. The links between physical attractiveness and the probability of success and social acceptability are well established. These links highlight the potential disadvantages for people affected by CLP because they may have an abnormal facial appearance [22–24].

Broder et al. [7] mainly showed higher levels of dissatisfaction with body image associated with an increase in apparent anxiety in patients related to their CLP.

Similarly, our psychological study revealed that only 2.5% of adolescents have self-confidence and 47.5% tend to take life on the bright side.

Several studies have reported that the majority of patients and their parents report that self-confidence has been affected or “very affected” by the cleft. Lower levels of self-esteem have also been observed in adults with CLP [25–28].

4.3 CLP and social aspect

In our study, socially, more than 60% of adolescents reported a better quality of life in their relationships with friends and 72.5% found that they are understood and reassured by their friends with only 27.5% of adolescents worried about their future. The highest index in this field explains our patients by the fact that they have developed a privileged relationship with their “best friend,” integrating almost total trust, a greater complicity than between classmates without a surgical background.

These results disagree with those observed in several studies, in particular that of Antoun et al. [29] who found that children with facial malformations may have specific attitudes that influence or even interfere with interactions with others. Facial malformations are not the most accepted physical abnormality in the population with a higher incidence of facial mockery; another factor that affects the social life of their children is the visible deficiency, nose and lips by this abnormality having a negative impact on peer interactions or even in the field of marriage.

Stock et al. [28] conducted a study in which they found that children with CLP were less socially motivated, less competent, and less effective in overall social functioning than their peers without CLP.

The study by François-Fiquet et al. [4] is consistent with our study which shows that these patients have achieved better results in the areas of friendship.

On the other hand, concerning the fields of schooling showed that the quality of life index was proportionally lower than that of the other fields [4]. Another study by Turner et al. [21] indicates that social anxiety was associated with poor academic performance, in addition to communication difficulties and words encountered in patients. The study by Broder et al. [7] found that patients with CLP requiring multiple surgical procedures had lower school scores.

4.4 Parent's relationship and quality of life

In our study, 75% of parents thought that their children spoke freely with them and 45% thought that their children spoke well with other family members as well.

The highest scores in the literature on parent-child relationships are partly explained by the importance of parents' investment in care over many years and also by daily concerns about the mockery and stigma that could affect their child [30].

The study by François-Fiquet et al. [4] confirmed the presence of a fusional and overprotective parental relationship that can be established, leading in some cases to an increased dependence of adolescents on their parents. This may even lead to a later departure from the family unit.

Parents' feelings about their children's facial anomaly are expected to be critical to their well-being in developing the child's self-esteem, although at the birth of their babies, they may experience feelings of uneasiness, shock, confusion, pain, and guilt; over time, they seek to adapt and better understand it to ensure maximum comfort and social integration.

The announcement of a facial malformation affecting their child is a major psychological test for parents. Other studies [10, 31–33] have found that parents' first relationships with their children are based on conscious and unconscious emotions, which essentially involve touch, sound of voice, gaze, and facial expression.

When the newborn is carrying a CLP, parents are brutally confronted with their child's "spoiled, open, cracked" face, and the emotional overload of this event can slow down their emotional investment. Thus, the parent-child relationship can be affected from birth [34]. The mother's attachment to her child during childhood does not seem to be a problem, quite the contrary. This is because a mother protects her child more when he or she has an unsightly face [8, 35].

Aslan et al. [36] identified in their study the multiple variables affecting family functions and life quality of parents with cleft lip and/or palate children. In fact, the parents of CLP children need to be strengthened in behavioral control, roles, and the required attention areas of family functions at early childhood and at required attention area in all age groups of children. In addition, families need to be supportive for social, physical, and the psychological fields of QoL when their children are in adolescence growth period. Therefore, concepts of psychological services in cleft centers should be developed, and a family-centered approach should be applied caring the psychosocial needs of parents, children, and their families.

4.5 Orofacial functions and quality of life

In our study, 50% of adolescents lacked vitality and energy according to them and 45%, according to their parents.

Grollemund et al. [9] and François-Fiquet et al. [4] confirmed that although patients with bilateral FLP are functionally satisfied with their speech, swallowing, and hearing, they are significantly dissatisfied with their appearance, particularly

in the upper lip and nose. This dissatisfaction with the esthetic result may even be an early sign of depression [37].

People with CLP can suffer from a variety of disorders: behavioral disorders, anxiety, depression, and facial esthetic dissatisfaction in both children and adults. The difficulty in interpreting these disorders lies in the multiplicity of factors that can influence the quality of life of these people.

A retrospective cohort study including 220 child born with unilateral CL+A, concluded that the findings of this study provide a reference for morphologic variations in CL+A and insight into the surgical burden of care until the age of 18 years. These results are consistent with the results of our study on the influence of the management of cleft lip and palate on the quality of life of children and adolescents [38].

4.6 Limitation of this study

Our study was a retrospective monocentric study for the evaluation of the quality of life in patients with cleft lip or labial palate and their parents. This is justified by the difficulty of accessing this particular population; in general, these anomalies affect with disparity a population with an unfavorable socio-economic and cultural context. On the other hand, a prospective longitudinal study with an evaluation at the beginning and at the end of treatment and long-term follow-up with a comparison group of children without CL and CLP would have been more relevant.

5. Conclusion

At the end of this work, we concluded that patients' and their parents' perceptions of quality of life remain average, with satisfaction rates of 59.61 for the former and 60.58 for the latter.

Teenagers had the lowest quality of life rates in the items: physical appearance and self-esteem, while their parents did not like the fact that their children were dissatisfied with their lives.

Multidisciplinary management is the rule in the treatment of the after-effects of cleft lip and palate. However, it will be necessary to strengthen the role of the psychologist in the therapeutic chain of these patients, as they are currently still neglected at the expense of surgeons and orthodontists.

Conflict of interest

The authors declare no conflict of interest in relation to this chapter.

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