

Approach to the Perception of the Quality of Life of Children and Adolescents with Non-Syndromic Cleft Lip and Palate: a Phenomenological Study*

Aproximación a la percepción de la calidad de vida de niños y adolescentes con fisura labiopalatina no sindrómica: Estudio fenomenológico

Aproximação a percepção da qualidade de vida de crianças e adolescentes com fissura labiopalatina não síndrômica: um estudo fenomenológico

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Abstract:

Background: Non-syndromic cleft lip and palate (NSCLP) is a congenital malformation that generates physical, functional and psychosocial complications. The latter are generally identified in quantitative studies. The affectation of the quality of life and the oral health approach of the experiences of people with NSCLP and their families have not been qualitatively documented. **Purpose:** To identify the perception of quality of life of children and adolescents with NSCLP undergoing comprehensive treatment at the Cleft Lip and Palate clinic of the Javeriana University from Bogotá, Colombia. **Methods:** It was a qualitative phenomenological study in which eight patients, five parents/guardians, and four professionals from the interdisciplinary care group participated. Semi-structured individual interviews were conducted with each participant and two focus groups, one with guardians/parents and another one with professionals, led by an expert. After transcription, findings were coded and classified according to the categories proposed using the Atlas TI software. Subsequently, a narrative reduction and the corresponding analysis were performed. **Results:** Participants shared their perspectives on the impact of living with NSCLP and how it impacted their quality of life. Social and psychological dimensions were the most affected. The narrations revealed feelings of sorrow, anguish, and shyness, as well as longings and desires for greater sociability. **Conclusion:** The reconstruction of the narratives showed how the experience of living with NSCLP generates challenges, situations, and thoughts that affect quality of life, especially from the social and psychological perspectives.

Keywords: cleft lip and palate, dentistry, non-syndromic cleft lip and palate, oral health, quality of life, phenomenological study, psychological dimension, qualitative research, social dimension.

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Resumen:

Antecedentes: La fisura labiopalatina no sindrómica (FLPNS) es una malformación congénita que genera complicaciones físicas, funcionales y psicosociales. Las últimas generalmente se identifican en estudios cuantitativos. La afectación de la calidad de vida y el abordaje en salud oral de las experiencias de personas con FLPNS y sus familias se han documentado poco cualitativamente.

Objetivo: Identificar la percepción de la calidad de vida de niños y adolescentes con FLPNS en tratamiento integral en la clínica de Labio y Paladar Hendido de la Universidad Javeriana de Bogotá, Colombia. **Métodos:** Fue un estudio cualitativo fenomenológico en el que participaron ocho pacientes, cinco padres/acudientes y cuatro profesionales del grupo de atención interdisciplinario. Se realizaron entrevistas individuales semiestructuradas a cada participante y dos grupos focales, uno con acudientes/padres de familia y otro con profesionales, conducidos por un experto. Después de transcrita, la información se codificó y clasificó de acuerdo con las categorías propuestas mediante el programa Atlas TI. Posteriormente, se realizaron una reducción narrativa y el correspondiente análisis. **Resultados:** Los participantes compartieron su perspectiva sobre la repercusión de vivir con FLPNS y cómo esta influía en su calidad de vida. Las dimensiones sociales y psicológicas eran las más afectadas. Las narraciones revelaron sensaciones de pena, angustia y timidez, así como anhelos y deseos de mayor sociabilidad. **Conclusión:** La reconstrucción de las narrativas mostró cómo la experiencia de vivir con FLPNS genera retos, situaciones y pensamientos que afectan la calidad de vida especialmente desde las perspectivas social y psicológica.

Palabras clave: calidad de vida, dimensión social, dimensión psicológica, estudio fenomenológico, fisura labiopalatina no sindrómica, investigación cualitativa, labio y paladar fisurado, odontología, percepción de calidad de vida, salud bucal.

Resumo:

Antecedentes: A fissura labiopalatina não sindrômica (FLPNS) é uma malformação congênita que gera complicações físicas, funcionais e psicossociais. Estes últimos são geralmente identificados em estudos quantitativos. A afetação da qualidade de vida e a abordagem da saúde bucal das experiências de pessoas com FLPNS e suas famílias não foram documentadas qualitativamente.

Objetivo: Identificar a percepção da qualidade de vida de crianças e adolescentes com FLPNS em tratamento integral na clínica de fissura labiopalatina da Universidade Javeriana de Bogotá, Colômbia. **Métodos:** Trata-se de um estudo fenomenológico qualitativo do qual participaram oito pacientes, cinco pais/responsáveis e quatro profissionais do grupo de atendimento interdisciplinar. Foram realizadas entrevistas individuais semiestructuradas com cada participante e dois grupos focais, um com responsáveis/pais e outro com profissionais, conduzidos por um especialista. Após a transcrição, os achados foram codificados e classificados de acordo com as categorias propostas no software Atlas TI. Posteriormente, uma redução narrativa e a análise correspondente foram realizados. **Resultados:** Os participantes compartilharam suas perspectivas sobre o impacto de viver com FLPNS e como isso afetou sua qualidade de vida. As dimensões social e psicológica foram as mais afetadas. As narrações revelaram sentimentos de tristeza, angústia e timidez, além de anseios e desejos de maior sociabilidade. **Conclusão:** A reconstrução das narrativas mostrou como a experiência de viver com FLPNS gera desafios, situações e pensamentos que afetam a qualidade de vida, principalmente do ponto de vista social e psicológico.

Palavras-chave: estudo fenomenológico, dimensão psicológica, dimensão social, fissura labiopalatina, fissura labiopalatina não sindrômica, odontologia, pesquisa qualitativa, qualidade de vida, saúde bucal.

INTRODUCCIÓN

Non-syndromic cleft lip and palate (NSCLP) is a structural congenital anomaly that affects the maxillofacial region, has a multifactorial etiology, and has genetic, environmental, and ethnic components (1,2). People with NSCLP frequently present altered facial proportions, feeding difficulties, phonation problems, hearing alterations, and periodontal and dental affections. Such conditions impact the quality of life as they alter physical and emotional development (3). Aesthetic and functional aspects require multidisciplinary and interdisciplinary attention from early childhood to late adolescence. Interventions cannot, however, guarantee adequate function in all cases, and patients face variations or deficiencies, as well as sequelae related to visible facial scars and intelligible speech, which expose the person and their family to psychosocial risks (4,5).

NSCLP is a physical condition that generates a series of individual experiences, treatments, and constant changes that can impact the person's life. However, it is clear that NSCLP is a physical deficiency and, although it can make some aspects of life difficult for those who suffer from it, it is not a disability. Socially, in some circumstances it is treated as such (6).

Different studies have shown that the sequelae generated in a person with NSCLP interfere with their psychosocial performance and their interpersonal relationships. Activities such as public speaking, being photographed, and socializing at school are described as the most affected. Also, for some people, hearing and speech are more important than facial and dental appearance (7,8).

Aspects such as psychosocial interaction, behavior, experiences, quality of life, satisfaction with treatment, and appearance have been considered in different studies that conduct quantitative analyses (9,10,11). However, the approach to patient perceptions from their own experiences has not been analyzed in depth (8,10,12). Similarly, studies related to the daily experiences of people, aimed at analyzing the quality of life and the factors that prevent the appearance of physical and mental illnesses, approached from health psychology, have been limited when conducting a state-of-art search (12,13). This justified conducting this qualitative study with a phenomenological approach. The research question was: How is the quality of life of children and adolescents with NSCLP who receive comprehensive treatment at the Cleft Lip and Palate (CLP) clinic of the Pontificia Universidad Javeriana in Bogotá, Colombia perceived? The development of the study allowed to obtain an approximation to the experiences of people and families with NSCLP, through a phenomenological approach (14). This method is useful to understand the representations of health-disease conditions in the context in which they develop, broadening their meaning. Sometimes, these conditions are limited to the medical experiences of people in the role of patients and make other areas of personal development invisible.

MATERIALS AND METHODS

This qualitative study was conducted using a phenomenological approach. Through a phenomenological design, people's experiences and the relationship of different processes with their cultural, ideological, and sociological contexts can be analyzed (14).

Participants

Eight people in the range of 10 to 20 years of age, who were active patients of the Javeriana CLP clinic, five relatives and caregivers, and four specialists that make up the CLP group participated in the study. There was a total of 17 participants. A selective, trial sampling technique was used (15). As part of the inclusion criteria, patients between the ages of 10 and 20, active users of the Javeriana CLP clinic, family members and caregivers who lived with the patients, and professionals from the interdisciplinary team were considered as mentioned above. Exclusion criteria were not considered. The analytical categories (general health dimensions) were analyzed from the perceptions, which were structured as follows:

- Biological perceptions: possibility of performing oral hygiene, presence of halitosis, and dental and gingival status.
- Functional perceptions: feeding, hearing, and speech.
- Aesthetic perceptions: facial condition, dental malposition, and scarring flanges.
- Psychological perceptions: self-image, self-esteem, social interaction, and other dimensions derived from the participants' reports (emerging categories).

These emergent (emic) categories arose from the participants' own perspectives, as well as their behavior patterns with respect to cultural and social beliefs. They were also a description in meaningful terms.

The Research and Ethics Committee of Javeriana's Dental School approved the study. Participation in the study groups and acceptance of recording was voluntary and signed through an informed consent. According to Resolution No. 008430 of 1993 of the Colombian Ministry of Health, this research was

considered of no risk. The proposed methodology included interviews and focus groups without performing any intentional intervention or modification of the biological, physiological, psychological, or social variables of the individuals who participated in the study.

Procedures

The study was conducted in 4 phases, distributed in three stages:

- Stage I: developed in 3 Phases, namely:
 - o Phase I: Approaching the individual with the condition and their family in order to inform about the goal and relevant aspects of the study. After reading and signing the informed consent by the patients and their families, the scope and objectives of the research, as well as the phases of the study, were explained to the participants.
 - o Phase II: Socialization process of the conditions and goal of the study in order to guide the thematic tracks of the interviews. For the orientation of the semi-structured interviews, scripts were designed considering the dimensions under analysis, which were reviewed and validated by an external advisor and expert in qualitative research.
 - o Phase III: Individual interviews were conducted with the participants of each group, using a voice recorder for recording. The content of the interviews was transcribed by a professional in psychology who was external to the research team.
This phase also included the development of two focus groups (one made up of family members and/or caregivers and the other by professionals). The units of analysis corresponded to the thematic tracks generated from the phenomenological reduction of the interviews, which were conducted by an expert advisor in qualitative studies and external to the research group.
- Stage II: contemplated the study of the understanding of the narratives where the content of the interviews and focus groups were read, delimiting the thematic units included, as well as the emerging categories.
- Stage III: the data analysis was conducted; it included reviewing the transcripts, coding and/or triangulation of themes, narrative reduction, and reviewing the findings by the research group. Regarding the content analysis process, the expert in qualitative analysis classified the findings through the Atlas Ti software, coding the dimensions proposed in the study, as well as the emerging categories. After coding, the information triangulation process was performed, in order to stem the results of the investigation.

RESULTS

For the analysis of the findings, the identified categories of analysis (from the dimensions of general health) were examined. Each person exposed their perceptions about the problem raised.

Categories were grouped in five dimensions:

1. Biological
2. Functional
3. Aesthetic
4. Psychological
5. Emerging or additional.

Biological Dimension

The following subcategories were included in this dimension: ability to perform oral hygiene, presence of halitosis, and perception of dental and gingival status. From the information obtained from the narrations in this subcategory of analysis, the importance of an accompanying and supervising adult was recognized, so that the minor develops oral hygiene habits. It was also associated with discomfort due to intraoral procedures and devices, which sometimes remains as an excuse for inadequate oral hygiene practices. As for the subcategories of presence of halitosis and perception of dental and gingival status, none of the interviewees or family members reported them (Table 1).

TABLE 1
Biological Dimension. Patient and Caregiver Narratives*

Subcategories	Patient Narratives	Parent/Caregiver Narratives
Possibility to perform oral hygiene	"I didn't use the device; brushing was very difficult and they changed them and at that time it was that the processes didn't progress because it was time to do everything again... and one was sad and worried..." Male patient (15 years old)	"Well, he is disciplined with his device and everything, with his mouthwash and everything, because I am very aware of that, waiting for him to put on the device, that he is washing his mouth and he does it"
Presence of halitosis	Not reported	Not reported
Perception of dental and gingival status	Not reported	Not reported

* Source: findings from the study

Functional Dimension

This dimension of analysis included aspects related to feeding, hearing, and speech. In the narratives, the children reconstructed their life histories and identified emotional situations, which in some cases led them to remain silent, isolate themselves, and experience various feelings of psychological discomfort, especially when they talked to other people. However, they re-signified that as part of their life before but not their current one, since they noticed the change or progress through external support such as speech therapy, demanding teachers, constant feedback from the family, and extracurricular school groups, until they developed metacognitive tools, self-instruction, acceptance, habits, and routines that allowed them to constantly monitor their prosody and expressive slang. Thus, their phonation improved and the difficulty in relating to others was reduced. On the other hand, the professionals' narratives highlighted the expertise with which some children face this difficulty and how interventions at an early age facilitate the child's feeding and were particularly important in establishing the function and giving parents peace of mind (Table 2).

TABLE 2
Functional Dimension. Patient, Caregiver, and Professionals of the Interdisciplinary Team

Subcategories	Patient Narrative	Caregiver Narrative	Professional Narrative
Feeding	"Before, food would come through my nose, but now with the surgery and treatment, well, not anymore." Male patient (10 years old)	"It has changed for the better, because before the surgery, the food, many things came up to the nose, and left him breathless, so they have been very positive changes."	"Well, they come with many doubts, the same as a first-time parent, for example, how do I feed him with a cleft without letting it go through his nostrils and this is more important because if even a father with a child who is born without a cleft has a hard time, because children born with cleft lip and palate have greater difficulty feeding."
Hearing	"I was nasal and I didn't listen well, but they taught me to speak well and did the exercises and controls and from there everything changed, because I could let go more and relate more." Male patient (18 years old)	Not reported	Not reported
Speech	"Now I speak well and I'm not embarrassed to speak since school and I've always liked theater and it wasn't like before when I was little because I was embarrassed because I couldn't speak, and I thought whether I'm doing it or not, but I tried and later, when I was older, I entered the theater group at school, in sixth grade more or less, and it was a good experience because it helped me loosen up more and relate to everyone..." Male patient (18 years old)	"He can't talk fast, when he wants to talk fast, he can't and it bothers him a bit."	"I think that it is not easy to develop in the society, today's children suffer from bullying, the normal child, now imagine the one with a condition of NSCLP that is evident, many people look at it and although with the same surgery it is noticeable and, because of the way they eat and speak, I have the perception these patients and their parents do not live as totally normal..."

* Source: findings from the study.

Aesthetic Dimension

Three subcategories were identified in this dimension: facial condition, dental malpositions, and scarring flanges. The narratives showed significant improvements in appearance and functionality. This reinforces a sense of progress in the process that was expressed more frequently by adolescents, who have spent more time in interdisciplinary treatment. This made it possible to give meaning to the important direct relationship between the self-perception of progress and improvement and the emergence of positive thoughts and feelings that result in better emotional and personal qualities. To a lesser extent, some children expressed verbal rejection or discomfort with their image, even denying this dimension in their life goals.

Regarding the subcategory dental malpositions, the relationship between adherence to treatment and its progress was identified. The family narratives exemplified how factors such as the use of orthodontic appliances, comorbidity with other physical, mental, and constitutive conditions of the person that involve their use and how they affect the duration of treatment or authorization for surgical procedures. Another of the family and children narratives evidenced the complexity of expectations and beliefs regarding the main factor that requires attention at a certain stage of the process. Some of them are expectant regarding the functional issue; others regarding the aesthetic issue, which constantly moves between the immediacy of the needs and the adequate progress of the process (Table 3).

TABLE 3
Aesthetic Dimension. Patient and Caregiver Narratives*

Subcategories	Patient Narrative	Caregiver Narrative
Facial condition	"When I see myself in front of the mirror, I don't like it because I still don't have a normal shape." Female patient (12 years old).	"It is already making a dent in her, the condition that knows that the physiognomy of the face is changing, and her nose has changed, as if it is going sideways ... When will the day come when I can operate? That is what she has right now, that makes her uncomfortable."
Dental malpositions	"Very well, I'm glad, because we've made a lot of progress and they did the reconstruction of the lip and I think that of the palate and from here and every time the teeth are better, I love it." Male patient (18 years old).	"... he wants his teeth to improve... like feeling like another child inside."
Scar bands	"In the mouth, in the form, from what I was before to what I am right now, I am another person. I have seen people who were born that way that you can see their teeth, their lip pulled back..." Female patient (19 years old)	Not reported

* Source: findings from the study.

Psychological Dimension

Subcategories identified in this dimension related to self-image, self-esteem, social interaction, and mood. Regarding self-image and self-esteem, the participants viewed positively how children and adolescents have experienced physical changes. For example, the value of a smile and social inclusion reflect the positive results of different therapeutic procedures.

It was evident that the children and adolescents reconstructed, from their narratives, how the NSCLP condition presents challenges, situations, and thoughts that put them in condition of vulnerability. However, it was observed how the children changed their passive roles by recognizing their condition and social stereotypes, since from an early age they developed social skills, character, and strategies to face negative aspects. In this regard, most of the participants defined themselves after overcoming the condition and, even, one of them identified it as his personal brand and from there he perceived himself as an example for people who share their condition.

Regarding the subcategory of social interaction, sensations of sorrow, anguish, and shyness are narrated, together with hope and desires to be more sociable. Likewise, the children and adolescents identified skills, attitudes, and strategies to successfully manage their relationships that have allowed them to feel increasingly competent. Most of the participants referred to meetings or activities with children with the same condition that resulted in positive experiences. They liked those contexts.

In the mood subcategory, at the beginning, children are exposed to situations, news, and procedures that affect their mood. However, they have the support of their mothers, psychologists, and friends who remind them that it is temporary and help them overcome those feelings. Given their condition and life history, they are children who from early ages are exposed to stressful events and procedures in which anxiety is natural. However, they have the necessary understanding and support from their families and support networks.

During the interviews, one case of comorbidity between FLP and mental health disorders was identified. A parent acknowledged that there is no knowledge or interest in including the particular needs that their child may have in relation to the NSCLP in relation to the affectation of mental health. In return, he favorably recognized the comprehensive approach offered by the Javeriana program since, thanks to it, it has been possible to assertively guide the patients.

On the other hand, for the professionals of the interdisciplinary group, the expectations expressed by children and adolescents suggest that the treatments and support offered at the CLP clinic offer results that transcend clinical procedures. Likewise, they contribute to strengthening self-esteem, which favors social interaction with their peers (Table 4).

TABLE 4
Psychological Dimension. Narratives of Patients, Caregivers,
and Professionals from the Interdisciplinary Team*

Subcategories	Patient Narrative	Caregiver Narrative	Professional Narrative
Self-image	"More than anything it was the lip and teeth because I felt bad and sorry. And, every time I took pictures, I tried not to smile or anything like that." Female patient (12 years old)	Not reported	Not reported
Self-esteem	"That was very painful, they are things that are never forgotten (bullying); but one adapts and accepts; one gets used to it and from a very young age they taught me to defend myself from being harassed and since you already have the strength and even more so when I started to speak well." Male patient (18 years old)	"He tried to commit suicide, in 2017. The psychiatrist has him with medication, it is time to continue with that and with his controls, because at the same time the development of the orthodontic and dental issue depends a lot on his mental part because, if he is without crisis and those attacks, because it will remain much longer, but the idea is to be able to manage it in the best way with all the support from psychiatry and psychology."	"... undergoing orthodontic treatment... When you see them smile, there is an impressive change... In fact, a girl recently arrived with her parents... She was happy because she had already finished her treatment... seeing her smile at 15 years old, with minimal surgeries and a totally normal girl, included in society because that's how she felt."
Social interaction	"When I went to the new school, there were some children who told me that I was very ugly, and there was one who became my friend because he didn't care that I was like that..." Male patient (10 years old)		"I believe that growing in the society is not easy. Today's children suffer from bullying, the normal child; now imagine the one with a condition of NSCLP that is evident..."
Mood	"Today I was going to have surgery. Unfortunately, it was not possible because I have heart problems and yesterday, I got too depressed... but as my mother explained to me, life continues." Male patient (16 years old)		Not reported

* Source: findings from the study.

Other Analytical Dimensions (Emerging Categories)

The following emerging categories were identified in the narratives: social discrimination, perception of pain, educational issue, family support/rejection, and other activities. Regarding social discrimination, most of the participants were victims of bullying in school, which generated emotional affectation for being exposed to nicknames, constant teasing, rejection and exclusion from groups and activities. Among some adolescents reactive (aggressive) behaviors were justified when facing derision, while for others harassment prompted them to be more selective with whom they hang around and to develop "filters" from the comments. Only loved ones and people who know about the child's condition were relevant. Some children justified people

who constantly ask them about their CLP and those who bother them, because they do not know anything about it or do not seek to cause harm.

In the family context, a mother's narrative recounting that, due to her son's NSCLP, the whole family moved to another place of residence stands out. They were tired of the derogatory treatment by other members of their community. In another case, a mother reports that she struggled getting the health system to provide care to her daughter due to issues related to bullying in school. She stressed that the comprehensive care they received from the Javeriana professional team has been fundamental to overcoming bullying.

On the other hand, the narratives of the professionals allow us to approach the impact of NSCLP and its treatment. They referred to the limited support available for people with this condition, which is evident in the long waiting times, the need for comprehensive treatment, and the disinterest of society in this population.

With reference to the perception of pain associated with dental treatments, a dichotomy towards relativization was perceived. Some participants did not acknowledge having experienced pain in their treatments, their daily life, or as a product of the CLP condition. In contrast, some participants assumed resilient postures that allowed them to empower themselves with their treatment and overcome the discomfort that it generated.

In the educational dimension, parents were concerned about the difficulty of finding educational institutions where their children feel supported. The existing institutions are expensive, which increases the "emotional exhaustion" that entails that the children complete cycles to adapt to new schools over and over again. From the interviews with the adolescents, it was evident that there are "desires and hopes" to pursue higher education studies.

The family support category was pertinent as a way of entry for caregivers and parents to be able to share and reconstruct the process and life story that accompanying their children with NSCLP has generated. As part of the highlighted learning and stories of personal struggle, it was found that some parents begin a process of acceptance through the basic stages of denial, uncertainty, and guilt. Some faced it alone and felt hopeless about the possibility of "normality" for their children. Other parents had professional support and guidance since their children birth, which allowed them to re-signify and objectify the condition of NSCLP from the beginning, which resulted in greater coping tools.

On the other hand, some adolescents highlighted having received family support with the presence, physical proximity of their relatives, and manifestations of care for them. One of the children spoke about the mother's feeling of guilt when she felt that the CLP was, perhaps, a consequence of inadequate prenatal care and controls.

Parents and caregivers expressed they unconditionally accompany their children, but recognize tensions and conflicts with their partners, when defining how to address their children's life situation. They go through moments in which they see them as disabled and sick, they overprotect them, until they perceive them as "as if nothing was happening." It is evident that parents who act together develop optimal parenting patterns and styles in the family. Another tension identified in the narratives of parents and caregivers is related to the conceptions, prejudices, and attitudes of the extended family, which sometimes go against the parents' determinations.

It is worth mentioning cases of family rejection in the life history of children with CLP, for short periods, while their parents and relatives assimilate the condition. In other cases, such rejection set the tone of the relationship with said relative. For their part, professionals acknowledge that they have developed skills to investigate, support, and inform families about the basic aspects of NSCLP and those areas of adjustment that improve adherence to and evolution of treatments. They are aware that each child and the family bring their own accumulation of fears, myths, beliefs and, therefore, different attitudes, which sometimes do not allow adherence to the process or coexistence with the minor.

Another emerging category is related to other activities that children and adolescents are usually unable to perform in daily life due to their NSCLP status. They include playing a musical instrument, whistling, sipping, and blowing. The children took such activities as personal challenges to measure or quantify their progress (Table 5).

TABLE 5
Emerging Dimensions. Patient, Caregivers, and Interdisciplinary Team Subcategories and Narratives*

Subcategories	Patient Narratives	Caregiver Narratives	Professional Narratives
Social discrimination	"I would say difficult... because there are people who don't understand this problem and what they do is criticizing me, make fun of me, mock me, they call me names." Male patient (15 years old) "Partly it's hard, because when you leave school, they start bullying you and you can start being aggressive; I say it for my part, because I was suspended many times because I have been bullied a lot." Male patient (18 years old)	"Everyone was: "that the girl is sick," "that the girl was born sick," "let us come and look at her," and that was like seeing something strange; so, we left Huila [department of Colombia]."	"The staff, the human resource is there, but the funding part is difficult; it would be necessary to look for more financing and that the health plan covered all the treatments, since there are some that are not covered. The part of the motivation or that the patients attend is another topic because the treatments are very long." Not reported
Perception of pain	"Yes, that was very painful; there are things that are never forgotten, but one adapts and accepts that because one gets used to it." Male patient (12 years old)	"For example, the mask; I know that she could improve faster if she wears it more constantly; but she sometimes, like she gets tired and, well, one understands and one also feels because she, well, she is also tired."	Not reported
Educational dimension	"Well, I study and prepare to, God willing, be a social worker." Female patient (12 years old)	"... the school he is in at the moment is very expensive, because it was not possible to have him accepted at another district school or at a private school; we knocked on many, many doors and they were closed to us."	Not reported
Family support or rejection	"... they told me that it was a surprise that I was born like this; it was like my mother's fault because she did not comply with the prenatal controls and things up to date; but they are things that are already past and we found out at my birth." Male patient (18 years old). "In my house they didn't talk about anything, but there was no lack of people who came and looked at me and asked who I was or what had happened to me and sometimes even the same relatives denied me." Male patient (18 years old) "... because practically my father was never there, so to speak, he was never good for anything; I did not have the support of my father, only that of my mother." Male patient (18 years old).	"... since she was a little girl we taught her to have high self-esteem, so that she would not feel less than anyone, and that she would never let herself be affected by it, and that is what we tell her now, that she is very beautiful, she is the same as all people, she has the capacity, she is very intelligent, I even managed to tell her that children like her had greater capacities than we had."	"... the support and presence of relatives is decisive in these patients because it marks the concept that the child has of themselves with respect to the condition; marks their adaptability, their adherence to different treatments; it marks the evolution of the treatments and, ultimately, marks the development of that person in the human and personal aspect of it."
Other activities	"... I limited myself to do many things; for example, many people told me that I could not play the flute, nor sip a straw, and in the end, I was able to do it; I ended up playing well, but I still haven't been able to sip with the straw." Female patient (15 years old)	"She's in the dance group and she's into all of that stuff. And it is what makes me think that she is confident and calm... right now."	Not reported

* Source: findings from the study.

Focal Groups

Through the focus groups, relevant information was obtained that showed the needs of the parents, by relating the treatment and its quality with the success and evolution of their children in the face of a good service. This

would have an impact on the life of each one of them, since each improvement, both physical and emotional, contributes to the quality of life of these patients.

Likewise, the professionals spoke about the experiences that, as a group, they have had. They also commented on the challenges and needs of the interdisciplinary team to provide quality services that contribute to each patient of the CLP clinic having the opportunity to obtain optimal results that favor their quality of life.

Regarding the pre-established dimensions, the most frequent to identify the themes of the focus groups were identified in the social dimension:

“... I think that children are very cruel and can make fun of a child with the condition, and that is due to lack of information; because, if there is a child with this condition in a classroom and some healthy children see him, parents should know about this situation so that the father of the healthy child can explain to him that the child with NSCLP is normal and that they should not make fun of them because they could hurt them.” Professional of the Interdisciplinary CLP group.

On the other hand, the categories derived from the interviews to conduct the focus groups were trajectory in the program and family support:

“... the support and presence of relatives is decisive in these patients because it marks the concept that the child has of themselves with respect to the condition; marks their adaptability, their adherence to different treatments; it marks the evolution of the treatments and, ultimately, marks the development of that person in the human and personal aspect of it.” Professional of the Interdisciplinary CLP group.

DISCUSSION

The concept of quality of life addresses all dimensions of general health and its perceptions. Under this concept, the facial condition, the biological implications (feeding, hearing and speech), self-image, self-esteem, social interaction, and the implications for the mental health of patients with CLP are evaluated. They provide information to determine the degree of emotional adjustment of people with CLP, which was clearly identified in this study and is consistent with what has been described by several authors (16,17). Carrera, *et al.*, in 2011 (10), mention that, “... studying the relationship between the perception of quality of life in children with NSCLP and other associated oral conditions could improve communication between patients, their parents, and the team treatment, as well as to improve the understanding of the relationship between oral health and the emotional states of children and the lives of their families...” This was perceived as an opportunity to understand how interdisciplinary treatment should adjust to what the person with CLP feels, desires, and experiences from their reality. On the other hand, the qualitative literature was scarce, which should be considered and valued in studies such as this one. Authors such as Sadala, *et al.*, (14) highlight the relevance of the interpretations that people give to life experiences.

In relation to the aspects that most affect quality of life, this research indicates that social acceptance, psychological aspects such as self-image and self-esteem, and social interaction are the most relevant in the lives of the patients and parents interviewed. They are followed by family support, which agrees with Palacios, *et al.*, in 1999 (6), Rando, *et al.*, in 2018 (18) and Márquez, *et al.*, in 2013 (19). Such studies have suggested that the child, adolescent, and adult population with CLP is vulnerable to equal integration into the family, school, and social environment. This situation makes it necessary to inquire about the family environment and coexistence, which was important in the development of this research, since it revealed that most relatives spoke of parenting with permissive and overprotective nuances to prevent social and family rejection from spreading. give in certain contexts.

The biological dimension suggested that oral hygiene is one of the most difficult activities to conduct due to the presence of orthodontic appliances, dental malpositions, and defects in the formation of the teeth adjacent to the fissure, among others. This agrees with what was described by Giusti, *et al.* (20), who warn of a

substantial risk of developing caries and gingival disease among these patients. In this regard, different authors agree that the accumulation of food debris and bacterial plaque, dental malpositions, orthodontic appliances and the presence of residual fistulae, among other factors, increase the risk of caries and periodontal disease in individuals with PLC (21, 22).

In the functional dimension, eating, hearing, and speech problems were included as elements that commonly affect facial appearance and social development, as well as cognitive functioning (23). In this regard, the impact of orofacial clefts on quality of life, according to Zeraatkar, *et al.* (24), include disability, pain, and suffering, as well as impairment of vital and daily functions such as eating, smiling, and communicating. This was evident in the research and in some patients' narratives, when referring to inappropriate speech as a reason for rejection and social and school exclusion.

Thus, psychological adjustment tends to be challenging for children with NSCLP, when addressing aesthetic concerns and speech difficulties, as also suggested by Escudero, *et al.* (25). Although the present study showed that the main problem is related to the difficulty in pronouncing words, it stands out that the articulation errors in the production of the sound are mainly due to the fact that the impact of the CLP is more related to compensatory failures in the production of sound than by the inability to emit them correctly.

On the other hand, regarding the aesthetic dimension, the research showed that physical appearance is more important in adolescents, especially women. However, in young children, looking different for some is important while for others it is not. These findings are consistent with what was described in 2018 by Hlongwa and Rispel (26), who explored self-concept and behavioral difficulties in children with different degrees of facial malformation and types of CLP and identified variable results. This suggests that not only the condition related to CLP influences self-image. Elements such as the family environment, the identification of the maternal and paternal image and stimuli from other contexts can influence self-perception, which could be expanded in future research with objectives similar to this one.

Breseke (27) applied a semi-structured survey to explore experiences among adolescents with acquired or congenital facial differences. Participants mentioned frequent stigmatization and discrimination that had negative social implications, among which self-esteem and self-image were negatively impacted. This was shown in our findings in the category of psychosocial aspect. One adolescent stated that the appearance of her nose was her most important concern.

According to Hunt, *et al.* (28), the differences in function and aesthetic abilities in patients with NSCLP put them at risk of psychosocial maladjustment. They found that a percentage of them are exposed to risks of social acceptance, behavior problems, and emotional distress, which was also found in the present study. The foregoing suggests exploring the perception of class in order to delve into the possible stigmatization and group and peer exclusion.

Regarding the psychological dimension, a representative affectation was observed, since by requiring multiple surgical interventions and long-term complementary treatments, the aesthetic and functional results can have a negative impact on the social and emotional development of the patients. These elements have a negative impact on health-related quality of life. These findings coincide with those described by Naros, *et al.* (29), who found affectation in self-esteem by correlating an increasingly higher social burden with increasing acceptance or rejection in the social circle of people with CLP, especially parents. This is explained from the contexts of social interaction in school settings that, somehow, can have a negative influence.

In the group of adolescents, especially among women, self-concept is lower due to social factors in which aesthetics represents a relevant component. This was also described by Naros, *et al.* (29), and Tedesco, *et al.*, in 1997, cited by Zeraatkar in 2019 (24), who found that patients with NSCLP had problems with being teased and exhibited anxious behaviors, were withdrawn, and were depressed. This was also identified in the narrative of an adolescent in the present study. On the other hand, Turner, *et al.*, in 1997, cited by Zeraatkar, *et al.*, in 2019 (24), indicated that psychological difficulties are not only limited to children with CLP, but

also to their parents, who experience emotional crises. Parents face the stress of raising a child with NSCLP, which was recounted by some parents interviewed in this study.

The present study shows that the impact of the CLP condition is a determinant in the well-being of the person in their self-image and their way of relating to their peers and family members. This is consistent with the findings of Hunt, Burden and Johnston, cited by Márquez in 2013 (6), who determined that the psychosocial impact of people with CLP is related to psychological functioning and personality, self-concept (including self-esteem and self-confidence), body image and satisfaction with facial appearance, speech difficulty, and aesthetics. Other associated factors include behavioral problems, social functioning, anxiety, depression and attachment, development, and learning (16,30).

Chiquito Coy (31) emphasizes that the ideas of remodeling biography and identity are related to the narratives of the participants. She highlights how identity can be transformed to express dreams and expectations framed in the quest to be "ordinary" people, without any facial alteration. This was evident in narratives such as wanting to be "normal" or less different (32). Rodríguez and González (5) describe the experiences of people who share the same condition. They relate physical appearance to psychosocial functioning, which is clearly visible in the participants of this study, for whom having NSCLP made them different (33).

Zeraatkar, *et al.* (24) explored the quality of life in patients with NSCLP from the point of view of caregivers and after surgical procedures. They describe that the most critical problems were related to functional well-being and socioemotional involvement that contributed to a lower quality of life in children. These findings are similar to those of this research, considering that the parents' reports about the surgical therapies their children underwent generated discomfort and socio-emotional effects due to pain and the inability to eat and perform oral hygiene.

In this study, some emerging categories were derived that were related to: presence of pain before dental treatments, educational expectations, and the possibility of performing or not performing activities in daily life such as whistling, blowing, sipping, and playing a musical instrument. This coincides with the findings of Vélez and Álvarez (34).

On the other hand, this study showed that, for some participants, being cared for by interdisciplinary teams makes treatment results optimal, because of the comprehensive approach. It includes the awareness of family members and the social circle in which the person operates. In this regard, Nicholls, *et al.* (35) concluded that multidisciplinary teams in charge of the comprehensive management of patients with CLP should sensitize parents, educators, and employers about the impact of this condition through the promotion of programs aimed at improving self-esteem and social inclusion and skills, such as confidence to speak in public.

As part of the qualitative methodology used in this work, focus groups sought, based on a carefully designed discussion, to identify the perceptions of the participants about a particular area of interest (36). In this case, due to the fact of being born with CLP, the focus groups sought to identify the perceptions, considering feelings, emotions and attitudes, both of the parents and of the professionals of the interdisciplinary group. This made it possible to obtain relevant content and an approach to the needs of the parents, who became more involved with the treatment, its quality and success, and the evolution of their children in the face of a good service. It was investigated how the latter affected the lives of each of them, in terms of physical and emotional improvement and the contribution to the quality of life of the patients. Our findings agree with those of Escobar and Bonilla (37), Cisneros, *et al.* (38) and Rosado, *et al.* (39).

Likewise, the professionals indicated that the purpose of the interdisciplinary team is to provide humanized and quality health care services. They must contribute so that each person who attends the CLP clinic obtains optimal results that will favor their quality of life. This has also been reported by Germec, *et al.* (40), Abualfaraj, *et al.* (4), and Han, *et al.* (41).

Regarding the focus groups, Krueger, *et al.* in 1991 (36) suggest that this strategy allows information to be obtained to identify how different programs are developed and improve the provision of services,

through the perceptions, emotions, and attitudes of the participants. This was found in this investigation. Additionally, focus groups are relevant as they allow exploring opinions and different responses about a product or service. They are developed through interaction with others in which perceptions may change during group discussion or may open the door to new discussions (36,37).

CONCLUSIONS AND RECOMMENDATIONS

Social and biomedical disciplines can be articulated through qualitative research, using methods such as phenomenology, which is useful to understand the meanings of experiences and human experiences through the narratives (interviews and observations) of the participants. This methodology allowed revealing the meaning and perceptions of patients with NSCLP, their parents, guardians, and the human health team, and the impact of these experiences on quality of life.

In this study, the participants reconstructed from their narratives how the NSCLP condition generates challenges, situations, and thoughts that affect quality of life, especially in the social and psychological dimensions.

Due to the fact that the reports of the participants did not reach the saturation point through the interviews, it is suggested to review additional categories and topics that allow continuing with this type of research to achieve greater depth on the perceptions of children and adolescents with NSCLP and their impact on the quality of life.

However, given the importance of the explanations of the phenomena that each person managed to convey, it was possible to identify, from their subjectivity, the comprehensive affectation of having NSCLP, which provided elements to the professionals involved in interdisciplinary management to improve the service, based on the needs and interests of these people (42).

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Notes

- * Original research

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