

Experiences of parents of children with cleft lip palate regarding care in the different stages of surgical treatment

Vivências de pais de crianças com fissura labiopalatina quanto aos cuidados nas diferentes etapas do tratamento cirúrgico

Vivencias de padres de niños con fisura labio palatina respecto al cuidado en las distintas etapas del tratamiento quirúrgico

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Abstract: The nurse is one of the healthcare professionals in charge of providing care to the patient with cleft lip palate malformation during the evolution of the treatment. However, there are not enough national or international studies regarding the parents' experience with the care that their children received, due to which the concern arises to investigate the experience of a group of parents from the south of Chile regarding the care that their children received from a professional nurse during the evolution of their child's disease. The objective is to unveil the experience of the parents of children with cleft lip palate regarding the nursing care received since the child is diagnosed until he/she is submitted to the surgical treatment, in the Hernan Henríquez Aravena Hospital during the first semester of 2019. It is a qualitative study with a descriptive phenomenological approach, done through an in-deep interview, field notes and audio recordings. Regarding the results, from the experience and the narrations of the parents, categories and subcategories arise allowing analyzing more clearly the investigation. These categories are: negative emotions experienced, experience with wealth care and expectations from nursing care. In conclusion the parents receive a permanent nursing invisibility, often confusing their care with the one provided by technicians and/or other healthcare professionals. Regarding nursing care, they express gratitude, but without distinction of who provided it, just to the healthcare team in general.

Keywords: cleft palate; anxiety; nursing; nursing care; emotions.

Resumo: O enfermeiro é um dos profissionais de saúde encarregados de cuidar do paciente com malformação labiopalatina durante a evolução do seu tratamento. No entanto, não existem estudos nacionais ou internacionais suficientes que mostrem a experiência dos pais em relação ao cuidado recebido por seus filhos, por isso surge a preocupação em investigar a experiência de um grupo de pais no sul do Chile a respeito dos cuidados recebidos pela enfermagem. Profissional durante a evolução da doença dos filhos. O objetivo é revelar experiências de pais de crianças com malformação labiopalatina, a respeito dos cuidados de enfermagem recebidos desde o momento do diagnóstico da criança até a realização do procedimento cirúrgico, no hospital Hernán Aravena, durante o primeiro semestre de 2019. É um estudo qualitativo com abordagem fenomenológica descritiva, realizado por meio de entrevistas em profundidade, notas de campo e gravações em áudio. Em relação aos resultados, emergem as vivências e narrativas dos pais, categorias e subcategorias que permitem uma análise mais clara da pesquisa. Essas categorias são: emoções negativas vivenciadas, vivência com o cuidado à saúde e expectativas do cuidado de enfermagem. Conclui-se que os pais percebem uma invisibilidade permanente da enfermagem, muitas vezes confundido seus cuidados com os prestados por técnicos e/ ou outros profissionais de saúde. Quanto aos cuidados de enfermagem, relatam gratidão, mas sem distinção de quem os fomentou, mas sim para com a equipe de saúde em geral.

Palavras-chave: fissura palatina; ansiedade; enfermagem; cuidados de enfermagem; emoções.

Resumen: La enfermera(o) es uno de los profesionales de la salud encargado(a) de proporcionar cuidados al paciente con malformación labio palatina durante la evolución de su tratamiento. Sin embargo, no existen suficientes estudios nacionales ni internacionales que evidencian la vivencia de los padres en relación al cuidado recibido por sus hijos, debido a lo cual nace la inquietud de investigar la experiencia de un grupo de padres del sur de Chile respecto a los cuidados recibidos por parte del profesional enfermero durante la evolución de la enfermedad de sus hijos. El objetivo es develar vivencias de padres de niños con malformación labio palatina, con respecto a los cuidados de enfermería recibidos desde que el niño es diagnosticado hasta que es sometido al procedimiento quirúrgico, en el hospital Hernán Henríquez Aravena, durante el primer semestre de 2019. Es un estudio cualitativo con enfoque fenomenológico descriptivo, realizado a través de entrevistas en profundidad, notas de campo y grabaciones de audio. Respecto de los resultados, de las vivencias y narraciones de los padres surgen categorías y subcategorías que permiten analizar más claramente la investigación. Estas categorías son: emociones negativas vividas, experiencia con los cuidados en salud y expectativas de cuidados de enfermería. Se concluye que los padres perciben una permanente invisibilidad de enfermería, confundiendo muchas veces su atención con la proporcionada por técnicos y/u otros profesionales de la salud. En cuanto a los cuidados de enfermería, relatan gratitud, pero sin distinción de quién la propició, sino más bien hacia el equipo de salud en general.

Palabras clave: fisura del paladar; ansiedad; enfermería; cuidados de enfermería; emociones.

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Introduction

The pregnancy is a moment of great expectation for the parents, who tend to idealize the future of their child, and only after the birth, the gap between this imaginary newborn and the real one is undone. Thus, when something unexpected happens, such as the birth of a child with a malformation, the parents experience an outbreak of unexpected feelings (1). When it corresponds to a lip and palate malformation, it is usually due to the large amount of childhood problems that arises as a product of the disease, such as feeding, facial appearance and vocalization, among others. The parents stated that facing the diagnosis, reorganizing the family structure, undergoing the treatment and hospitalization could be difficult (2, 3).

Regarding the cleft lip palate, the incidence in Chile corresponds to 1.7 per 1000 newborns, around 400 cases per year; and in the Araucanía region, according to the information given by a nurse at the Unidad de Niños Fisurados at the Hernán Henríquez Aravena Hospital (HHAH), from 2005 to 2018, 605 children were born with this malformation. Among its etiologies is described the hereditary, ambiental and unknown factors; regarding the treatment, it is mainly surgical, with a multidisciplinary team intervening. It starts at between 3 to 6 months of life and it continues until the age of 15 years old, with different surgeries according to the age of the patient (4, 5). In relation to the surgical process, Gómez-Carretero describes that in the preoperative stage, feelings such as anxieties arises (6), also, in the child's case, a surgery is a source of psychological stress, due to the facing of an unknown situation, adding to the parents fear undergoing this event (7). When the parents experience this kind of feelings without achieving to control them, they could generate insecurity in the child; this could be because of the lack of information about the surgical process, more than the surgery itself (8). For this reason, the importance of the preoperative information, which improves the understanding of the process, reducing the feelings of anxiety and stress due to the intervention (9, 10).

On the other hand, the hospital environment should offer the necessary conditions to confront the stress of this treatment, gaining importance the nursing care, because they are the ones that spend the most time with the patients and their families, helping with the adaptation process, through a warm and empathic behavior (6, 9). This is why it is important for the nursing team to know how the family members perceive the care of this professionals, it is a tool to find solutions and to improve the quality of the service. One of the main challenges is that the patient and their family show confidence and security in the care provided by the nurses; this will be perceived in the respond of both of them, as the objectified reflection of the satisfaction as users. This is why it is important to be rigorous and delicate in delivering care, to ensure its quality (11).

On the other hand, regarding the public health policies in Chile, the document "Estrategia Nacional de Salud 2011-2020", states that the goals, as much as the set-out indicators, respond to a rigorous prioritization regarding health issues. Primarily focuses on the analysis and elaboration of proposals for the different fields related to health, divided on 9 thematic areas and 4 general objectives (12). This investigation approaches the user satisfaction issue, which corresponds to the results of the provision of services according to the need, being a permanent concern in the healthcare services (12).

Because of the previously exposed, arises the concern to investigate the experiences of the mothers and/or fathers of children with cleft lip palate malformation regarding the nursing care they received during the surgical process. Also taking into consideration the high percentage of newborns with this type of malformation in the country, the lack of published studies about the experiences lived by the parents regarding the nursing care, being the latter the ones that provide

direct care during the course of this treatment. What is more, the utility and the social value of the investigation is in describing the phenomenon from the parents' perspective, who have been classified according to a specific pathology and its evolution over the time.

Objective

Unveil the experiences of parents of children with cleft lip palate malformation, regarding the nursing care provided since the diagnosis of the child until the surgical process, at the Hernán Henríquez Aravena Hospital during the first semester of 2019.

Method

This is a qualitative study with a descriptive phenomenological approach. Once the information was collected, a clearly subjective analysis was carried out, allowing an approach to the experiences of the group of study (13-15), rescuing the main essence of each interview, regarding the nursing care received on a determined period. As a philosophical methodological reference, the investigation supports itself in the theory of Edmund Husserl (16-20), and as a nursing reference, in the theory of care of Kristen Swanson (21, 22).

The population of the study correspond to the parents of children with cleft lip palate malformation, who are in the diagnosis stage or have already undergone the surgical process, which is part of the treatment of the disease. The sample was obtained from the nursing database, belonging to the Unidad de Niños Fisurados, of the HHAH in 2019, with authorization from the director of the institution and the Comité Ético Científico del Servicio Araucanía. Once the information was collected, the parents who attended a medical check-up and who met the inclusion criteria were located; inviting them to participate on the project, later an in-depth interview was conducted with each participant. The studied population correspond to the total that allowed the saturation of information regarding with the proposed objectives. Regarding to the type of the sample, it belongs to a homogeneous sample combined with standard cases, since the studied population have as a similar characteristic, the medical diagnosis of their children, also rescuing the essence of the narratives (23). The inclusion criteria correspond to mothers and/or fathers of children treated at the HHAH, due to their cleft lip palate.

The data collection was obtained through: in-depths interviews, filed notes and audio recordings, later they were transcribed and analyzed until the saturation of the information, defining criterion to stop the process of informant selection (13).

Regarding the analysis plan, it was carried out manually and informatic, this last one was done with the support of the Atlas-ti version 8.4 program; in this way the data was reduced, until they were categorized, codified, synthesized, and grouped (13, 24). Finally, the results and conclusions were obtained, allowing to understand and know the reality studied (23).

In relation to the ethical considerations, in addition to the evaluation of the Comité Ético Científico del Servicio Araucanía and the authorization of the HHAH, the ethical principles of E. Emanuel (25) were applied, applying an informed consent form to the participants, who were treated with respect, maintaining their privacy, and safeguarding the information provided. In order to do this, they were assigned a pseudonym to facilitate the analysis of their narratives. Regarding the rigorous criteria, to safeguard the scientific quality of the study, the criteria described by Guba and Lincoln (26) were used.

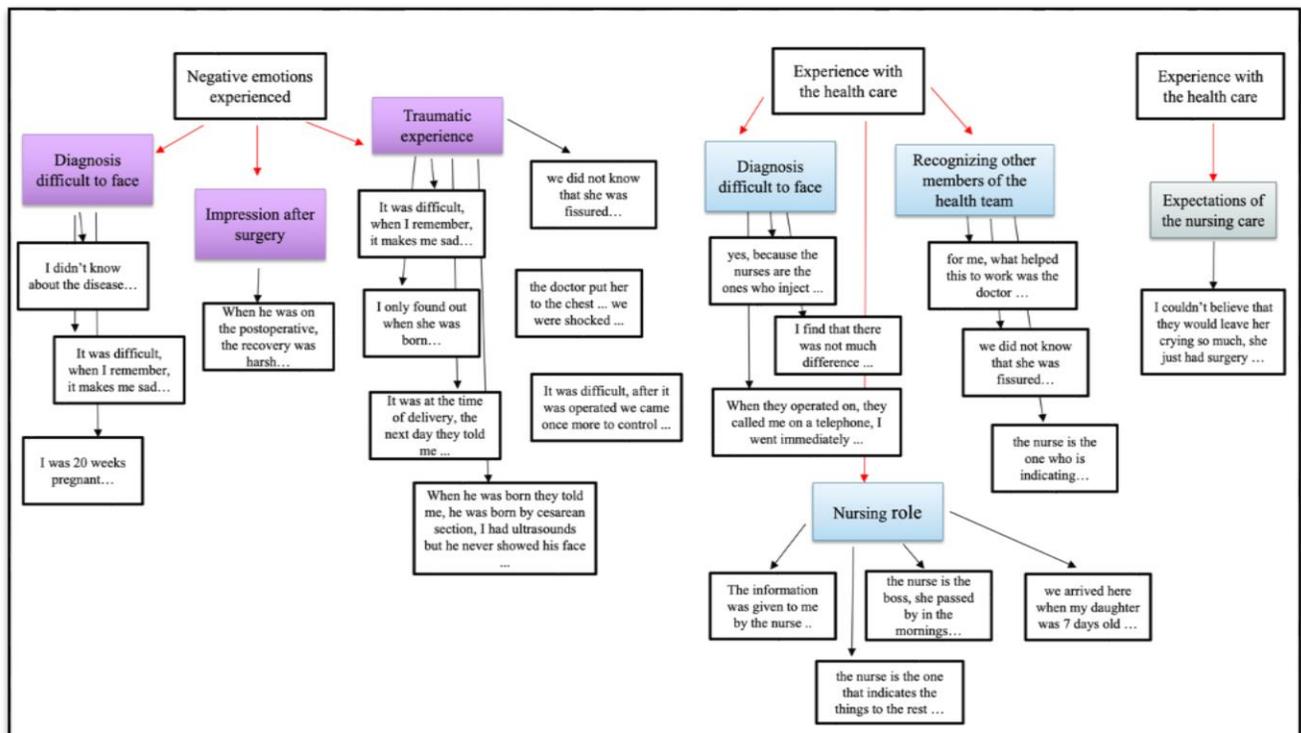
Results

The experience of the parents was unveiled during the different stages of life where their children were hospitalized and cared by nurses for their recovery, emerging from their narrations categories and subcategories, which are analyzed below:

Table 1: Description of categories, according to the proposed objectives and to the indicated by the interviewed.

Category	Subcategory	Category definition
1.Negative emotions experienced	-Impression after the surgery. - Difficult diagnose to face. - Traumatic experience.	Impressions experienced by the interviewed, it begins when they found out about the malformation of their child, evolving though the course of the process, for example, mothers unable to breastfeed their newborn, face the treatment by themselves; fathers who take on the role pf the provider cannot accompany their children.
2.Experience with the health care	- Nurse invisibility - Nursing role - Acknowledging other members of the health team.	The care and the subcategories are mainly related to the hospitalization in the anesthetic recovery unit and the pediatric surgery service.
3.Expectations of the nursing care		Nursing care requirements expected by parents during the treatment of their children.

Figure 1: Families of categories and subcategories, according to the reports from the interviewed. Program Atlas-Ti analysis.



Below we analyze each category:

1. Negative emotions experienced

This category is present in most of the interviews, and from it emerge three subcategories: impression after surgery, diagnosis difficult to face and traumatic experience. This supported by the following stories:

Impression after the surgery, child's condition when leaving the operating room: "When he was on the postoperative, the recovery was harsh, his mouth came with a plastic prosthesis, open and full of blood, he complained a lot because of the pain, it was impressive" (E1).

Diagnosis difficult to face, parents find out about the malformation: "I didn't know about the disease, when they did the ultrasound, they said: «The baby is fine, but with a malformation», it was difficult" (E5). "It was difficult, when I remember, it makes me sad, I cried, I didn't know what to do, they told me that I didn't need to be sad, and there was a treatment if she survived" (E7). The crying of the mothers at the time of the narration supports both stories (NC 5, 7). "I was 20 weeks pregnant; the ultrasound showed the malformation, it was complicated because one always thinks that the children will come good" (E9).

Traumatic experience, experiences when confronting the unexpected diagnosis, they talk about the lack of information about the pathology and its possible complications; mothers unable to breastfeed felt alone during the treatment, because the father had to continue working:

When she was born, they told me she had this disease, it was hard, I started crying, I didn't understand why, I was so excited to have a daughter, she had trouble sucking, so they had to feed her with the other milk (E2).

I found out when she was born, I didn't understand anything, I wanted to breastfeed her, but I couldn't, it was terrible, she couldn't suck, because she would choke, so I had to express the milk and spoon it to her. After surgery I stayed with her day and night, it was exhausting (E4).

My daughter was born with a cleft palate, I found out the next day, but I didn't understand anything, she wouldn't suck. After the surgery, we only came back only to one check-up, I got bored of coming to the hospital, sometimes I had to bring her without sleeping all night, it was exhausting, and I came alone because my husband worked (E6).

2. Experience with the health care

This is marked by relationships established with different team members, emerged three subcategories: nursing invisibility, nursing role and recognizing other members of the health team. The following are their stories:

Nursing invisibility, little clarity perceived by the parents regarding the nursing care, they are not able to distinguish the nurse from the rest of the medical team, except for some procedures or the blue uniform:

There was not much difference between the ones that worked in the recovery room, nobody introduced themselves, I think the young lady that came to look for me to accompany my daughter was the nurse, but I don't really know, they can be distinguished by their blue uniform (E2).

When they operated on her, they called me on a pager, they told me that my baby was waking up, it was a round room, and we could ask questions to the nurse but only if there were doubts, she did not come to us, she was with the more complicated patients (E3).

In the recovery room there was no difference between nurses and technician, in general, my daughter has not received much care from the nurses, the technicians are the ones who have been with her (E4).

Nursing role, they related mainly with administrative functions, such as headship, supervision of the personnel and the indication of the procedures:

The nurse gave me the information, all about the care; the CDT nurse was more in charge of the administration (E1).

The nurse is the boss; she passed by in the mornings or during the day, supervising the charts, looked around and ask a few questions, that is all (E2).

We arrived here when my daughter was 7 days old, the fissure program nurse attended us, she gave us all the information, she was always ready to help us (E3).

The nurse is the one that indicates the things to the rest, when the other nurse arrives to take the shift, they introduce themselves and then they give the shift, there we get to know who is going to be in the shift (E7).

Recognizing other members of the health team, related to the care provided by other members of the medical team, other than the nurse, such as the surgeons and the nursing technicians:

For me, the one who helped was the doctor, when she was born we noticed, so I called the doctor, and she said that if we needed help she was going to help, she demanded that we could not miss any control. She was the one who opened the door for us, when you are a professional you think you don't need help from anyone, but when my daughter was born, even the person who swept the floors was of help, because I was lost, that's when I realized that each person has it worth, we need everyone (E3).

When he was born, they told us: "you need to go to Temuco, with the doctor in charge of the fissured program", she asked us if we were taking or leaving the treatment, my husband said that we were taking it, we continued to do everything they told us to do (E7).

3. Expectations of the nursing care

Concerning to the requirements of the nursing care, what they would have expected during the hospitalization of their children, they highlighted the hope of obtaining greater presence and closeness from the nurses:

I couldn't believe that they would leave her crying so much, she just had surgery. I feel like they did not care that much about her. I would have liked to be in the recovery room since the beginning, that they tried to calm her down a little bit, we needed more support, more information. Later, she was hospitalized in child surgery, I was with her all the time, but I did not like that they would only allow mothers to stay in the night, one still needs to rest. There the nurse is the boss; she

passed by in the mornings or during the day, supervising the charts, looked around and ask a few questions, that's all (E2).

And there was the nurse; we could ask questions to her but only if there were doubts, she did not come to us (E3).

Discussion and final considerations

The result show certain similarity in the stories, highlighting the way of facing the diagnosis, many times, unexpected: emerging negative feelings and emotions, such as pain, sadness, and uncertainty. On the other hand, the perception of the parents regarding the nursing care is unveiled, in the different moments they were required by their children; identifying, in addition, the role of the nurse, according to the concept that they have of them, which being contrasted with the invisibility of nursing, recognizing how difficult it is to distinguish the nurse from the rest of the personnel that attended them.

The birth of a child with a malformation is usually an unexpected situation, generating a great impact, arising feelings of anguish, denial and confusion, which are presented consciously or unconsciously and are expressed as traumatic experiences, leading to a state of vulnerability (5, 27, 28). The interviewed parents, supporting the results of the investigation, narrated these feelings.

Child's diseases usually affects the children as much as the parents, the latter reacting in different ways: mothers tend to show feelings of sadness and anguish, and being them who, in most of the cases, are in charge of the care. This was also demonstrated in the study "Madres cuidadoras de niños(as) con cáncer: vivencias, percepciones y necesidades", carried out by Lafaurie et al (29). Because the disease implies a family reorganization, where parents need to make decisions such as who is going to assume the role of primary caregiver. This was evidenced in the research carried out by Grau et al, "Percepciones de los padres de niños enfermos de cáncer sobre los cambios en las relaciones familiares" (30). In the same way the role of caregiver mother appeared in some mothers of the study, who justified the absence of the father, because they had to continue to provide for the family. In addition to this, complementing the traumatic experienced, the breastfeeding was another factor that increases this state, because the anatomical and functional alterations of the newborn makes this process difficult, causing a feeling of loss in the mothers that desired to breastfeed them, interfering in the mother-child bond, also influenced by their emotional state, the previous expectations of this process and the incompetence feeling. This is evidenced in studies such as "Guía Clínica AUGÉ Fisura Labiopalatina" by MINSAL, "Rigor y calidad metodológica: un reto a la investigación social cualitativa" by Cornejo and "Madres cuidadoras de niños(as) con cáncer: vivencias, percepciones y necesidades" by Lafaurie et al (5, 26, 29), occurring to most of the mothers, who recalling this experience, began to cry. The before mentioned reactions were revealed to both parents, mainly when they found out about their children's state, they described negative feelings, pointing out that it was a difficult and complicated situation to face; similar to the study made by Badillo et al (28). The exposed investigations support the present study, showing similarities in most of the narrated experiences.

Continuing with the order of the categories, health and disease are common circumstances in people's life, and each social group develops different health strategies to give solution to them, in this way, the health care is understood as a social practice. This is how, the nursing care is born from this common genesis with the health care (31). In this context, the nursing care comprises a

humanistic commitment and interest in their peers and their environment, characteristics of the *management of care*, which is understood as the professional practice of nursing, supported by its discipline, the science of caring; the care management must allow the provision of planned care, establishing objectives, goals and strategies, which implies the professional creativity, ensuring the quality of the care provided to users and their families. To accomplish this, the nurse must see the individual as an holistic being, including the biological perspective, active hearing, respecting at all time their rights, as revealed in the studies made by Milos, Grau and Ortiz (32-34). However, contrasting the definition of *nursing care*, the present investigation unveil a distant nurse, not very empathic, more concerned with administrative task than with accompaniment.

According to what was investigated by Suárez et al (35), in a group of mothers of children who suffered from some form of congenital malformation, said that the mothers felt discrimination against their children, which was to be expected from society, but not when it was from the health team, causing negative and incomprehensible impact on them; this discrimination was presented by doctors, paramedics and nurses, especially the nurses (35). In contrast, in this study, the parents reported feeling grateful by the care provided by the health team, without making distinction from *nursing care*, upfronting the surgeon, who operated on their children. When they talked about the nurse, they said that they could mainly distinguish him/her by their blue uniforms and not by the care that they provided. Regarding their role, they highlighted their administrative work, such as the head of a service and the supervision of the personnel; they also reported that they were responsible for the delivery of education to the parents. In relation to the direct contact with them, they mention that the instance of rapprochement occurred only when they have doubts. On the other side, the majority of them stated that they had experienced a traumatic and sad situation during the treatment of their children, highlighting the experience in the anesthetic recovery room, they mention feeling hopeless and lonely due to the lack of closeness of the nurses, who only came in the presence of doubts and most of the time were with other patients or in the nursing station. In this service, they did not clearly identify the nurse from the rest of the team, they only believed to know who they were due to the color of their uniform. As for the *nursing care*, they related it to the education on the care of treatment for their children, and the execution of some procedures. Contrasting these experiences with what was perceived regarding the nurse of the Unidad de Niños Fisurados, the interviewed recognized their management, closeness and dedication, highlighting their good willingness to answer questions, and they identified then as a reference in everything related to the pathology.

Regarding to the expectations about the nursing care, these are influenced by the information obtained from the activity of this professional, reflected in the degree of satisfaction, used as a health indicator, since it provides information about the quality of care noticed by users.

Care is perceived in response of both, patients and their parents, who expect a dignified, friendly and pertinent treatment, as revealed in the study “Nursing in the role of health care manager” made by Estefo et al (36). In relation to this, the expectations of the parents interviewed, were varied, from those who only focused on the definitive improvement of the malformation, to those who expected better care from the team of nurses; coinciding with the second group, parents whose experience in the immediate postoperative was painful and shocking, which according to Estefo et al’s investigation (36) these experiences are considered by health users to assess the level of satisfaction regarding the care received. Regarding the nursing care, the feelings were ambivalent, referring to gratitude towards the nurses, acknowledging their dedication to administrative tasks, but upfronting their distant attitude with their patients and themselves.

Regarding the care and identification of the professional nurse, the parents expressed gratitude for the care provided, recognizing the nurse as the one in charge of the administrative tasks, but who is not closer to the patient nor companions, they only approach when the user have any question related to the health-illness situation, whenever is solicited. The nurse was distinguish from the rest of the medical team by the color blue of their uniforms, this being the most relevant and discriminatory characteristic to identify them.

Despite the existence of studies such as the one of Milos or Grau (30-32), where they refer that the nurse must see and treat the individual as the holistic being, reality showed the opposite, evidencing in the narrations that the nursing work is mostly focused on administrative functions, far from the patient, without showing great empathy for the users and even less for the relatives of this patients, showing dehumanized care, also highlighting the evident invisibility of nursing that the interviewed parents could perceive.

Regarding to the disciplinary contribution of the investigation, corresponds to the application of the *Theory of Care* by K. Swanson, who, through its five basic processes, allow us to ponder on how the professional nurses is exercising the nursing care (21, 22), showing which are the weakest processes in the exercise of the profession, which require intervention to acquire a holistic care, maintaining humanized caring, so requested by the patients and their companions. Three processes stand out as the most altered in the experiences expressed by the interviewed. The first process is *being with*, according to Swanson, it is related to emotionality, the accompaniment of those who are vulnerable due to the presence of the disease (21, 22). According to the narrations, it is altered, since the parents recognize the lack of accompaniment by the nursing staff, the failure to be listened to and to deal directly with them, highlighting the work of other professional from the medical team, but not the nurses. The second process is the *doing for*, which correspond to the ability to do what one would do for oneself, developing, for example, the empathy tool (21, 22). The interviewed parents did not perceive this, they recognized this empathy, but in other professionals; they would have expected a more friendly, sensible and closer touch from the nurses. And the third altered process correspond to the *enabling*, which, according to K. Swanson, concerns facilitating the next step towards the unknown (21, 22). In the investigation it is related to the cleft lip palate malformation, the preparation that they have to receive in each one of the steps of the treatment since they were diagnosed. Although some of the mothers receive information about the disease from the nurse at the Unidad de Niños Fisurados, the rest of the process experienced were not explained in advanced, there was no evidence of preparation prior to surgery, or postoperative recovery, which, perhaps, would have helped cope better with experience they were subjected.

To finalize, the investigation was based on the phenomenological theory of E. Husserl, trying to rescue and reveal the experience of the parents whose common aspect was the diagnosis of their children; managing to describe the experience as they were narrated, complemented with the emotionality of the human being at the moment of referring to painful events, allowing to understate and demonstrate the essence of what is escribed.

Conclusions

It is concluded that the presence of a cleft lip palate malformation in a child is always a traumatic experience, regardless of the stage of life the child is in, which can be reflected in the different reports obtained in the investigation; highlighting the presence of negative feelings and emotions, also present during the surgical process to which this type of patient is subjected.

On the other hand, with regard to the care received, parents are generally grateful for the care provided by the health team, without highlighting the nursing care, since they are identified by their administrative function. Within this team, referring to the fact that they do not have greater closeness to patients or their companions, they only approach when users have doubts related to their health-disease situation, and whenever they are requested. They identify the nursing professionals as a distant, unethical official who provides dehumanized care to users and their families, recognizing him/her in the team mainly by the blue color of their uniforms.

Finally, the research aims to contribute to the nursing profession regarding the care given to users, demonstrating through a group of parents, the importance of being closer to patients, providing warmer and more humanized care, and that not only the technical procedures are important in their work.

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