

## EMPOWERMENT MECHANISMS USED BY THE FAMILY OF A CHILD WITH CLEFT LI AND PALATE TO A RESILIENT PATH

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### ABSTRACT

Cleft lip and palate have aesthetic and functional implications. A satisfactory adaptation depends more on the family and their attitude, rather than on the very presence of the malformation. The active process of endurance, growth, and restructuring, in response to the crisis and challenge is called resilience. To adapt, the family needs to be equipped through empowerment: developing skills to cope and deal with life events, gaining mastery over their issues, becoming stronger and capable of managing the demands of everyday life. We sought to understand the mechanisms of empowerment that families with children with cleft lip and palate have developed or enhanced in order to be resilient when facing this unfavorable situation. This is a clinical-qualitative research and content analysis was used for data processing. Two categories emerged from the analysis: "**Living one day at a time: overcoming the stages**", "**Giving Support and receiving support**", the latter of which is composed of two sub-categories "*For pairs*" and "*For the multi-professional team*". Lack of knowledge deprives the patient and his/her family from knowing how to manage the disease, preventing them from taking responsibility, generating the sensation that their lives are out of control, which negatively impacts the family's quality of life.

**Keywords:** Vaccination. Occupational Health. Nursing Team.

### INTRODUCTION

Before the birth of a child with deformity, the family is undergoing a process of mourning about the loss of their idealized baby. In this context, negative emotions are described as parental response to this event, being the most characteristic: anxiety, confusion, depression, shock, anger, disbelief, resentment and frustration<sup>(1)</sup>.

The implications of cleft lip and palate are aesthetic and functional. The rehabilitation surgeries begin at three months of age with the repair of cleft lip and at twelve months with the repair of cleft palate. Other surgeries, benefiting the functional and aesthetic scope, are required during child development and have a positive impact regarding the psychological aspect of the child and the family. Passing through the long and sorrowful rehabilitation process, the family feels that they haven't been assisted by the health team in all their needs<sup>(2)</sup>.

Parents' attitudes regarding the situation are crucial for the adjustment of children with a cleft. A satisfactory adaptation depends more on

the family and their attitudes than on the presence of the deformity. The active process of resistance, restructuring and growth in response to the crisis and the challenge is called resilience<sup>(3)</sup>. The human being is able to overcome adversity and potentially traumatic situations. Such a process is neither airtight nor linear, because an individual can present oneself resilient facing a determined situation and not facing another one, or even not present oneself resilient towards the same situation later. It is a complex, dynamic phenomenon, formed within the interactions between human beings and their environment. These interactions can promote the capability to face situations which pose a threat to their well-being successfully<sup>(4)</sup>.

Within the framework of family resilience, conceptualizes as resilient family one that can resist the problems arising from changes and adapts to crisis situations. This process depends beyond the spiritual factor on both the internal resources of the family and the external resources of the community<sup>(5)</sup>.

The *empowerment* (a neologism in the Portuguese language) is the development of skills needed to face and cope with life events,

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obtain mastery over the day to day issues, be stronger and capable of handling the demands of everyday life. For this, the family needs to be empowered. Its members, through feeling empowered to make decisions and identify needs, may acquire greater autonomy and independence towards the professionals. For this to occur, the family needs to have access to resources and their control, needs to strengthen the decision-making process and the skills to solve their problems and acquire appropriate behavior which is necessary to interact effectively with others in order to obtain resources<sup>(6)</sup>.

In this form, the empowerment presupposes the potentiation of already existing skills or their development. For that, health professionals need to build horizontal relations with the family, exercising the dialogue to overcome the power inequalities, provide and enable the family to access information, motivate the members to strive for autonomy regarding decision-making and problem identification<sup>(6)</sup>.

In this context, it is to wonder how the family pattern has been in search of empowerment mechanisms that allow for facing situations which present themselves in the coexistence with the child with a cleft.

This study therefore aims to get to know the empowerment mechanisms that families of children with cleft lip and palate have developed or enhanced to be resilient against the presence of this adverse situation.

## METHODOLOGICAL PATTERN

It is a qualitative research that works with the universe of meanings. In the context of qualitative research it was opted for the qualitative clinical method, conceived as a scientific research pattern, an individualization of the generic qualitative human science methods that aim to understand and interpret the meanings that individuals give to the phenomena in the binomial health-disease area<sup>(7)</sup>.

The used data collection technique was the semi-structured interview, which made it possible to obtain data of subjective nature, not simply being a work of data collection, but always a situation of interaction in which the

information given by the subjects can be deeply affected by the nature of the personal relations with the interviewer<sup>(7)</sup>.

The trigger element of the interview with the family was: "Tell me how the experience of caring for a child with cleft lip and palate has been for you". Throughout the conversation, the researcher used questions and places to encourage exploration, clarification and extension of relevant exposed cores. For example: What are the biggest difficulties? Have you received guidelines on how to handle the situation? Where? Who gave you those guidelines? By means of the interview it was striven for understanding the empowerment mechanisms that these families have used facing the needs, peculiarities and difficulties in caring for the child with a cleft.

All the interviews, conducted within the months December/2011 to July/2012, were performed at the respecting home of the family and were recorded after the participants' signature of the Informed Consent. Subject of this study are families of children with cleft lip and palate, registered in the Association for Cleft Support of a city in the interior of São Paulo. From the cadastral records was made a list of children and families who met the inclusion criteria: families of children with cleft lip and palate with up to 3 years of age who lived in the native city; children with only a cleft lip outside the designated age group. Undecided individuals and families towards the proposal were not part of the study.

Ten families of children with cleft lip and palate of up to 3 years of age were participants in this study. There were five interviews with both mother and father and five only with the mother. The collection was closed as we reached the data saturation.

Because it is a research involving people, all ethical aspects were observed and respected. The project was evaluated and approved by the Ethics in Research with Humans Committee of the Medical School São José do Rio Preto – FAMERP (Reference No. 415/2011, November 2011).

The data analysis was accomplished according to Bardin's Content Analysis<sup>(8)</sup>, which requires the text itemization into thematic units.

Taking as a basis the objective proposed in the study, the following operational steps were developed: 1. Constitution of the Corpus: the set of interviews; 2. Composition of the analysis units: skimming interviews and definitions of the emerging subcategories, with option for the context units covered by larger themes of the interviews, which then were broken down into thematic analysis units and afterwards into simpler semantic issues; 3. Categorization: the subcategories were grouped in categories and subsequently analyzed.

To elucidate the categories and subcategories, the participants' talks were presented, using the following standardization: each one of them is accompanied by the information who talked and the interview number, i.e. (*M, E2*) means the Mother, interview with the family 2 and (*P, E1*) Father, interview with the family 1.

## RESULTS AND DISCUSSION

Two thematic categories emerged: "Living one day at a time: winning steps" and "Supporting and being supported", the latter being composed of two subcategories: "Peers" and "The multidisciplinary team".

### Living one day at a time: winning steps

The journey of the family of children with cleft lip and palate is long, stressful, painful and exhausting and requires constant adaptation and learning in the light of new situations which arise during the course of life.

The first challenges are related to the care of the newborn child with cleft. For the family members arises the initial feeling of not knowing what to do and there are doubts over the care. In the dynamics of everyday life, the family is learning to take care of their child, customizing this care.

Another challenge is related to the process of rehabilitation and has its beginning shortly after the child's birth, extending for many years. This process involves several surgical procedures that are considered as essential stages in the treatment.

Thus, the family faces the challenges of care and surgical procedures, living one day at a time, step by step, constantly adapting and learning to overcome each step. The families, in this process of empowerment, avail internal and external

resources, knowledge and skills to solve the problems that arise in the daily child care and become resilient. The talks indicate how these families become resilient when appropriating resources and striving to overcome the difficulties as well as clearing their doubts. Adapting and recovering when facing these challenges, feeling able and empowered to review a situation of suffering.

I say that the work with them, I think, never ends, even mentioned it to my husband, I think it's a continuous thing, because we go back there [name of the Reference Center city], next year we have to go back again, they send a letter calling us. We go and there is always something new. (*M, E9*)

In the beginning it is very difficult because you don't know how to handle it.[...] It was more to gain practice, but at first it was pretty hard to take care. [...] It has to be the right care, careful, clean well, avoid being close to dirt, near animals, these things that convey a bit of dirt, sometimes the child will, passes the hand over all this and then put its hand in the mouth, so avoid the contact as far as possible. (*M, E3*)

If a little blister bursts, everything would open. He couldn't [...], I had to avoid letting him keep crying, he couldn't keep crying, he loved to laugh, I couldn't make him laugh, you know. It was all in patience. Avoid visits, you know, because it's so complicated that everybody wants to see him, you know. [...] Everything I gave him [...], had to smash it as if he were still a little baby, a newborn. [...] He spent almost a month without eating, it was all liquid, all in a cup. (*M, E1*)

But, we have to learn [...]. You get used to it really easy, take on simple habits, so it gets better every day. (*M, E7*)

The family (re)adaptation starting at the moment of diagnosis, birth and at every stage of the treatment of a child with cleft lip and palate is a complex process faced on a daily basis, requiring and enabling a learning process to the family.

Regarding the category *Living one day at a time: winning steps*, literature allows for reflecting that the treatment is long and gradual, since the child's birth, extending for many years<sup>(9)</sup>.

On the way passed day by day, step by step, winning stages is that the family develops its empowerment to overcome each new challenge, in the hope of victory by means of each battle,

always being aware that the struggle still continues and a new spirit and breath are indispensable to proceed with lightness and courage.

In the early days of the child's life, the family begins the therapeutic journey, making decisions related to future treatment. During childhood and adolescence, parents' concerns are related to: surgery, orthodontics, therapy for the speech problems of their children, hearing loss, facial and dental appearance, breathing and alimentary difficulties<sup>(10)</sup>.

The surgeries are noted, by some authors, as the main factor that positively affects the life quality of the child, while the family satisfaction does not only depend on surgical results, but also on established empathy of and communication with health professionals, the expectations and achievement of post-surgical care. Most parents attach more relevance to pre- and post-surgical care than to the surgery itself. In addition, they also point out that the most striking and important moments of their experience are related to the diagnosis, the first surgery and the insertion of the child into school<sup>(11)</sup>.

### **Supporting and being supported**

The importance of social support is emphasized by the families, especially those associated with two major dimensions: the emotional and the informational ones. The participating families have exchanged these supports with other families that also experience the presence of cleft lip and palate in a child.

As for the social support of health professionals, the respondents reported a big deficiency in several services. The exception is the multidisciplinary team of the Specialized Center for Treatment of Cleft Lip and Palate, where the professionals were identified as strong sources of social support.

### **Peers**

It is in the relationship with other families of children with cleft lip and palate where understanding of peers is found. In this relation they have the possibility to share their doubts, concerns, struggles, victories with other families who are experiencing the same situation.

The interviewed families emphasized the importance of this interaction as valuable

therapeutic tool. Empathy is the propellant of this relationship that is establishing and that provides family members to recognize themselves through their experiences and opportunities to: speak and be understood, listen and understand, be comforted and comforting, to be encouraged and encourage, be supported and support, help and be helped, inform and be informed. The sharing of experiences among families is a valuable therapeutic tool for their empowerment.

When I met other mothers with the same problem, we stayed at the same place there in the nursery, and we exchanged views. [...] When I arrived, I saw that I was at home, all the mothers experiencing what I was going through, we exchanged information, they were experiencing the same prejudices. It was very important to know that it wasn't just my reality what I was going through, that there were other people going through this and helping me, it was very good. [...] When I go now, there are babies of 2 months, 3 months, the mothers weep with fear of choking, sometimes the grandmother has to take care because the mother is so distressed, depressed, the thud they took, and I say: oh, no, it's not like that. I do what I wish had been done to me, because I say: oh, him too, he choked, he didn't know what, keep calm. Then they look, like they don't believe, and say: ' Oh, she's talking because [...] '. They don't believe much. The person says to already have been there, you wonder: ah, is that so? Just you can make yourself believe, but what I can do to help mothers I know, I do. (M, E5)

The health team has an important role to establish contacts and to promote communication among the families of children with cleft. Parents suggest that this support should be added to the treatment process by means of the creation of a network of parents for parents. They also propose developing an information leaflet directed to parents<sup>(12)</sup>.

The opportunity to meet other parents of children with cleft lip and palate allows for exchanging thoughts and practical advice in a perspective different to that brought by health professionals<sup>(13)</sup>.

Despite the difficulties faced as a result of infant cleft lip and palate, parents believe that there are no significant differences between their children with such problems and other

children<sup>(14)</sup>. Thus, despite the potential of social stigmatization and the stress associated with several medical procedures, the difference of the psychosocial problems that exist between children with and without cleft lip and palate, as well as between their parents, is minimal, suggesting that families of children with orofacial clefts are resilient and have adapted satisfactorily<sup>(15)</sup>.

To be placed as an active participant in the care of the patient, the family feels full of empowerment and has the strength to assume the care responsibility, being respected as important partner.

Confidence in the health team is essential to the feeling of empowerment of the family members and this trust is shaping up as the family believes that the patient is receiving appropriate care. The experience of continuity of quality care and meeting the needs sustain the security and trust. Understanding the disease through knowledge and obtaining answers to their questions is pointed out as an important instrument of empowerment by family members. They strive to overcome the knowledge gaps by talking to the health team, via the Internet or appropriating of literature. Thus, the health professional's role is to create a supportive environment that enhances the autonomy and the participation of family members in the care of the patient, inviting them to play an active role in health care decisions. The counterpoint appears when they're on the sides, with no knowledge about how to support the patient and the feeling of not being recognized as partners in the discussion about health care. In addition, the family experiences limitations when not being able to influence the treatment and feels being unconsidered as well as unsure about its role in the care<sup>(16)</sup>.

The study<sup>(17)</sup> which discusses coping strategies of people with a chronic neurological disease reveals that the social support emerged as the most vital component in the management of this disease. Family and friends have been pointed out as a source of support by the group that presented the highest levels of resiliency. In this group, the coping strategies involve enjoying life and reducing the focus on the disease, avoiding stressful situations and thus reducing the pressure in everyday life. However,

the group that showed low levels of resilience endorsed coping strategies with focus on disease, such as medication. The most resilient group was very interested in providing itself with information, whereas the other group was more interested in receiving external financial assistance and services.

Hence, this study allows grasping that the higher the social support received by family members, the greater the possibility of them becoming resilient. In addition, it is noticed that resilient families use coping strategies that are not limited to the focus on the disease itself.

Another research<sup>(18)</sup> identified present protective factors in the resilient group: greater sense of domain (i.e. self-efficacy) about the stress in their lives, social functioning and social support. It was observed that these three factors are considered protectors and contributors to the process of resilience, each playing a role in adaptation and coping when facing the adversity associated to a chronic illness.

The family perceives the lack of preparation of health professionals to deal with the presence of cleft lip and palate. They don't know how to communicate the news, don't have knowledge on the subject to clarify the doubts of the family and end up scaring the families with unfortunate and misleading estimations<sup>(19)</sup>.

The lack of knowledge about the disease deprives the patient and his family from disease management, prevents them from assuming responsibility, generates the feeling that their life is out of control, which impacts negatively the quality of these people. The patient and the respective family nurture the expectation that the health care professionals will provide positive stimulus and relevant information so that they can effectively manage the disease and take effective decisions for the care. However, this expectation is often not met. The capacity to sustain the hope for a better future, through a long journey of experience, is a key element in the empowerment<sup>(20)</sup>.

### **The multidisciplinary team**

In the Specialized Center the family is attended by the multidisciplinary team which counts on professionals from several knowledge domains, such as: Social Assistance, Nursing, Physiotherapy, Speech Therapy, Medicine, Nutrition, Dentistry, Pedagogy, Psychology and

Occupational Therapy. The professionals receive recognition from the family for the emotional and informational support which had been given to them.

The informational support consists of guidelines on the mediate and immediate post-operative care of children with cleft as well as clarification of doubts. These professionals are qualified to effectively treat not only the surgical correction of the fissure itself, but also repercussions in other areas, such as the psychological and emotional ones.

The social support of health professionals has been configured as an important tool within the family attendance, reducing levels of anxiety. This by families highlighted support is considered a protective factor that boosts those families to overcome the experienced adversities and represents therefore favorable conditions to become resilient.

The nurses of [City of the Specialized Center], when we are free they go there, they teach us to clean the points, they taught all of us to clean the points, for us to be able to come here. [...] They taught me to apply the massage, after they had removed the stitches, as we wouldn't go there so soon back and remove the stitches in our city, taught how to do a massage, to not get [...], to be perfect the point, the surgery. (M, E2)

Wow, they have a whole care, you know, they are concerned about the child, but also about the parents. They are all the time asking, 'Oh mother, are you okay? How are you psychologically?' [...]. They care about the parents, because they say that if the mother is not ok, how will she take care of the child? Before the surgery the psychologist called me and said: 'Mother, how are you? Because once he has made the surgery you have to be well, he's going to need you'. So there I felt welcome, to see cases like his and even more serious ones, to know that I'm safe there because what happens up there, they're there to guide, so it's the best place for me as well, until I pass the attendance of maternity, where I felt totally lost. (M, E5)

The family makes a reference to the satisfaction with the received services, describing them as excellent<sup>(12)</sup>. Some parents mention that different techniques or craniofacial interventions implemented by the members of the team were useful, as they allowed for:

reiterate information, see pictures of other children (before and after the surgery), acquire preventive guidance on how to deal with the stares of other people facing the child with cleft lip and palate, understand the surgical procedure and the monitoring of the surgeries and information about the future development of the child. Some parents, however, requested more resources of informational support, especially in writing, such as, for example, pamphlets on the topics which were most commonly faced: difficulties with feeding, the right amount of calories, calories conversions, nursing guidelines about problems after surgery, advice on the difficulties that children can have with alimentation after surgery, and more information on the length of time involved in this adaptation. Moreover, they suggested the creation of an online resource for information on alimentation, feeding difficulties, surgeries, surgical care and monitoring, etiology of fissures as well as tips.

Families of children with cleft identify some crucial factors for life quality. The first highlighted factor was the need for immediate support, shortly after birth (including support groups to families), and even the exchange of reliable information and advice for everyday life in different life stages of the child. Receiving the support of health professionals is of extreme importance to the family, because, often, it becomes the main, if not the sole support on which the family can count<sup>(11)</sup>.

The lack of guidelines deprives the family of appropriating the situation it is going through, increasing the suffering and despair. In this way, the support acts as to modulate the experience of family. Therefore, the more support is received in an effective and efficient manner, the more quickly and satisfactorily the family adapts to the situation, redefining it.

Families are unable to take significant health decisions when there is a lack of adequate information. The idea that this cognizance provides a sense of empowerment is a potential topic to be further explored in the experience of these parents<sup>(13)</sup>.

## FINAL CONSIDERATIONS

In this study the empowerment mechanisms used by families of children with cleft for a satisfactory adaptation and greater life quality were identified and discussed.

The nursing professional interacts with the patient and the respective family in several stages of the progression and not only can but must work on the empowerment of those who are supported. It is necessary to strive for understanding the barriers and facilitating mechanisms of empowerment regarding each supported patient and family, with an effective care to help them materialize their empowerment in view.

It is expected that the results of this study are useful for constructing an approach that aims at the empowerment of the family of the child with

cleft by actually endowing nurses and other health professionals. The need for nurses to get involved in the education and counseling of the family and not only the provision of clinical care is to highlight. That professional must have individualized and personalized care for and with the family according to its needs and expectations as well as accompaniment that allows that family to deal comfortably with the situation in view.

This study was limited to families of children with cleft lip and palate in the age group of 0 to 3 years, what stresses the need for more studies that explore this perspective and cover other age groups, with a focus not only on the family but as well on the child and adolescent with cleft lip and palate.

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## MECANISMOS DE *EMPOWERMENT* UTILIZADOS PELA FAMÍLIA DE UMA CRIANÇA COM FISSURA LABIOPALATINA PARA UMA TRAJETÓRIA RESILIENTE

### RESUMO

As implicações das fissuras labiopalatinas são estéticas e funcionais. Uma adaptação satisfatória depende mais da família e de suas atitudes do que da própria presença da malformação. O processo ativo de resistência, reestruturação e crescimento em resposta à crise e ao desafio é denominado resiliência. Para adaptar-se a família necessita ser instrumentalizada por meio do *empowerment*: desenvolver habilidades necessárias para enfrentar e lidar com os eventos de vida, obter domínio sobre as suas questões, ser mais forte e capaz de administrar as demandas do cotidiano. Buscamos conhecer os mecanismos de *empowerment* que famílias de criança com fissura labiopalatina têm desenvolvido ou potencializado para ser resilientes frente à presença dessa situação adversa. Trata-se de uma pesquisa clínico-qualitativa em que foi utilizada a Análise de Conteúdo para o tratamento dos dados. Da análise emergiram duas categorias: "**Vivendo um dia de cada vez: vencendo etapas**", "**Apoiando e sendo apoiado**", sendo esta última composta de duas subcategorias "*Pelos pares*" e "*Pela equipe multiprofissional*". A falta de conhecimento priva o paciente e sua família da gestão da doença, impede-os de assumirem a responsabilidade, gera o sentimento de que sua vida está fora de controle, o que impacta negativamente na qualidade da vida da família.

**Palavras-chave:** Fissura Palatina. Família. Criança. Resiliência Psicológica.

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## MECANISMOS DE *EMPOWERMENT* UTILIZADOS POR LA FAMILIA DE UN NIÑO CON FISURA LABIAL PARA UNA TRAYECTORIA RESILIENTE

### RESUMEN

Las implicaciones de la fisura labial son estéticas y funcionales. Una adaptación satisfactoria depende más de la familia y sus actitudes que de la propia presencia de la malformación. El proceso activo de resistencia, reestructuración y crecimiento en respuesta a la crisis y al reto es denominado resiliencia. Para adaptarse, la familia necesita ser instrumentalizada a través del *empowerment*: desarrollar habilidades necesarias para enfrentar y lidiar con eventos de la vida, obtener dominio sobre sus problemas, ser más fuerte y capaz de administrar las demandas de la vida cotidiana. Buscamos conocer los mecanismos del *empowerment* que familias de niños con fisura labial han desarrollado o mejorado para ser resilientes delante de la presencia de esta situación adversa. Se trata de una investigación clínica-cualitativa en que fue utilizado el Análisis de Contenido para el procesamiento de los datos. Del análisis emergieron dos categorías: "**Viviendo un día a la vez: venciendo etapas**" y "**Apoyando y siendo apoyado**", siendo esta última compuesta de dos subcategorías "*Por la pareja*" y "*Para el equipo multidisciplinario*". La falta de conocimiento priva al paciente y a su familia de la gestión de la enfermedad, les impide de asumir la responsabilidad, genera el sentimiento de que su vida está fuera de control, impactando negativamente en la calidad de la vida de la familia.

**Palabras clave:** Fisura labial, Familia, Niño, Resiliencia Psicológica.

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