


Chapter 91

University Extension of Health Care: Multiprofessional care for people with cleft lip and palate

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ABSTRACT

Introduction: University extension enables a connection of the learning of students and teachers with the community, having multidirectional benefits for comprehensive and multidisciplinary health care. On the other hand, one of the most common congenital craniofacial malformations are cleft lip and palate (CLP), which need multidisciplinary attention from birth to optimize the process of habilitation and rehabilitation in health and monitor individual neuropsychological development. Objective: To report an extension proposal in health care for people with CLP. Materials and Methods: This is an experience report of an extension action in health care for children and adolescents with CLP. Results: This extension proposal counts on the interdisciplinary attention of the speech therapy, odontology, physiotherapy and psychology areas and, multidisciplinary of the medical area. The purpose of this extension activity involves the reception, habilitation of oral functions, neuropsychological development and rehabilitation of people with CLP. Conclusions: The reception and health care of individuals with CLP and their families can benefit from health care activities through university extension.

Keywords: Cleft lip, Cleft palate, Health plans and programs.

1 INTRODUCTION

University extension activities are encouraged by the national education plan of Brazil, as one of the parts of the triad teaching-research-extension and, whose goal is to encourage students and teachers participants to acquire practical skills with a critical and multidisciplinary look that is applicable to the service of community care (OLIVEIRA; ALMEIDA JUNIOR, 2015; ALVES et al., 2016). In this sense, in the area of health, actions of promotion, prevention and rehabilitation are involved through the student's experience in a real scenario of action with society (SÍVERES, 2013; MINETTO et al., 2016). It is noteworthy the contribution of these activities in the humanization of care and the view of the other as an active agent of their own health processes (SANTANA et al., 2021).

The country's public health system is called the Unified Health System (SUS) and, within it, the extension follows the principle of integrality that it has, with the contribution of various knowledge and multiprofessional training, considering the individual in his entirety and being a tool to reduce social inequality of access to health (ALVARENGA et al., 2013; BRITO et al., 2021)

One of the health conditions seen in the clinical and outreach environment are cleft lip and palate (CLP), congenital malformations, which have a multifactorial origin and can compromise the lips and/or palate in their intrauterine formation. The World Health Organization (WHO, 2020) describes an incidence of 1 case per 500 or 700 births, with variations by ethnic origin and geographic location. In Brazil, this rate ranges from 0.19 to 1.54 per 1,000 live births (SOUZA-FREITAS et al., 2004; MARTELLI et al., 2012).

The cleft lip is due to the lack of fusion of the frontonasal process with the maxillary process between the fourth and eighth week of intrauterine life. The cleft palate is caused by the failure of mesodermal tissue to penetrate the ectodermal sulcus in the midline of the posterior palate and lateral premaxilla (RIBEIRO and MOREIRA, 2005).

The fissures can be differentiated, for example, by Spina's (1972) classification, which defines them by extension and uses the incisive foramen as anatomical reference, separating them into: pre-incisive foramen fissure (lip and alveolar arch, up to the incisive foramen), which can be bilateral or unilateral, complete or incomplete; post-incisive foramen fissure (hard and soft palate), complete or incomplete; trans-incisive foramen fissure (lip, alveolar arch, hard and soft palate), which can be uni or bilateral. Complementing this classification is Gardenal (2011) rare clefts, which compromise other facial structures, as well as the occurrence of cleft palate submucosa, where there is the junction of only mucosal tissue and there is a deficiency in muscle and bone tissue (Gardenal, 2011).

Right at birth, babies diagnosed with CLP should be treated by a multiprofessional team and their guardians should be instructed. In cases of greater fissure involvement, rehabilitation may last until adulthood, undergoing several corrective and aesthetic surgeries (CERQUEIRA et al., 2005).

Administrative rule 62 of the Health Assistance Secretariat of the Ministry of Health (SAS/MS) establishes that the follow-up of people with CLP must be done by a multidisciplinary team, and the health

services that must participate in the team are: medical practice, speech therapy, otorhinolaryngology, general dentistry, orthodontics, oral and maxillofacial surgery, social work, psychology, plastic surgery, anesthesia, nursing, physiotherapy, nutrition, and family care.

In Brazil, 28 reference centers for health care for people with craniofacial anomalies are registered in SUS - 1 in the North Region; 4 in the Northeast; 3 in the Midwest; 12 in the Southeast and 8 in the South (MONLLEÓ et al., 2014). Some of these centers have their own programs for the care of CLP. Other programs, with a multidisciplinary nature, exist as projects linked to universities, such as: CERLAP (Center for Rehabilitation of Cleft Lip and Palate) of the Pontifical Catholic University of Rio Grande do Sul (PUCRS) and the Cleft Lip and Palate Extension Project (PFLP) of the Universidade Federal de Ciências da Saúde de Porto Alegre (UFCSPA) (DA RÉ et al., 2022a; DA RÉ et al., 2022b).

The present study aims to propose an action in multiprofessional health care, directed to people with CLP, from the description of an experience report of an extension program for children and adolescents with CLP.

2 MATERIALS AND METHODS

The present experience report is of a health action, extensionists, of academics and graduate students of the project "Cleft Lip and Palate", developed in the outpatient clinics of the SUS of the Santo Antônio Children's Hospital (HCSA) and linked to the Universidade Federal de Ciências da Saúde de Porto Alegre (UFCSPA). The extension project counts on the participation of students from the Speech Therapy course, master's and doctoral students from the Postgraduate Program in Rehabilitation Sciences, as well as from the Postgraduate Program in Psychology, all from UFCSPA.

The students provide phonoaudiological care to children and adolescents with CLP, evaluate and orient those responsible for these patients in the areas of phonoaudiology, dentistry, physiotherapy and psychology. The master's and doctoral students carry out their research at the clinic, as well as collaborating with the care and supervision of the patients. The coordination of the research projects is the responsibility of the Speech Therapy and/or Psychology professors, involving teachers from several areas of the courses.

The therapeutic actions of the project take place weekly, with an average duration of forty minutes each. The patients can access the project from internal referrals made by the pediatrics, neurology, pediatric surgery, plastic surgery, and otorhinolaryngology teams of the coparticipating health unit. The patients are from several regions of the state of Rio Grande do Sul; however, there is a prevalence of subjects from the city of Porto Alegre and the metropolitan region, due to the established and necessary frequency of these sessions.

The research actions developed with the project are linked to and approved by the Research Ethics Committee (REC) of the coparticipating health unit. Among these, we highlight the development of course

completion papers, master's dissertations, doctoral theses, as well as research related to activities and therapies applied to this population.

3 RESULTS AND DISCUSSION

The actions developed with the cleft lip and palate extension project follow differentiated actions depending on the age of the subject with CLP (0 to 12 months; 12 to 24 months; 24 to 48 months; 48 months to 18 years), as well as on the type of cleft (because the more extensive the malformation, the greater the complexity of the case).

People with CLP are referred to the HCSA's SUS ambulatory service by internal referrals from the following medical areas: Plastic Surgery, Otorhinolaryngology and/or Pediatrics. From this request to the Speech Therapy service, people are welcomed and assisted by the Speech Therapy undergraduate students, in Supervised Internships.

Speech Therapy

In this extension program, the first contact with the child and/or adolescent and their family is the reception, considered as an action of the relationship between the user and the care team, from qualified listening to their needs (SILVA; DAVID; CALDAS; MARTINS; FERREIRA, 2018). It is at this moment when the users are received and the initial orientations about the follow-up proposal are given, considering the variations relevant to each stage of neuropsychological development, as well as data about CLP, their occurrence, etiology, and related comorbidities. In addition, parents receive an informative booklet about CLP and an informative folder about the areas of care.

The general information about the children, the family's socioeconomic conditions, the reparative surgery timetable, data regarding the gestational period and post-natal development, and the results of the hearing screening tests or evaluation, the oroscopy, and the otorhinolaryngological evaluation are investigated in the Anamnesis.

The evaluations of Orofacial Motricity (OM), swallowing and Neuropsychological Development (NPD) are performed by the PhD students of the PGG Rehabilitation Sciences and by the students of the Speech Therapy course and occur after the reception and Anamnesis stage. The MO is evaluated with the Orofacial Myofunctional Evaluation Protocol - PROFITI (GRAZIANI, 2015) and the swallowing with the Clinical Evaluation of Dysphagia Protocol - PAD-PED (ALMEIDA, 2014) of children aged between 0 and 12 months.

As feeding is a vital function, the evaluation of sucking and swallowing in the early life of children with CLP are essential, regardless of whether the baby has an isolated cleft or associated with a genetic syndrome. Some infants with CLP may present with oropharyngeal dysphagia since the neonatal period (FREITAS; CARDOSO, 2018), symptoms can be: choking, nasal reflux, and difficulty sucking

(CAMPILLAY, 2010). Therefore, the clinical evaluation of dysphagia and specialized follow-up are essential for the maintenance of the child's health (FREITAS; CARDOSO, 2018).

Regarding breastfeeding, this should be the first feeding option in neonates and infants with orofacial clefts (MINSAL, 2015). Mothers are guided and encouraged to breastfeed for its direct benefits, i.e., in the proper establishment of eating patterns, as well as for the specific aspects of this population, such as hearing, development and growth of the cranium-cervical-mandibular complex (MARQUES, 2007).

Considering the evaluative results, the phonoaudiological intervention is planned and executed, with the objective of maintaining stable clinical standards, with a safe and personalized diet every day. Also, guidance is given as to the handle and positions during breastfeeding, for mandible stability, besides other specific strategies for better comfort of mother and infant (MARQUES, 2007). Together with the infant, the caregivers are advised to keep the baby semi-seated to avoid nasal reflux, the feeding time should not exceed 30 minutes, and oral and nasal hygiene is requested before and after feeding.

In cases where exclusive breastfeeding is not possible, the caregivers are guided to an appropriate method, such as the use of a bottle. In this context, the Speech Therapist evaluates which type of nipple is the safest and most effective for the baby. Generally, a nipple with a milk flow of no more than two drops per second is recommended (ALTMANN, 1997).

As of 6 months of age, if the babies already present the signs of readiness for Food Introduction (AI) (sitting with/without support, interest in food, ability to take objects into the mouth, and decreased tongue protrusion), those responsible are instructed to use the Baby-Led Weaning (BLW) method, because its objective is a feeding guided by the baby. The motivation, through BLW, is based on the natural curiosity of exploration of food, always respecting the time of each meal determined by the baby (RAPLEY, 2008).

As in the BLW method, the child is the one who promotes feeding, the risks of choking are lower, because it is based on the principle of functional order, in which babies who do not take the food into their mouths are not ready to manipulate and swallow it. Parents are advised to offer a varied diet in colors, textures, and flavors. As for liquids, breastfeeding in free demand and offering water are suggested (RAPLEY, 2008).

It is important to note that in cases of CLP, one should consider the time of reparative surgeries, respecting the postoperative period of 30 days, with the AI, during this period, characterized by homogeneous liquid diet (BARROS et al., 2009). This same time is respected for the start of scar massages for the lip (Rodrigues et. al, 2022).

The work on the scar is performed as prevention of recurrence of muscle contracture (CLAYTON, 2009). One of the complications after lipoplasty are hypertrophic scars, lip retraction and asymmetries in the region. These complications can compromise both the appearance and function of the lip (MENECHIN; VATTIMO, 2003; ROSSI et.al., 2005).

To reduce the sequels, the application of massage in the labial region is used to contain the edema of the region, prevent hypertrophy and retraction, increase blood irrigation and improve the mobility of the perioral region. The massages are started after the stitches are removed with rectilinear movements from top to bottom and circular movements to both sides, with light pressure in the labial region and under the surgical scar. The frequency is three times a day, for 10 minutes each time and for a period of approximately one year (ALTMANN, 1997; ROQUES, 2002; ROONEY, 2005).

From 12 months of age on, the participants of this extension project remain in management, with reevaluations every three months and with a return visit one month after lip and palate surgery. At this stage, speech therapists and speech therapy students from the educational institution reevaluate the MO, swallowing, oral language, DNP, and start the scar massages (which are introduced and oriented to the caregivers one month after the lip and palate surgery).

As in this age group the development is marked by the first words and the first steps, Oral Language and DNP are evaluated with the Denver II protocol (FRANKENBURG, 1992) to verify if the children participating in the project are in the adequate period of global development or if they need speech therapy for stimulation.

The Denver II test verifies the global development of children and its results allow parents to be guided as to daily life situations that may favor the process of language and/or neuropsychological acquisition. It also proposes training situations for the family with playful materials, so that the parents can work on the stimulation proposal at home.

The children with ages between 18 and 24 months of the "Cleft Lip and Palate" project start having a phonoaudiological follow-up every 15 days, so that the therapy is more frequent and, in this way, effective, with special attention to the DNP. Also, there are conducts for OM, language stimulation, cicatricial massages, as well as general orientations to those responsible.

Those with delayed PND are stimulated through practical life activities and play therapy, and their parents or caregivers are instructed to do the stimulation at home, such as enabling them to: take off clothes by themselves, wash and dry their hands, brush their teeth under supervision, use a spoon or fork, among other practical life actions.

The procedures in OM are directed to intraoral stimulation and lip scar massage. Language is stimulated through play therapy and guidance to parents and caregivers regarding waiting for the child's response, using short sentences, and requesting actions and oral productions from the children.

From 24 to 48 months, the project participants are seen by a speech therapist every 15 days, with a therapeutic focus on language/speech stimulation, vocal resonance, scar massages if necessary, oromiofacial exercises, and DNP stimulation.

With the objective of stimulating the correct production of speech sounds, without the intention of correction, since in this period children are in the process of acquiring the phonetic-phonological system,

phonotherapy is carried out in a playful way, providing the child with an environment, toys and games to help establish this system.

Children with CLP usually have hypernasal vocal resonance, due to the direction of airflow to the nasal cavity and / or the inability of the velopharyngeal mechanism (CONTERNO, 2011). Therefore, vocal resonance is also stimulated from this age group on, through playful activities. The oromiofacial stimuli, scar massage and DNP remain if necessary, with the same clinical direction detailed previously.

From the age of 4, the participants in this project have access to speech rehabilitation in several areas, mainly speech, to correct phonetic, phonological, resonance and fluency alterations. The sessions are held weekly and last an average of forty minutes.

Speech is evaluated using the Phonological Assessment Instrument (RIBAS, in press) and a speech perceptual-auditory evaluation. Speech analysis indicates the child's level of phonological system acquisition, as well as altered phonological features and processes. Compensatory articulatory disorders related to CLP and hypernasality are classified as mild, moderate or severe.

Speech therapy aims to produce speech that is closer to normal, according to the articulatory possibilities of each patient. Based on the evaluation, a therapeutic plan is established that sequentially aims at the rehabilitation of all aspects of altered speech (DE MELO et al., 2013).

The articulatory points of the altered speech phones are stimulated from the correct model to the child and, usually, with the help of sensory cues (BRANDÃO, 2013; CARDOSO, 2015). The phonetic acquisition process is monitored by the Speech Therapist and, when necessary, is corrected.

When patients present altered vocal resonance, vocal exercises such as *vocal fry* (CONTERNO et al., 2011; ELIAS et al., 2016) are performed, airflow direction and mobility and/or velopharyngeal sphincter strengthening are stimulated to balance resonance and decrease hypernasality.

It should be noted that each patient has his or her own particularities, so therapy is designed according to their preferences and needs. Since these are children, it is very important that the activities are playful (PARO et al., 2013). As for adolescents, the therapist should take into account the personality aspects, so that they adhere better to the therapeutic proposal and thus generate effective results in rehabilitation (PARO et al., 2013).

Aiming at the continuity of therapy, patients and their guardians are oriented of the objectives and the importance of performing the exercises, which are sent to be performed at their homes (PARO et al., 2013).

Children at this age (from 4 years old on) also need to be evaluated regarding aspects of Phonological Awareness (FC), since it is a metalinguistic ability and one of the prerequisites for learning to read and write. In this extension project, the speech therapists use the Sequential Evaluation Instrument - CONFIAS (MOOJEN et al., 2003). Reading and Writing are evaluated as to their development process (FERREIRO; TEBEROSKY, 1999).

When the CONFIAS results show a lowering of CF and/or the children have difficulties with reading and writing, the PhD students and speech therapists include activities that stimulate these skills in the treatment plan.

The patients are periodically re-evaluated and, according to their progress during therapy, they are discharged from the hospital with assistance or have the periodicity of their appointments altered. The subjects are seen every other week, every month, or phonoaudiologic management, according to the results of their evaluation.

Those enrolled in management are re-evaluated every six months or annually in order to monitor and analyze the speech changes resulting from craniofacial growth and development. Speech therapy follows children and adolescents with CLP until they are eighteen years old.

Dentistry

The dental evaluations of the children participating in the project are performed by a dentist specialized in orthodontics, together with the students of the Speech Therapy course and PhD students in Rehabilitation Sciences at UFCSPA. The guardians and the patients are oriented about oral hygiene, dental eruption aspects, and craniofacial growth and development. When orthodontic rehabilitation or oral and maxillofacial surgery is needed, these patients are referred to the different services.

To assist in the evaluation, the students and PhD students use the "Clinical Evaluation Form of Orthodontics Applied to Speech Therapy", developed by the orthodontist who is part of the group. This assessment consists of three steps: anamnesis, clinical examination and complementary tests (Da Ré et. al, 2022).

The clinical examination consists of evaluating oral aspects in order to identify the dental alterations that require further examinations and treatment. The elements analyzed are: facial typology, facial symmetry, structural and functional aspects of the lips and tongue, appearance of the mucosa and gums, insertion of the labial frenum and tongue frenulum, shape of the hard palate and dental arches, oral lesions, lesions suggestive of caries, malocclusions and individual dental malpositions, as well as indications of previous or current orthodontic treatment (Da Ré et. al, 2022).

The complementary exams evaluated are: dental radiographs (mainly panoramic to verify aspects such as missing teeth and eruption chronology), extra and intra-oral photographs, and study models.

Concluding these evaluations, periodical orthodontic orientations and clinical re-evaluations are carried out, to follow the craniofacial growth and development and the dental exchanges, and, in the cases under orthodontic treatment, to follow and orient the patients, aligned with the speech therapy treatment.

Hearing

The literature indicates that the most frequent audiological alteration in children with CLP is otitis media (GARCIA-VAQUERO et al., 2018; SANTOS et al., 2011; RUEGG et al, 2017). The prevalence of this inflammation is significantly higher in children with CLP when compared to children without CLP, and the latter present recurrent episodes during childhood due to anatomical and functional alterations of the auditory tube and velopharyngeal sphincter (MANZI et al, 2013; NARAYANAN et al, 2013).

Repeated otitis media impairs sound detection and proper perception of sounds, which impairs the development of Central Auditory Processing (CAP), language, learning and listening skills (AMARAL et al, 2010; MORAES et al, 2011). Therefore, the complete audiological evaluation, early and periodically, with this population is necessary.

The audiological action proposes the following procedures: anamnesis, visual inspection of the external acoustic meatus using an otoscope, audiometric evaluation with procedures compatible with the child's development, immittance testing, and transient evoked otoacoustic emissions.

The assessment of CAP should be performed in individuals aged seven years or older. Initially, specific questionnaires for *screening CAP* are applied to those responsible for the patient, and a battery of behavioral and electrophysiological tests are performed.

With the results of these evaluations, family members are guided and the appropriate treatments for the patient can be determined, referrals to the clinic in otorhinolaryngology and, depending on each case, help in the therapeutic conduct of speech therapy (Da Ré et. al, 2022a).

Physiotherapy

People with CLP have head postural deviations (anteriorly) and cervical hyperlordosis, which make the upper trapezius, sternocleidomastoid, pectoralis major and minor, masseter, zygomatic, buccinator, and temporalis muscles tense, making it difficult to perform the orofacial functions of chewing, speaking, swallowing, and breathing.

Given these findings, physical therapy proposes an evaluation through inspection of the face, palpation of facial and cervical muscles, postural assessment and evaluation of respiratory capacity. With this clinical direction, it is possible to aim a better conduct, as well as the identification of respiratory and postural changes that can harm the child's development (SOUSA; PAÇOL; PINHO, 2017).

Taking into account the findings of the evaluation, physical therapy approaches the subjects with manual myofascial release techniques and muscle stretching in regions with strained muscles, active breathing exercises and with devices, in addition to guidance to parents regarding body posture due to positions in everyday life and weight carried in backpacks. These approaches bring several benefits to the subject and, in addition, help in better results in interdisciplinary work (PEREIRA, 2018).

The myofascial release technique performed in the face and cervical region, from two years of age on, favors speech therapy. With the use of this technique one can observe a decrease in tensions of the soft tissues, as well as an improvement in body awareness and speech articulation.

Psychology

CLP is a complex malformation that involves several psychosocial factors, which can generate anxiety, insecurity, and even guilt or rejection by the patient's family (UEKI et al, 2019). In addition, the family's daily life requires some adaptations, due to the treatment that usually occurs in specialized centers that are located far from their homes. These factors can cause overload mainly for those responsible for these patients (FILGUEIRA et al., 2015).

In most health care treatments, family participation and support are fundamental during the rehabilitation process, which must be early and, in some cases, longitudinal (BARROSO; MACHADO, 2010; GUTIERREZ; MINAYO, 2010).

In view of the above, it can be seen that families of children with CLP need psychological help and assistance in order to cope with various feelings and many adjustments.

The participation of psychologists in the multidisciplinary team is extremely important so that the psychosocial repercussions experienced by these patients and their families are dealt with in a positive way.

4 FINAL CONSIDERATIONS

The present study brings a reflection of a proposal for clinical habilitation and rehabilitation, as well as, reinforces the importance of a health care program for children and adolescents with CLP.

Based on the guidelines and experience of the assistance centers spread throughout the country, there is the multidisciplinary action for the reception and follow-up of children with CLP and their families, from birth to adulthood, with guidance and through clinical rehabilitation, promoting a better quality of life.

A university extension health action directed to this population favors the integration of differentiated areas and enables interdisciplinary actions. This proposal counts on the direct and interdisciplinary participation of the areas of Speech Therapy, Physiotherapy, Dentistry, and Psychology, and multidisciplinary with the areas of Plastic Surgery, Oral and Maxillofacial Surgery, Medical Genetics, Pediatrics, and Otorhinolaryngology. The partnership between the University and the hospital health institution allows this union of knowledge and the comprehensive care of children and adolescents with CLP.

The initial reception of families and children with CLP favors and strengthens the therapeutic bonds. The integration between the areas of rehabilitation allows for better clinical results, as well as the identification of necessary interventions for each stage of development of the person with CLP and their direction to complementary treatments.

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