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ORIGINAL ARTICLE

Characteristics of the treatment received by children with cleft lip and palate in Argentina

Características del tratamiento recibido por los niños con fisura labio alvéolo palatina en Argentina

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What do we know about the subject matter of this study?

In Argentina, there are publications on the short-term surgical outcomes of treatment of cleft children; however, there is little knowledge about the medium-term evolution regarding the interdisciplinary and comprehensive follow-up of the disease.

What does this study contribute to what is already known?

This is the first research in Argentina that provides information on the evolution during the first years of childhood of children born with isolated orofacial cleft, seen at the Flap Network of public health care providers. It also proposes a set of indicators for the evaluation of treatment based on timeliness, interdisciplinarity, and comprehensiveness.

Abstract

Cleft lip and palate (CLP) are congenital abnormalities that affect anatomically and functionally the face and mouth, involving lip (CL), palate (CP), or both (CL/CP). **Objective:** to characterize the treatment of children with CLP in public institutions in Argentina. **Patients and Method:** Cross-sectional study in a random sample of 100 children from the *Flap* Network. We included children with isolated CL, CP, and CL/CP, of both sexes, with birth weight of 2500 grams or more and gestational age over 36 weeks. The following data were recorded date of birth, hospital of birth, birth weight, gestational age, sex, specific diagnosis of the cleft, and initial surgery data. A telephone survey was conducted with the children's parents. To characterize the treatment, three indicators were constructed: interdisciplinary, opportunity, and integrality. These indicators were composed of different variables, and according to the sum of the score attributed to each one, the treatment was categorized as high, medium or low based on the treatment guidelines used by the *Sumar* Program. **Results:** 30%

Keywords:
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of the patients started early treatment, 58% underwent timely surgery, and 29% of the children were in follow-up with basic specialties. The mother's high educational level was associated with higher probability of having interdisciplinary (OR2.9; 95%CI 1.3-6.8), comprehensive (OR3.7; 95%CI 1.6-8.7), and timely treatment (OR2.9; 95%CI 1.3-6.7). **Conclusions:** There are barriers to accessing care, such as long distances or shift management. Less social vulnerability of families was associated with greater likelihood of receiving treatment close to standards.

Introduction

Cleft lip and palate (CLP) are congenital craniofacial anomalies that affect anatomically and functionally the face and mouth, involving the lip (CL), the palate (CP), or both (CL/CP). The etiology of CLP is multifactorial, with predisposing genetic factors and environmental triggers. The best-known risk factor is maternal smoking during gestation[1,2]. Other factors have also been studied such as maternal alcohol consumption during pregnancy[3], advanced parental age[4,5], consanguinity[6], and low socioeconomic status, among others[7,8]. Some studies have found that prenatal consumption of folic acid is a protective factor[9].

The CLP prevalence at birth is heterogeneous, high among Asians and Amerindians (8 to 37 per 10,000 live births), intermediate in Caucasians (9 to 27 per 10,000), and low in Africans (2 to 17 per 10,000) (10). In 2018, the prevalence in Argentina was 16.85 (15.32-18.49) per 10,000 births, estimating 1,100 to 1,200 new affected newborns (NB) each year[11].

Orofacial clefts may occur in isolation, associated with other congenital anomalies or syndromes. Some orofacial clefts can be detected by prenatal ultrasonography, especially when occurring with other anomalies.

In general, the malformation is not life-threatening, but its morbidity is higher than in unaffected children[12]. The main comorbidities in the first years of life are audiology and speech-language and dental pathologies, and then, their possible consequences such asspeech-language disorders, learning disorders, and poor school performance[13,14]. Therefore, the treatment of a child with CLP is complex, requiring several years and multiple surgical and non-surgical interventions, from birth to adolescence.

As in most chronic diseases in children, there are organizational and geographical barriers that hinder access to treatment. All local and international recommendations agree that the treatment should be interdisciplinary, timely, and comprehensive[15-18].

As precedent, in 2006, a national network was organized with different rehabilitation services for patients with CLP (public and private) in order to obtain local information on the treatment outcomes of cleft children[19].

In 2009, the National Registry (later Network) of Congenital Anomalies (RENAC) was created in Argentina in order to establish a national surveillance system for congenital defects, which was under the coordination of the National Center of Medical Genetics (National Administration of Laboratories and Health Institutes) of the Ministry of Health. RENAC covers 62% of births in the public health sector and 43% of all births in Argentina. As of 2015, RENAC was the coordinating center of the National Health Care Network for Children with Orofacial clefts (from now on called the *Flap Network*), created in partnership with the *Sumar* Program* to strengthen care practices for children with exclusive public health coverage.

At the time of this report, there were 64 accredited public institutions in all provinces of the country, except Tierra del Fuego. Most of them have a complete professional team, meaning that they have the three specialties considered basic: speech-language therapy, dentistry, and surgery (SDS). In the rest of them, a large part completes it in another institution in their location or another one, and a small part does not complete it at all.

Currently, there is only one published work showing the preliminary organization and functioning of the Flap Network[20], but there is no countrywide data on the treatment of children with orofacial clefts in the public subsector. The objective of this study was to describe the characteristics of the treatment of children born between 2015 and 2016, with isolated CL, CP, or CL/CP, seen at the institutions of the Flap Network in Argentina.

Patients and Method

RENAC includes about 150 maternity units in all Argentine provinces. In each maternity unit, two pe-

*_Sumar_ is a program of the Ministry of Health of the Nation (Argentina), which supports the population without social security coverage and pays the provinces for the performance of specific prioritized actions. Through the *Sumar* program, the Nation transfers resources to the provinces based on the fulfillment of health goals. With the resources obtained, the provinces finance health care services provided to the population in public health institutions.

diatricians or neonatologists report monthly the NB with severe congenital anomalies identified from birth to hospital discharge. Also, in the case of newborns with CLP, within the first 48 hours of life, notification is made, the referral is arranged and follow-up and treatment are planned with the treating institutions certified by the Flap Network according to the residence of the families. In addition to the basic specialties (SDS), there is a referral plan coordinated by a pediatrician with otolaryngology, social services, psychology, genetics, and cardiology, depending on the case.

This study has a quantitative, observational-analytical, cross-sectional approach. The unit of analysis is the child and her/his family. The inclusion criteria were children with isolated CL, CP and CL/CP, both sexes, birth weight ≥ 2,500 gr, and gestational age > 36 weeks; and the exclusion criteria were children with CLP associated with other congenital anomalies or with social or private health insurance coverage at birth.

A random sample, representative of the population, was selected following the inclusion criteria. 100 children had to be included since the sample resulted in an estimated prevalence of 50%, precision of 5%, and a 95% confidence interval.

Cases were randomly selected from the number list of the reference population of 623 NBs with CLP, reported between January 1, 2015, and December 31, 2016, in RENAC maternities. In case of non-acceptance or failure to meet the inclusion criteria, the selected child was replaced by the previous and/or subsequent record until found a valid one.

Existing reports in the Flap Network (secondary source) provided the date of birth, hospital of birth, birth weight, gestational age, sex, filiation data of the child and her/his mother, specific cleft diagnosis, name of the referring institution, and performance of the first surgery.

The parents of the children were surveyed by telephone (primary source), which included a structured questionnaire of 30 closed questions made *ad hoc*, and took between 13 and 22 minutes. For the social variables, validated questions from the questionnaires used by the National Institute of Statistics and Censuses (INDEC)[21] were used; for the prenatal control ones, those from the Perinatal Information System[22]; and for the geographical barrier ones, those from a published study of children with CLP[23]. All surveys were conducted between August 2018 and May 2019, by the same person. There were only two refusals to participate. The survey was answered by one of the child's parents (90% mothers, 10% fathers).

To characterize treatment, three indicators were constructed: interdiscipline, timeliness, and comprehensiveness (see Appendix). Each indicator was composed of different variables and, according to the sum of the score attributed to each one, it was categorized as high, medium, or low as defined in the treatment guidelines used by the *Sumar* Program[15].

To evaluate the barriers to access to treatment, two indicators were created: organizational and geographic barriers. The first one considered the management of the variable of the first visit and management of subsequent visits, and the second one considered how long the family usually takes to get from their home to the treating institution, how they usually travel, and the number of means of transport used.

To analyze which child, family, or access barrier factors were associated with treatment indicators, the OR with 95% confidence interval and the Chi-square test with 0.05 of alpha level were used. The Epi Info 7.2 software was used for all analyses.

The study protocol was approved by the Ethics Committee of the National Center of Medical Genetics. All the parents interviewed signed an informed consent that was read to them beforehand; the interviews were not recorded. Statistical confidentiality was respected at all times, ensuring the anonymity of the information, as established by national laws on statistical confidentiality and personal data protection.

Results

The mean age of the 100 children at the time of the interview was 36.2 months, median 36.1, and range 21.8 to 49.4 months. As a diagnosis of CLP, 17 children had CL, 62 had CL/CP, and 21 had CP. The children were seen at 31 institutions, 20 of them had complete CLP equipment, two with complete equipment were in the same area, one in another area and two did not have complete equipment. Table 1 shows the social and health characteristics of the children and their families.

Interdiscipline

Table 2 shows the results of the variables of this indicator. Out of the 100 children, 29 were in follow-up with all three specialties (SDS) and 23 were not in follow-up with any of the three, predominantly children with CL. 7% of the children were never in follow-up with a speech-language specialist. Out of the 82 children seen at the full equipment institutions, almost a quarter (n = 22) received joint interdisciplinary care (all three SDS professionals), at least in the first year of treatment.

Timeliness

To assess the treatment timeliness, the age at which the children started treatment and the age at which they underwent the first and second surgeries, respecti-

vely, were observed, and then compared with the standards. There was no association between having had a prenatal diagnosis and early initiation of care, but early initiation of treatment was more frequent among children who had been born in the treating institution (OR = 3.7; 95% CI 1.4-10.1). 30% of the children started treatment within the first 48 hours of life (i.e. had the first dental and/or surgical and/or speech-language therapy intervention). 63 children started treatment within the first week of life and 5 children after three months of age. Figure 1 shows the distribution of the children who underwent surgery (first and second surgery, respectively) and their timeliness status.

Comprehensiveness

Table 2 shows the results of the variables of this indicator. 8% of the children were never referred to the complementary specialties (psychology, social services, genetics, and otolaryngology), and 11% were referred to all four. 54% of the children usually were in pediatric follow-up at the primary health care and 8 children at the treating institution.

Table 3 shows the scores for each treatment indicator (interdisciplinary, timeliness, and comprehensiveness), distributed into high, medium, and low categories and according to the type of cleft.

Organizational barriers

23 children started treatment in the same institution where they were born, while 77 were referred at birth to another hospital to start treatment. In 47 of them (61%), the appointment for the first consultation

Table 1. Social and health characteristics of children and their families, OFC Network, Argentina, 2015-2016

Characteristics	Categories	n
Gender	Male	58
	Female	42
Date of birth	2015	46
	2016	54
Country region	Center	49
	Northwest	18
	Northeast	14
	Cuyo	13
	Patagonia	6
Age	Till 24 months	2
	From 24to 35 months	48
	From 36 a 47 months	47
	From 48 meses orolder	3
Type of cleft	Lip and palate	62
	Palate	21
	Lip	17
Prenatal care	Enough (5 visitsor more)	72
	Early (before 13 weeks)	72
	Adequate (enough and early)	72
Prenatal diagnosis of cleft	No	65
	Yes (CL/FP = 24; CL = 9; CP = 2)	35
Father and mother living together	Yes	74
	No	26
Mother age	Till20	5
	Between 21 and 39	84
	40 orolder	11
Father and mother educational level	Mother with secondary completed or more	51
	Father with secondary completedor more	29
	Mother and father with secondary completed or more	27
Father and mother employment status	Mother employed	37
	Father employed	78
	Mother and father employed	30

CL = cleft lip, CP = cleft palate; CL/CP cleft lip and palate.

was arranged by the Flap Network and in 30 (39%), it was arranged by the family. For subsequent consultations, 44% of the 100 families did not have scheduled appointments and had to make them each time the child was seen.

One-third of the families usually took more than two hours to get to the treatment institution, 77% used public transportation and half of them used two forms of transportation.

Tables 4.a., 4.b. and 4.c. show the bivariate analysis that relates which factors of the child, family, or barriers to access were significantly associated with the categories (high/medium/low) of the treatment indicators.

Discussion

So far, only one study has described the implementation process of the Flap Network[20]. This work is the first national evaluation of its results.

It was decided to include children born during 2015-2016 because they would all be old enough to be evaluated for the interventions needed for treatment compliance, and to exclude children with associated

Table 2. Treatment characteristics: Interdiscipline and Comprehensiveness OFC Network, Argentina, 2015-2016

Interdiscipline	
In follow up with basic specialties (SDS)	n
Speech-language therapy	52
Dentistry	55
Surgery	54
All three specialities	29
Type of care with basic specialties SDS*	
Joint care	22
During the same day	48
In different days	12
Comprehensiveness	
Reference to complementary specialties	
Otolaryngology	74
Genetics	40
Social Services	37
Psychology	36
Pediatric follow-up	
Regular and updated	89
Doneduring the last 6 months	81

SDS: Speech-language therapy, Dentistry and Surgery *Only those children assisted in institutions with complete team.

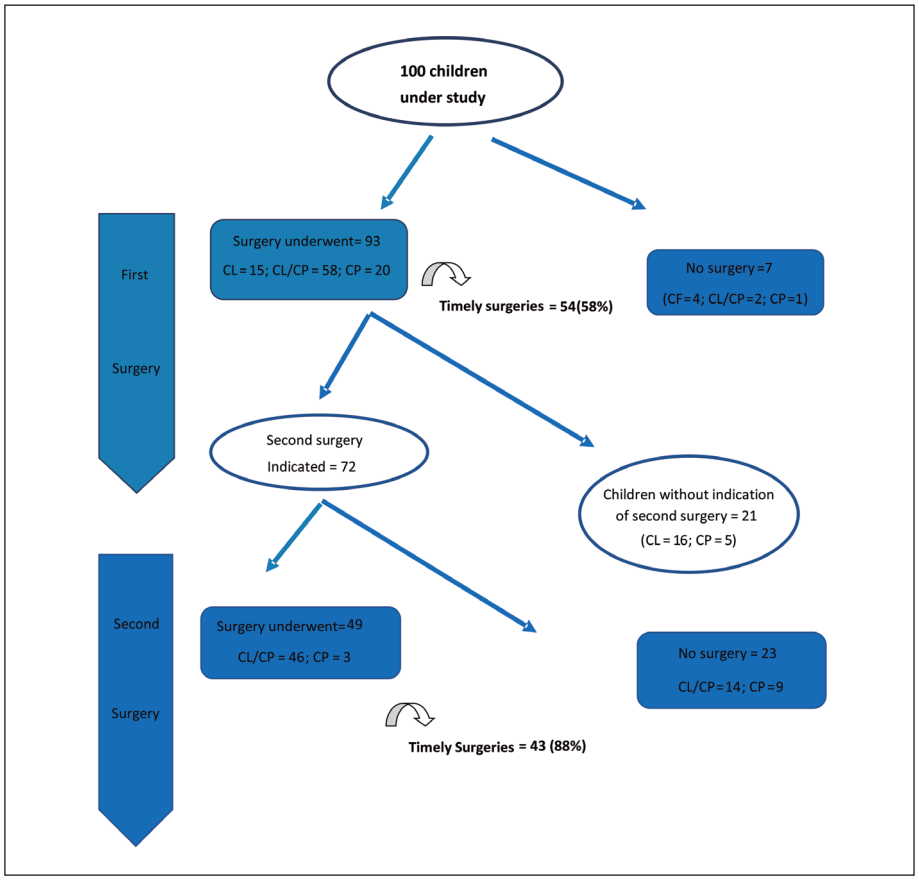

Figure 1. Timeliness of first and second surgeries, OFC Network, Argentina, 2015-2016.

or syndromic clefts because their treatment needs and evolution are not comparable to those of children with isolated clefts.

The proportional distribution of the children's type of cleft in the sample does not differ from that reported by the RENAC in Argentina in recent years[24,25].

This study shows that, although most of the children were seen at an institution with complete basic equipment, at the time of the survey, one third had dropped out of follow-up. This differs from standards[15,18,26] and contrasts with data from high-income countries such as Canada[27], butis in line with other countries such as Brazil[28] or Mexico[29]. Children with CL/CP were the ones who mostly remained in follow-up with SDS, while children with CL were the ones who had mostly discontinued follow-up. A local study that evaluated adherence to treatment in children with CLP found no differences by type of cleft[30].

It was satisfactory that at least in the first year of treatment, almost 60% of the children seen at institutions with complete equipment were usually seen by the basic specialties on the same day of consultation, although only a quarter received joint care with all three professionals. Joint care by interdisciplinary teams is strongly recommended by experts[31]. In Iran, a study compared the strategy of interdisciplinary team care of children with isolated CLP with another group with similar characteristics but treated by specialists individually, and found very favorable differences in post-treatment quality of life indicators in the first group[32].

The access barriers analyzed in this study could

Table 3. Distribution of score of treatment indicators (high, medium, low) and type of OFC Network, Argentina, 2015-2016

Type ofcleft		Interdiscipline			Timeliness			Comprehensiveness		
		High	Medium	Low	High	Medium	Low	High	Medium	Low
Labio	n	0	4	13	7	3	7	1	5	11
	%		23.5	76.5	41.2	17.7	41.2	10	29.4	64.7
Labio y paladar	n	9	19	33*	36	15	11	8	23	30*
	%	14.8	31.2	54.1	58.1	24.2	17.7	13.1	37.7	49.2
Paladar	n	4	4	13	2	5	14	1	7	12*
	%	19.1	19.1	61.9	9.5	23.8	66.7	10	35	60
Total		13	27	59	45	23	32	10	35	53

*No data in 1 child. p = 0,0003.

Table 4a. Associated factors with high/medium score in Interdisciplinary indicator of children treated, OFC Network, Argentina, 2015-2016

Indicator	Associated factors		Score		OR (IC 95%)
			High/medium (n = 40)*	Low (n = 59)	
			n (%)	n (%)	
Interdiscipline	Referred to otolaryngology	Yes	34 (85.0)	39 (66.1)	2.9 (1.1-8.1)
		No	6 (15.0)	20 (33.9)	
	Referred to Social Services	Yes	23 (57.5)	14 (24.6)	4.2 (1.7-9.9)
		No	17 (42.5)	43 (75.4)	
	Mother with secondary completed or more	Yes	25 (64.1)	22 (37.9)	2.9 (1.3-6.8)
		No	14 (35.9)	36 (62.1)	
	Medical institution arranges appointments	Yes	24 (61.5)	20 (33.9)	3.1 (1.3-7.2)
		No	15 (38.5)	39 (66.1)	

*No data in 1 child .

Table 4b. Associated factors with high/medium score in Timeliness indicator of children treated OFC Network, Argentina, 2015-2016

Indicator	Associated factors		Score		OR (IC 95%)
			High (n = 45)	Medium/Low (n = 55)	
			n (%)	n (%)	
Timeliness	In follow-up with Speech-language therapy	Yes	32 (71.1)	20 (36.4)	4.3 (1.9-10.0)
		No	13 (28.9)	35 (63.6)	
	In follow-up with Dentistry	Yes	32 (71.1)	23 (41.8)	3.4 (1.8-7.9)
		No	13 (28.9)	32 (58.2)	
	Referred to Psychology	Yes	22 (48.9)	14 (25.5)	2.7 (1.2-6.5)
		No	23 (51.1)	41 (74.6)	
	Mother and father with secondary completed or more	Yes	19 (43.2)	8 (15.7)	4.2 (1.6-10.7)
		No	25 (56.8)	43 (84.3)	
	Mother with secondary completed or more	Yes	28 (62.2)	19 (35.9)	2.9 (1.3-6.7)
		No	17 (37.8)	34 (64.2)	
	Time to getinstitution of treatment	≤ de 2 h	38 (84.4)	32 (59.3)	2.9 (1.4-9.9)
		> de 2 h	7 (15.6)	22 (40.7)	
	Type of cleft*	CL/CP	36 (80.0)	26 (47.3)	p = 0.0003
		CL	7 (15.6)	10 (18.2)	
		CP	2 (4.4)	19 (34.6)	

CL = cleft lip, CP= cleft palate; CL/CP cleft lip and cleft palate.

Table 4c. Associated factors with high/medium score in Comprehensiveness indicator of children treated, OFC Network, Argentina, 2015-2016

Indicators	Associated factors		Score		OR (IC 95%)
			High/Medium (n = 45)	Low* (n = 53)	
			n (%)	n (%)	
Compre-Hensiveness	In follow-up with Speech-language therapy	Sí	29 (64,4)	21 (39,6)	2,8 (1,2 - 6,3)
		No	16 (35,6)	32 (60,4)	
	In follow-up with Dentistry	Sí	32 (71,1)	21 (39,6)	3,8 (1,6 - 8,8)
		No	13 (28,9)	32 (60,4)	
	In follow-up with Surgery	Sí	31 (68,9)	23 (43,4)	2,9 (1,3 - 6,6)
		No	14 (31,1)	30 (66,6)	
	Joint interdisciplinary care (SDS)	Sí	31 (68,9)	17 (32,7)	4,6 (1,9-10,7)
		No	14 (31,1)	35 (67,3)	
	Mother and father employed	Sí	23 (54,8)	7 (15,2)	7,4 (2,6-19,6)
		No	18 (45,2)	39 (84,8)	
	Mother and father with secondary completed or more	Sí	18 (40,9)	9 (18,0)	3,2 (1,2-8,1)
		No	26 (59,1)	41 (82,0)	
	Mother with secondary completed or more	Sí	29 (64,4)	17 (32,7)	3,7 (1,6-8,7)
		No	16 (35,6)	35 (67,3)	
	Medical institution arranges appointments	Sí	29 (64,4)	18 (35,3)	3,3 (1,4-7,7)
		No	16 (35,6)	33 (64,7)	
	Timeliness (High	Sí	27 (60,0)	17 (32,1)	3,2 (1,4-7,3)
		No	18 (40,0)	36 (67,9)	

*No data in 2 children. SDS: Speech-language therapy, Dentistry and Surgery.

partly explain the treatment discontinuation, since many families take considerable time to get to the place of care and often have to use more than one means of transportation. Children whose institutions provided scheduled appointments for consultations with SDS had better scores in interdisciplinary and comprehensive treatment. On this point, one of the few published studies on distances and times to CLP care centers in the United States found that parents did not consider longdistances to be "a problem", although that study did not assess the characteristics or outcomes of the treatment received[33]. Another study analyzed the barriers to treatment perceived by parents and found that those who mentioned that it was too expensive to travel to the treatment center were more likely to have had the surgery performed late[34].

It is worth discussing the organizational models of public health care institutions. The experience of the United Kingdom showed that the centralization of services and increasing the volume of cleft children seen by each team improve medium- and long-term outcome indicators, identified through indicators such as speech-language, physical appearance, and dentition[35]. In contrast, a 2018 publication highlights the inconsistency of the policy of regionalization and decentralization of treating centers implemented years ago in Brazil due to the lack of institutions capable of performing highly complex surgical procedures, according to the author[36]. Unfortunately, this study does not analyze the situation of care based on objective data from Brazil (number of patients and care centers, access to care, etc.).

In this study, 7 children had not undergone surgery at the time of the survey, and 23 children of the 72 who required a second surgery had not undergone it, so these results do not comply with evidence-based recommendations[15,17,18,26]. The timeliness of the first surgery is extremely important that it has been proposed that the age at which children undergo this intervention be used as an indicator of access to compare inequalities in children with CLP between and within countries[37].

Regarding other publications on the timeliness of surgery, this study found a relevant number of children with a high score in timeliness. It is worth mentioning that in this case the variable start of treatment, which is the first contact of the child with one of the three basic specialties (SDS), was included in the indicator since early referral of the child to the treatment team is one of the priorities of the Flap Network, and also, as established by local and international standards[15,17,18,26], treatment was defined as the sum of all the interventions required for the comprehensive rehabilitation of the cleft child and not only the surgical correction of the defect.

Similarly, Interdiscipline was considered as the modality of care that, unlike multidiscipline, implies the participation of several specialties with a collaborative spirit and a shared perspective, centered on the patient[31]. Likewise, in line with treatment centers with extensive international experience in CLP, in order to define comprehensiveness, the focus was on the pediatrician's responsibility in the longitudinal follow-up of the child's health, through health control and interconsultation with complementary specialties, to detect and treat in time the comorbidities that go along with orofacial clefting[38,39].

90% of the parents reported a regular and updated pediatric follow-up, which is similar to that of the general pediatric population in Argentina[40]. Although the proportion of children under pediatric follow-up was high and the pediatrician has a central role in motivating parents to maintain follow-up, there was not the same proportion of cases that met the indicators.

Finally, the only factors that were significantly associated with higher scores on the three treatment indicators were the social characteristics of the families. Having employed or more educated parents allowed cleft children to access treatment with better indicators. It has been proposed that families with unfavorable social characteristics are at higher risk of conceiving a cleft child[7,8], therefore, if these families have a child with CLP, they face a double inequity.

The main weakness of the study is the common one in the telephone surveys, where there may have been a selection bias of subjects who were easier to contact, by excluding those who do not have a telephone or live in areas with poor telephone signal. However, some of the children included in the study were contacted through neighbors or relatives, therefore families who did not have their own telephone could be included.

In addition, there could be a recall bias of the mothers in the data of the first months of their child's life due to their age. However, mothers tend to remember their children's health events very well, which has been studied by comparing it with medical records[41]. Maternal reporting from household surveys is a good source of information regardless of maternal characteristics such as age, number of children, or living conditions[42].

As a strength, the survey allowed to obtain a representative sample of the Flap Network from all regions of Argentina, with a reduced cost in time and money, and was able to "find" families that might not have been possible to convene from the services.

The few national publications on the results of treatment of children with orofacial clefts describe mostly esthetic results or innovations in surgical techniques[43]. In this work, we present data of the whole treatment process, from the identification of the NB, her/his referral to the treatment centers, and the char-

acteristics of the follow-up in the first years of childhood. It would be important to deepen in investigations that describe the long-term outcomes of these children, evaluating their social insertion upon entering the school system.

In Argentina, although care in the public health system is free of charge for the entire population, the range of services offered is not equal. The country's extension makes it difficult for the population with fewer resources to have access to specialized care. For NBs with congenital anomalies, the situation is even more tragic, since they often require highly specialized professionals with wide experience to treat them. The policy of regionalization of perinatal care has achieved improvements in the care of at-risk neonates, especially those who are premature and/or underweight[44]. Network care of NBs with congenital anomalies requires further development in the immediate future.

In conclusion, although children with CLP underwent periodic health check-ups and were seen at institutions with multidisciplinary teams, half received treatment with high and medium scores in the interdisciplinary and comprehensiveness indicators, and two-thirds had treatment with high timeliness scores. There are still barriers that hinder access to care, such as long distances or the management of appointments. In families with lower social vulnerability, mainly composed of parents with jobs and higher education, the proportion of children who received treatment according to standards was higher.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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References

1. Wyszynski D, Duffy D BT. Maternal cigarette smoking and oral clefts. a meta-analysis. Cleft Palate-Craniofacial J. 1997;34(3):206-10.
2. Kallen K. Maternal smoking and orofacial clefts. Cleft Palate-Craniofacial J. 1997;34(1):11-6.
3. Leite ICG, Koifman S. Oral clefts, consanguinity, parental tobacco and alcohol use: a case-control study in Rio de Janeiro, Brazil. Braz Oral Res [Internet]. 2009;23(1):31-7. Available from: http://www.ncbi.nlm.nih.gov/pubmed/19488469
4. De Queiroz Correa Herkrath A, Herkrath F, Besa Rebelo M, Vianna Vettore M. Parental age as a risk factor for non-syndromic oral clefts: A meta-analysis. J Dent. 2012;40(1):3-14.
5. Berg E, Lie RT, Sivertsen A, Haaland ØA. Parental age and the risk of isolated cleft lip: A registry-based study. Ann Epidemiol [Internet]. 2015;25(12):942-7. Available from: http://dx.doi.org/10.1016/j.annepidem.2015.05.003
6. Sabbagh HJ, Hassan MHA, Innes NPT, Al Baik A, Mossey PA. Parental consanguinity and nonsyndromic orofacial clefts in children: A systematic review and meta-analyses. Cleft Palate-Craniofacial J. 2014;51(5):501-13.
7. Lupo PJ, Danysh HE, Symanski E, Langlois PH, Cai Y, Swartz MD. Neighborhood-based socioeconomic position and risk of oral clefts among offspring. Am J Public Health. 2015;105(12):2518-25.
8. Escoffié-Ramirez M, Medina-Solís CE, Pontigo-Loyola AP, Acuña-González G, Casanova-Rosado JF, Colome-Ruiz GE. Asociación de labio y/o paladar hendido con variables de posición socioeconómica: un estudio de casos y controles. Rev Bras Saúde Matern Infant [Internet]. 2010;10(3):323-9. Available from: http://search.ebscohost.com/login.aspx?direct=true&db=asx&AN=57192850&site=eds-live
9. Prescott NJ, Sue M. Folate and the face: Evaluating the evidence for the influence of folate genes on craniofacial development. Cleft Palate-Craniofacial J. 2002;39(3):327-31.
10. Vieira-Machado CD, de Carvalho FM, Santana da Silva LC, et al. Analysis of the genetic ancestry of patients with oral clefts from South American admixed populations. Eur J Oral Sci. 2016;124(4):406-11.
11. Barbero P, Bidondo M, Duarte S, Groisman B, Liascovich R, Piola A. Reporte Anual RENAC 2019 [Internet]. 2019. [citado el 13 de junio de 2020]. Available from: http://www.anlis.gov.ar/cenagem/wp-content/uploads/2017/07/Reporte-RENAC-2019.pdf
12. Christensen K, Mortensen PB. Facial clefting and psychiatric diseases: A follow-up of the Danish 1936-1987 Facial Cleft Cohort. Cleft Palate-Craniofacial J. 2002;39(4):392-6.
13. Wehby GL, Collett BR, Barron S, Romitti P, Ansley T. Children with oral clefts are at greater risk for persistent low achievement in school than classmates. Arch Dis Child. 2015;100(12):1148-54.
14. Wehby GL, Moreno LM. Oral clefts and wellbeing: A lifelong perspective and an agenda for comparative effectiveness research. J Comp Eff Res. 2014;3(1):23-8.
15. Ministerio de salud. Guía Clínica AUGE: Fisura Labiopalatina. Minist Salud Pública Chile [Internet]. 2015 [citado el 13 de junio de 2020];3:1-97. Available from: http://www.bibliotecaminsal.cl/wp/wp-content/uploads/2016/04/guia-FisuraLabioPalatina-2015-CM.pdf
16. Instituto de Seguridad Social de Uruguay. Guia Clinica Diagnostico y Tratamiento Fisura Labio Alveolo Palatina [Internet]. 2014 [citado el 13 de junio de 2020]. Available from: https://www.bps.gub.uy/bps/file/13116/1/guia_clinica_fisura_labio_alveolo_palatina.pdf
17. Equipo Multidisciplinario Integral Hospital Nacional Prof. Alejandro. Guía para la Atención de Pacientes con Fisuras Naso-Labio-Alveolo-Palatinas [Internet]. Haedo; 2010 [citado el 7 de julio de 2020]. p. 1-57. Available from: https://www.yumpu.com/es/document/view/13452413/descargar-la-guia-clinica-para-el-tratamiento-de-hospital-posadas
18. CEN. Early care services for babies born wit cleft lip and/or palate. Cen [Internet]. 2015; [citado el 13 de junio de 2020]. Available from: http://europeancleft.org/wp-content/uploads/2016/02/CEN.pdf
19. Andrade J, Chuit R, Consoli N, et al. Análisis Epidemiológico de 970 pacientes con fisura labio-alveolo-palatina con tratamiento pre-quirúrgico y quirúrgico, Argentina 2009. Bol A N Med. 2009;87(2) (ISSN 0374-647 X):261-272.
20. Cassinelli A, Pauselli N, Piola A, et al. Red nacional para la atención de niños/as con fisuras orales: organización, funcionamiento y primeros resultados. Arch Argent Pediatr [Internet]. 2018;116(1):e26-33. Available from: http://www.sap.org.ar/docs/publicaciones/archivosarg/2018/v116n1a14.pdf
21. Indec. Encuesta Permanente de Hogares [Internet]. INDEC. Instituto Nacional de Estadística y Censos. 2019 [citado el 13 de junio de 2020]. p. 33. Available from: tps://www.indec.gob.ar/ftp/cuadros/menusuperior/eph/EPH_registro_t318.pdf
22. Ministerio de Salud y Desarrollo Social. Sistema Informático Perinatal para la Gestión (SIP-G) Indicadores básicos 2017 República Argentina [Internet]. Buenos Aires; 2018. [citado el 13 de junio de 2020]Available from: tps://www.indec.gob.ar/ftp/cuadros/menusuperior/eph/EPH_registro_t318.pdf
23. Seid M, Opipari-Arrigan L, Gelhard LR, Varni JW, Driscoll K. Barriers to Care Questionnaire: Reliability, Validity, and Responsiveness to Change Among Parents of Children With Asthma. Acad Pediatr [Internet]. 2009;9(2):106-13. Available from: http://dx.doi.org/10.1016/j.acap.2008.12.003
24. Groisman B, Tardivo A, Gili J, et al. Reporte Anual RENAC 2015 [Internet]. 2015. [citado el 13 de junio de 2020] Available from: http://www.anlis.gov.ar/cenagem/wp-content/uploads/2017/07/Reporte-Renac-2015-web.pdf
25. Groisman B, Duarte S, Gili J, et al. Reporte Anual RENAC 2016 [Internet]. 2016. [citado el 13 de junio de 2020] Available from: http://www.anlis.gov.ar/cenagem/wp-content/uploads/2017/07/Reporte-Renac-2016-web.pdf
26. Association ACP-C. Standards for Approval of Cleft Palate and Craniofacial Teams-Commission on Approval of Teams. 2019. www. acpa-cpf. org. Stand pdf [Internet]. 2019; [citado el 7 de julio de 2020] Available from: https://acpa-cpf.org/team-care/standardscat/standards-of-approval-for-team-care/
27. Matthews JLK, Oddone-Paolucci E, Harrop RA. The epidemiology of cleft lip and palate in Canada, 1998 to 2007. Cleft Palate-Craniofacial J. 2015;52(4):417-24.
28. Silva HPV da, Arruda TTS, Souza KSC de, et al. Risk factors and comorbidities in Brazilian patients with orofacial clefts. Braz Oral Res. 2018;32(0):1-12.
29. Pons-Bonals A, Pons-Bonals L, Hidalgo-Martínez SM, Sosa-Ferreyra CF. Clinical-epidemiological study in children with cleft lip palate in a secondary-level hospital. Bol Med Hosp Infant Mex [Internet]. 2017;74(2):107-21. Available from: http://dx.doi.org/10.1016/j.bmhimx.2016.11.008
30. Andrade J, Chuit R, Infante L, Ling C, Miranda T, Nalda F. Adherencia al tratamiento del paciente con fisura labio-palatina (FLAP) 2006-2013. Bol AN Med. 2014;92(2):281-90.
31. Murphy MT. Collaborative interdisciplinary agreements: A new paradigm in laboratory and specialist communication and patient care. J Am Dent Assoc. 2006;137(8):1164-7.
32. Khanchezar F, Moradi N, Tahmasebi Fard N, Latifi SM, Bassak Nejad S, Hosseini Beidokhti M. The Effect of Teamwork on Children With Cleft Lip and Palate and Their Mother's Quality of Life.

Cleft Palate-Craniofacial J [Internet]. 2019;105566561985374. Available from: http://journals.sagepub.com/doi/10.1177/1055665619853749
33. Cassell CH, Strassle P, Mendez DD, et al. Barriers to care for children with orofacial clefts in North Carolina. Birth Defects Res Part A - Clin Mol Teratol. 2014;100(11):837-47.
34. Ise A, Menezes C, Neto JB, et al. Patient-Perceived Barriers to Accessing Cleft Care at a Tertiary Referral Center in Sao Paulo, Brazil. Cleft Palate Craniofac J. 2019;56(5):639-645.
35. Ness AR, Wills AK, Waylen A, et al. Centralization of cleft care in the UK. Part 6: A tale of two studies. Orthod Craniofacial Res. 2015;18:56-62.
36. Tovani Palone M, Treatment of Nonsyndromic Cleft Lip and/or Palate in Brazil: Existing Consensus and Legislation, Scope of the Unified Health System, Inconsistencies and Future Perspectives. World Health and Population. 2018; 17(4): 31-36.
37. Mossey PA, Shaw WC, Munger RG, Murray JC, Murthy J, Little J. Global oral health inequalities: challenges in the prevention and management of orofacial clefts and potential solutions. Adv Dent Res. 2011;23(2):247-58.
38. Lewis CW, Jacob LS, Lehmann CU. The Primary Care Pediatrician and the Care of Children With Cleft Lip and/or Cleft Palate. Pediatrics. 2017;139(5):e20170628.
39. Lombardo-Aburto E. The intervention of the pediatrician in the child with cleft lip and palate. Acta Pediatr Mex. 2017;38(4):267-73.
40. Ministerio de Salud. Indicadores seleccionados de salud y nutrición población materno-infantil [Internet]. 2019. [citado el 13 de junio de 2020] Available from: http://www.msal.gob.ar/images/stories/bes/graficos/0000001785cnt-ennys-materno-infantil.pdf
41. Pless C, Pless B. How well they remember. Arch Pediatr Adolesc Med. 1995;149:553-558.
42. D'Souza-Vazirani D, Minkovitz C, Strobino D. Validity of maternal report of acute health care use for children younger than 3 years. Arch Pediatr Adolesc Med. 2005;159(2):167-72.
43. Bennun RD, Langsam AC. Long-term results after using dynamic presurgical nasoalveolar remodeling technique in patients with unilateral and bilateral cleft lips and palates. J Craniofac Surg. 2009;
44. De Maucio B, Fecina R, Schwarcz A, Garibaldi M, Mendez Valdemarin G. Regionalización de la Atención Perinatal [Internet]. Ministerio de Salud. 2011 [citado el 13 de junio de 2020]. p. 119. Available from: http://www.msal.gob.ar/images/stories/bes/graficos/0000000176cnt-n02-regionalizacion.pdf