Original Article

Family care practitioners experience with individuals with orofacial clefts in Brazil

Experiência de profissionais de saúde da família com pessoas com fendas orofaciais no Brasil

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Abstract

Introduction: Orofacial clefts are among the most prevalent birth defects worldwide. Specialized treatment and surveillance of basic health needs are critical. Few studies have investigated primary care practitioners' experience in caring for individuals with clefts. **Objective:** It was to describe experience and current interest of family care practitioners on the management of individuals with clefts. **Methods:** Observational cohort of 104 practitioners from Maceió (AL) e Campinas (SP). Demographic, academic and professional characteristics, didactic experience and desire in continuing education on clefts were assessed using a questionnaire. **Results:** Seventy-four practitioners were located in Maceió and 30 in Campinas. Female gender and low academic qualification were predominant. Physicians and nurses prevailed over dentists, 78 (75%) participants had clinical experience with clefts. Use of protocols was mentioned by 3/104 (2.9%), provision of information on clefts by 58/104 (56%) and referrals to the Brazilian Reference Network by 7/104 (6.7%). Almost 50% reported didactic experience and 94%, desire on continuing education in this field. **Conclusion:** Results corroborate the literature and reinforce the need of improving family care practitioners' skills to manage individuals with clefts. Education and strengthen ties between primary level of the health system and specialized teams must be focused. Some strategies are presented in this regard.

Keywords: orofacial clefts; primary care; continuing education.

Resumo

Introdução: As fendas orofaciais estão entre os mais prevalentes defeitos congênitos em todo o mundo. Atenção especializada e vigilância de necessidades básicas de saúde são críticas no cuidado aos indivíduos. **Objetivo:** Foi descrever a experiência e o interesse de profissionais da Estratégia Saúde da Família no acompanhamento de indivíduos com fendas orofaciais. **Métodos:** Coorte observacional com 104 profissionais de Maceió (AL) e Campinas (SP). Características demográficas, acadêmicas e profissionais, bem como a experiência didática e o desejo por educação continuada, foram colhidas por meio de questionário. **Resultados:** Setenta e quatro profissionais atuavam em Maceió e 30 em Campinas. O gênero feminino e a baixa qualificação acadêmica foram predominantes. Médicos e enfermeiros prevaleceram sobre dentistas, e 78 (75%) participantes tinham experiência clínica com fendas. O uso de protocolos foi mencionado por 3/104 (2,9%), a oferta de informações sobre fendas por 58/104 (56%) e o encaminhamento para unidades especializadas da Rede de Referência por 7/104 (6,7%). Cerca de 50% dos participantes referiram experiência didática e 94%, desejo por educação continuada. **Conclusão:** Os resultados corroboram a literatura e reforçam a necessidade de melhorar a capacitação de profissionais nesta área. Para tanto, são apresentadas estratégias para promover educação e reforçar laços entre a atenção básica e equipes especializadas.

Palavras-chave: fendas orofaciais; atenção básica; educação continuada.

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INTRODUCTION

For more than ten years, birth defects are the second most common cause of infant mortality in Brazil[1]. Orofacial clefts (OC) are among the most prevalent defects in the world, with prevalence around 1:600–1,000 newborns. In 70% of the cases, they are isolated malformations (non-syndromic), but can also be classified as a syndromic picture if other defects are present. Etiology of non-syndromic OC is complex and involves several genetic and environmental risk factors following multifactorial threshold model of inheritance. Teratogenic effects, chromosomal and mendelian abnormalities respond to many syndromic cases[2-4].

Among more than 20 investigated genes, *IRF6*, *VAX1* and 8q24 *locus* have confirmed role in non-syndromic OC. Maternal exposure to tobacco and alcohol use, metabolic status (diabetes, obesity and underweight), viral infection, medicinal drugs (anticonvulsivants) and teratogens (solvents and agricultural chemicals), as well as the preventive role of vitamin supplements, have been investigated. Maternal smoke during pregnancy is consistently linked with increased risk of OC. Findings on the other risk factors and gene-environment interactions have been inconclusive due to methodological issues[2-6].

Besides these factors, a meta-analysis approach of parental age showed that 40-year-old fathers or older have a 58% higher probability of having a child with cleft palate (CP), and for mothers aged over 40 years the probability is 28% higher for CP and 56% higher for cleft lip with or without cleft palate (CLP)[7].

Individuals with OC need timely and multi-professional care to cope with primary surgical repair, and aesthetic and functional rehabilitation. Effective cure is defined as a situation in which individuals can normally function in society and residual problems, if present, grade into the normal range. It is estimated that this is achieved for 80–85% of patients who receive the so called best available modern treatment[3,8-10].

Good outcomes, however, depend on various factors, such as experience of the cleft team, engagement of the family and appropriate management of basic health needs. Family education and support, monitoring of growth and development, immunization, dental hygiene, prevention and early treatment of infections play a crucial role[11-15].

These issues should be addressed as close as possible to the community where patient lives. This is much important when there is great distance between the patients' domicile and their reference cleft centre and even more when there are not enough specialized centers in the country. Therefore, a partnership between primary care providers and cleft teams is critical to ensure optimum outcomes[11,13,14].

Public health in Brazil is provided through the Unified Health System (*Sistema Único de Saúde* – SUS). It was established in 1988 as a constitutional right. The SUS was conceptualized to provide integral care through a network of units arranged according to areas of coverage and crescent levels of complexity. Funding and management of primary and secondary levels are under municipal responsibility, whereas the most specialized procedures are under federal administration[16].

There was not universal access to services for caring of persons with OC in Brazil before the implementation of the SUS. First action was taken in 1993 when the government created a specific fund for cleft surgery. An important improvement occurred in 1998 through the establishment of the Brazilian Reference Network for Craniofacial Treatment (*Rede de Referência no Tratamento de Deformidades Craniofaciais* – RRTDCF)[16-18].

Currently, 20 multi-professional units are listed in the RRTDCF and distributed all over the country (Figure 1). All of them are accredited by the Ministry of Health and funded by federal resources[19,20]. Despite of this, annual volume of patients and composition of the teams are greatly variable. Regional disparities and lack of coordination between specialized units and low complexity services within the SUS are unsolved problems[16-18].

Family Care Program (*Programa Saúde da Família* – PSF) was initiated in 1994 and rapidly evolved into a national strategy (*Estratégia Saúde da Família* – ESF]), which structures primary care in the country. According to the Ministry of Health, ESF should focus on integral care instead of management of diseases. This means professionals should entrust with continuous promotion and protection of health, prevention of diseases, early and low complexity care, management of chronic diseases and community-based rehabilitation[21].

ESF teams are responsible for a defined territory of 2,400–4,500 citizens. Basic teams are composed by one physician, one nurse and one assistant nurse, and five to six community health agents. Oral caring extended teams include one dentist, one dental assistant and one dental hygiene technician. Aiming to quality improvement, the Ministry of Health created offices for continuing education of ESF teams. Offices have autonomy to plan and delivery training programs in accordance with demands of the local teams[21].

Based on the conception of the SUS, it is expected that ESF teams play a role in the caring of basic health needs of patients with OC throughout life. This is particularly important considering Brazil's territorial extension, and the recognized dearth and concentration of units of the RRTDCF. In this context, it is also desirable that ESF teams are qualified to promote health education regarding risk factors and recurrence for families under their care.

Few reports have investigated primary care physicians roles, responsibilities and skills in caring for individuals with OC[11-14,22]. In Brazil, these issues have not been investigated yet.

The aims of this study were: (1) to describe experience and current interest of primary care practitioners — physicians, nurses and dentists — linked to ESF teams from two different regions of Brazil on the management of individuals with OC; and (2) to provide strategies on how to improve liaison between primary and specialized levels of cleft care.

METHODS

Primary care practitioners were asked to participate in this study during three training courses promoted by their respective ESF educating boards in 2009. Two of these courses took place in Maceió (Alagoas) and one in Campinas (São Paulo), respectively located in the Northeast and Southeast of Brazil (Figure 1). Participants were not identified by their unit of origin.

Information was gathered using a multiple choice, fill-in-the-blank and anonymous questionnaire adapted from a similar study performed in the United States of America (USA)[12]. It comprised 18 questions covering the following: age, gender, occupation, highest academic qualification, years since graduation and in practice, number of patients with OC treated throughout career and in the last year, time past since treating a patient with OC, use of protocols, pattern of information given and referral of patients, didactic experience on OC (literature readings, conference or lecture attendance), desire for continuing education and current interest in OC.

A total of 185 questionnaires (111 in Maceió plus 74 in Campinas) were distributed to the participants at the beginning of the training course. Response rates were 81% (90/111) in Maceió and 51% (38/74) in Campinas ($p<0.02$) for a combined rate of 69% (128/185). Primary care practitioners not linked to an ESF team were not eligible. Therefore, the final sample amounted to 104 individuals. Information was compiled in a database. Some variables show different amounts because of incompleteness of the questionnaire.

The software package Epi Info™ Version 3.5.1 (http://www.cdc.gov/epiinfo/) was used for data processing and analysis. Kruskal-Wallis Test, Fisher Test and Chi Square were used for statistics in order to check preferential association between independent variables (age, gender, years since graduation and in practice, academic qualification, number of patients with OC treated throughout career and in the last year, time past since treating a patient with OC, use of protocols, pattern of information given and referral of patients, literature readings, conference or lecture attendance, desire for continuing education and current interest in OC) and the professional location and category. Differences were considered statically significant if the p-value was <0.05.

The study was approved by the local Institutional Review Boards and the National Research Ethics Committee (CONEP protocol number 709/2008).

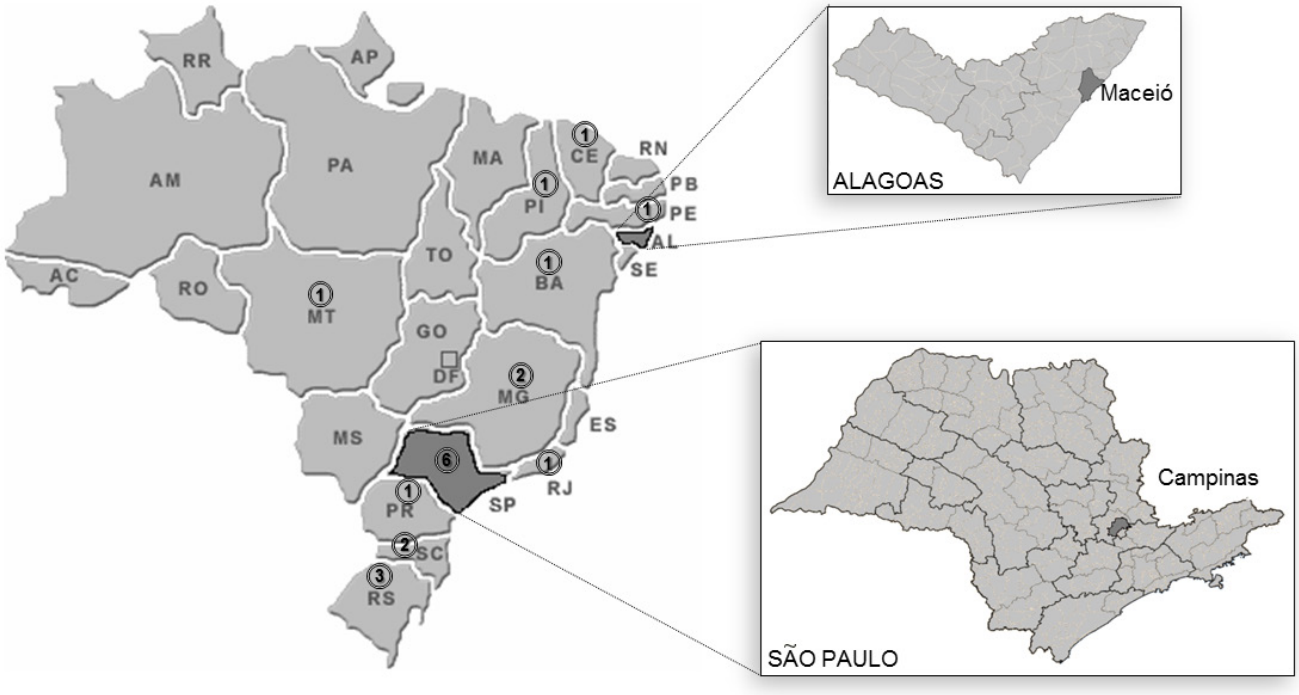

Figure 1. Brazil's map showing distribution and number of units of the Brazilian Reference Network for Craniofacial Treatment with the towns of Maceió and Campinas in evidence

RESULTS

Seventy-four practitioners (71%) were located within the area of Maceió and 30 (29%) within Campinas. Physicians amounted to 40 (38.5%), nurses to 38 (36.5%) and dentists to 26 (25%) individuals of the sample. Demographic and occupational characteristics are shown in Table 1.

Ages ranged from 24 to 66 years (mean of 38 years and SD±9.2). There were 89 (86%) females and 15 (14%) males. Years since university graduation ranged from 2 to 38 (mean of 14 years and SD±9.2). Years of practice in ESF ranged from 0 to 15 (mean of 6 years and SD±3.5). Eighty-four (81%) participants were specialists, 17 (16%) had bachelors' and three (3%) Master's degree. There was no statistically significant difference between professionals from Maceió and Campinas with regard these characteristics. Comparisons between professional categories, however, showed that physicians had significantly higher mean of ages (p<0.006) and years since graduation (p<0.001), and that all Masters were physicians.

Seventy-eight (75%) participants had already cared for patients with OC. This characteristic was not statistically different among respondents with regard to their geographic location and professional category. Time elapsed since last treated patient ranged from less than a year to more than five years. Among practitioners who had ever seen a patient with OC, 31 (57%) had treated at least a patient within the past year, while 17 (12%) had seen one for over five years. None statistically significant difference was found between professionals from Maceió and Campinas or among professional categories with regard to time interval since last treated patient (p<0.52 and p<0.97, respectively).

Volume of treated patients ranged from 1–10 (global mean of 2.6 and SD±1.9) per professional. Within the past year, it ranged from 1–7 (global mean of 1.8 and SD±1.3). Twenty-two (32%) practitioners had hitherto treated just one patient, 17 of which had done so within the previous 12 months (Table 2).

Table1. Demographic and occupational characteristics

	Maceió n (%)	Campinas n (%)	Physicians n (%)	Nurses n (%)	Dentists n (%)	Total n (%)
	74 (71)	**30 (29)**	**40 (38)**	**38 (37)**	**26 (25)**	**104 (100)**
Age in years						
<30	10 (14)	6 (21)	4 (10)	8 (21)	4 (16)	16 (16)
30–39	31 (44)	13 (45)	15 (40)	18 (49)	11 (44)	44 (44)
40–49	22 (31)	7 (24)	10 (27)	10 (27)	9 (36)	29 (29)
50–59	6 (8)	3 (10)	7 (18)	1 (3)	1 (4)	9 (9)
≥60	2 (3)	–	2 (5)	–	–	2 (2)
Mean	39	38 (p<0.59[#])	43	36	36 (p<0.006[#])	38
Gender						
Female	65 (88)	24 (80)	31 (78)	38 (100)	20 (77)	89 (86)
Male	9 (12)	6 (20) (p<0.23[§])	9 (22)	–	6 (23)	15 (14)
Years since university graduation						
≤5	15 (21)	10 (33)	6 (16)	15 (39)	4 (16)	25 (24)
6–10	12 (16)	4 (13)	3 (8)	6 (15)	7 (27)	16 (15)
11–15	17 (23)	5 (17)	9 (23)	10 (26)	3 (11)	22 (21)
16–20	10 (13)	3 (10)	4 (10)	4 (10)	5 (19)	13 (13)
21–25	9 (12)	8 (27)	9 (23)	4 (10)	4 (16)	17 (16)
≥26	11 (15)	–	8 (20)	–	3 (11)	11 (11)
Mean	15	12 (p<0.42[#])	18	10	14 (p<0.001[#])	14
Years of practice in ESF						
<1	4 (5)	1 (4)	3 (7)	2 (5)	–	5 (5)
1–5	26 (36)	15 (50)	11 (28)	19 (50)	11 (42)	41 (39)
6–10	36 (49)	11 (37)	20 (50)	12 (32)	15 (58)	47 (45)
11–15	8 (10)	3 (9)	6 (15)	5 (13)	–	11 (11)
Mean	6	6 (p<0.19[#])	7	6	6 (p<0.29[#])	6
Academic qualification						
Bachelor	13 (18)	4 (13)	6 (15)	7 (18)	4 (15)	17 (16)
Specialist	60 (81)	24 (7)	31 (78)	31 (82)	22 (85)	84 (81)
Master (physicians)	1 (1)	2 (80) (p<0.31*)	3 (7)	–	–	3 (3)

[#]Kruskal-Wallis Test; [§] Fisher Test; *χ^2; ESF: Estratégia Saúde da Família

There was no statistically significant difference between professionals from Maceió and Campinas with regard to the mean of treated patients considering the entire career. However, the mean of treated patients during the past year was statistically higher among those from Campinas.

Although physicians had shown significantly higher global mean of treated patients, none statistical difference among professional categories was observed regarding volume of patients within the past year.

Three out of 75 respondents (a physician from Campinas and two dentists from Maceió) affirmed they follow a protocol while treating an individual with OC. Among 74 who answered questions about provision of health information, 16 (22%) stated they do not provide any specific guidance for patients and parents, 44 (59%) give only verbal and 14 (19%) give verbal and written information on OC. These characteristics were not statistically different among participants with regard to their geographic location (p<0.11) and professional category (p<0.05).

Forty-seven out of 72 (65%) respondents asserted they refer patients to specialized centers. None statistically significant difference was verified between professionals from Maceió and Campinas or among professional categories with regard to the practice of referring patients (Table 2). On the other hand, only seven (9.7%) practitioners, all of them from Campinas, mentioned a unit of the RRTDCF. The remaining hospitals and clinics listed are not cleft teams.

A total of 102 participants answered questions regarding continuing education (Table 3). Among them, 60 (59%) mentioned didactic experience such as participation in conferences and lectures or literature readings. Dentists appeared

Table 2. Clinical experience and characteristics of care

	Maceió n (%)	Campinas n (%)	Physicians n (%)	Nurses n (%)	Dentists n (%)	Total n (%)
	74 (71)	**30 (29)**	**40 (38)**	**38 (37)**	**26 (25)**	**104 (100)**
Ever provided care since university graduation						
Yes	54 (73)	24 (80)	34 (85)	24 (63)	20 (77)	78 (75)
No	20 (27)	6 (20) (p<0.31§)	6 (15)	14 (27)	6 (23) (p<0.08*)	26 (25)
Time interval since last treated patient						
≤12 months	22 (42)	9 (45) (p<0.52§)	13 (42)	10 (43)	8 (44) (p<0.97*)	31 (57)
13–36 months	15 (29)	6 (30)	9 (29)	5 (22)	7 (39)	21 (15)
37 months–5 years	7 (14)	1 (5)	2 (6)	3 (13)	3 (17)	8 (11)
>5 years	8 (15)	4 (20)	7 (23)	5 (22)	–	12 (17)
Total	52	20	31	23	18	72 (100)
Amount of patients carried for throughout carrier						
1	18 (37)	4 (21)	5 (22)	10 (37)	7 (38)	22 (32)
2	16 (33)	6 (32)	7 (30)	9 (34)	6 (33)	22 (32)
3	5 (10)	3 (16)	7 (30)	–	1 (6)	8 (12)
4	3 (6)	2 (10)	2 (9)	2 (7)	1 (6)	5 (7)
5–10	7 (14)	4 (21)	2 (9)	6 (22)	3 (17)	11 (17)
Total	49	19				
Mean	2.4	3.2 (p<0.13#)	3.3	2.1	2.2 (p<0.04#)	2.6
Amount of patients carried for within past year						
1	15 (68)	2 (22)	7 (54)	6 (60)	4 (50)	17 (55)
2	7 (32)	4 (44)	3 (23)	4 (40)	4 (50)	11 (35)
3	–	–	–	–	–	–
4	–	1 (11)	1 (8)	–	–	1 (3)
5–7	–	2 (22)	2 (15)	–	–	2 (6)
Mean	1.3	2.9 (p<0.006#)	2.2	1.4	1.5 (p<0.76#)	1.8
Provision of health information						
No	9 (17)	7 (33)	11 (33)	4 (18)	1 (5)	16 (22)
Yes, verbal	34 (64)	10 (48)	17 (52)	13 (59)	14 (74)	44 (59)
Yes, verbal and written	10 (19)	4 (19) (p<0.11§)	5 (15)	5 (23)	4 (21) (p<0.05*)	14 (19)
Referral to specialized treatment						
No	16 (30)	9 (47)	7 (22)	11 (52)	7 (37)	25 (35)
Yes, to the RRTDCF	–	7 (37)	5 (16)	2 (10)	–	7 (10)
Yes, to non-cleft teams	37 (70)	3 (16) (p<0.14§)	20 (62)	8 (38)	12 (63)(p<0.07*)	40 (55)

#Kruskal-Wallis Test; § Fisher Test; *χ^2

Table 3. Didactic experience, occupational and cleft care characteristics

	Didactic Experience		p-value
	Yes n (%)	No n (%)	
	60 (59)	42 (41)	
Professional location			
Maceió	45 (75)	29 (69)	
Campinas	15 (25)	13 (31)	<0.32§
Professional category			
Physicians	18 (30)	21 (50)	
Nurses	18 (30)	19 (45)	
Dentists	24 (40)	2 (5)	<0.000*
Academic qualification			
Bachelor	11 (18)	6 (14)	
Specialist or Master	49 (82)	36 (86)	<0.39§
Provide information			
Yes	37 (88)	21 (66)	
No	5 (12)	11 (34)	<0.02§
Give referral			
Yes	27 (66)	20 (65)	
No	14 (34)	11 (35)	<0.55§

§ Fisher Test; *χ^2

most likely to have had didactic experience than the other categories (p<0.000). None statistical difference was verified with regard to the geographic location (p<0.32) and academic qualification (p<0.39) of the practitioner.

Provision of information was statistically associated with didactic experience (p<0.02), but not with academic qualification (p<0.44). Referral of patients was not statistically associated with either (p<0.55 and p<0.57, respectively). Desire for continuing education in this area was expressed by 96 (94.1%) participants without statistical difference among the analyzed groups (p<0.20).

DISCUSSION

Alagoas and São Paulo have opposite economical position, with São Paulo being the richest state of the country. Maceió, the capital of the state of Alagoas, is located in the Northeast coast of Brazil. With 936,313 inhabitants, it counts with 72 ESF teams which serve 26.8% of the population. Campinas is a country-side town of 1,064,669 inhabitants in the state of São Paulo, southeast of the country. With 102 teams, 33.2% of the population is covered by the ESF[23]. Despite significant economical and social differences, both town are under the same health policy and have similar coverage of ESF teams.

Our sample consisted mostly of professionals from Maceió, where the training course and survey was conducted twice. Global and town-specific response rates followed current trend in surveys involving physicians which ranges from 52 to 81% with a mean of 68%[24].

Inter-town comparison showed that response rate was higher in Maceió. We presume there was a lack of motivation among professionals from Campinas concerning this survey due to limited knowledge or experience in the field related, perhaps, to the existence of a multi-professional cleft centre in Campinas which probably absorbs a large number of patients. Despite of this, and with the exception of volume of treated patients within the past year, there were not statistically significant differences between professionals from Maceió and Campinas.

Non-response bias tests were not performed because we did not record information on non-respondents. We recognize this is a weakness of our study, however we agree with Damiano et al.[14] that shortfall of reports on this issue justifies the analysis of the collected data.

Physicians and nurses prevailed over dentists. All participants of the last category were from Maceió because local ESF office decided to extend the training course to this professional category.

Young female practitioners with low academic qualification were predominant in the sample. Mean of years since graduation and years in ESF teams were low despite the wide variation verified. Physicians were significantly older and had more years of practice since graduation, however there was no difference among professional categories regarding academic qualification. These results corroborate the current profile of Brazilian community-based practitioners linked to the ESF[25,26].

One quarter of the surveyed professionals had never cared for patients with OC. Among professionals with some experience, there was a shortfall in total and last year's number of patients. Despite differences concerning structure of health systems, similar result was found in two studies carried out in the USA[12,14]. Nevertheless, considering Brazil's OC prevalence rate of 19.34/10,000[27] and even taking years of practice into account, these figures still are unexpected.

Very few professionals use protocols while caring for patients with OC. Although many provide information, they consist predominantly of verbal guidance with just few using written resources. Majority (65%) of the participants refer patients to specialized centers. However, a large number of them actually refer to hospitals where there are not cleft teams and just 7 (9.7%) mentioned units of the RRTDCF. These rates are lower than those found by Grow and Lehman[12] among American family practitioners.

There are not multi-professional centers for OC care in Maceió. The closest unit is part of the RRTDCF and is located in Recife, the capital of the state of Pernambuco, which is 25 miles away. In Campinas, OC care is provided through a unit of the RRTDCF[20]. This unit is seeded into a specialized hospital with multidisciplinary craniofacial rehabilitation with a volume of more than 1,000 surgeries per year, clefts

included. It also performs research and provides professional education through medical residence and short-term courses on speech-language therapy[28].

Geographic proximity must have been the reason why all professionals who referred patients to units of the RRTDCF were from Campinas. However, it was unforeseen that there were not significant differences regarding other characteristics of caring between professionals from Maceió and Campinas.

Our results show that the existence of the RRTDCF is unknown among the majority of primary care practitioners and suggest they are unaware on how the Brazilian system for OC care is structured. This is not totally surprising considering that care provided through the SUS is still fragmented. With regard to OC care, a national survey showed serious problems of coordination between units of the RRTDCF and other levels of the health system[16,17].

Our data also suggest primary care professionals do not have a course of action to take with their patients. There seems to be not clear which role and responsibilities should they take, and perhaps they feel unprepared and uncomfortable to care for these patients.

A study conducted with primary care physicians from three states of the USA showed they were much comfortable in providing services that were similar to those they provide to other children in their practice and less comfortable in OC-specific approach and counseling[14].

A study performed with last year students from college of Medicine, Dentistry, Nursing and Speech Language Therapy of the University of Campinas (UNICAMP) concluded they are not able to meet primary health needs of patients with OC[29]. This situation probably applies to other regions of Brazil, such as Maceió.

In our sample, almost 60% of the participants mentioned some didactic experience on OC, more than a half of the participants read specialized literature, but just a minor percentage (7.8%) attended to conferences or lectures. The last result is probably similar to 9% reported in a study with American family practitioners[12]. Provision of information to patients/parents was the only characteristic of caring significantly associated with previous didactic experience in our sample.

A survey conducted in 2010 found that 75% of surveyed primary care physicians had experienced providing care for a child with OC during medical school or residency[14]. A limitation of our study is that professionals were not asked about when, where and how often they had educational experiences. Despite of this, we found high percentage of professionals interested in updating knowledge on OC. Didactic experience and current desire for updating were not influenced by the professionals' geographic location.

Bearing country differences in mind, our results corroborate studies carried out in the USA[12,14] with regard to the limited experience of primary care professionals in caring for children with OC and to the need of improving their knowledge in this field through didactic experience during college, residence and continuing education programs.

In Brazil, within the structure of SUS, ESF teams have an essential role for patients and families with OC. They are invaluable when dealing with parent's stress, confusion, fears and misunderstandings. Besides preparing parents and patients for a lifelong specialized treatment, they should care for ideal health conditions in order to ensure their patients will thrive throughout life.

Neonatal period is such a challenging phase. Specialized treatment depends on how successful parents are in dealing with nutritional problems of their child. A study performed at a secondary hospital of Brazil showed parents did not receive systematic guidance on how to feed their babies. Many of them reported surgical delays associated with poor gain weight in this period of life[30].

In a multicenter study carried out in different regions of Brazil, it was verified that delays on lip surgery were associated with low gain weight in 25% patients. Anemia was the reason for delays in 50% of patients who were waiting for palate repair. These results reinforced concerns on nutritional patterns in children with OC in the country[15].

In addition to nutritional issues, ESF professionals should take action to prevent other physical problems, such as recurrent infections. They also should support family to deal successfully with psychological and social effects of OC, and to understand genetic susceptibility and recurrence risk of non-syndromic cases[11-14,22].

All of these actions involve low density technology and cost, and are fully compatible with primary care level of the health system. However, patients will not benefit from them if unknown and fragmentation which still surrounds OC care in Brazil persist. Education of primary care professionals and strengthening ties between primary level of the SUS and specialized teams must be focused.

Strategies to address identified problems comprise local meetings between ESF boards and cleft teams in order to form a pact on how to coordinate efforts, to promote the exchange of experience between primary care professionals and specialists, and to agree on core content on OC to be regularly included on ESF courses. The following topics on OC are given as a matrix for additional discussion:

- Epidemiology and impact
- Clinical classification
- Etiology and risk factors
- Prevention and Genetic counseling

- Health needs and comorbidity according cycles of life (infancy, childhood, adolescence and adulthood)
- Psychosocial implications
- The concept of multi-professional team

Authors believe that the implementation of these strategies is an achievable and cost-effective way to reduce current fragmentation and improve the standards of care for patients with orofacial clefts in Brazil and other middle income countries.

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