

Original Article

Are There Regionalisation of High Complexity Surgeries and Decentralisation of Outpatient Treatment Services for Cleft Lip and/or Palate in the State of São Paulo, Brazil?

MR TOVANI-PALONE, A FORMENTON, SR BERTOLINI

Abstract

Objective: To investigate the existence of regionalisation of high complexity surgeries and decentralisation of outpatient treatment services for cleft lip and/or palate linked to the Brazilian Unified Health System (*Sistema Único de Saúde* - SUS) and/or of philanthropic nature in the state of *São Paulo*, Brazil, during the period between 2000 and 2015. **Methods:** This was a descriptive and comparative study, comprising searches on the National Register of Health Establishments, National Register of Associations of the PROFIS Network, free access sites and documents on the Internet. Further data were obtained from the Department of Informatics of SUS, by searching with the corresponding codes for surgical treatments of cleft lip and/or palate. **Results:** According to the National Register of Health Establishments, there are nine centres accredited as specialised in the high complexity treatment for cleft lip and/or palate throughout the state of *São Paulo*, located in eight cities. Six new centres have been accredited since 2000. Overall, there are 13 associations in the state, and two associations were created in the last 15 years. There is only one nucleus directed to cleft lip and/or palate. Among accredited establishments, a much larger number of Authorisations of Hospital Internment approved for performing high complexity surgeries was observed to the Hospital for Rehabilitation of Craniofacial Anomalies, University of *São Paulo*. **Conclusion:** There are indications of centralisation of high complexity surgeries for the treatment of cleft lip and/or palate, while a trend toward decentralisation was observed for outpatient services.

Key words

Cleft lip; Cleft palate; Organisational Policy; Public Health Practice; Regional Health Planning

Introduction

Cleft lip and/or palate (CL/P) are the most common craniofacial malformations affecting humans, with a prevalence of approximately 1:650 live births in Brazil.¹ They present a multifactorial aetiology^{2,3} and occur during the embryonic and early fetal periods, due to failures of fusion among facial processes.⁴

The anatomic deformities more frequent are the discontinuity of the lip, alveolar ridge and palate, which require an appropriate rehabilitation program with surgeries and outpatient assistance.¹

Although there are several treatment protocols for CL/P, the vast majority of them are complex⁵ and very expensive.⁶ The treatments are often long, that is, from childhood to adulthood, requiring specialised centres with interdisciplinary teams.⁵

At present, Brazil has 28 establishments accredited by the Ministry of Health as specialised in the high complexity treatment for CL/P.⁷ Notwithstanding, this treatment remains a great challenge in less developed regions of the country, whether by shortage of centres for craniofacial rehabilitation⁸ or unpreparedness of health teams.⁹

Surprisingly, in the state of *São Paulo*, Brazil, where there are various rehabilitation centres⁷ and formation of qualified manpower for the treatment of CL/P, these patients

Federal University of São Paulo, São Paulo, SP, Brazil

MR TOVANI-PALONE DDS, MSc, PhD(in degree)

A FORMENTON RN, MSc

SR BERTOLINI BSW

Correspondence to: Dr MR TOVANI-PALONE

Email: marcos_palone@hotmail.com

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also face difficulties in obtaining adequate access to health care services.⁹

The explanation for this may lie in the fact that the professional formation aimed at the treatment for CL/P is restricted to a few professionals. Thus, non-specialised health professionals and those specialised in other fields have little or no knowledge on this matter.^{9,10}

This, in turn, may be related to recurrent failures in health assistance by the Brazilian Unified Health System (*Sistema Único de Saúde – SUS*) in establishments of medium complexity that are non-specialised for CL/P, and in basic health units located in the cities of residence.⁹

Moreover, *São Paulo* is the most populous Brazilian state. It has a population estimated at 44 million people¹¹ and around 68,000 individuals with CL/P.

It is worth mentioning that there are two principles of SUS, regionalisation and decentralisation, which regulate the political-territorial organisation processes of this health system.¹²

Regionalisation is a political process, which occurs by relationships established among different social actors (governments, organisations, citizens) in a geographic space without restrictions to its administrative limits, with a very significant intergovernmental interdependence. It considers the geographic concentration of high complexity services, differences in population size and political-institutional conditions of different Brazilian states for the development of regional arrangements for health care. Other objectives include the development of strategies and planning tools, integration, management, regulation, and financing of a network of activities and services in the territory.¹²

Decentralisation is related to the transfer of elements concentrated at the federal level, including the decision-making power, management driven by providers, and financial resources to the states and especially the municipalities. This principle redefines the responsibilities among government entities, highlighting the relevance of subnational executives in the conduct of the health policy.¹²

From these considerations, it is clear that regionalisation and decentralisation can be very important to improve quality of health services for CL/P. However, there are very few information can be found in the literature about the political-territorial organisation of the treatment services for CL/P offered by SUS and/or free of charge in the state of *São Paulo*.

Thereby, this study aimed to investigate the existence of regionalisation of high complexity surgeries and decentralisation of outpatient treatment services for CL/P linked to SUS and/or of philanthropic nature in the state of *São Paulo*, during the period between 2000 and 2015.

Methods

This descriptive and comparative study comprised the identification, location and date of initial accreditation/starting year of existing establishments for the treatment of CL/P in the year 2015 by searches on the National Register of Health Establishments (*Cadastro Nacional de Estabelecimentos de Saúde – CNES*),⁷ National Register of Associations of the PROFIS Network,¹³ free access sites and documents on the Internet. To achieve some data on the starting year of establishments, informational contacts were additionally conducted by phone. The mapping of cities was carried out by searches in the IBGE-Cities database.¹⁴

To compare the specialised centres accredited by CNES and to verify the comprehensiveness of these institutions for surgical procedures of high complexity, secondary data extracted from the Department of Informatics of SUS (*Departamento de Informática do SUS – DATASUS*) were used.¹⁵

The surgical procedures chosen were based on the main primary and secondary surgeries performed routinely by the Hospital for Rehabilitation of Craniofacial Anomalies, University of *São Paulo*, Brazil (*Hospital de Reabilitação de Anomalias Craniofaciais da Universidade de São Paulo, Brasil – HRAC/USP*). These procedures were correlated with the codes of the Management System of the Table of Procedures, Drugs and OPM of SUS (*Sistema de Gerenciamento da Tabela de Procedimentos, Medicamentos e OPM do SUS – Sigtap*).¹⁶

Surgical routine – HRAC/USP:

- Primary cheiloplasty – 3 months of age;¹
- Primary palatoplasty – 12 months of age;¹
- Secondary palatoplasty and cheiloplasty – 6 years of age;¹
- Secondary alveolar grafting – between 9 and 12 years of age.^{6,17,18}

Surgical procedures and codes of the Sigtap:¹⁶

- Unilateral Labiaplasty in two stages: 0404030076;
- Total reconstruction of lip in patient with skull and maxillofacial anomaly: 0404030157;
- Secondary Labiaplasty in patient with skull and maxillofacial anomaly: 0404030122;
- Primary Palatoplasty in patient with skull and maxillofacial anomaly: 0404030106;
- Secondary Palatoplasty in patient with skull and maxillofacial anomaly: 0404030262;
- Alveoloplasty with bone grafting in patients with craniofacial anomaly: 0404030084.

From this, with these procedure codes were performed searches in the periods from January to December 2008

and January to December 2015, based on the number of Authorizations of Hospital Internment (*Autorizações de Internação Hospitalar – AIHs*) approved for each surgical procedure. The data were tabulated using the TabNet program.¹⁵

Moreover, institutions not accredited by CNES as specialised centres for the treatment of CL/P were not included in comparisons regarding AIHs approved for performed surgeries, and in mappings.

This study was approved by the Human Research Ethics Committee of the Federal University of *São Paulo* (*Universidade Federal de São Paulo*) (Nº 1481507).

Results

According to the CNES database (Table 1) there are nine centres accredited as specialised in the high complexity treatment for CL/P in the state of *São Paulo*, located in eight cities. A greater concentration of these institutions was observed in cities located between and along the central region and capital, which have more than half the state's population.¹⁴ Furthermore, the absence of these services in the western, southwest, far south and coast of the state of *São Paulo* was also verified (Figure 1).

Until the year 2000 there were only three accredited

centres. From then on there has been the incorporation of six new centres. The most recent is that of *São José do Rio Preto* (Table 1).

In view of the total of AIHs approved for performing primary and secondary surgeries for rehabilitation of CL/P in accredited centres, it was verified in 2008 and 2015 a much larger number of approved AIHs to HRAC/USP, followed respectively by the Sobrapar Skull and Face Hospital (*Hospital Sobrapar Crânio e Face - SOBRAPAR*) and the Clinical Hospital of the Faculty of Medicine of the University of *São Paulo* (*Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo - HCFMUSP*). The values found to other institutions were quite low, or even null (Table 2).

In order to assist the shortage of specialised services for CL/P, private non-profit organisations such as associations were created, offering technical assistance directly related to rehabilitation in some specialties, as well as social assistance. The so-called regional nuclei have also been created to provide support for the treatment of CL/P through the provision of outpatient services in the fields of medicine, dentistry, speech therapy, psychology and social work, and thus function as support centres to the rehabilitation process.⁹

A higher number and better distribution of parents and friends associations compared to accredited centres was verified (Table 3; Figure 2).

Table 1 Specialised treatment centres for CL/P in the state of *São Paulo* to the year 2015

Accredited centres	Cities	Date of initial accreditation
FUNCRAF - <i>Fundação para Estudo e Tratamento das Deformidades Craniofaciais</i>	<i>São Bernardo do Campo</i>	06/2001
FUNCRAF	<i>Itapetininga</i>	06/2001
HCFMUSP - <i>Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo</i>	<i>São Paulo</i>	09/2003
<i>Hospital de Base de São José do Rio Preto</i>	<i>São José do Rio Preto</i>	12/2013
HRAC/USP- <i>Hospital de Reabilitação de Anomalias Craniofaciais da Universidade de São Paulo</i>	<i>Bauru</i>	09/1993
<i>Hospital São Paulo - Hospital de Ensino Unifesp</i>	<i>São Paulo</i>	01/1997
<i>Santa Casa de Araraquara</i>	<i>Araraquara</i>	11/2007
<i>Santa Casa de Piracicaba</i>	<i>Piracicaba</i>	12/2001
SOBRAPAR- <i>Hospital Sobrapar Crânio e Face</i>	<i>Campinas</i>	09/1993
Total: 9	Total: 8	

Source: Adapted from CNES - Habilitations 0401.⁷

Over the past 15 years there has been the creation of two new associations in the state. However, there is only one nucleus directed to CL/P, located in *Ribeirão Preto* (Table 3).

There are also other institutions for the treatment of CL/P in the state of *São Paulo*, such as *Hospital Municipal Infantil Menino Jesus* and *Hospital Guilherme Álvaro*, located respectively in the cities of *São Paulo* e *Santos*. They are not accredited by CNES as specialised centres for the treatment of CL/P, but offer medium and/or high complexity treatments.^{29,30}

Discussion

The interdisciplinary teams that work in the rehabilitation of CL/P continuously face the psychological, aesthetic and functional implications inherent in this type of malformation. The treatment is highly specialised, requiring teams with professionals from different health fields and integral care for achieving success.³¹ Moreover, serious problems for integral care of individuals with CL/P are the geographical distance and the long duration of treatment for most of the cases, with a very expensive cost especially for the lower social class individuals.³²

According to the results of this study, from 2000 there was a significant increase in the number of high complexity specialised centres for the treatment of CL/P in the state of *São Paulo*, with geographic distribution mainly in regions with high population density. Thus, it is worth mentioning that there were initiatives aiming at the regionalisation of these centres, what is in principle of eminent importance, taking as base the large area of this state, equivalent to 95.839,190 mi².³³

In addition, another data evaluated in this research was the number of AIHS approved for performing of high complexity surgeries for the treatment of CL/P in 2008 and 2015. In this item, HRAC/USP presented a much larger number, compared to the other accredited institutions. Also, it should be noted that, this treatment centre is located in *Bauru*, where there is a lower population concentration than in other regions, such as in *Campinas* and the state capital itself.¹⁴ Consequently, a greater centralisation of high complexity surgeries in HRAC/USP is suggested.

This can be related to the fact that HRAC/USP is the largest treatment centre for craniofacial anomalies in South America and a world class reference in the treatment of CL/P. It performs all the surgical and outpatient care required for full rehabilitation of individuals with CL/P, especially in the high and medium complexity care levels.

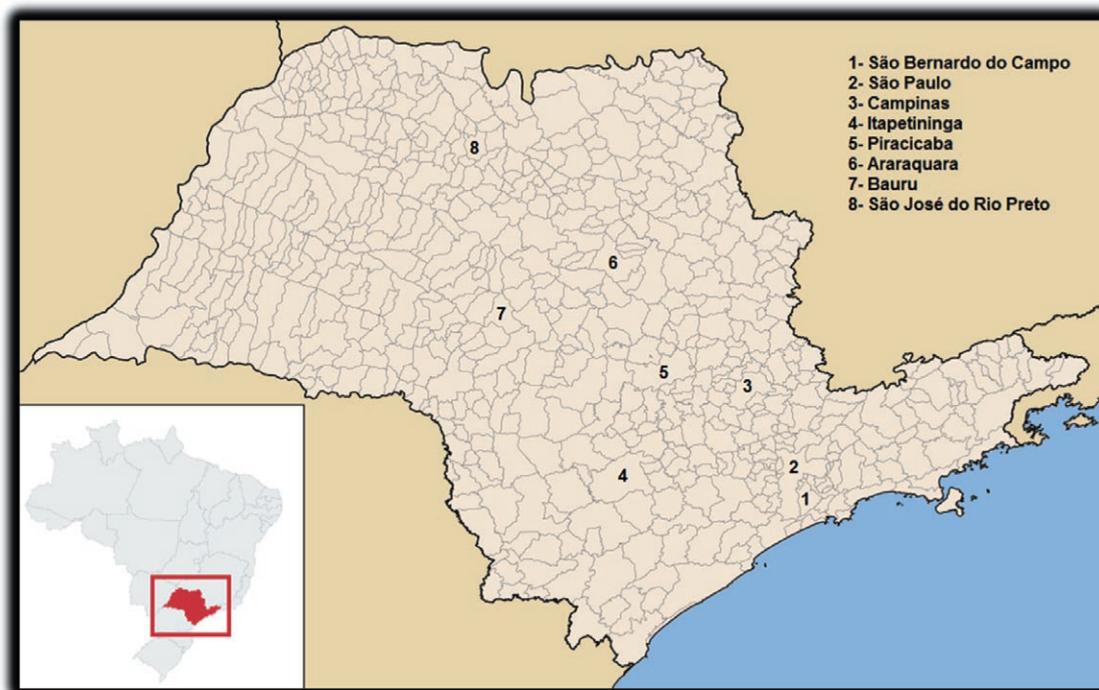


Figure 1 Mapping of cities with centres accredited for the treatment of CL/P in the state of *São Paulo*.

Source: Adapted from IBGE- Cities¹⁴ and Wikipedia.¹⁹

Other important characteristics are its humanistic philosophy, vast experience and the development of relevant researches in the field of CL/P.^{1,34} In addition, HRAC/USP serves patients from all regions of Brazil and others arising from abroad,¹ so that such amount of performed surgical procedures does not reflect in the attendance only of patients from the state of *São Paulo*.

SOBRAPAR and HCFMUSP, in turn, presented considerably smaller numbers of approved AIHs compared to HRAC/USP. However, they also acts as important centres for performing of these surgeries in the state of *São Paulo*.

With the exception of HRAC/USP, SOBRAPAR and the accredited centres of the Foundation for Study and Treatment of Craniofacial Deformities (*Fundação para*

Estudo e Tratamento das Deformidades Craniofaciais - FUNCRAF), the other accredited centres provide assistance for the treatment of several other diseases.³⁵ Three of these institutions performed these surgeries in much smaller scale. Furthermore, some institutions not accredited by CNES as specialised centres for the treatment of CL/P also offer surgical treatments for CL/P,^{29,30} and may contribute to performing of these surgeries in the state of *São Paulo*.¹⁵

In view of the above, it should be emphasized that, there may be benefits associated when the regionalisation of surgeries for craniofacial treatment involve only centres of excellence, such as HRAC/USP.^{34,36} In localities as this, there is probably better surgical results, reduction of operative and postsurgical mortality, reduction of the time

Table 2 AIHs approved for surgical procedures performed by specialised treatment centres for CL/P in the state of *São Paulo* from January to December 2008 and January to December 2015

Accredited centres - 2008	Cheiloplasty			Palatoplasty		Alveolar	Total
	ULTS	TRL	SL	PP	SP	Grafting	
FUNCRAF - <i>São Bernardo do Campo</i>	–	–	–	–	–	–	0
FUNCRAF - <i>Itapetininga</i>	–	–	–	–	–	–	0
HCFMUSP	9	–	15	31	–	13	68
HRAC/USP	–	115	364	862	–	2	1343
<i>Hospital São Paulo - Hospital de Ensino Unifesp</i>	1	–	1	1	–	3	6
<i>Santa Casa de Araraquara</i>	–	–	–	–	–	–	0
<i>Santa Casa de Piracicaba</i>	–	–	–	1	–	1	2
SOBRAPAR	27	–	57	104	–	40	228
Accredited Centres - 2015	ULTS	Cheiloplasty TRL	SL	Palatoplasty PP SP		Alveolar Grafting	Total
FUNCRAF - <i>São Bernardo do Campo</i>	–	–	–	–	–	–	0
FUNCRAF - <i>Itapetininga</i>	–	–	–	–	–	–	0
HCFMUSP	4	3	5	31	6	24	73
<i>São José do Rio Preto Hospital de Ensino Unifesp</i>	1	–	1	2	1	–	5
HRAC/USP	55	106	82	427	144	33	847
<i>Hospital São Paulo - Hospital de Ensino Unifesp</i>	2	–	1	5	4	1	13
<i>Santa Casa de Araraquara</i>	–	–	–	–	–	–	0
<i>Santa Casa de Piracicaba</i>	–	–	–	1	–	–	1
SOBRAPAR	52	–	29	42	21	49	193

ULTS=Unilateral Labiaplasty in two stages; TRL=Total reconstruction of lip; SL=Secondary Labiaplasty; PP=Primary Palatoplasty; SP=Secondary Palatoplasty.

Source: DATASUS.¹⁵

of stay in hospitals and greater access to provide more comprehensive care, due to the multidisciplinary and interdisciplinarity character of the teams working for this purpose.³⁶ This is quite relevant because work performed well does not generate further work, readmissions and so many other unnecessary procedures.

Another point is that, there are also problems in the work process and organisation of the reference and counter-reference system that impede the continuation of the treatment of individuals with CL/P. The treatment is frequently fragmented, with focuses on healing practices and restricted to specialised centres in the field.³²

Thus, ideally, insofar as specialised professionals are not required in all locations, but all individuals with CL/P should have access to the specialists and equipment when needed; the patients should, then, be forwarded from a service that performs certain healthcare to another more complex when required (reference), that is, in treatments requiring different

levels of attention as in the case of CL/P. When the requested treatment has been performed, the patient should then be redirected back to the health service of origin (counter-reference) with a lower complexity.³²

A further problem is that there is unpreparedness of the public health services or even total ignorance of professionals regarding the care of monitoring and maintenance, even if basic, for these individuals in primary and secondary attention, not specific for CL/P.⁹ The cause may be directly related to the absence of this theme in the curriculums of undergraduate and postgraduate courses in health across the country. It is worth highlighting that, at postgraduate level, only HRAC/USP offers effective and humanised courses about CL/P, whether as an improvement, specialisation, master's, doctoral or postdoctoral.¹

In this context, associations and nuclei for the treatment of CL/P are very important, because in addition to providing knowledge of the peculiarities of CL/P and of the

Table 3 Associations and support nucleus for the treatment of CL/P in the state of *São Paulo* to the year 2015

Associations	Cities	Starting year
Metamorfis (quondam <i>Vaso Novo, Vida Nova</i>)	<i>São Paulo</i>	1998
AFIPP - <i>Associação de Apoio ao Fissurado Lábio Palatal de Presidente Prudente e Região</i>	<i>Presidente Prudente</i>	2000
AAFLAP - <i>Associação de Apoio aos Fissurados Lábio Palatais</i>	<i>Sao José dos Campos</i>	1987
AFISC- <i>Associação de Apoio aos Fissurados Lábio Palatais de São Carlos</i>	<i>São Carlos</i>	1984
APAFI-MC - <i>Associação de Pais e Amigos dos Portadores de Fissuras Lábio Palatais de Mogi das Cruzes</i>	<i>Mogi das Cruzes</i>	1993
PROFIS - <i>Associação de Promoção do Fissurado Lábio Palatal</i>	<i>Catanduva</i>	1992
ADAF - <i>Associação dos Deficientes Auditivos e Fissurados</i>	<i>Ribeirão Preto</i>	1995
ADAP - <i>Associação dos Deficientes Auditivos, Pais, Amigos e Usuários de Implante Coclear</i>	<i>Bauru</i>	1998
AFISSORE - <i>Associação dos Fissurados Lábio-Palatais de Sorocaba e Região</i>	<i>Sorocaba</i>	1989
AFISFRAN - <i>Associação dos Fissurados de Franca</i>	<i>Franca</i>	1993
CAPI - <i>Centro de Amparo e Proteção à Infância São Francisco de Assis</i>	<i>São Paulo</i>	1986
PROFIS - <i>Sociedade de Promoção Social do Fissurado Lábio Palatal</i>	<i>Bauru</i>	1975
<i>Recém Sorrindo</i>	<i>Pindamonhangaba</i>	2012
Total: 13	Total: 11	
Nucleus	City	Starting year
NADEF - <i>Núcleo de Assistência à Pessoa com Deficiência</i>	<i>Ribeirão Preto</i>	1994
Total: 1	Total: 1	

Source: PROFIS Network,¹³ Metamorfis,²⁰ AFIPP,²¹ AAFLAP,²² Municipal Prefecture of *São Carlos*,²³ APAFI-MC,²⁴ ADAP,²⁵ AFISSORE,²⁶ PROFIS-Bauru,²⁷ *Recém Sorrindo*,²⁸ contacts by telephone.

rehabilitation process to patients and families, many of them have their own supplementary assistance services⁹ in 11 cities spread in several regions of the state. However, there is not the availability of all ancillary services for primary and medium complexity care in all units, not even a broad coverage to the demand for treatment. Moreover, the state of *São Paulo* has one regional nucleus, which together with the associations and other institutions not accredited by CNES as specialised centres for the treatment of CL/P may contribute to the decentralisation of outpatient treatment services for CL/P in this state.

It should be noted also that the accredited centres of FUNCRAF do not perform high complexity surgical procedures, such as primary and secondary surgeries for CL/P. They correspond to outpatient units of high and medium complexity care and primary care under the responsibility of FUNCRAF,⁹ which are designed to minimise the problem of displacement and long trips of patients and contribute to the continuity of the treatment. Their current locations in the state of *São Paulo* are in the cities of *Itapetininga* and *São Bernardo do Campo*.³⁷

Furthermore, decentralisation to health units of SUS including both the basic and the specialised assistance that are non-specific for CL/P, as is the case of the Medical

Ambulatories of Specialties (*Ambulatórios Médicos de Especialidades*)³⁸ and Centres of Dental Specialties (*Centros de Especialidades Odontológicas*)³⁹ existing in the state of *São Paulo*, would be possible to be carried out, since improvements were incorporated into the reference and counter-reference system, as well as to the expansion of theoretical/practical basic training courses on additional peculiarities of these anomalies for health teams.

Limitations of the Study

The accredited centres can have used other procedure codes for cheiloplasty, palatoplasty and alveolar grafting performed, which were not included in this research. We therefore can not make any kind of statement about the exact total number of surgeries performed in each institution, limiting us only at inform the number of AIHs approved available on the DATASUS database for performed surgeries whose procedure codes were used in our searches.

Further studies should be carried out to verify the feasibility or not to the current political-territorial organisation of the surgical and outpatient services for CL/P in the state of *São Paulo*.

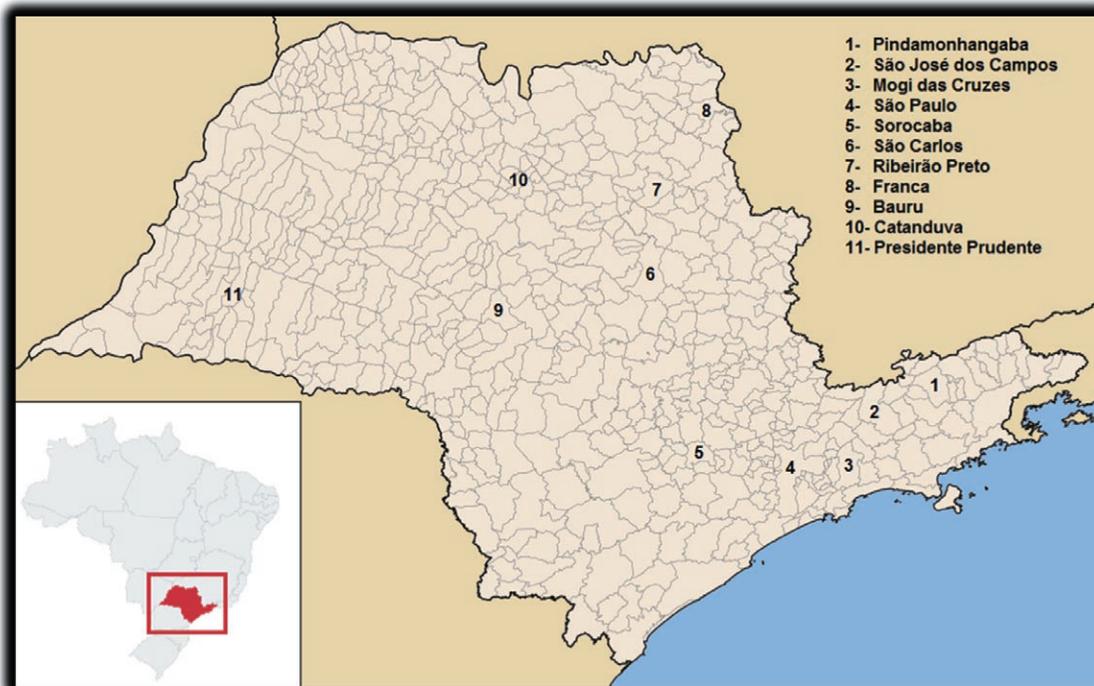


Figure 2 Mapping of cities with associations and nucleus for the treatment of CL/P in the state of *São Paulo*.

Source: Adapted from IBGE-Cities¹⁴ and Wikipedia.¹⁹

Conclusion

Despite the creation of new specialised centres for the treatment of CL/P in the state of *São Paulo*, there are still indications of the occurrence of centralisation of high complexity surgeries for the treatment of CL/P, which are performed mostly by the Hospital for Rehabilitation of Craniofacial Anomalies, University of *São Paulo*, while for outpatient services a trend toward decentralisation was observed.

The matter regarding CL/P should be incorporated in the curriculum of undergraduate health field courses. The training courses for SUS professionals need to be expanded to decentralise part of the activities of CL/P for basic health units and specialised health centres that are non-specific in this field. Thus, confirming the improvement in the quality of life of patients and their families with lower costs to them as well as the government.

Note

All words in italics are written in Portuguese.

Declaration of Interest

The authors report no declaration of interest.

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