



Treatment of Nonsyndromic Cleft Lip and/or Palate in Brazil: Existing Consensus and Legislation, Scope of the Unified Health System, Inconsistencies and Future Perspectives



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Abstract

Cleft lip and/or palate (CL/P) are the most prevalent craniofacial birth defects in humans, affecting around ten and a half million people across the world and over three hundred thousand in Brazil. Of that, about 70% of the cases occur as a nonsyndromic form, while the remaining 30% are syndromic. In turn, individuals with nonsyndromic CL/P (NSCL/P) often have anatomic deformities involving the lip, alveolar ridge and palate. In this case, the treatments generally require multiple surgeries and various other health interventions throughout childhood, adolescence and adulthood. Another relevant point is that various problems regarding the treatment of NSCL/P in Brazil through the Unified Health System (SUS) have been reported. There are also many inconsistencies in this scenario, including the

territorial coverage of healthcare assistance from the craniofacial centres across the country. However, very little data can be found in the scientific literature about the current situation for the treatment of NSCL/P in Brazil. Thus, the present article discusses the existing consensus and legislation, the scope of the SUS, as well as inconsistencies and future perspectives related to the treatment of these craniofacial abnormalities at a national level.

Introduction

One of the most common birth defects of the head and neck are the cleft lip and/or palate (CL/P). Such malformations affect approximately 1 in 700 live births worldwide, representing a major public health burden. The related etiology is complex and multifactorial, and is associated with an interaction between genetic and environmental factors (Freitas et al. 2012). In this context, there are contributions from several genes together with inadequate nutrition, use of some medications, exposure to ionizing radiation, viral infections, smoking, alcoholism, pesticides in food and physical or mental stress (Freitas et al. 2012; Tovani-Palone and Saldias-Vargas 2016).

It should be noted that about 70% of CL/P cases occur as a nonsyndromic form, without association to syndromes or malformations. The remaining 30% appear as a syndromic form, which are associated with genetic disorders (Mendelian or chromosomal), teratogenic and sporadic conditions (Freitas et al. 2012). These syndromic characteristics can interfere with the offered treatment, requiring higher demands and complexity for the healthcare.

In turn, individuals with nonsyndromic CL/P (NSCL/P) often have anatomic deformities involving the lip, alveolar ridge and palate. Treatments generally require multiple surgeries (Freitas et al. 2012; Palone et al. 2015; Tovani-Palone et al. 2017) and various other health interventions throughout childhood, adolescence and adulthood (Freitas et al. 2012).

Another aspect that is very important is that various problems regarding the treatment of NSCL/P in Brazil through the Unified Health System (*Sistema Único de Saúde – SUS*) have been reported. There are also many inconsistencies in this scenario, including the territorial coverage of healthcare assistance from the craniofacial centres across the country (Tovani-Palone et al. in press).

Notwithstanding, there are still very few data available in the scientific literature about the current situation for the treatment of NSCL/P in Brazil. Thus, this article discusses the existing consensus and legislation, the scope of the SUS, as well as inconsistencies and future perspectives related to the treatment of these craniofacial abnormalities at a national level.

Consensus about the Need for Comprehensive Treatment of Individuals with NSCL/P

In 2002, groups of professionals of renowned centres for rehabilitation of individuals with CL/P, from all over the world, gathered in Geneva (Switzerland) with the support of the World Health Organization (WHO 2004).

On this occasion, they discussed new global strategies aiming to promote advances in offered treatments. The various adopted recommendations recognized the need for improvements in the quality of services for the treatment of NSCL/P, with a focus on the development of methodologies for monitoring and identification of strategies that maximize the healthcare access to appropriate levels (WHO 2004).

Several Brazilian authors (Custódio 2013; Freitas et al. 2012; Raposo-Amaral and Raposo-Amaral 2012), furthermore, have reinforced the need for multidisciplinary care for the treatment of individuals with NSCL/P as a strategy to promote improvements in the quality of life of this population group. In their view, healthcare must always be comprehensive, contemplating guidelines, reconstructive surgeries and various other procedures, such as orthodontics and speech therapy.

Legislation for the Treatment of NSCL/P in Brazil

Currently, in Brazil there is still no specific legislation for the composition of healthcare teams and of their organizational model (if they are multidisciplinary, interdisciplinary, transdisciplinary or isolated).

However, the Ordinance SAS/MS n. 62/1994 of the Secretary of Health Care and Ministry of Health determines that all accredited hospitals performing integrated procedures for aesthetic and functional rehabilitation of individuals with NSCL/P should provide the following services: anesthesia, aesthetic and reconstructive plastic surgery, otorhinolaryngology, internal medicine, pediatrics, speech therapy, psychology, physiotherapy, nursing, social service, nutrition, general dentistry, pediatric dentistry, orthodontics, prosthodontics and implantology, oral and maxillo-facial surgery, and family care (Tovani-Palone and Bertolini 2017).

Scope of the SUS for the Treatment of NSCL/P in Brazil

At present, healthcare in the SUS is divided into three hierarchical levels: high complexity, medium complexity and basic health attention (Custódio 2007, 2013). It is thus important to discuss the actions for the treatment of NSCL/P in this arrangement.

The high complexity level refers to the set of procedures in the context of the SUS, which involve high technology and high cost.

Its aim is to provide access to qualified services for the population, integrating them with other healthcare levels of this system. The procedures for the treatment of NSCL/P are contemplated in this care level (Custódio 2007, 2013) and they correspond to the specialized and specific procedures that are performed in outpatient and/or hospital regimen, especially surgical procedures (cheiloplasty, palatoplasty and alveolar graft).

The medium complexity level, in turn, comprises actions and services aimed at solving various problems and health disorders. To this end, the complexity of care in clinical practice involves the availability of trained professionals, as well as the use of technological resources to provide diagnosis and treatment. In this case, the treatment of NSCL/P is achieved through outpatient surgeries, actions in dentistry and speech-language therapies, prosthesis and orthosis, clinical pathology, anatomopathology and cytopathology, radiodiagnosis, anesthesia, diagnosis, physiotherapy, nutritional and psychological care (Custódio 2007, 2013).

In addition, the other care level, basic health attention, represents the first level of care in SUS (preferred contact of the users). It is guided by all the principles of this system, however, using low-density technology (Custódio 2007, 2013). Several actions can be performed for the treatment of NSCL/P in basic health attention, such as primary dental treatment, pediatric monitoring, periodic assessments of general health, treatment of recurrent diseases (recurrent otitis) and social assistance.

In view of all this, the implementation of Healthcare Networks would seem essential. According to the SUS legislation, such Networks are defined as organizational arrangements of health actions and services, with different technological densities, that are integrated through technical support systems, logistics and management intended mainly to provide guaranteed comprehensive care (Brazilian Ministry of Health 2010).

Consensus about the Political-Territorial Organization of the Craniofacial Centres in Brazil

Another very relevant point of concern to the authorities is the political-territorial organization of the craniofacial centres in Brazil.

According to Trettene et al. (2014), there has been a decentralization trend of outpatient services for the treatment of NSCL/P in the country. They also highlight the need for dissemination of knowledge about post-operative care to health professionals in general. This is because sometimes without assistance in their home cities, individuals with NSCL/P and their families encounter difficulties with care of possible post-operative complications.

Moreover, Custódio (2007) has stated that the existing program of decentralization of services of the Hospital for Rehabilitation of Craniofacial Anomalies of the University of Sao Paulo – Brazil (*Hospital de Reabilitação de Anomalias Craniofaciais da Universidade de São Paulo – HRAC/USP*) has over the years involved several actions, such as the creation of subcentres, nuclei and associations for treatment of NSCL/P. Their objectives have been to facilitate patients' access to the health services in their home cities, so that the demand for care in HRAC/USP decreases, along with the geographic, financial and social difficulties of many of these patients.

In an interview in 2010, Capelozza Filho defended the existence of multidisciplinary centres for the treatment of NSCL/P distributed in strategic areas, as consistent protocols are respected (Capelozza Filho 2010). Raposo-Amaral and Raposo-Amaral (2012) have suggested more guidelines to consolidate the centres for treatment of NSCL/P in Brazil based on the planned geographic distribution across the country, i.e., the regionalization of the specialized comprehensive treatment centres.

Therefore, both the effective regionalization of high complexity treatment services and decentralization of outpatient treatment services for individuals with NSCL/P are issues of great interest for all regions of Brazil. This is because there are large geographical distances and long durations of treatment for most of the cases that often come at a very expensive cost to the patients and/or their families, making comprehensive treatment very difficult to obtain (Tovani-Palone et al. in press).

Inconsistencies and Future Perspectives for the Treatment of NSCL/P in Brazil

Recently, even with the creation of health policies for the treatment of NSCL/P (Tovani-Palone and Bertolini 2017) and implementation of Telemedicine in this field (Custódio 2013), health services and institutions have not been organized in conformity with two of the principles of SUS, regionalization and decentralization. A significant example of this is what happens in the state of Sao Paulo, considered the richest and most populous of the nation, with indications of centralization of high-complexity surgeries for the treatment of NSCL/P and only a trend toward decentralization of outpatient services (Tovani-Palone et al. in press).

In this sense, it is also important to point out that HRAC/USP (located in the city of Bauru in the state of Sao Paulo) is the largest craniofacial centre in Brazil, and it was the Brazilian establishment that assisted a higher number of patients with NSCL/P in the recent years (Tovani-Palone et al. in press). The attended patients came from all five regions of the country (Freitas et al. 2012).

In contrast, in 2017 members of the University of Sao Paulo (USP), including the Rector and the Superintendent of HRAC/USP, together with politicians, negotiated the transfer of management of HRAC/USP, as

well as a new building of this hospital, to the State Health Secretariat of Sao Paulo. The new building was completed about five years ago and had been intended to be put to use to expand the physical structure of HRAC/USP. Now, however, it will be to set up as a general tertiary hospital. Therefore, from 2018 the contribution of resources to maintain the activities and new hires to HRAC/USP and the new general hospital will be under the responsibility of the State Government and not USP. In both health institutions, the University will only do the academic management. (Assessoria de Imprensa HRAC/USP 2017). I believe that all these changes could affect the quality and maintenance of the service provided by HRAC/USP as well as limit the assistance of new cases.

From that, an important issue arises: Is an immediate regionalization policy to delimit the territorial area for coverage of healthcare assistance from each of the craniofacial centres of Brazil a good option at this time?

I do not think so, because this can result in negative consequences to many patients, including the possibility of discontinuation of treatment for those depending on healthcare assistance from HRAC/USP. First, new specific rules for the organization and operation of craniofacial centres, as well as effective health policies for the treatment of NSCL/P, should be implemented in practice. This is necessary because, although the number of centres accredited by the National Register of Health Establishments as specialized in high complexity treatment for individuals with NSCL/P has increased over the years, several of them provide very few surgical procedures of high complexity or even none at all (Tovani-Palone et al. in press).

It is important that all of these craniofacial centres could, in fact, offer comprehensive care for the treatment of NSCL/P. Other than that, many of them need improvement in their service quality. Thus, the new rules and health policies for the treatment of such

craniofacial malformations should take into consideration mainly these two aspects.

Other measures, such as the incorporation of NSCL/P issues in the curriculum of undergraduate health courses, and the expansion of treatment of these anomalies to specialized care centres for the general population, as well as to the basic health units, are also fundamental actions to be carried out. Thereby, together with improvements in the work process and organization of the reference and counter reference system, they may contribute to the decentralization of outpatient treatment services for individuals with NSCL/P (Tovani-Palone et al. in press). This would lead to advances in the effectiveness of Healthcare Networks.

However, it is worth stressing that such expansion of treatment would only be viable/possible after adequate training of the professionals of SUS to attend the needs of the public, in order to satisfactorily provide both medium complexity healthcare and basic assistance.

In conclusion, new studies should be conducted periodically to verify the impact of the distribution of treatment services for individuals with NSCL/P and their coverage throughout the country, beyond the occurrence of changes in this scenario and their implications. Information of this type may undoubtedly help in health planning aiming to improve the quality of life of this population group.

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