Rethinking health care provision for individuals with cleft lip and palate in the Brazilian Unified Health Care System

Paola Calvasina[1] (Orcid: 0000-0003-0356-6205) (paola.calvasina@ufc.br)

[1] Universidade Federal do Ceará. Fortaleza-CE, Brazil.

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The cleft lip and palate (CLP) is the most prevalent craniofacial anomaly in the population, with a prevalence of approximately 0.45 per thousand live births (Salari *et al*., 2022). In Brazil, the prevalence is 5.86 (Sousa; Roncalli, 2017). This condition results from failures in the fusion of embryonic facial processes in the early weeks of intrauterine life (Dixon *et al*., 2011), potentially affecting the lip, palate, or both. The etiology of CLP involves the interaction of genetic, syndromic, or environmental factors (Vyas *et al*., 2020). Among environmental factors, notable ones include smoking, alcohol consumption, malnutrition, hormonal disorders, and medications. Children affected by CLP may develop problems in speech, hearing, dentition, and nutrition, as well as emotional and social issues (Dixon *et al*., 2011).

In Brazil, healthcare professionals, researchers, and families have long advocated for the inclusion of craniofacial anomalies in public health policies (Monlleó; Silva-Lopes, 2006). Within the Unified Health System (SUS), this persistent advocacy effort began in 1993 with the introduction of procedures for correcting CLP in the Hospital Information System (SIH/SUS) table (Brasil, 1993). Subsequently, Ordinance No. 62 was published on April 19, 1994, establishing norms for the registration of hospitals and rehabilitation services in this field (Brasil, 1994). In

1998, the Ministry of Health established the Reference Network for the Treatment of Craniofacial Deformities (RRTDCF), aimed at reducing inequality in access and organizing service delivery within the Unified Health Care System (SUS) (Brasil, 1999). Building upon these efforts, in 2013, the Ministry of Health formed a Working Group dedicated to CLP and set the goal for 2014 to conclude the restructuring of specialized care, implementing criteria for the organization of this care, along with specific guidelines (Brasil, 2004). These objectives remained focal points in the Management Reports for the years 2015 and 2016 (Brasil, 2014, 2015).

However, since then, governmental actions in this area have been limited to the expansion of cleft lip and palate (CLP) rehabilitation services in the country. Currently, the RRTDCF comprises 33 centers accredited by the Ministry of Health for CLP treatment: six in the Northeast region, six in the Midwest region, 13 in the Southeast region, seven in the South region, and one in the North region of Brazil (Brasil, 2023). These treatment centers adopt care protocols based on American guidelines, which recommend that the first lip closure surgery be performed within the child's first 12 months, while palatal closure surgery should occur before the child reaches 18 months of age (ACPA *et al*., 2009; Queirós *et al*., 2013). Timely and appropriate treatment helps prevent long-term sequelae in adult life (Monlleó; Silva-Lopes, 2006).

In recent decades, there has been a growing interest in studying the care provided to individuals with CLP within the SUS (Unified Health System) in Brazil. Initially, Monlléo and Silva-Lopes (2006) assessed 29 centers offering services for craniofacial anomalies, noting a concentration of these services in the Southeast region. Subsequent studies: 1) analyzed the socio-historical context surrounding the establishment of a center for individuals with CLP in the Brazilian Northeast (Chaves; Silva; Almeida, 2016); 2) proposed an evaluative model aligned with SUS principles for rehabilitation centers (Almeida *et al*., 2017); 3) applied this model to assess a reference service in Bahia (Almeida; Chaves, 2019); 4) investigated the correlation between the prevalence of live births with CLP and the number of corrective surgeries performed within the SUS (Sousa; Roncalli, 2017); and finally, 5) evaluated the delay in primary surgical treatment for newborns in Brazil (Sousa; Roncalli, 2021).

These studies concluded that despite the expansion of care for individuals with CLP within the SUS, the response remains fragile (Monlléo; Silva-Lopes, 2006;

Chaves; Silva; Almeida, 2016; Almeida *et al*., 2017; Almeida; Chaves, 2019; Sousa; Roncalli, 2017; Sousa; Roncalli, 2021). The low coverage of surgical procedures to treat CLP (18.9%) (Sousa; Roncalli, 2017) and a delay of over 66% in surgical treatment, with worse percentages in the North and Northeast regions (Sousa; Roncalli, 2021), indicate significant challenges. Additionally, the fragmentation and discontinuity in the rehabilitation care of these patients (Sousa; Roncalli, 2017) compromise the quality of care, potentially leading to irreversible sequelae for these individuals. This study contributes to the discussion on the regionalization/decentralization of health care services for individuals with CLP within the SUS, using the state of Ceará as an illustrative example.

Based on my experience in formulating and implementing the care pathway for individuals with CLP in the state of Ceará, I offer insights into the challenges and opportunities associated with operationalizing this network within the Brazilian Unified Health System (SUS). Notably, the state has a comprehensive outpatient/specialized network consisting of five hospitals, 22 Regional Specialized Health Clinics, known as Polyclinics, and 22 Regional Specialized Dental Care Centers (RSDCCs), serving as pivotal references for health regions (Ceará, 2019).

While this analysis emphasizes the situation in the state of Ceará, the insights presented in this essay can be applied to other regions, as they reevaluate the care provided to individuals with CLP, particularly within the SUS. This care is often provided by philanthropic organizations, whether contracted by the SUS or operating independently.

Regionalized and integrated networks provide a more suitable framework to ensure comprehensive healthcare, thereby reducing service costs through a more rational utilization of resources (Sousa; Roncalli, 2021). Consequently, each node within the health care network assumes specific functions along the continuum of care. Primary Health Care should: 1) focus on preventing and promoting the health of children and families with CLP, including investigating family history, providing prenatal consultations for expectant mothers, and offering guidance on infant feeding practices; 2) actively identify initial cases and address treatment discontinuation; and 3) deliver prenatal/pediatric dental care and oral health support (Ceará, 2022).

Outpatient/specialized dental care should provide specialized assistance in the specialties offered by RSDCCs (such as endodontics, periodontics, and dental care for people with special needs among others), including orthodontic treatment.

Other services that offer specialized outpatient care healthcare services in a regionalized manner, such as Polyclinics, or even Specialized Rehabilitation Centers (SRCs) integrated into the healthcare network for people with disabilities, would be responsible for rehabilitative treatment (Ceará, 2022).

Hospital care comprises a multidisciplinary team, including healthcare professionals in areas such as anesthesiology, dentistry, nursing, orthodontics, pediatrics, psychology, speech therapy, surgery, and genetics. These professionals are responsible for both pre-operative and post-operative care of patients. Additionally, this team is tasked with training professionals in health regions, implementing inter-provider communication support strategies for Primary and outpatient/specialized Care professionals in the cleft care pathway; thus, ensuring comprehensive care closer to users (Ceará, 2022).

In Ceará, as in other states of the federation, the usual treatment of patients with CLP is carried out in a centralized manner at the Albert Sabin Children's Hospital (HIAS), the only unit accredited in the RRTDCF in the state. In addition to surgical procedures, HIAS houses the Comprehensive Care Center for Individuals with CLP (Known as NAIF, in Portuguese), comprised of psychologists, speech therapists, social workers, nutritionists, nurses, general practitioners, dentists, pediatric dentists, and orthodontists. This center conducts pre-operative and post-operative consultations, dental and orthodontic treatment (Batista, 2022). Patients from various regions of the state of Ceará are assisted by a single centralized service in the capital, with some traveling over 596 km, an unfeasible situation for children who sometimes require speech therapy rehabilitation at least twice a week.

In this context, the rehabilitation care structure has been regionalized through coordination with regional specialized state services. The Regional Dental Specialty Centers (RDSCs) provide services in all specialties outlined in the National Oral Health Policy (PNSB), along with orthodontics. Additionally, polyclinics have multidisciplinary teams, including social workers, nurses, speech therapists, and psychologists. Furthermore, the state also has four Specialized Rehabilitation Centers (SRCs) (Ceará, 2021).

The NAIF, in collaboration with the Health Department of Ceará, implemented a training program for professionals in a macro-region. This initiative enabled Regional Dental Specialty Centers (RDSCs), polyclinics, and Primary Health Care Services (PHC) to take on the rehabilitation of CLP patients, with inter-

provider communication support from the NAIF team. Consequently, patients who underwent surgical procedures were subsequently referred to healthcare professionals in their respective health regions.

Several challenges persist in consolidating the regionalization of cleft lip and palate (CLP) care pathways in the state. These include: 1) High turnover of Primary Health Care (APS) professionals, due to precarious contracts, hindering community engagement; 2) Rotational issues among healthcare professionals in CEOs and polyclinics, often on temporary contracts lasting two years; 3) Ongoing qualification processes required for the other four health regions of the state; 4) Implementation of continuous education programs for the CLP care pathway, with designated hours for the NAIF team to conduct statewide educational activities; 5) Strengthening employment ties for NAIF professionals, currently contracted through a cooperative; 6) Regionalization of CLP care centers, including maxillofacial/plastic surgeons and multiprofessional support, particularly for health regions further from the capital.

It is important to note that the organization of cleft lip and palate (CLP) services varies significantly among countries. While Scandinavia adopts a centralized specialized model, countries like Italy, Germany, and Switzerland provide care across numerous services with a small number of cases (WHO, 2022). In the 1990s, England chose to reduce regional centers after a national survey revealed that less than 10% of cleft surgeons in the UK handled five or more cases per year, with most being unaware of the quality of their outcomes (Colbert *et al*., 2015). Presently, British services are structured into managed networks of clinics, overseen by a clinical director and supported by a coordinator or manager, managing a minimum of 80 to 100 babies per year. These clinics also include multidisciplinary teams that monitor patients through their growth and development into adulthood (Colbert *et al*., 2015).

In the Brazilian context, further studies are necessary to analyze the CLP care pathway and explore opportunities for enhancing this care within the Unified Health System (SUS). National evaluative research of these centers should include input from professionals, managers, and users, as well as chart audits and analysis of clinical outcomes in treated patients. The findings of these studies should inform the revision of Ordinance No. 62/94, which currently focuses solely on authorizing services based on the performance of a minimum of ten surgeries and the presence of a multidisciplinary team.

The new ordinance should establish a regionalized framework for the care network of individuals with cleft lip and palate (CLP), utilizing criteria based on epidemiological prevalence. It should offer guidance on the optimal number of surgeries per rehabilitation center, establish referral and counter-referral protocols to rehabilitation clinics within the SUS, and facilitate coordination with existing policies and health care networks, such as maxillofacial services in hospitals, specialized dental care services, polyclinics, and rehabilitation centers.

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