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ORIGINAL ARTICLE

Epidemiological and healthcare access profiles of children and adolescents with cerebral palsy in a municipality in the Brazilian state of Espírito Santo

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cerebral palsy, health services accessibility, adolescent, child care

Abstract

Objective: To analyze the epidemiological profile and the access to multidisciplinary healthcare of children and adolescents with cerebral palsy (CP) seen at a hospital in the Brazilian State of Espírito Santo. **Method:** This descriptive quantitative observational cross-sectional study included 30 children and adolescents with CP aged 19 years and younger seen at a pediatric hospital. The subjects were interviewed for data on pre-, peri-, and post-natal life, access to healthcare, and availability of a multidisciplinary team at the time of diagnosis of CP and during the interview. **Results:** Most of the included patients were males (n=22; 73.3%) coming from low-income households (n=21; 70.0%). Twenty-eight (93.3%) had their mothers as primary caretakers. Eight (26.7%) were born prematurely, 12 (40.0%) had low birth weight, and six (20.0%) had neonatal asphyxia. Many patients did not have access to healthcare for a number of reasons, including long waiting lines, lack of or insufficient healthcare staff, lack of referrals, and trouble transporting patients. **Conclusion:** It is important to have organized teams and take all aspects of care into account to ultimately improve the quality of healthcare provided to the studied population.

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INTRODUCTION

The National Health System (SUS, Brazilian acronym) was established to promote social justice and overcome issues linked to providing healthcare to the Brazilian population. However, Brazil is fraught with inequalities in other areas such as housing, employment, education, healthcare, and income. These factors have direct impact on the lives of people and individuals with disabilities in particular, on their health status and exposure to disease.^{1,2}

Cerebral palsy is the main cause of disability in childhood that persists to adult age. Various factors have been associated with the origin of the condition, including prenatal, perinatal, and postnatal factors; extent of brain injury and affected areas, which by their turn produce sequelae and the limitations experienced by patients with cerebral palsy.^{3,4}

The global incidence of CP has been estimated at 1.5-5.9 cases per 1,000 live births in developed nations and seven cases per 1,000 live births in developing nations. Few studies have looked into the prevalence of CP in Brazil. However, based on the rates observed in developing nations, an estimated 30,000-40,000 new cases of CP are seen in the nation every year.^{5,6,7}

In 1893, Sigmund Freud identified three groups of factors connected to CP: prenatal (before birth), perinatal (from the start of delivery to six hours after birth), and postnatal (after birth and into childhood). They include asphyxia during delivery, preterm birth, low birth weight, stroke, prenatal infection, meningitis, encephalitis, nervous system anomalies, seizures, kernicterus, trauma, infection, drug abuse during pregnancy (alcohol, tobacco, other drugs).^{4,8,9,10,11,12}

The factors potentially connected to CP are directly affected by the conditions of intrauterine fetal life, prenatal conditions, and the effects derived from unequal access to healthcare in the form of delivery of inferior care, trouble scheduling visits, and obstacles to ordering tests.^{1,7,12,13,14,15}

Patients with CP may suffer from mild to severe sequelae covering a wide array of motor, behavioral, learning, intellectual, visual, auditory, and overlapping disorders, which by a greater or lesser degree limit their ability to perform activities of daily living such as feeding, bathing, handling objects, walking, changing clothes, and studying. A multidisciplinary care team should also follow individuals with CP in order to minimize the effects of the sequelae and limitations affecting them.^{16,17}

Availability and knowledge of pre-, peri-, and postnatal care and of rehabilitation to individuals with CP is a prerequisite to identify gaps in care and required interventions.

This study aimed to describe the epidemiological and healthcare access profiles of children and adolescents with CP seen at a non-profit hospital in southern Espírito Santo, Brazil, so as to provide input to initiatives devised to decrease the incidence of a condition that poses a significant burden on patient families and puts a significant strain on municipal, state, and federal funding.

METHOD

Guardians and parents of children and adolescents with cerebral palsy were invited to join the study. The Research Ethics Committee of the School of Sciences of Santa Casa de Misericórdia in Vitória approved the study and issued certificate no. 1.865.032. The study complied with the guidelines of the Regulations for Research with Human Subjects contained in Resolution 366/12 of the National Board of Health of the Ministry of Health.

The purposes of the study were explained and read to the guardians and parents of the patients before they consented to participating in the study.

The descriptive and observational elements of the study derive from the fact that data points were systematically collected, while its cross-sectional nature stems from the fact that the data points were collected at a specific moment in time to describe children and adolescents with cerebral palsy aged 19 and younger seen at a non-profit pediatric hospital in southern Espírito Santo, Brazil. The data from 30 children and adolescents with CP aged 19 years and younger residing in the municipality of Cachoeiro de Itapemirim seen at a hospital from May 2016 to August 2017 were analyzed. Individuals aged <10 years were categorized as children, whereas subjects aged between 10 and 19 were categorized as adolescents in accordance with criteria set out by the World Health Organization (WHO).

Patients originally included in the study that had to be hospitalized again at the same hospital or lodged in shelters were excluded. The endpoints of the study listed in the data collection instrument (APPENDIX A) were sorted into the following groups:

I - Children and adolescents with CP: name, chart number, date of birth, sex (male/female), age, skin color (white/brown/black).

II - Parents/guardians of children and adolescents with CP: name; age; sex (male or female); skin color (white, brown, black); education (elementary school, middle school, high school, vocational school, higher education); occupation (job and compensation); municipality of residence; religion (catholic, evangelical, other); housing conditions; mode of transportation used to go to hospital; enrollment in government social programs; individuals in the household playing the roles of caretaker and provider; and number of individuals living in the household. Categories skin color; sex; marital status; education; and religion were described as per the terms defined by the Brazilian Institute of Geography and Statistics (IBGE, Brazilian acronym).

The Brazilian Economic Classification Criteria (Associação Brasileira de Empresas de Pesquisa, 2015) were used to describe the socioeconomic status of patients and their families. Participant answers were assigned scores and added up to reflect their socioeconomic status within the following categories or classes: Class A (42-100 points), Class B1 (38-44 points), Class B2 (29-37 points), Class C1 (23-28 points), Class

C2 (17-22 points), Class D-E (0-16 points). The final scores were recorded in the assessment instruments.

III - Gestational risk assessment: preexisting clinical conditions; number of prenatal visits; diseases and adverse events recorded during pregnancy based on questions asked to the mother and/or notes made on the pregnancy monitoring card.

IV - Delivery and neonate characteristics: type of pregnancy (singleton or multiple); type of delivery (vaginal, cesarean, forceps); gestational age; neonate gender; birth weight; weight and gestational age categorization (based on criteria set out by the Ministry of Health); Apgar score at 2 and 5 minutes after birth; need for resuscitation in the delivery room and referral to intermediate or intensive care units.

Gestational age was recorded based on answers given by the mothers or notes made in their prenatal care cards. The infants were categorized as preterm neonates (born after up to 36 weeks and six days - 258 - days of gestation); full term neonates (born after 37 - 41 weeks - 259 to 293 days - of gestation); or postterm neonates (born after 42+ weeks - 294+ days - of gestation) (BRASIL, 2012a). Birth weight was recorded based on the notes made in the infant's cards or in their certificates of live birth. The infants were categorized as having low birth weight (<2500g); very low birth weight (<1500g); or being large for gestational age (>4000g) (BRASIL, 2012a).

V - Multidisciplinary care characteristics: participants were asked whether their children were visited by members of a basic healthcare unit and, if not, why they were not visited; time to the first visit; interval between visits and whether the child/adolescent is still being followed by healthcare staff. Questions were asked about how often they had visits with a pediatrician, physical therapist, speech therapist, psychologist, nutritionist, dietitian, occupational therapist, neurologist, orthopedist, ophthalmologist, otolaryngologist, and social worker.

The patients were assigned an identification number and anonymized after data collection. The assigned numbers and the respective data for each included patient were entered into Excel 2013 by one of the authors. The data were processed and analyzed on software package SPSS version 23 for Windows and on Microsoft Office Excel 2007. For purposes of descriptive statistics, the data were reported in the form of median values and proportions (simple frequency distribution).

RESULTS

Thirty patients with a median age of 77.1 (5-216) months were included in the study. Twenty-two (73.3%) were males; 21 (70.0%) were described as having white skin; eight (26.7%) as having brown skin; and one (3.3%) as having black skin.

The households had 3.7 (2-5) individuals on average. Fathers were described as the sole providers in 25 (83.3%) households, followed by mothers in three (10.0%), and the two parents on two (6.7%) households. Mothers were the caretakers in 28 (93.3%) cases, followed by grandmothers in two (6.7%).

Most fathers (n=42; 70.0%) and mothers (n=49; 81.7%) were Catholics, whereas six (10.0%) fathers and eight (13.3%) mothers were Evangelicals. The remaining parents did not report a specific religious following or were not found to answer the question.

In regard to household income, 25 (83.3%) were on the Continuous Cash Benefit Program (BPC, Brazilian acronym) for vulnerable individuals. Household income ranged from one to two Brazilian minimum wages - including BPC payments - in 20 (66.7%) of the families. Seven (23.3%) earned two to three minimum wages and three (10.0%) families made more than three minimum wages a month. In reference to the Brazilian Economic Classification Criteria, 22 (73.4%) families were categorized as belonging to classes D or E, four (13.3%) to class C2, three (10.0%) to class C1, and one (3.3%) to class B1.

In terms of number of prenatal care visits, 20 (66.7%) mothers had two to five visits and ten (33.3%) had six to ten visits. The most common adverse events during pregnancy were urinary tract infection (n=8; 26.7%), high blood pressure (n=4; 13.3%), TORCH infections (n=2; 6.7%), and hemorrhagic dengue (n=1; 3.3%). Fifteen (50.0%) did not report adverse events during pregnancy.

Six (20.0%) mothers had vaginal deliveries and 24 (80.0%) had cesarean sections. Interviews held with coordinators of medical services at private and public hospitals in the municipality of the study revealed that cesarean sections account for approximately 95% of the deliveries held at private hospitals versus 60% in public hospitals.

Twenty-nine (96.7%) mothers had singleton pregnancies and one (3.3%) had a multiple pregnancy. Twenty-two (73.3%) neonates had gestational ages >37 weeks and eight (26.7%) had gestational ages <37 weeks. Ten (33.3%) neonates had Apgar scores between 4 and 7 and 20 had scores greater than 7 five minutes after birth, i.e., a third of the babies were exposed to some degree of fetal distress. Six (20.0%) individuals in the studied group progressed to CP.

Twelve (40.0%) neonates had low birth weight and suffered with complications.

Table 1 describes the conditions connected to CP recorded at the time of hospitalization, among which are hypoxic-ischemic encephalopathy; prematurity; postnatal nervous system infections (meningitis and encephalitis); congenital infections (TORCH: toxoplasmosis, rubella, cytomegalovirus, herpes, syphilis); and nervous system malformations.

Most patients (n=20; 66.6%) were diagnosed with CP before six months of age (Table 2). Eighteen patients (60.0%) were diagnosed in the neonatal period (asphyxia, prematurity, kernicterus).

Table 1. Conditions associated with cerebral palsy in children and adolescents seen at a hospital in southern Espírito Santo (n=60).

Variables	Proportion (%)
Conditions associated with cerebral palsy	
Hypoxic-ischemic encephalopathy (HIE)	5 (16.7%)
Prematurity	8 (26.7%)
Meningitis (neonatal and late)/encephalitis	6 (20.0%)
Status epilepticus	3 (10.0%)
Kernicterus	3 (10.0%)
Microcephaly	2 (6.7%)
TORCH	2 (6.7%)
Nervous system malformations (myelomeningocele, hydrocephalus)	1 (3.2%)

Source: data gathered by the author.

Table 2. Age of diagnosis of CP of children and adolescents seen at a non-profit hospital in southern Espírito Santo, Brazil, 2017, (n=30)

Variables (%)	
Age of diagnosis of CP	
Before six months of age	20 (66.6%)
6 to 24 months of age	5 (16.7%)
More than 24 months of age	5 (16.7%)

Source: data gathered by the author.

Table 3 describes the access the patients had to multidisciplinary staff at the time of diagnosis of CP and during the course of the study.

DISCUSSION

The study showed that the primary caretakers of children and adolescents with CP were their mothers, who were often forced to quit their jobs to take care of the house and their children. Overwhelmed by the burden of caring for their children and managing their houses, these mothers need support from their friends, families, and society to cope with stress and improve their overall quality-of-life.²⁵

Moving around with their children becomes more difficult as they grow and gain weight. Streets and transportation systems were not designed to address the needs of individuals with CP, and their mothers become more isolated and confined in their new lives. Mothers, primary caretakers, and families suffer with the troubles inherent to searching for information on the condition of their children, scheduling numerous visits with doctors, repeatedly admitting their children to hospital, and spending money with medication. The entire family is affected by the disease and needs an integrated support network to cater to a wider array of needs in addition to the ones more obviously connected to the condition.²⁶

Low income level, poor parent schooling, insufficient prenatal care, and inadequate care at the time of delivery may

Table 3. Healthcare provided to children and adolescents with CP seen at a non-profit hospital in southern Espírito Santo, Brazil, 2017(n=30).

Variables of interest	Proportion (%)	
Seen at a basic healthcare unit soon after diagnosis	At the time of diagnosis	At the time of the interview
	Yes	8 (26.7%)
Access to a physical therapist	At the time of diagnosis	At the time of the interview
	Yes	14 (66.7%)
Access to a speech therapist	At the time of diagnosis	At the time of the interview
	Yes	14 (46.7%)
Access to a neurologist	At the time of diagnosis	At the time of the interview
	Yes	18 (60.0%)
Access to a nutritionist; dietitian; psychologist; social worker; orthopedist; ophthalmologist; otolaryngologist; dentist	At the time of diagnosis	At the time of the interview
	Yes	9 (30%)

Source: data gathered by the author.

increase the chances of CP. Quality improvement programs in healthcare must also consider universal access to good quality education.²⁶ Studies have validated these findings by showing that patients coming from lower income households and less-favored economic classes have less access to healthcare services and, when they are able to have access to these services, they are generally of lower quality.²⁷

In terms of access to healthcare services in the group included in this study, 20 mothers (66.7%) of children and adolescents with CP had fewer than six doctor visits. The troubles they possibly had with having access to proper prenatal care may have increased the chances of occurrence of preterm births, neonatal infection, and neonatal asphyxia, among other issues.²⁷ Kolola et al. (2016) reported that children born from mothers deprived of proper prenatal care were at higher risk of dying within 28 days of birth.²⁸

The instrument used in this study did not gather information about the moments during pregnancy in which the patients were consulting with their doctors, whether the results of the ordered tests were issued in a timely fashion, or whether the gathered information were correlated with the quality of prenatal care.

The findings reported for prematurity, low birth weight, and neonatal asphyxia in particular - whose incidence

was significantly higher than the numbers reported in the literature - may reflect the quality of prenatal care and the care delivered to mothers and their neonates in the delivery room.^{27,29,30,31}

In high-risk infants, factors such as gestational age, birth weight, asphyxia, meningitis and/or respiratory disorder have been significantly correlated with risk of neurological injury, including CP. This calls for the implementation of stronger care and follow-up models for high-risk neonates.³²

The results seen in this study corroborate the literature. Neonatal life is the most critical period in terms of infant mortality, while matters such as the quality of care provided to pregnant women, thorough examination during doctor visits, careful analysis of maternal test results, care given at the time of delivery, choice of mode of delivery, and post-delivery care also play a pivotal role.³³

Women must be offered proper care in basic care units during pregnancy and at the time of delivery, thereby mitigating the inequalities in access to healthcare and managing the preventable causes of CP.

Basic care units and referral and counter-referral systems are particularly relevant for patients with CP requiring multidisciplinary integral care. However, 81.2% of the families included in this study claimed that their children with CP did not have access to a Basic Healthcare Unit or a family physician, revealing a gap between what public policy dictates and what patients are actually offered.^{34,35,36}

Although multidisciplinary care involving assistant physicians and a multi-professional team featuring physical therapists, speech therapists, dentists, neurologists, pediatricians, family physicians, nutritionists, dietitians, orthopedists, otolaryngologists, ophthalmologists, occupational therapists, psychologists, and social workers improves the care provided to patients with CP,³⁷ many of the individuals included in this study did not have access to basic care units or multidisciplinary care teams.³⁸

The troubles faced by the group of patients included in this study ranged from the lack of (e.g.: dietitian) or an insufficient number of medical personnel in public clinics; long waiting lines; physicians in basic care units not referring patients to additional care; to poor access to transportation provided by the municipality for individuals with CP. Six (20.0%) patients in the study had private health insurance coverage, but none had been followed by a multidisciplinary care team. Many reported difficulties gaining access to certain medical specialties, mobility devices, and medical procedures, which occasionally forced them to travel to the State Capital of Vitória.

Efforts are required to mitigate the disparities in healthcare and improve the quality of care provided prenatally, during delivery, after delivery, and during rehabilitation, so that the number of cases of CP is decreased and sequelae from the condition are minimized.

Effective universal coverage including the availability of proper healthcare is required to help manage the variables around the mother-child binomial and thus decrease the risk of CP and its consequences to children, their families, and society.^{12,36}

In addition, interdisciplinary knowledge acquired in the process must be shared and transferred so as to enable families and involved healthcare providers to better cater to the needs of individuals with CP.³⁹

CONCLUSION

In this study, poor parent schooling, belonging to a lower socioeconomic class, prematurity, low birth weight, and neonatal asphyxia were often present in children and adolescents with CP.

The identification of these conditions may help stratify groups and provide input to action plans devised to restructure basic healthcare systems to facilitate access to prenatal and perinatal care and mitigate the occurrence of preventable cases of CP.

The results reported in this study indicate that patients with CP have more trouble having access to healthcare professionals and required services.

The study indicated the need to have well-connected teams committed to delivering integral healthcare; improve the quality of care provided to the studied population; and to implement public policy devised to decrease the existing inequalities in access to healthcare.

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APPENDIX A - Research data collection instrument

Identification of the research participant: Nº _____

1. Identification

Name: _____
Nº. pront.: _____ Race: _____
Birth date: _____ Hospitalization date: _____ Evaluation date: _____
Municipality where you reside: _____
Legal guardian: () father () mother () other: _____
Mother: _____
Color (white/black/brown/yellow/indigenous/undeclared): _____
Profession: _____
Religion: _____
Years of study: _____
Marital status (single/married/widowed/divorced/stable/other): _____
Father: _____
Father's profession: _____
Father's age: _____
Father's Religion: _____
Father's years of study: _____

2. Social conditions:

Who is the child's caregiver: _____
Who is the home provider (s): _____
Participates in government social programs: () yes - () no BPC ()
Number of cohabitants: _____
What is the total family income of the family: R\$ _____
Social class (ABEP criterion, 2015): _____
Has health insurance: () yes () no

The house has:

- A) Piped water: () yes - () no
- B) Sewer system: () yes - () no
- C) Filtered water: () yes - () no
- D) Garbage collection: () yes - () no
- E) Vehicle access to the residence: () yes - () no
- F) Sidewalk or paved street: () yes - () no
- G) Electric light: () yes - () no
- H) Own house () - Rented ()

Transport used by the evaluation for consultations / exams:

- A) Family car: yes () - No ()
- B) Conventional bus: yes () - No ()
- C) Transport provided by the municipality: yes () - No ()
- Why can't you: _____
- D) Bus adapted and provided by the company: yes () - No ()
- E) Has health insurance: yes () - No ()
- F) Other means of transport (motorcycle / neighbor car):

3. Gestation:

Did prenatal care: yes () - No ()
Number of prenatal consultations:
Problems during pregnancy:

- () Systemic arterial hypertension () Pre-eclampsia () Eclampsia
 () DM management () Urinary infection () TORCHS
 () Others:

4. Alcohol / tobacco and illicit drugs during pregnancy:

- () Alcoholism - amount: _____
 () Smoking - how many cigarettes per day: _____
 () Illicit drugs - which: _____

5. Birth:

- Type of delivery: () normal () cesarean section () forceps
 Pregnancy: single () multiple ()
 Needed resuscitation in the delivery room: () yes - () no
 After delivery she was: () ICU () UADC () rooming-in
 ERASE: 1st minute: _____ 5th minute: _____ 10th minute: _____
 Anthropometry: birth weight: _____ Length: _____ CP: _____
 Gestational age: _____

Classified. Newborn according to birth weight (BRASIL, 2010a)

- () extremely low weight weight < 1000g
 () low weight < 2500g
 () suitable weight 2500g to 4000g
 () macrosomia weight > 4000g

Classified . Newborn according to gestational age (BRASIL, 2010a)

- () term 37 to 41 weeks of gestational age
 () preterm < 37 weeks of gestational age

6. About multiprofessional service:

- Receives UBS visit: () yes - () no
 Why don't you get a UBS visit?

Immediately after the diagnosis of CP:

- | Professional | Service (yes/no) | Main difficulties |
|----------------------|------------------|-------------------|
| Pediatrics | | |
| Physiotherapy | | |
| Speech Therapy | | |
| Psychological | | |
| Nutritionist | | |
| Nutrition | | |
| Neurology | | |
| Occupational therapy | | |
| Orthopedist | | |
| Ophthalmology | | |
| ENT | | |
| Assisi. Social | | |
| Others | | |

Currently continues to follow up with:

- | Professional | Service (yes/no) | Main difficulties |
|----------------|------------------|-------------------|
| Pediatrics | | |
| Physiotherapy | | |
| Speech Therapy | | |

Psychological
Nutritionist
Nutrition
Neurology
Occupational therapy
Orthopedist
Ophthalmology
ENT
Assisi. Social
Others