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Profile Of Children Aged 0-3 Years With Disability In A University Hospital In The South Of Brazil

Perfil De Crianças De 0-3 Anos Com Deficiência Em Um Hospital Universitário No Sul Do Brasil

Perfil De Niños De 0 A 3 Años Con Discapacidad En Un Hospital Universitario Del Sur De Brasil

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ABSTRACT

Introduction: Research and data on childhood disabilities are scarce worldwide, particularly in low- and middle-income countries, where such data are not only limited but also outdated. In Brazil, according to IBGE 2019 data, there are over 17 million Brazilians with some degree of disability, representing 8.4% of the population aged over 2 years. This study aims to assess the prevalence of disabilities in children aged 0-3 years under follow-up at a university hospital in the southern region of Brazil. **Methods**: Descriptive, retrospective study with data collection from medical records of children treated between 2017 and 2019. Children with disabilities were divided into four major groups: genetic, prematurity-related, congenital, and neurodevelopmental disorders. Data analyzed included sex distribution, weight, height, head circumference, APGAR score, average length of hospital stay, type of delivery, maternal age, presence of comorbidities, and parental care in the patients treated. **Results**: During the study period, 3,091 children were treated, of whom 429 (13.9%) presented some degree of disability, with 8.4% due to genetic conditions, 34.3% premature, 20.9% congenital disorders, and 12% neurodevelopmental disorders. Significant differences were observed among the studied groups, particularly regarding birth weight. The rate of cesarean deliveries was high in all groups. **Conclusions**: The sample of children with disabilities in our study was higher than the data reported in the last Brazilian census. Further research is needed in children aged 0-3 years in Brazil.
Keywords: Infant; Developmental Disabilities; Child.

RESUMO

Introdução: Pesquisas e dados sobre deficiência infantil são escassos em todo o mundo, principalmente em países de baixa e média renda, onde além de escassos, esses dados também não são atuais. No Brasil, segundo dados do IBGE de 2019, existem mais de 17 milhões de brasileiros com algum grau de deficiência, ou 8,4% da população com mais de 2 anos de idade. O objetivo deste estudo é avaliar a prevalência de deficiências em crianças de 0-3 anos de idade, em acompanhamento em um hospital universitário na região sul do Brasil. **Métodos**: Estudo descritivo, retrospectivo, com coleta de dados em prontuários de crianças atendidas entre 2017-2019. As crianças portadoras de alguma deficiência foram divididas em quatro grandes grupos: genética, por prematuridade, deficiências congênitas e do neurodesenvolvimento. Foram analisados dados de distribuição de sexo, peso, estatura, perímetro cefálico, escore de APGAR, média de internação hospitalar, tipo de parto, idade materna, presença de comorbidades e cuidado parental nos pacientes atendidos. **Resultados**: durante o período do estudo foram atendidas 3091 crianças, das quais 429 (13,9%) apresentavam algum grau de deficiência infantil, sendo 8.4% por alterações genéticas, 34,3% prematuros, 20,9% alterações congênitas e 12% alterações de neurodesenvolvimento. Foram observadas diferenças significativas entre os grupos estudados, principalmente referente ao peso de nascimento. O índice de partos cesáreos foi elevado em todos os grupos. **Conclusões**: A amostra de crianças com deficiência em nosso estudo foi superior aos dados do último censo brasileiro. Mais estudos precisam ser realizados em crianças de 0-3 anos no Brasil.
Palavras-chave: Lactente; Deficiências do Desenvolvimento; Criança.

RESUMEN

Introducción: La investigación y los datos sobre discapacidades infantiles son escasos en todo el mundo, especialmente en países de ingresos bajos y medios, donde, además de ser escasos, estos datos también están desactualizados. En Brasil, según datos del IBGE de 2019, hay más de 17 millones de brasileños con algún grado de discapacidad, o el 8,4% de la población mayor de 2 años. El objetivo de este estudio es evaluar la prevalencia de discapacidades en niños de 0 a 3 años, seguidos en un hospital universitario en la región sur de Brasil. **Métodos**: Estudio descriptivo, retrospectivo, con datos recopilados de historias clínicas de niños tratados entre 2017 y 2019. Los niños con discapacidades se dividieron en cuatro grupos principales: genéticos, prematuros, discapacidades congénitas y discapacidades del neurodesarrollo. Se analizaron datos sobre distribución por sexo, peso, altura, perímetro cefálico, puntaje de APGAR, duración promedio de la estadía hospitalaria, tipo de parto, edad materna, presencia de comorbilidades y cuidado parental en los pacientes tratados. **Resultados**: Durante el período de estudio, se atendió a 3.091 niños, de los cuales 429 (13,9%) presentaron algún grado de discapacidad infantil: el 8,4% se debió a alteraciones genéticas, el 34,3% a prematuros, el 20,9% a alteraciones congénitas y el 12% a trastornos del neurodesarrollo. Se observaron diferencias significativas entre los grupos estudiados, principalmente en cuanto al peso al nacer. La tasa de cesáreas fue alta en todos los grupos. **Conclusiones**: La muestra de niños con discapacidad en nuestro estudio fue mayor que la del último censo brasileño. Es necesario realizar más estudios en niños de 0 a 3 años en Brasil.
Palabras clave: Infante; Discapacidades del Desarrollo; Niño.

INTRODUCTION

According to the World Report on Disability, more than one billion people worldwide live with some form of disability, and about 200 million have experienced significant functional difficulties.[1] The vast majority of people with disabilities do not have equal access to medical care, education, employment opportunities, and do not receive the services corresponding to the disability they need.[1]

The World Health Organization (WHO) defines disability as: any long-term impairment of a physical, mental, intellectual or sensory nature which, in interaction with one or more barriers, may hinder full and effective participation in society on an equal basis with others.[2] Research and data on childhood disability are scarce worldwide, especially in low- and middle-income countries, where, in addition to being scarce, this data is also not up-to-date. In Brazil, according to IBGE data from 2019, there are more than 17 million Brazilians with some degree of disability, that is, 8.4% of the population over 2 years of age.[3]

Regarding the distribution and frequency of disabilities, 8.4% have at least one disability. Motor disability is described as the most frequent: 5.5%, followed by visual: 3.4%, hearing: 1.1% and intellectual: 1.2%. As for age, 1.5% of the population with disabilities is 0 to 2 years old; 2.3% are 10 to 17 years old; and 2.9% are 18 to 29 years old. Of the 14.5 million Brazilians with disabilities, 23.7% reside in the Northeast Region, 16.5% in the Southeast Region; and in the Central-West Region, 23.5%.[3,4]

In Brazil, children with special health needs face delays in diagnosis and referral for specialized care, and have difficulty accessing primary care consultations when their chronic condition worsens.[5] Furthermore, although there is a considerable number of programs that include children aged 0-3 years with disabilities, few propose a specific approach to this population. These children, therefore, remain invisible in the documents that present the programs or, when they are mentioned, the proposed actions are quite generic and do not clearly explain their objective and procedures.[6]

According to the 2013 State of the World's Children Report from the United Nations Children's Fund (UNICEF), for a huge number of children with disabilities, the opportunity to participate simply does not exist. Very often, children with disabilities are among the last to receive resources and services, especially in places where such resources and services are already scarce. Similarly, they are simply subject to pity or, even worse, discrimination and abuse.

To address this reality, UNICEF proposes, as a broader framework on which different strategies are anchored, "Community-based Rehabilitation", a proposal developed by the WHO in the late 1970s that aims to transfer responsibility for care from institutions and specialists to care within communities.[6] This implies investment to enable access and improve the quality of life in local communities, including the full range of essential services (health, education, social assistance, and others). Therefore, a logic of segregation is replaced by a logic of inclusion.

From this perspective, the earlier individuals with disabilities are given access to these resources, the greater the impact on their quality of life. Hence the relevance of Early Intervention Programs that aim not only to detect the risk condition but also to intervene in it.[7,8]

The 2006 United Nations Convention on the Rights of Persons with Disabilities establishes that children with "long-term physical, mental, intellectual and/or sensory disabilities" should enjoy the same human rights and freedoms as other children.[9] In Brazil, we have Law No. 13,146, of July 6, 2015, which in its article 1 assumes the country's commitment to "ensure and promote, under conditions of equality, the exercise of fundamental rights and freedoms by persons with disabilities, aiming at their social inclusion and citizenship".[8] According to the same document, a person with a disability is considered to be someone who has "a long-term impairment of a physical, mental,

intellectual or sensory nature, which, in interaction with one or more barriers, it can hinder their full and effective participation in society on an equal basis with others" (Art. 2).[8]

Based on these assumptions, it is understood that the condition of disability, especially in childhood, needs to be better understood and identified. In this context, research in this area and data updating on the number of children and adolescents with some degree of disability becomes fundamental.

OBJECTIVE

This study aims to evaluate the prevalence of disabilities in children aged 0-3 years, followed up at a university hospital in the Southern Region of Brazil. The secondary objective is to evaluate demographic and clinical data of the patients and compare them between classifications of disabilities (genetic alterations; premature infants; congenital alterations; and neurodevelopmental disorders).

MATERIAL AND METHODS

Data source and study design

The data used were obtained from digital medical records of a tertiary hospital in the Southern Region of Brazil between January 1, 2017, and December 25, 2019.

Recruitment methods and study population

Data were collected from children aged 0-3 years seen in an outpatient clinic at a university hospital in southern Brazil from January 2017 to December 2019. This period was chosen because the hospital began digitizing its data during that time. Data were collected on the number of children seen during this two-year period and the number of children with some degree of disability seen in the genetics, developmental and behavioral disorders, neurology, premature infants (neonatal ICU follow-up), and children registered with ECLAMC (Latin American Collaborative Study of Congenital Malformations) outpatient clinics.

Selected data

Medical records were reviewed, highlighting the following relevant clinical information: maternal (name, maternal age at delivery, number of pregnancies, abortions and deliveries, prenatal care received, number of prenatal visits). In addition, the following socioeconomic information about the families was collected: family type, type of housing, receipt of scholarships/aid, primary and secondary caregivers of the children, parents' ethnicity, parents' level of education, and attendance at specialized services. Data on the child's clinical information included: birth weight, date of birth, length at birth, head circumference at birth, APGAR 1'5', need for ICU admission, length of stay, pathologies (anoxia, jaundice, meningitis, infections, sepsis), specialist consultations, requested tests, referrals, attendance at daycare/school, and diagnoses. The data were selected to create an individual profile of each patient, considering their origins, the socioeconomic and sociodemographic situation of their families, and their clinical presentation.

Classification of types of disability

The children served were classified into five main groups: group with genetic disabilities, group with disabilities due to prematurity, group with congenital disabilities, group with neurodevelopmental disabilities, and group without a diagnosis.

Ethical approval

The work was approved by the Ethics Committee. Approval protocol number: CAAE 25468619.9.0000.5336.

Statistical analysis

Quantitative demographic and clinical data (mean and standard deviation) were compared between disability classification groups using analysis of variance. The chi-square test was used for comparisons of categorical variables between groups. A

significance level of 5% was used. Analyses were performed using SPSS version 19.

RESULTS

Over three years, from 2017 to 2019, 3,091 children were treated, of which 429 (13.9%) presented some degree of childhood disability, whether genetic, congenital, due to prematurity and/or neurodevelopmental disorders.

Of the 429 children surveyed, 322 children had sufficient medical record data to be analyzed and compared. Children with some childhood disabilities were divided into four main groups: genetic alterations (8.4%), presence of prematurity (34.3%), children with congenital alterations (20.9%) and children with neurodevelopmental disorders (12%). More than 24% of patients who circulated through genetics, development and prematurity outpatient clinics did not present any classification or diagnosis (Table 1).

Table 1 - Descriptive frequency analysis (percentage) of cases according to diagnostic classification groups (0, 1, 2, 3 and 4)

Classification

GROUPS		Frequency	Percentage	Valid percentage	Cumulative percentage
Valid	0	104	24.2	24.4	24.4
	1 (GENET)	36	8.4	8.5	32.9
	2 (PMT)	146	34.0	34.3	67.1
	3 (CN)	89	20.7	20.9	88.0
	4 (NEURO)	51	11.9	12.0	100.0
	Total	426	99.3	100.0	
Omitted	System	3	.7		
Total		429	100.0		

GROUPS: 0 - unclassified; 1 - GENET (genetic alterations); 2 - PMT (premature infants); 3 - CN (congenital alterations); 4 - Neuro (neurodevelopmental disorders).

Assessing the distribution by sex, males were found in 49% of premature infants, as well as 52% of children with neurodevelopmental disorders and 44% of children with congenital abnormalities.

The average birth weight found in premature infants was 1,409 kg; in children with congenital disabilities, it was 2,950 g; and 3,195 g in children with neurodevelopmental disorders, indicating significant differences between these groups ($p<0.0001$), as shown in Table 2. Weight data were not found and recorded in the group of individuals with genetic diseases.

Table 2 - Data from the statistical analysis comparing the groups – ANOVA (Significant values = 0.000 indicate significant differences between the groups)

Group		N	Average	Standard deviation
Birth_weight	2 PMT	78	1409.42	547.14
	3 CN	35	2950.25	637.35
	4 NEURO	38	3195.50	726.55
	Total	151	2216.04	1040.72
Height_at_birth	PMT	49	37.85	4.83
	CN	21	45.80	3.97
	NEURO	27	48.19	2.78
	Total	97	42.45	6.29
Head_circumference	2 PMT	48	28.56	6.45

	3 CN	21	33.33	2.97
	4 NEURO	26	34.50	2.45
	Total	95	31.24	5.64
Gestational_age_at_delivery	2 PMT	84	33.20	3.32
	3 CN	34	40.26	2.75
	4 NEURO	41	40.83	1.98
	Total	159	36.68	4.69
Apgar_1	2 PMT	64	6.41	2.22
	3 CN	31	8.19	1.27
	4 NEURO	31	8.26	1.29
	Total	126	7.30	2.02
Apgar_5	2 PMT	64	8.08	1.31
	3 CN	31	8.94	.62
	4 NEURO	31	9.06	1.09
	Total	126	8.53	1.21
Days_hospitalization	2 PMT	60	56.00	41.75
	3 CN	14	16.86	18.87
	4 NEURO	12	14.25	15.19
	Total	86	43.80	40.53
Maternal_age	2 PMT	55	27.65	7.71
	3 CN	13	23.76	6.97
	4 NEURO	12	24.41	5.85
	Total	80	26.53	7.46

		Z	Sig.
Birth_weight	Between groups	139.18	.000
Height_at_birth	Between groups	61.96	.000
Head_circumference	Between groups	14.34	.000
Gestational_age_at_delivery	Between groups	126.79	.000
Apgar_1	Between groups	15.64	.000
Apgar_5	Between groups	10.62	.000
Days_hospitalization	Between groups	11.15	.000
Maternal_age	Between groups	2.04	.13
	In the groups		
	Total		

GROUPS: 2 - PMT (premature infants); 3 - CN (congenital abnormalities); 4 - NEURO (neurodevelopmental disorders).

The average height of children with neurodevelopmental disorders was 48 cm, 45 cm in children with congenital abnormalities, and 37.9 cm in premature infants, showing significant differences between the groups ($p<0.001$) (Table 2). The head circumference at birth in premature infants was 28 cm, 33 cm in the group of children with congenital

abnormalities, and 34.5 cm in the group with neurodevelopmental disabilities. The average gestational age (GA) found in our sample of premature infants was 33.2 weeks. The average gestational age of children with congenital abnormalities and neurodevelopmental disorders was 40 weeks (Table 2).

The average Apgar score at one minute was 6 in the premature group and 8 in the other groups (p<0.001). The Apgar score at five minutes ranged from 7 to 9 in all four groups (p<0.001) (Table 2).

The average length of hospital stay was 56 days in the premature group, 17 in children with congenital abnormalities, and 14 in children with neurodevelopmental disabilities. ICU hospitalization occurred in 98.4% of premature infants, 73% of children with congenital abnormalities, and 50% of children with neurodevelopmental disabilities (p<0.001) (Table 3).

Table 3 - Comparisons of categorical variables between groups = Occurrence of ICU admission

			Group 2 PMT	3 CN	4 NEURO	Total
Neonatal_ICU_admission	yes	Count	60	19	13	92
		% em Neonatal_ICU_admission	65.2%	20.7%	14.1%	100.0%
		% in group	98.4%	73.1%	50.0%	81.4%
	no	Count	1	7	13	21
		% em Neonatal_ICU_admission	4.8%	33.3%	61.9%	100.0%
		% in group	1.6%	26.9%	50.0%	18.6%
Total		Count	61	26	26	113
		% em Neonatal_ICU_admission	54.0%	23.0%	23.0%	100.0%
		% in group	100.0%	100.0%	100.0%	100.0%

Average number of days in neonatal ICU	2 PMT	3 CN	4 NEURO
	56 days	17 days	14 days

Chi-square tests

	Value	gl	Asymptotic (Bilateral) Significance
Pearson's chi-square	29.731[a]	2	.000

GROUPS: 2 - PMT (premature infants); 3 - CN (congenital abnormalities); 4 - NEURO (neurodevelopmental disorders).

When the type of delivery was evaluated, the percentage of cesarean deliveries was higher in the premature group (60.6%), with similar percentages in the other groups, 46.9% in the group of patients with congenital abnormalities and 47.1% in the group of patients with neurodevelopmental disorders (p= ,291) (Table 4).

Table 4 - Comparisons of categorical variables between groups = Type of delivery

			Group 2 PMT	3 CN	4 NEURO	Total
Type_of_delivery	vaginal	Count	26	17	18	61
		% in Type_of_delivery	42.6%	27.9%	29.5%	100.0%
		% in group	39.4%	53.1%	52.9%	46.2%
	cesarean	Count	40	15	16	71
		% in Type_of_delivery	56.3%	21.1%	22.5%	100.0%
		% in group	60.6%	46.9%	47.1%	53.8%
Total		Count	66	32	34	132

	% in Type_of_delivery	50.0%	24.2%	25.8%	100.0%
	% in group	100.0%	100.0%	100.0%	100.0%

Chi-square tests

	Value	gl	Asymptotic (Bilateral) Significance
Pearson's chi-square	2.469[a]	2	.291

GROUPS: 2 - PMT (premature infants); 3 - CN (congenital abnormalities); 4 - NEURO (neurodevelopmental disorders).

A significant number of children had only one caregiver (single-parent care). The percentage of single-parent care found in the groups was 12% for premature infants, and close to 20% in the groups of children with congenital and neurodevelopmental disorders.

The presence of associated comorbidities was also evaluated and showed a quite significant number. Approximately 97% of premature infants presented associated comorbidities, as did 65% of children with congenital disorders and 56% of children with neurodevelopmental disorders. The average maternal age at the time of delivery was similar in all groups, being 23.8 years in the congenital disease group, 24.4 years in the neurodevelopmental disease group, and 27.7 years in the premature infant group (p= 0.136).

DISCUSSION

The results found in the research allow for new comparisons to be made to understand the studied population within the Brazilian and global context. Therefore, based on the data presented, we can compare our findings with other studies already carried out around the world.

The sample of children with disabilities corresponds to 13.9% of all children treated in an outpatient clinic of a tertiary hospital in southern Brazil, which is much higher than the number of children with disabilities found in the last Brazilian Census of IBGE, from 2022, which was 7.3%.[4,10] It is believed that our data are still underestimated compared to the number of patients who are without data recorded in their medical records. The loss of data on children with disabilities was 25%. It is believed that the main factor for the lack of registration was the absence of a basic and unique care protocol.

Regarding the rate of premature births in Brazil, according to the Brazilian Society of Pediatrics, the prevalence of prematurity in the country is 11.5%, less than half the number found among children seen in pediatrics at a tertiary outpatient service in this study (34%). This difference in prevalence is probably because it is a tertiary referral hospital for premature infants where postnatal follow-up of the newborns seen at the hospital was carried out.[11]

In the Latin American scenario, in a meta-analysis carried out by Blencowe et al.,[12] the incidence of prematurity was 8.4% and 9.2% for Brazil, with most premature infants having a gestational age above 32 weeks. The same study shows us that 55% of these premature infants are male. These latter data on gestational age and sex distribution are similar to the findings in our study, which showed an average gestational age of 33 weeks among premature infants, with 46% being male.

According to Queiroz et al.,[13] the average weight of Brazilian premature infants at 33 weeks of gestational age was 1,929 g, classified as low birth weight (LBW), a higher weight compared to the average weight found in our sample of patients, which was 1,409 g, classified as very low birth weight.

In a study conducted in Porto Alegre-RS, Brazil (the same municipality where data was collected for the present study), Oliveira et al.[14] found that low birth weight is four times more common in children born before 37 weeks of gestation, a strong correlation also evidenced in this study. The average birth weight in the Porto Alegre study was 1,478 g and the average gestational age was 30 weeks. In the same study, there was no difference in the sex distribution of premature births.

In a study conducted in São Paulo,[15] premature newborns admitted to the NICU had an average gestational age of 30 weeks, slightly lower compared to our study. The average maternal age was 25.7 years, and male sex was present in 51.8% of premature infants.

Regarding APGAR scores, Queiroz et al.[13] showed that the average found in the first minute in premature infants was 6, a value similar to that found in our study. Kawasaki et al.,[16] studying premature infants between 29-32 weeks, found an APGAR score below 4 in the first minute, a value well below the average found in our study, which is probably due to the extreme degree of prematurity of the sample selected for the study.

In the study by Oliveira et al.,[15] the APGAR score found in premature infants was above 7 in the fifth minute of life (95.5% of premature infants). Similar values were found in 99.3% of term newborns. The same study shows a higher rate of prematurity among the extreme maternal age groups below 19 years and above 35 years of age, as well as in those with inadequate prenatal care and twin pregnancies. In addition, cesarean delivery (61.7%) and induction of labor (25.4%) were significant factors for the incidence of premature births, with cesarean section being able to increase the risk of prematurity by 15 times. The percentage of cesarean delivery in premature infants found in the previous study is similar to our findings (60.6%), corroborating the high rate of cesarean sections in the capital of Rio Grande do Sul and its strong correlation with prematurity.

Regarding the prevalence rates of congenital defects, Thompson et al. [17] report rates of 3 to 5% of live births in the world population. In Brazil, the prevalence of congenital defects is similar to that found worldwide, 6%. However, our study shows a prevalence of 20.7%. This result may also be explained by the fact that it was conducted in a tertiary childcare center and/or by the low reporting of cases in the Brazilian population.

Kawasaki et al.[16] found a higher prevalence of congenital diseases in premature newborns, with gestational age between 29-32 weeks. Among premature infants, 97% presented associated comorbidities, with 65% having congenital abnormalities and 56% of the children having neurodevelopmental disorders. Our study corroborates the data presented above, with 97% of our premature infants having associated comorbidities, 65% of them having congenital abnormalities and 56% having neurodevelopmental disorders.

In the context of parental care, Kadosaki et al.[18] found the absence of a father figure in raising children in 32% of children with neurodevelopmental disorders in the Amazon, also showing separated parents in the family dynamics in 41% of families. These data are high, as are the data on single-parent care found in 20% of children with neurodevelopmental disorders in our study.

According to world and Brazilian literature, there is a strong association between neurodevelopmental disorders in childhood and low birth weight.[19-23] Our data showed quite different situations, that is, children with childhood neurodevelopmental disorders had an average weight of 3,195 g. This difference in findings can probably be explained by the lack of separation of data from studies regarding gestational age and prematurity. Our study separates premature infants from children with neurodevelopmental disorders, finding diverse results that can be studied in the future to be better understood.

A methodological limitation of the present study is the absence of essential data from medical records, such as complete anthropometric measurements, socio-environmental profile, and support networks. This same limitation is also evident in other studies on children with disabilities in Brazil.[17]

The difficulty in population monitoring children with disabilities can also be explained by the lack of a common clinical care protocol and the lack of training of health professionals in assisting children with disabilities.

CONCLUSION

Studies describing the profile of children with disabilities in early childhood, especially in the first three years of life in Brazil, are still scarce. More studies need to be conducted to

elucidate the clinical and socio-environmental characteristics of these children.

This study allowed us to shed some light on disability in the first three years of life and the importance of creating public policies for this segment of the population, which appears to be prevalent. The lack of a care protocol for these children became evident, as many data are incomplete and inadequately filled out.

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