Profile of children with disabilities attending an early intervention program

Perfil de crianças com deficiência participantes de um programa de estimulação precoce

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André de Souza Rocha
Master’s degree in Human Movement Science from Santa Catarina State University - UDESC.
Bachelor’s degree in Physical Therapy from Lutheran University of Brazil - ULBRA.
Institution: Institute of Higher Education from Greater Florianópolis - IESGF and Santa Catarina Foundation for Special Education - FCEE.
Address: Paulino Pedro Hermes St., 2785 - Nossa Senhora do Rosário, São José – SC, Brazil.
E-mail: andredsr@gmail.com

Paloma Cristina Degering
Bachelor’s degree in Physical Therapy from Institute of Higher Education from Greater Florianópolis - IESGF.
Institution: Institute of Higher Education from Greater Florianópolis - IESGF.
Address: Salvador Di Bernardi Ave., 503 - Campinas, São José - SC, Brasil.
E-mail: palomadegering@gmail.com

Kelly Cristine Schmidt
Master’s degree in Human Movement Science from Santa Catarina State University - UDESC.
Bachelor’s degree in Physical Therapy from Santa Catarina State University - UDESC.
Institution: Institute of Higher Education from Greater Florianópolis - IESGF and Santa Catarina Foundation for Special Education - FCEE.
Address: Paulino Pedro Hermes St., 2785 - Nossa Senhora do Rosário, São José – SC, Brazil.
E-mail: kelly.dffcee@gmail.com

Elaine Carmelita Piucco
Master’s degree in Human Movement Science from Santa Catarina State University - UDESC.
Bachelor’s degree in Physical Therapy from Santa Catarina State University - UDESC.
Institution: Santa Catarina Foundation for Special Education - FCEE.
Address: Paulino Pedro Hermes, 2785 - Nossa Senhora do Rosário, São José – SC, Brazil.
E-mail: elainepiucco@yahoo.com.br

Ana Carolina Rodrigues Savall
Master’s degree in Human Movement Science from Santa Catarina State University - UDESC.
Bachelor’s degree in Occupational Therapy from Pontifical Catholic University of Goiás – PUC Goiás
Institution: Santa Catarina Foundation for Special Education - FCEE.
Address: Paulino Pedro Hermes, 2785 - Nossa Senhora do Rosário, São José – SC, Brazil.
E-mail: carolsavall@gmail.com
ABSTRACT

Aim: To analyze the profile of children with disabilities attending an Early Intervention program (EI) and describe the evaluations and interventions delivered. Methods: A document based, retrospective descriptive-exploratory study was carried out from February-April/2019. Medical records of children with disabilities from a referral foundation were included, focused on the main diagnoses involving neurodevelopmental disorders, including Cerebral Palsy (CP), Down Syndrome (DS) and Autistic Spectrum Disorder (ASD). Records of 79 children were analyzed for family data, children's clinical variables, initial evaluations and EI data (admission, permanence, type/quantity of therapeutic interventions). Results: There was an even distribution among diagnoses, where 26 children had DS, 26 children had ASD and 27 children had CP. The initial evaluation occurred at a mean of 22 ± 16.7 (0.1-59) months, involving mainly pediatrician (46%), speech therapist (95%), physical therapist (83%) and educator (77%). They began the EI at a mean of 28 ± 19.6 (1.1-69) months, remaining for 3.5 ± 2.0 (0.2-6.2) years. The most frequent interventions included speech therapy (100%), special education (80%) and physical therapy (70%). Most (66%) attended 02 to 05 areas of intervention. Conclusion: Children with disabilities attending EI had different types of diagnoses. Both initial evaluation and EI entry occurred late. They attended the EI around three years, undergoing multidisciplinary care. These findings provide relevant data for structuring and modifying EI programs in children with disabilities.

Keywords: Disabled Children; Early Intervention; Child development.

RESUMO

Objetivos: Analisar o perfil de crianças com deficiência atendidas em um programa de Estimulação Precoce (EP) e descrever os aspectos das avaliações e intervenções realizadas. Métodos: Estudo descritivo-exploratório de caráter retrospectivo e base documental, realizado de fevereiro-abril/2019. Foram incluídos prontuários de crianças com deficiência atendidas em uma fundação de referência, restringindo-se aos principais diagnósticos envolvendo alterações do neurodesenvolvimento, incluindo Paralisia Cerebral (PC), Síndrome de Down (SD) e Transtorno do Espectro Autista (TEA). Os registros de 79 crianças foram analisados quanto aos dados familiares, variáveis clínicas das crianças, avaliações iniciais e dados da EP (início, permanência, tipo/quantidade de intervenções terapêuticas). Resultados: Houve uma distribuição homogênea entre os diagnósticos incluídos, verificando-se 26 crianças com SD, 26 crianças com TEA e 27 crianças com PC. A avaliação inicial foi realizada em média aos 22±16,7 (0,1-59) meses, principalmente com médico pediatra (46%), fonaiudiólogo (95%), fisioterapeuta (83%) e pedagogo (77%). Ingressaram na EP em média aos 28±19,6 (1,1-69) meses, permanecendo em atendimento em média por 3,5±2,0 (0,2-6,2) anos. As intervenções mais frequentes incluíram fonoaudiologia (100%), pedagogia (80%) e fisioterapia (70%). A maioria (66%) passou por duas a cinco áreas de intervenção. Conclusão: Crianças com deficiência participantes da EP apresentaram diferentes tipos de diagnósticos. Avaliação inicial e ingresso na EP ocorreram tardiamente. Realizaram a EP por cerca de três anos, passando por atendimentos multidisciplinares. Estes achados fornecem dados relevantes para estruturação e modificação de programas de EP em crianças com deficiência.

Palavras-chave: Crianças com deficiência; Estimulação Precoce; Desenvolvimento Infantil.
1 INTRODUCTION

Neurodevelopment is a sequential, continuous and age-related process whereby children acquire a large amount of time-progressing skills\(^1,2\). This process occurs in a dynamic way and is liable to be shaped from various environmental inputs\(^1,4\).

Several factors can harm a child's neurodevelopment. Children who show signs of delay or even those with diagnosed disabilities may show significant functional gains when properly treated and stimulated\(^3,7\). In this respect, when analyzing the main causes of childhood functional disability, such as Down Syndrome (DS), Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP)\(^4,6\), is well known that these children’s development in not only delayed, but follows an abnormal course \(^4,7\). In these cases where the central nervous system (CNS) is impaired, early stimulation must be delivered, preferably, between zero and three years, a critical period to induce proper brain plasticity \(^4,6\). Thus, these children may potentially achieve the highest functional level, improving their health status and increasing social inclusion\(^3,6\).

The conditions presented by children with disabilities require multidisciplinary health care, mostly available only in specialized centers. In addition, assessment, diagnosis and intervention must occur as early as possible to a proper treatment planning, both child and family-centered\(^5,8\). Early intervention (EI) is conceived as a systematic and sequential approach aimed to prevent or mitigate eventual neurodevelopmental damages through therapeutic techniques and resources. It seeks to stimulate all domains interfering with the child's maturation, in order to favor motor, cognitive, sensory, linguistic and social development\(^6,9\). A great deal of researches has pointed out the benefits of EI in children with disabilities, bringing advances which can last years ahead. However, considering the varied target audience, along with the multi and interdisciplinary aspect of this approach, it is still relevant to study issues such as participant’s profile as well as type and duration of interventions, to better inform health care providers and families on how the EI programs for neurodevelopmental disabilities are planned and structured\(^4,6-11\).

In this regard, it is important to identify the clinical and sociodemographic characteristics of infants with developmental conditions receiving EI, as well as to explore the program contents and duration in order to enhance or modify future interventions and guide family support. Given the above, this study aimed to analyze the profile of children with neurodevelopmental disabilities attending an EI program.
2 METHODS

This is a document-based, retrospective and exploratory study with a quantitative approach. The research was approved by the Human Research Ethics Committee of Santa Catarina State University under the register number 1.016.357 of 03/30/2015 with CAAEE n. 39722114.7.0000.0118, in accordance with National Health Council resolution 466/12.

Data were gathered between February and April 2019 from the medical records of children with a confirmed diagnosis attending the EI program held at the Rehabilitation Center of Santa Catarina Foundation for Special Education (FCEE). The study’s population consisted of all medical records of children with a confirmed diagnosis, previously or currently involved in the EI program, registered between 2014 and 2018, time frame in which medical records were electronically available.

The study included children diagnosed with DS, ASD or CP, the main children’s disabilities assisted at the center, who have participated or are currently involved in the EI program, with a properly registered institutional medical record. Children without a defined diagnosis or with diagnoses other than the abovementioned were excluded from the study. Registers of children, who took part in other EI programs or without an available record at the data collection period, were also excluded. Figure 1 shows the records analysis flowchart and number of records included and excluded according to the criteria described above.
Figure 1. Flowchart for the medical record selection process (EI = early intervention; SD = Down's Syndrome; ASD = Autistic Spectrum Disorder; CP = Cerebral Palsy).

The medical records analysis focused on children’s clinical and sociodemographic data (age, sex, pregnancy time and type, birth delivery, diagnose and number of associated conditions); family information (parent’s age, education level and family income); evaluation and intervention data (initial evaluation date, type and number of medical and therapeutic/social evaluations, EI program admission date and duration, type and number of both regular therapeutic interventions and complementary interventions (e.g. hydrotherapy, equine therapy, visual stimulation). Birth ages less than 37 weeks were considered “preterm” and those from 37 to 42 weeks were classified as “term”\(^{10}\).

Data were collected and stored in an electronic spreadsheet through Excel® software. The data analysis involved descriptive statistics, where categorical variables are presented as frequency distribution whereas numeric variables are presented as means with standard deviations and amplitude.

3 RESULTS

Based on the children’s clinical and sociodemographic data, Table 1 shows an even distribution among the three clinical conditions analyzed, with each condition standing for
around 30% of total sample. Male sex was prevalent (71%), as well as cesarean delivery, with gestational time of around 36 weeks, with more frequent term births. Most children presented with one to three associated conditions.

The data related to parents’ characteristics are shown in Table 2. Parents had similar mean ages at child’s births, both mothers and fathers slightly over 30 years old. Most families had high school education and family income was greater than five minimum wages, more than half of the families receiving no social benefits.

Table 1- Children’s clinical and sociodemographic characteristics (n=79).

| Variables                      | f (%) | Mean ± SD | Min.- Max. |
|--------------------------------|-------|-----------|------------|
| **Main diagnoses distribution and sex** |       |           |            |
| DS                             | 26 (32)|           |            |
| Male                           | 18 (70)|           |            |
| Female                         | 08 (30)|           |            |
| ASD                            | 26 (34)|           |            |
| Male                           | 23 (89)|           |            |
| Female                         | 03 (11)|           |            |
| CP                             | 27 (34)|           |            |
| Male                           | 15 (56)|           |            |
| Female                         | 12 (44)|           |            |
| **Sex (total)**                |       |           |            |
| Male                           | 56 (71)|           |            |
| Female                         | 23 (29)|           |            |
| **Birth delivery**             |       |           |            |
| Cesarean                       | 48 (60)|           |            |
| Natural                        | 29 (37)|           |            |
| Not informed (Adoption)        | 02 (03)|           |            |
| **Pregnancy time (weeks)**     |       | 36.2 ± 4.18| 24 - 42    |
| Term                           | 49 (62)|           |            |
| Preterm                        | 30 (38)|           |            |
| **Associated conditions**      |       |           |            |
| 02 to 03                       | 62 (78)|           |            |
| 04 to 07                       | 17 (22)|           |            |

f - simple frequency; % - relative frequency; SD - standard deviation; Min.- Max. - Minimum and maximum. DS = Down syndrome; ASD = Autistic Spectrum Disorder; CP = Cerebral Palsy.
Table 2. Parents’ sociodemographic characteristics (n=79).

| Variables                              | f (%) | Mean ± SD | Min.- Max. |
|----------------------------------------|-------|-----------|------------|
| Mother’s age at birth (years)          |       | 31.5 ± 8.3| 14.7 - 47.9|
| Father’s age at birth (years)          |       | 33.6 ± 8.2| 18.9 - 51.4|
| **Mother Education**                   |       |           |            |
| Elementary School (Complete or Incomplete) | 24 (30) |           |            |
| High School (Complete or Incomplete)   | 36 (46)|           |            |
| Higher Education (Complete or Incomplete) | 16 (20) |           |            |
| Not available                          | 03 (04)|           |            |
| **Father Education**                   |       |           |            |
| Elementary School (Complete or Incomplete) | 25 (32) |           |            |
| High School (Complete or Incomplete)   | 33 (42)|           |            |
| Higher Education (Complete or Incomplete) | 12 (15) |           |            |
| Not available                          | 09 (11)|           |            |
| **Family income**                      |       |           |            |
| > 5 MW                                 | 26 (33)|           |            |
| 2 - 5 MW                               | 25 (32)|           |            |
| ≤ 1 MW                                 | 22 (28)|           |            |
| Not available                          | 06 (07)|           |            |
| **Social Benefits**                    |       |           |            |
| Yes                                    | 18 (23)|           |            |
| No                                     | 54 (68)|           |            |
| Not available                          | 07 (09)|           |            |

f - simple frequency; % - relative frequency; SD - standard deviation; Min.- Max. - Minimum and maximum; MW - minimum wage.

For initial evaluation and EI admission, Table 3 shows that children were first evaluated with almost two years old and were admitted to the EI program at around two and half years old. The records indicated that about 20% of the children did not undergo a medical evaluation. Among those evaluated, there was a prevalence of evaluations with a pediatrician (46%), less than half of children was evaluated by an otolaryngologist (37%) or neurologist (20%), and only four children were evaluated by a psychiatrist. In the initial social and therapeutic evaluation, the medical records pointed out that children with disabilities were mostly assessed in areas such as physical therapy, speech therapy, psychology and special...
education, with occupational therapy and nutrition as the least frequent areas of evaluation. Most children underwent an initial evaluation of four to six professionals in addition to physicians (Table 3).

Table 3. Data on the initial assessment and admission to the EI program for children with disabilities. (n=79).

| Variables | f (%) | Mean ± SD | Min.- Max. |
|-----------|-------|-----------|------------|
| Age at initial assessment (months) | 22 ± 16,7 | 0,1 - 59 |
| Age of admission to EI program (months) | 28 ± 19,6 | 1,1 - 69 |
| Time between initial assessment and EI admission (months) | 7,1 ± 6,2 | 0,2 - 29 |
| Number of medical evaluations | 1,2 ± 0,8 | 0 - 3,0 |
| None | 15 (19) | | |
| One | 43 (54) | | |
| Two | 15 (19) | | |
| Three | 06 (08) | | |
| Medical evaluation specialties (n = 5) | | |
| Pediatrician | 37 (47) | | |
| Otolaryngologist | 29 (37) | | |
| Neurologist | 16 (20) | | |
| Ophthalmologist | 05 (06) | | |
| Psychiatrist | 04 (05) | | |
| Areas of Initial social and therapeutic evaluation (n=8) | | |
| Speech Therapy | 75 (95) | | |
| Physical Therapy | 66 (83) | | |
| Special Education | 61 (77) | | |
| Psychology | 55 (70) | | |
| Social services | 47 (59) | | |
| Dentistry | 19 (24) | | |
| Occupational Therapy | 03 (04) | | |
| Nutrition | 01 (01) | | |
| Number of areas of initial social and therapeutic evaluation. | 4,1 ± 1,0 | 2,0 – 6,0 |
| 02 to 03 | 18 (23) | | |
| 04 to 06 | 61 (76) | | |

f - simple frequency; % - relative frequency; SD - standard deviation; Min.- Max. - Minimum and maximum; EI – early Intervention.
Table 4 brings the data of regular therapeutic interventions in the EI program. The records showed that, among the six identified intervention modalities, the areas of physical therapy, speech therapy, special education and occupational therapy reached higher proportions. With respect to complementary interventions, hydrotherapy and hippotherapy were more frequent. The children with disabilities participated in the EI for a mean of 2.7 years, most of them receiving two to five intervention areas.

| Intervention areas (n=9) | f (%) | Intervention time in years (Mean ± SD) | Min. - Max. |
|-------------------------|-------|----------------------------------------|-------------|
| **Regular (n=6)**       |       |                                        |             |
| Speech Therapy          | 79 (100) | 3.5 ± 2.0                              | 0.2 - 6.2   |
| Special Education       | 63 (80)  | 3.0 ± 1.8                              | 0.1 - 5.8   |
| Physical Therapy        | 55 (70)  | 3.8 ± 1.8                              | 0.1 - 5.8   |
| Occupational Therapy    | 40 (51)  | 2.5 ± 2.0                              | 0.1 - 5.8   |
| Psychomotricity (Physical Education) | 36 (46)   | 1.7 ± 1.4                              | 0.2 - 5.7   |
| Psychology              | 22 (28)  | 2.0 ± 1.9                              | 0.2 - 5.8   |
| **Complementary (n=3)** |       |                                        |             |
| Hydrotherapy            | 34 (43)  | 2.5 ± 1.9                              | 0.2 - 5.8   |
| Hippotherapy            | 30 (38)  | 1.9 ± 1.4                              | 0.3 - 5.4   |
| Visual stimulation      | 16 (20)  | 2.0 ± 1.8                              | 0.5 - 5.9   |
| **Total EI time**       |       |                                        | 3.5 ± 2.0   | 0.2 - 6.2   |
| **Number of intervention areas in the EI program** |     |                                        |             |
| 02 to 05                | 52 (66)  |                                        |             |
| 06 to 08                | 27 (34)  |                                        |             |

f - simple frequency; % - relative frequency; SD - standard deviation; Min.- Max. - Minimum and maximum; EI – early Intervention.

4 DISCUSSION

This study aimed to analyze the main clinical and sociodemographic characteristics of children with disabilities treated in an early intervention program. The conditions analyzed in the present study included disorders involving the developing CNS, focusing on the diagnoses of DS, ASD and CP. It was possible to observe a homogeneous distribution among the three
clinical conditions, with each diagnosis representing about 30% of the 79 children with analyzed records. Boys prevailed through the three conditions, mainly in DS and ASD, with a more uniform sex distribution in CP. Most children had up to three associated conditions and were born at term by cesarean section. These results agree with previous studies\textsuperscript{7,9,11-13} demonstrating the prevalence of males in DS and ASD, despite the lack of clear evidence explaining why ASD would be more common in boys\textsuperscript{12,13}. Regarding the gestational profile and type of delivery, similar findings were observed in Alves et al.\textsuperscript{14} who verified 85% of cesarean delivery in a sample of 13 children with DS. Johnston et al.\textsuperscript{15} pointed that the risk of CP may increase with shorter gestation time and cesarean delivery. The current study found a mean close to 36 weeks’ gestation, with 40% of children born preterm, which can increase the odds of pre and perinatal complications, and interfere negatively in the development\textsuperscript{6,16,17}. Accordingly, even when disorders may not be recognized or diagnosed at birth, as in CP and ASD, children could still be eligible for an EI program due to prematurity and birth complications\textsuperscript{4,13,17,18}.

When analyzing the family data of children with disabilities, it was observed an educational and economic variability, with families reporting low earnings and poor literacy while others had better education and income status. Less than half of the sample reported earnings up to one minimum wage (28%) and one third informed incomes above five minimum wages (33%), which seems to have resulted on a low number of families receiving social benefits. This data is relevant to health care and education providers working with EI, in order to offer both family-centered guidance and advice that match the parents’ understanding and context\textsuperscript{19-22}. The income and educational levels variety may indicate that families tend to weigh more the wide availability of multidisciplinary interventions than the program free and public access\textsuperscript{5,6,19-22}. Thus, maybe the assumption that only low income families tend to seek for public health services, does not apply to EI programs.\textsuperscript{5,7,18-22}.

The study found a late initial evaluation process, when the children were close to two years old. Even though the evaluations started after the period recommended by the literature\textsuperscript{4-6,17}, they involved a multidisciplinary team, both medical and therapeutic, which is very relevant for diagnosis definition and therapeutic planning. In this respect, over 50% of the children underwent an evaluation in some medical specialty, mostly by a pediatrician. This is expected, since the pediatrician is the child first contact professional, able to carry out detailed assessments and early detect neurological signs, as well as suggest other professionals follow-up\textsuperscript{4,6,17,18}. In contrast, only 20% of the children were evaluated by a neurologist and only five
went through a psychiatrist. Although these areas of medical specialty may be less frequent in EI when compared to pediatrics, previous studies\(^5,17,20\) highlight the importance of monitoring with those clinicians, especially in the ASD, once they contribute to identify neurodevelopmental dysfunctions.

Among the initial social and therapeutic evaluations, speech therapy and physical therapy were the specialties most frequently registered. In fact, delays in both communication and motor development areas represent the main warning signs for developmental problems, which makes these assessments prevalent in EI programs and of relevance according to families\(^7,19,22,23\). However, there seems to have been less attention to sensory aspects and self-care, since there were no records of initial assessment with an occupational therapist. This gap can impact the identification of sensorimotor dysfunctions, which are of concern especially in suspected ASD\(^19,23\).

Regarding the EI entry, the children's data indicated they started the EI close to 2.5 years old, with an eight-month waiting period until admission, considering they were only evaluated with almost two years old. These findings of EI entry age are way above the 12-month limit to start early intervention as recommended on previous researches\(^4,7,24\). Certainly, the potential to reduce the impact of CNS impairment occurs when the intervention stimulus start soon after the birth, thus making it possible to minimize the development damages and promote brain plasticity\(^4,6,24,25\). Nevertheless, the increasing demand for EI programs surpasses the offer of such specialized service, with qualified care through a multidisciplinary team\(^3,19,20,24\). Consequently, the pent-up demand influences the waiting time to enter the program. Besides, since de evaluation and EI program are two separate services at the institution, this may have influenced the standby time as well. All those aspects undermine the urgency of access to these interventions, which, in addition to providing functional gains to children, can reduce the significant family and social costs related to these disabilities throughout life\(^20,24\).

The children participated in the EI program for a little over three years on average, given the program holds an age limit of six years old. Scherzer et al.\(^24\), carried out a systematic review of early intervention studies in children with disabilities and found out a wide variation for programs duration, intensity and types of therapies involved. Our data showed that speech therapy, special education and physical therapy were the most frequent interventions, while less than 30% received psychological counseling. Both communication and motor development are areas commonly covered in most EI programs, with different professionals...
acting in these components. Language acquisition stimulation, communication strategies and motor milestones achievement are crucial during EI, especially for a family-centered care. 21,22,24-27. The cognitive area was addressed by the special educator, although other services have the psychologist as a reference professional. The intervention in this development component receives influences from several specialties, and the program audience and context directs the professional acting in this aspect 6,7,17,19,25.

Most children went through two to five areas of care, reaching up to eight different types of intervention and varying length of stay. Complementary therapies such as hydrotherapy and hippotherapy were performed by about 40% of children. Different approaches aim to expand the brain's learning potential in face of different inputs, providing children with experiences that will make them explore, acquire skills and understand what is happening around them, relevant principles for improving development 19,24,25,30. Nonetheless, once a child receives several interventions by a multidisciplinary team, even if they are clinically relevant in this population 28-30, it becomes difficulty to distinguish the most effective intervention and when excessive stimulation may occur 4,7,18,24,25.

The study has some limitations, such as the lack of records evidencing outcome measures to evaluate interventions. Furthermore, there was no clear information on the duration of sessions and their weekly frequency. Another issue was the inconsistent data on possible EI prior to the program addressed. The data analysis from medical records brings a variety of information of great relevance 5,7,24, but when choosing the variables of interest, it has to be considered the professionals' capacity of registration and, therefore, some important data could not be analyzed due to the lack of homogeneity for some information.

5 CONCLUSION
In conclusion, amid the 79 records of children with CNS-related disabilities in the EI program, there was an even distribution of clinical conditions, most with at least one associated diagnosis. In addition, families have a wide variation in educational level and financial resources. Most children were initially evaluated by a pediatrician and a multidisciplinary team. Both evaluations and EI entry occurred late, when children were around two years old. Once admitted in the EI program, the majority went through interventions with speech therapist, special educator, physical therapist and occupational therapist. Children remain in the EI for about three years, going through two to five areas of intervention.
The findings presented are relevant in order to provide information for structuring and modifying EI programs aimed at children with disabilities, mainly for CNS impairments. Early evaluation and intervention programs based on a multidisciplinary approach require professionals familiar with teamwork and prepared to deal with different diagnoses and a varied family context. Thus, the team members must suit their communication skills to meet the families' needs, thereby strengthening the interventions offered.

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