School inclusion of children and adolescents with cerebral palsy: is this possible for all of them in our days?

Inclusão escolar de crianças e adolescentes com paralisia cerebral: esta é uma realidade possível para todas elas em nossos dias?

Inclusión escolar de niños y adolescentes con parálisis cerebral: ¿es ésta una realidad posible para todos ellos los días actuales?

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ABSTRACT

Objective: To describe the school distribution of a group of children and adolescents with cerebral palsy (CP) and to analyze the impact of gross motor function and other deficits in the inclusion process.

Methods: Prospective study of patients from de Outpatient Clinic for Cerebral Palsy of the Federal University of Paraná, Brazil, in 2005. Parents or caregivers completed a questionnaire about type of school attended at the moment, learning disabilities, and need for psychopedagogic and speech-language support. Data collected included who was primary caregiver, his/her school level and *per capita* income. Data obtained from medical records were: perinatal and post natal antecedents, topographic classification of CP and motor function (Gross Motor Function Classification System – GMFCS), speech classification and presence of epilepsy.

Results: 105 children and adolescents were included. Mean age was 10.8 years old and 61 (58%) were male; 97 (92%) attended school, with 36 (34%) in regular classes, 7 (6.5%) in special classes and 54 (51%) in special schools. Most of the children attending regular school had GMFCS level I or II, hemiplegia, absence of epilepsy or good control of seizures and either normal speech or dysarthria. Those in special schools had GMFCS levels III, IV or V, diplegia or tetraplegia, refractory epilepsy and a delayed speech or muteness.

Conclusions: Up to now, inclusion of children with CP in regular schools proved to be indicated for those hemiplegic, with GMFCS level I or II, without epilepsy and with normal speech.

Key-words: cerebral palsy; school inclusion; child; adolescent.

RESUMO

Objetivo: Descrever a distribuição escolar de um grupo de crianças e adolescentes com paralisia cerebral (PC) e analisar o impacto da função motora grossa e outros déficits no processo de inclusão.

Métodos: Estudo prospectivo de pacientes do Ambulatório de Paralisia Cerebral da Universidade Federal do Paraná, avaliados em 2005. Pais ou cuidador completaram um questionário com dados relativos a: tipo de escola frequentada, dificuldades do aprendizado e necessidade de suporte psicopedagógico e fonoaudiológico. Os dados obtidos incluíram quem era o cuidador primário, seu nível de escolaridade e renda. As variáveis coletadas dos prontuários foram antecedentes perinatais e pós-natais, classificação topográfica da PC e função motora (Sistema de Classificação Motora Grossa – SCFMG), classificação da fala e presença de epilepsia.

Resultados: 105 crianças e adolescentes foram incluídos. A média de idade foi 10,8 anos, 61 (58%) masculinos. Dentre

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as 105 crianças, 97 (92%) frequentavam a escola, 36 (34%) em classe regular, 7 (6,5%) em classe especial e 54 (51%) em escola especial. Crianças que frequentavam a escolar regular apresentavam predominantemente SCFMG nível I ou II, hemiplegia, epilepsia ausente ou com bom controle e fala normal ou disartria. Aqueles em escola especial eram crianças com SCFMG níveis III, IV e V, diplegia ou tetraplegia, epilepsia refratária e atraso na fala ou sua ausência.

Conclusões: Até o momento, a inclusão de crianças com PC em escolas regulares parece trazer benefícios para aquelas com hemiplegia, nível I ou II do SCMFG, sem epilepsia e com fala normal.

Palavras-chave: paralisia cerebral; inclusão escolar; criança; adolescente.

RESUMEN

Objetivo: Describir la distribución escolar de un grupo de niños y adolescentes con Parálisis Cerebral (PC) y analizar el impacto de la función motor gruesa y otros déficits en el proceso de inclusión.

Métodos: Estudio prospectivo de pacientes del Ambulatorio de Parálisis Cerebral de la Universidad Federal de Paraná, Brasil, evaluados en 2005. Padres o cuidador completaron un cuestionario con datos relativos a: tipo de escuela frecuentado, dificultades de aprendizaje y necesidad de auxilio psicopedagógico y fonoaudiológico. Los datos obtenidos incluyeron quién era el cuidador primario, su nivel de escolaridad e ingresos. Los datos recogidos de los prontuarios fueron antecedentes perinatales y post-natales, clasificación topográfica de la PC y función motora (Sistema de Clasificación Motora Gruesa - SCFMG), clasificación del habla y presencia de epilepsia.

Resultados: Se incluyó a 105 niños y adolescentes. El promedio de edad fue de 10,8 años, 61 (58%) masculinos. Entre los 105 niños, 97 (92%) frecuentaban la escuela, 36 (34%) en clase regular, 7 (6,5%) en clase especial y 54 (51%) en escuela especial. Niños que frecuentaban la escuela regular presentaban predominantemente SCFMG nivel I o II, hemiplejía, epilepsia ausente o con buen control y habla normal o disartria. Aquellos en escuela especial eran niños con SCFMG niveles III, IV y V, diplejía o tetraplejía, epilepsia refractaria y retraso en el habla o su ausencia.

Conclusiones: La inclusión escolar de niños con PC es un tema complejo. Hasta el momento, la inclusión de niños con PC en escuelas regulares parece traer beneficios para aquellos con hemiplejía, nivel I o II del SCMFG, sin epilepsia y con habla normal.

Palabras clave: parálisis cerebral; inclusión escolar; niños; adolescentes.

Introduction

Cerebral palsy (CP) describes a group of permanent developmental disorders of movement and posture that limit activities and are attributed to non-progressive damage occurring in the fetal or infant brain. The motor disorders caused by CP are often combined with disorders of the senses, of perception, cognition, communication and behavior; and epilepsy and musculoskeletal problems are also commonly observed in these children[1]. Cerebral palsy affects approximately two out of every thousand live births and is the most common cause of physical incapacity in childhood[2,3].

Cerebral palsy can be classified on the basis of type of movement, topographical distribution, etiology, the time of insult and neuroimaging findings, among other variables[1]. Palisano *et al*[4] developed a Gross Motor Function Classification System (GMFCS) that was published in 1997 and has been adopted by researchers and clinicians all over the world. The system was developed in order to respond to the need for a standardized classification for the gross motor function of children with CP aged 1 to 12 years[4]. Focus is on movement initiated by the children themselves. The (GMFCS) is based on 5 levels of an ordinal scale, but the distance between them is not equal and there is no expectation that children with CP will be equally distributed across the levels. The differences between the levels of the GMFCS are focused on functional limitations and the need for assistive technologies, including mobility accessories and wheelchair use, more than on the quality of movement[4]. The version adapted for Portuguese is supposed to be available on the internet: http://www.hc.ufpr.br/acad/pediatrics/index.htm.

The World Health Organization[5] considers that the ability to perform activities and to participate in day-to-day situations is an essential component of good health. It is therefore believed that including children with special needs in regular schools should be beneficial to their development and should improve their quality of life. Schenker *et al*[6] examined the relationship between school participation and academic performance (normal class and special class) and motor (GMFCS), cognitive and behavioral impairments. Their results suggested that both participation

and performance increase for those with less severe motor incapacities. Children who were always included in regular classes suffered less impact from their difficulties with communication and learning than children in special classes. Unesco[7] has been conducting a worldwide project to promote the inclusion of children with incapacities into the general education system and the number of inclusion programs has risen over recent decades. In Canada, the number of children with CP being taught in regular classes has increased from 20% in the 1970s to 75%[8].

On December 20 of 1999, the President of Brazil signed decree number 3,298 into law, formalizing a provisional law of 1989 which had proposed the integration of people with disabilities, thereby making it obligatory for people with physical, auditory, visual and mental disabilities to be included in regular schools[9]. It is within this context that this study was designed to analyze the inter-relationships between functional difficulties faced by children with CP in a school setting and to evaluate the differences in levels of participation when analyzed with respect to type of CP, functional level and presence of other associated neurological impairments, preparatory to a discussion of whether all children with CP are able to adapt to the system of inclusion mandated by the legislation mentioned above.

Method

The parents of 105 children and adolescents with a diagnosis of CP were asked to give permission for their children's participation in the study. The sample was selected by convenience from consecutive patients attending a tertiary neuropediatrics center at the UFPR Hospital de Clínicas' cerebral palsy clinic for previously arranged follow-up appointments, between March and July of 2005. Inclusion criteria were a diagnosis of Cerebral palsy, regular attendance at the clinic and age up to 19 years. Exclusion criteria were carers who were unable to provide the information requested, did not agree to participation or were prevented from completing the questionnaire by some impediment such as illiteracy or a lack of reading glasses. The study was approved by the Human Research Ethics Committee at the Universidade Federal do Paraná (UFPR) and informed consent was obtained from parents/guardians.

The following data were harvested from medical records: prenatal, perinatal and postnatal events that led to CP, predominant CP movement type, topographical CP classification, GMFCS class, speech class (normal, dysarthria, delayed and none) and whether epilepsy was present and, if so, the level of epilepsy control. At the time of data collection, and in the presence of the patient, all of these data were discussed with the lead author, who is responsible for the clinic. Parents and/or carers were asked to fill out a standardized questionnaire about the child's educational status, the type of school and the type of classes they were attending, specific learning difficulties and any need for support from a psychopedagogist or speech therapist. They were also asked who the child's primary carer was, what level of education they had reached (the carer) and what the child's family's per capita income was. At the end of the interview the difference between the child's actual grade and the normal grade for their age was calculated (in Brazil children must pass an end-of-year examination to proceed to the next grade). The parents responded to these questionnaires during the interviews and any questions they raised were answered by the lead author.

Data were tabulated in a spreadsheet and analyzed using MedCalc to perform the chi-square test to test for associations between categorical variables.

Results

The cerebral palsy clinic has approximately 2,000 children, adolescents and young adults with a diagnosis of CP on its register and around half of them attend regular

Table 1 - Distribution of the population by type of school attended and GMFCS level

	Regular		Special Class		Special school		Does not go to school	
	n	%	n	%	n	%	n	%
GMFCS I	14	13.2	3	3	2	2	0	0
GMFCS II	14	13.2	3	3	6	5.7	0	0
GMFCS III	5	5	1	1	7	6.5	0	0
GMFCS IV	3	3	0	0	21	20	3	3
GMFCS V	0	0	0	0	18	17	5	5

GMFCS: Gross Motor Function Classification System

follow-up appointments. Five of the patients seen during the study period were not enrolled, three of them because their carers were illiterate and two because their carers had presented without their reading glasses. As a result, 105 of the 110 patients seen during the period were actually analyzed for the study.

General characteristics of the sample were as follows: there was a predominance of males, with 61 (58%) male patients; mean age was 10.8 years, with a range of 6 to 19 years and a standard deviation (SD) of 3.6 years; 91 (87%) of the children and adolescents' carers were their mothers, 6 (6%) were cared for by their fathers and 8 (7%) had carers who were not their parents; 2% of carers were illiterate, 49.5% had attended, but not graduated from, elementary school, 16% had graduated elementary school, but not attended high school, 14% had attended, but not graduated from, high school, 13% had graduated high school, 3% had been accepted on, but not graduated from, higher education courses and 2% had graduated higher education; family income varied from R$40.00 to R$500.00 per month with a mean of R$196.06 (SD: 103.34); and 9.6% of the families lived entirely on the benefits awarded to their children by social security (INSS).

With regard to the etiology of CP, 25% of causes could be traced back to the prenatal period, with the most common etiologies being malformations and cerebral vascular accidents; 56% of causes occurred during the perinatal period, with hypoxia-ischemia and prematurity the most common, in 14% cerebral palsy was the result of postnatal events and in 5% the causes were unknown. Ninety-one of the 105 CP patients had spasticity, with 31 (29.5%) suffering from hemiplegia: 12 (39%) on the right and 19 (61%) on the left; 14 (13%) patients had diplegia, 23 (22%) had double hemiplegia and 23 (22%) patients were suffering from tetraplegia. Mixed forms were observed in 14 (13%) patients. The GMFCS classifications were as follows: 19 (18%) children were at level I, 23 (22%) at level II, 13 (12%) at level III, 27 (26%) at level IV and 23 (22%) children were at level V.

Ninety-seven (92%) of the 105 patients analyzed were attending school and 36 (34%) were in regular classes, 7 (6.5%) were taught in special classes within a regular school and 54 (51%) patients attended a special school (Table 1). Eighteen of the children in regular classes at regular school were behind the expected grade for their age, by a mean of 2 years, and 12 of them were receiving support from a psychopedagogist. The majority of these children suffered from spasticity; 23 with hemiplegia, 5 with diplegia and 5 with double hemiplegia. Three had mixed forms. The GMFCS classifications for the 36 children in regular classes were as follows: 14 at level I, 14 at level II, 5 at level III and 3 at level IV. The majority of those in special classes within regular schools also suffered from spasticity: 4 had hemiplegia and 1 had double hemiplegia. Two of these children had mixed CP. Three of them were classified at GMFCS level I, 3 at level II and 1 at level III. All of the children at special schools had spasticity, with 21 suffering tetraplegia, 14 double hemiplegia, 8 diplegia and 3 hemiplegia. Twenty-one of the special-school pupils were GMFCS level IV and 18 were level V. Spasticity also predominated among the eight children who did not go to school, two of whom had tetraplegia, 3 of whom had double hemiplegia and 1 of whom had hemiplegia. One of these patients had mixed CP.

With regard to associated neurological problems, 85 (80%) of the patients had language and speech disorders. Twenty-seven of them had no speech whatsoever, 20 had language delays and 38 had dysarthria. Sixty-one children were being treated by a speech therapist, with mean age at start of treatment of 68 months (SD: 38.5 months) and mean treatment duration of 46 months (SD: 20 months). It will be observed from Table 2 that speech classed as normal predominated among the children at regular school, followed by dysarthria, (Dysarthria predominated in regular classes of regular school followed by normal speech) and just one child at regular school could not speak at all. Dysarthria was the most common speech classification among the children in special classes at regular schools. The majority of the children

Table 2 - Distribution of the population by type of school attended and speech assessment result

	Regular		Special Class		Special school		Does not go to school	
	n	%	n	%	n	%	n	%
Normal	16	15	1	1	3	3	0	0
Delayed	1	1	1	1	16	15	2	2
Dysarthria	18	17	4	4	16	15	0	0
No speech	1	1	1	1	19	18	6	5.7

at special schools were unable to speak, with delayed speech and dysarthria in equal second rank, and just three children at special schools had speech classified as normal.

With regard to sight, 11 (10%) patients had visual impairments, 2 of them were in regular classes, 1 was in a special class at a regular school and 7 were at special schools. Hearing deficits were detected in 3 (3%) patients, all at special schools.

Forty-eight (46%) of the patients had epilepsy. In 34 of them the epilepsy was under good control and 11 of them were taught in regular classes. Fourteen patients suffered from refractory epilepsy: 9 who attended special school, 4 who did not go to school and just 1 who went to regular classes.

Discussion

The policies of integration and inclusion in regular school activities have promoted the social participation of disabled children. Schools are the primordial environment for educating and socializing developing children and school activities have positive effects on children's health and well-being. Simeonsson *et al*[10] studied groups of children with special needs who were taught in regular or special classes and observed that the children in regular classes exhibited a greater degree of social interaction with children without disabilities and had more friends, when compared with those in special classes.

All of the children in this study had a diagnosis of CP with motor impairment plus at least one other disorder and were classified at different GMFCS levels. Few studies have investigated the relationship between incapacities and participation in school activities. The results of this study show that inclusion in regular education was dependent on better functional levels, i.e., GMFCS levels I and II and fewer intercurrent disorders. Children with visual or hearing impairments did not attend regular classes. Schenker *et al*[6] observed that visual difficulties constitute a barrier to children attending regular lessons. The same authors also observed significant differences in participation and performance between children at different GMFCS levels, with patients at levels III and IV having more restricted participation. The study did not describe any level V patients, probably because they attend special institutions in that country, (Israel) In the present study it was also observed that the majority of children in regular schools had hemiplegia and were at GMFCS levels I or II, in line with the observations reported by Schenker *et al*[6] Mancini *et al*[11] classified children exclusively on the basis of the degree and severity of their motor limitations and found that reduced participation may be more closely associated with increasing motor incapacity than with topographic CP type. These data indicate the importance of classifying patients according to their motor function, rather than giving their topographic classification too much weight, and stressed the need for professionals who care for these children to familiarize themselves with the GMFCS.

Another variable that limits participation in regular school activities is the presence of cognitive deficits. Schenker *et al*[6] and Menkes and Sarnat[12] found significant differences in the cognitive/behavioral disorders of children with motor limitations, showing that greater motor impairment was related with poorer cognitive performance. Cognitive assessments were not analyzed for this sample because approximately 40% of participants could not be evaluated with the scales used at the clinic.

Language is a prerequisite for socialization and in part is a reflection of a person's cognition and their resulting participation in activities that are normal for children of their age, meaning it is very important for inclusion at school. Certain longitudinal studies have shown that language development delay is a predictor of below-average intelligence and of mental retardation diagnosed when at school age[13-15]. It has also been reported that delays learning to speak are related to reduced reading ability and behavioral problems[14]. The patients in the present sample had varying degrees of language problems, but those with the greatest difficulties, particularly those who could not talk, were attending special schools. Schenker *et al*[6] reported similar results, observing that children with language difficulties were less likely to take part in school activities, and concluded that disorders affecting communication have the potential to isolate children from other people in the school environment.

In conclusion, it was found that not only do motor limitations caused by CP have a negative impact on school inclusion, but also that the presence of associated problems, such as speech disorders and refractory epilepsy, can constitute a significant barrier to true school inclusion. In this study, no resistance was observed on the part of parents or carers with relation to access to different types of school. The homogeneity of the population in terms of educational level and low per capita income precluded analyses of these data in this study.

Simeonsson *et al*[10] reminds us that the participation of children with special needs is not only dependent on

individual factors, but also on adapting the school environment to make it possible for them to access these activities.

The question therefore remains of whether it is possible, today, to apply the inclusion legislation to all children with CP and close down the special schools. Is it possible for regular schools to absorb children with CP at GMFCS levels IV and V combined with moderate to severe mental retardation and/or no language function? Do today's schools have staff who are adequately prepared to care for these children, the necessary environmental conditions and the modifications to enable positioning and mobility that are required in order to include this population? It is of fundamental importance to understand that this is an extremely complex subject and one which must be considered with great deal of attention and forethought if teachers and schools are to be enabled to adapt to this situation, transforming schools into places for social integration where people learn tolerance for differences. The possibility of offering specialized attention combined with socialization during leisure time, which is a characteristic of special classes, would appear an interesting option during this time of transition. There is no doubt that the most important priority is to protect these children, since if they were to be exposed to environments that are not appropriate for their inclusion they could find themselves in situations of complete social exclusion. Meanwhile, we await the conditions under which the policy of inclusion can be comprehensively applied to all disabled children, including those with severe CP.

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