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Profile of children with neurodevelopmental disabilities who are referred to rehabilitation clinics: A pilot study

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Summary

Aim: The aim of the study was to define the profile of the children with neurodevelopmental disabilities who were referred to a pediatric rehabilitation clinic and to identify the risk factors related to their problems.

Material and Method: Three hundred and ninety-six children and their parents who were referred to a rehabilitation clinic for special education, physiotherapy and rehabilitation between April 2000 and April 2012 were included in this study. All their records were analysed retrospectively.

Results: 52.8% (n=209) of the children were boys and 47.2% (n=187) were girls. The number of children with Cerebral Palsy (CP) were in the first order and the number of children with Mental Retardation (MR) were in the second order among children with neurodevelopment disabilities. The quadriparetic type of CP was observed with the highest rate both in spontaneous vaginal deliveries and cesarean deliveries. There was no statistical difference between the gestational age and types of CP ($p<.05$). Types of CP were different according to the type of delivery ($z=-3.021$, $p=0.003$). 32.8% of the mothers and 73.5% of the fathers were working. 92.2% of the mothers had undegone regular health control during pregnancy, 97% of them delivered in a hospital, 51% had normal vaginal delivery and 49% had cesarean section.

Conclusions: This is the first and only study which defines the profile of the children with neurodevelopmental disorders who are referred to pediatric rehabilitation clinics. The results of this study will contribute to define the needs of the children and their families who apply to a pediatric rehabilitation clinic and will help to identify the framework and concept of special education, physiotherapy and rehabilitation programs according to their states and needs. *(Turk Arch Ped 2013; 48: 303-309)*

Key words: Cerebral palsy, neurodevelopmental, rehabilitation, physiotherapy

Introduction

Many disorders occur as a result of delays or changes in the process of development of the brain of the child. These disorders affect one of every 20 children. Neurodevelopmental disorder is known as disruption in growth and development of the brain or central nervous system (1). This term is sometimes used incorrectly specifically for autism or autistic spectrum disorder (2). The causes of neurodevelopmental disorder include genetic factors, premature birth, metabolic, immunological and infectious diseases, nutritional factors, physical trauma and toxic and environmental factors (3,4).

To understand that the disorder has arised from neurodevelopmental failure, it should have occurred in infancy or early childhood. Attention deficit and hyperactivity disorder, autism or autistic spectrum disorders, congenital injuries including cerebral palsy (CP), communication, language and speech disorders, genetic disorders including fragile-X, Down syndrome and Rett syndrome, neurological and psychiatric disorders including epilepsy and learning difficulty are defined as neurodevelopmental disorders (5,6,7). The common symtomps of the disorders observed in this spectrum include motor development problems, sensory integration disorders and failure in

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certain conginitive abilities including language and speech retardations and learning difficulty, weakness in organized abilities and behavioral problems. Special education, physiotherapy and rehabilitations applications are used to minimize these disabilities, eliminate them if possible and to provide independence in daily life conditions.

In Turkey, special education, physiotherapy and rehabilitation applications for children with neurodevelopmental disorders have been continued in special education and rehabiltation centers and/or special education schools since 1995. However, it is remarkable that there is no study related with children with neurodevelopmental disorders who need special education and rehabilitation service and their families in our country. There is no data related with the prenatal and postnatal history, risk factors, familial characteristics, environmental conditions and present disability states in these children. Identifying clear data related with the demographic properties and demonstration of states and sociodemographic properties of the children with neurodevelopmental disorders attending special education and rehabilitation centers and/or schools will provide evaluation of the service which is being given currently. Considering all these, our study was planned to demonstrate the states of the children and their families who were referred to a child rehabilitation center in which special education and rehabilitation service was given between 2000 and 2012 and to determine the risk factors. This study is the first study performed in Turkey with this objective.

Material and Methods

The files of the children who were referred by physicians to a Disabled Children Rehabilitation Center between April 2000 and April 2012 for special education, physiotherapy and rehabilitation service were examined retrospectively. Children diagnosed with neurodevelopmental disorder including CP, mental retardation (MR), motor-mental retardation (MMR), Down syndrome (DS), learning difficulty, autism, pervasive developmental disorder, brachial plexus injury and microcephaly and their families were included in the study. In addition to the above mentioned diagnoses, rare syndromic disorders were included under the title of "other" (Noonan syndrome, Rett syndrome, tuberosclerosis, Canavan disease etc.). This study was evaluated by the ethics committee of Medical, Surgical and Pharmaceutical Investigations of Gazi University and found to be appropriate in terms of medical ethics.

Information about gender, gestational ages, birth height, birth weight, mode of delivery, time of delivery, type if CP (palsy, quadriplegic, diplegia), accompanying problems, stages of physical development and findings accompanying the disorders was recorded from the files of the children included in the study.

In terms of sociodemographic properties, information about ages of the parents at the time of delivery, consanguinity, presence of any other member with disability in the family and education levels was recorded.

"SPSS 15.0 for Windows" statistics program was used for statistical analyses. All variables were espressed as mean±standard deviation (X±SD). Descriptive analyses and Pearson's correlation test were used. A p value of <.05 was considered significant.

Results

A total of 396 children with neurodevelopmental disorder who presented to a private special education, physiotherapy and rehabilitation center between 2000 and 2012 to receive physical therapy and rehabilitation service and their families were included in the study. 52.8% of the children (n=209) were male and 47.2% (n=187) were female. It was found that the youngest child presented was 1 month 8 days old and the oldest one was 32 years 5 months and 9 days.

The diagnoses, mean ages, birth weights and heights, ages at the time of onset of special education, presence of epilepsy and school attendance states of the children are shown in Table 1. The distribution of the children diagnosed with CP according to CP type is shown in Table 2. While mental retardation was observed in 74.5% of all children, no mental problem was observed in 25.5%. It was found that the type of CP showed difference by mode of delivery ($z=-3.021$, $p=0.003$). CP types by mode of delivery are shown in Table 5. No relation could be found between birth weight and CP type ($p>.05$)

When the sociodemographic properties of the families were examined, it was observed that no consanguinity was present in 80.1%, while 19.9% had consanguinity. However, it was found that another disabled member was present in the family in only 9.1% of the children and no other disabled member was present in 90.9%.

While 67.2% of the mothers were housewives, 32.8% were working. 26.6% of the fathers were retired and 73.5% were working. The education levels of the parents are shown in Table 3. It was found that there was a relation between the age of the mother at the time of delivery and problem during pregnancy ($r=0.138$; $p=0.006$).

The relation between gestational age, ages of the parents at the time of delivery and times to reach motor development stages is shown in Table 4. It was found that gestational age was negatively related with times to attain the abilities to hold the head and sit ($p<.05$). The distribution of the children by gestational age is shown in Table 6.

It was found that 92.2% of the parents had regular doctor visits during pregnancy, 97% delivered in healthcare institutions, 92.2% were delivered by a physician, 51% delivered by spontaneous vaginal route and 49% delivered by cesarean section.

It was found that the accompanying problems in children with neurodevelopmental disorder were mostly in the auditory and visual areas. The problems accompanying disability groups are shown in Table 6. Gestational age and distribution of disability groups are shown in Table 7.

Discussion

Our study is the first study which demonstrates the sociocultural and demographic states of children with neurodevelopmental disorders presenting to special education, physiotherapy and rehabilitation centers and

Table 1. Distribution and general properties of neurodevelopmental disorders

Diagnosis	n	%	Age (year) (X±SD)	Birth weight (kg) (X±SD)	Birth height (cm) (X±SD)	Age at which special education was started (X±SD)	Patients with ccompanying epilepsy %	School attendence %
Mental retardation	69	17.4	8.9±6.5	3.0±0.75	48.3±3.6	8.8±6.2	17.4	58
Mental-motor retardation	32	8.1	4.6±4.5	2.7±0.86	47.1±0.8	3.3±3.8	18.8	12.5
Cerebral palsy	187	47.2	5.5±5.6	2.4±0.98	45.4±5.7	3.4±4.4	30.5	19.3
Down sydrome	23	5.8	5.5±5.7	3.3±0.5	49.7±3.6	3.9±4.7	0	8.7
Autism-PDD	19	4.8	7.3±5.5	3.6±0.6	50.3±1.4	4.0±1.6	5.3	52.6
Muscle diseases	8	2	7.4±5.2	3.3±0.5	51.4±1.6	3.1±3.0	0	62.5
Learning difficulty	9	2.3	6.8±2.9	3.1±0.5	50.6±1.5	6.8±3.5	11.1	66.7
Other	23	5.8	3.6±2.5	2.7±0.8	48.4±4.6	2.8±2.2	12.5	31.3
Spina Bifida	9	2.3	4.6±3	3.0±0.5	47.5±4.2	2.7±2.0	11.1	11.1
Brachial plexus	17	4.3	4.0±2.7	4.4±0.6	51.8±2.4	3.6±3.2	0	23.7

X: arithmetic mean, SD: standard deviation, PDD: pervasive developmental disorder

Table 2. Distribution of cerebral palsy

CP type	N	%
Diparesia	31	16.6
Hemiparesia	49	26.2
Quadriparesia	107	57.2

CP: Cerebral palsy

Table 3. Education level of the parents

Education level	Mother		Father	
	N	%	N	%
Illiterate	13	3.3	6	1.5
Primary school	126	31.8	95	24
High school	125	31.6	105	26.5
University	131	33.1	188	47.5
Postgraduate	1	0.3	2	0.5

Table 4. Relation between gestational age, age of the mother and father at the time of birth and motor development

	Holding the head		Sitting		Walking		Speaking		Eating		Toilet	
	r	p	r	p	r	p	r	p	r	p	r	p
Gestational age (months)	-.280	.000*	-.206	.002*	-.115	.174	.011	.902	.058	.565	-.008	.941
Age of the mother at the time of delivery (years)	-.038	.472	-.05	.386	-.064	.364	-.081	.267	.063	.445	-.029	.723
Age of the father at the time of delivery (years)	-.031	.556	.004	.944	-.055	.435	.039	.594	.199	.015*	.123	.133

p<.001

Table 5. Delivery mode and CP type frequencies				
BF Type	**Normal delivery**		**Cesarean section**	
	n	%	n	%
Diparesia	12	15	19	17.7
Hemiparesia	24	30	25	23.4
Quadriparesia	44	55	63	58.9

their families in our country. The results of this study will contribute to identification of the requirements of the children presenting to centers and their families and the scope and content of the approaches of education, physiotherapy and rehabilitation. In addition, our study is considerably important in terms of contributing to and directing development of intervention programs for these children.

When children with neurodevelopmental disorder presenting to the rehabilitation center were examined, it was observed that most of the children were in the CP group and the MR group was in the second order. The prevalence of cerebral palsy ranges between 1,5 in every 1000 live births and 3%. In Europe, CP is the most common childhood physical disability with a prevalence of 2-3 in every 1000 live births (8). In our country, the prevalence of CP is 3-4 in every 1000 live births which is higher compared to the developed countries (9). When we examined the distribution of the disorders in the center in our study, the CP group was in the first order and the MR group was in the second order in parallel to the prevalences in Turkey and Europe. In these centers in Turkey in which children with CP are served more intensively compared to the other groups, it is important to include specific programs and arrangements for children with CP in education and rehabilitation services given.

Studies related with the type of cerebral palsy have reported many different etiologies of CP types (10). CP types show variance especially according to the states of small for gestational age children who survived (8). In our study, no relation was found between birth weight and CP types, although the children in the CP group had the lowest birth weight ($p<.05$). Investigation of low birth weight, premature delivery, factors related with pregnancy and delivery will allow discussion of the issue in a multi-directional way.

In the study of Özmen et al. (11) conducted with 1873 subjects, 88% of CP types were reported to be spastic (57% quadriparetic, 18% hemiparetic and 13% diparetic) and 12% were reported to be diskinetic. When the CP types in the children included in our study were examined, quadriparetic CP which showes a more severe involvement

Table 6. Accompanying problems according to diagnoses									
Diagnosis	**Auditory proble %**	**Visual problem %**	**Swallowing problem %**	**Sleep problem %**	**Problem in commicating with sibling %**	**Problem in commicating with parents %**	**Problem in commicating with other children %**	**Behavioral problem %**
Mental retardation	5.8	15.9	1.4	1.4	5.8	1.4	1.4	2.9
Motor mental retardation	15.6	25	0	0	3.1	3.1	3.1	0
Cerebral palsy	5.9	32.1	3.7	3.2	1.1	1.6	1.1	1.6
Down syndrome	4.3	17.4	4.3	4.3	0	0	0	0
Autism-PDD	5.3	0	0	0	5.3	5.3	5.3	10.5
Muslce diseases	0	0	0	0	12.5	12.5	0	0
Learning difficulty	0	33.3	0	0	11.1	0	0	11.1
Other	6.3	31.3	0	0	0	6.3	6.3	0
Spina Bifida	0	0	0	0	0	0	11.1	11.1
Brachial plexus	0	5.9	0	0	0	0	0	0

PDD: Pervasive developmental disorder

Table 7. Gestational age according to diagnoses			
Diagnosis	**Premature birth %**	**Term birth %**	**Postmature birth %**
Mental retardation	18	79.2	2.1
Motor mental retardation	29.2	66.7	4.2
Cerebral palsy	51.4	47.9	0.7
Down syndrome	27.8	72.2	0
Autism-PDD	0	100	0
Muscle diseases	0	100	0
Learning difficulty	33.3	66.7	0
Other	25	75	0
Spina Bifida	42.9	57.1	0
Brachial plexus	8.3	83.3	8.3

PDD:Pervasive developmental disorder

and prognosis was found with the highest rate among children with neurodevelopmental disorder who were referred to rehabilitation. This is compatible with the fact that the quadriparetic type is the most common CP type and supports the results of Özmen et al. (11). However, it was observed that children born both by normal delivery and cesarean section were mostly in the quadriparetic CP group. Thus, it was thought that both modes of deliveries did not cause to difference in terms of CP type. In addition, similar rates of diparesia and hemiparesia were observed in both modes of delivery. Therefore, our study shows that rehabilitation approaches should be arranged such as to cover children with all types of CP. In addition, devices and equipment used in settings where these approaches are applied should be arranged in such a way as to meet the requirements of children with different types of CP.

Epilpesy is observed with a higher frequency in children with cognitive dysfunction as well as in children with CP compared to the general population (12,13). When the groups included in our study were examined, it was remarkable that epilepsy was found in almost all groups except for DS and brachial plexus injuries. No special work has been performed in terms of injuries which may arise from epilepsy and first aid applications in special education and rehabilitation centers. This study showes that it is important to take the necessary precautions to prevent injuries related with epilepsy and to inform and educate the families and the personnel working in rehabilitation centers.

In our study, it was observed that the rate of school attendence was higher in the groups with mental problem and lower in the groups with physical disability. This may be related with the fact that there is insufficient number of appropriate schools and qualified personnel to give education in these schools in our country. In addition, difficult accessibility because of architectural obstacles of these schools furhter decreases the rate of school attendence of these groups. Opening accessible schools with appropriate physical conditions will increase the rate of school attendence especially for children with CP.

Aybay et al. (14) reported the age of onset of rehabilitation to be 5,5 years in children with CP in our country. An average age has not been reported for the other groups. In our study, the age of onset of rehabilitation was found to be 3,4 years in the CP group. It was thought that the fact that the age of onset of rehabilitation was different in children with CP compared to the other groups in both studies was related with early detection of physical disorder. In addition, special education and rehabilitation services are more extensive and accessible in our country. This arises from the fact that this service is provided for all groups independent of social security in the context of social state.

The earliest mean age at which education and rehabilitation program was started was 2.7 years which was found in the spina bifida group. This was thought to be related with a definite diagnosis at an early stage. The mean age of onset of rehabilitation was 3.4 years in the CP group which constituted the majority of our study group. Considering that children are regularly followed up after birth, this result shows the urgency of using different evaluation and screening methods to detect CP at an earlier period. As Burns et al. (15) showed, CP with moderate severity can be diagnosed up to the 8th month. The presence of the problem can be detected at an early period with regular monitoring of mild-moderate signs. On the other hand, leaving the growth of the child with CP to time without intervention leads to problems including increase in mental retardation, epilepsy and difficulty in speech. These

findings cause to neurological and behavioral problems and make adaptation difficult in the school age (16).

The social, economical and cultural level of the family is among the important factors which affect the growth and development of the child (17). Vohr et al. (18) reported that sociodemographic factors had limited effects on development in the first one year, but they were substantially important by the age of five. Thus, increase in the education levels of parents will contribute positively to development and education of these children.

The social status of parents affects the academic success of children in different ways. In terms of special education this influence is increased further. The social status is always related with the economic states of families. If the social status of the family who have a disabled child is good, it will be easy for them to meet the high rehabilitation expenses and this will influence the continuing rehabilitation processes positively (19). Especially the education of the disabled child gains importance compared to the healthy one (20). In our study, it was observed that the fathers had a higher education level compared to the mothers. It was remarkable that the majority of the fathers were university graduates. The low number of illiterate parents suggested that families who referred to rehabilitation centers were more conscious. This finding showed the importance of increasing consciousness in families with a low education level.

When the relation of motor development with gestational age and ages of the parents at the time of delivery was examined, it was observed that the ability to hold the head and sit delayed with decreased gestational age. In the study performed by Gabriel et al. (21), it was found that infants who were born prematurely with a birth weight below 1500 g sat without support and walked later compared to the infants who were born at term. The fact that the birth weight and gestational age were low in the CP group in our study caused to delayed attaintment of the abilities of holding the head and sitting. The decrease in the impact of low gestational age with growth showed that there was no difference in abilites including walking, speaking, eating and toilet training. Especially when the mean ages of onset of education and rehabilitation were examined, the fact that the mean age was generally above 4 years supported this.

There may be many porblems accompanying neurodevelopmental disorders. These problems influence the success of the child and also lead to various psychosocial problems. In our study, especially visual and auditory problems were observed with a higher rate in the MR, MMR and CP groups. Thus, some changes should be made in approaches directed to the symptoms of dysfunction in the intervention methods used in these centers considering the presence of these problems. In addition, it should be kept in mind that support should be received from related physician groups to minimize accompanying problems. Informing the families about regular visual and auditory examinations for children who are diagnosed with mental retardation and motor mental retardation, since they cannot express their complaints easily is important in terms of an efficient service. In addition, when intra-familial problems were examined, it was observed that they occured mostly in the group with muscle disease, though not very prominent. It was conlcuded that psychosocial support was important for children and families to cope with these problems which were also observed in the other groups with a lower rate.

In our study, the highest rate of premature delivery was observed in the spina bifida and CP group. Stoknes et al. (22) reported high prenatal risk to be the cause of premature delivery. In a different study performed by Prusich et al. (23), it was concluded that the risk of premature delivery increased considerably and caused to different congenital disorders. In our study, failure to prevent premature delivery was observed, although the rate of doctor visits during pregnancy was high. Therefore, education of mothers in terms of risk factors in addition to routine visits during pregnancy will prevent potential injuries and eliminate the potential risk.

Conclusively, our study is considerably important in terms of being the first study to demonstrate the sociodemographic properties of children and families referring to special education. It will be helpful in directing education and rehabilitation programs which will be prepared for children with different neurodevelopmental disorders, in rendering these programs efficient, in establishing appropriate methods and in educating families. Important data was obtained especially in terms of prevention and rehabilitation of CP.

The most important feature of our study was the fact that the investigation was conducted in a single center. Although this center is one of the largest and first rehabilitation centers in Ankara, future investigations in the whole of Turkey will provide more significant results.

Conflict of interest: None declared.

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