

Demographic and Diagnostic Characteristics of Pediatric Neurology Outpatients

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A three month study was carried out at the Pediatric Neurology Department of Hacettepe University Children's Hospital in Ankara to collect descriptive data on patients contacting the pediatric neurology out-patient clinic. The data were collected according to the following classifications:

1. Demographic information on parents: Education and occupation, geographic location of their residence, number of children in the family.

2. Demographic information on patients: Age, sex, education, age at which disease started, age at which first contacted Hacettepe Hospital.

3. Diagnoses and defects: Number and type of diagnoses; distribution according to age and sex; physical defects and behavioral disorders.

The purpose of this study was to obtain information about the pediatric neurology patients in order to determine the relevant psychological test materials, experimental apparatus, and other related measurement devices which would be appropriate for the age, educational, and socio-economic level of the patients; to provide the necessary services required by the specific needs of the patients (i.e. speech therapy); to have a list of patients who could be used as subjects for other studies to be conducted in the department; and to provide a baseline for studying trends over time within the department.

The Pediatric Neurology Department at Hacettepe University Children's Hospital was officially founded in 1963 with two attending

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physicians. Presently, there are three pediatric neurologists as full time physicians, two fellows in pediatric neurology, two pediatric residents, two or three interns, one research psychologist, and one speech therapist working. Patients from all over Turkey are referred to the outpatient clinic. During 1974 estimated 3000 cases were seen in the clinic (some of them repeats).

Method

Descriptive data were collected on 329 patients between the ages 0-19 who contacted the outpatient clinic, between September 1974 and January 1975.

A data form sheet composed of check lists and open-end questions was filled out by the researcher for each new case during the interview, which took place in the small room in the department on the same day, with patient and patient's family. During the interview the researcher observed and talked to the child briefly to assess his speech, and to note any apparent physical disorders. This information was marked on the data sheet accordingly.

The information about the patient's diagnoses was taken from the medical files of each patient. When indicated, the physician who examined the patient made additions to the diagnoses after he completed physical examination.

After the data sheet was filled out for a particular patient, his medical file was marked so that if he returned within the three-month period during which the research took place, he would not be interviewed again.

In the analysis of the collected data, the only problem was the number of diagnoses. 188 separate diagnoses were encountered, these diagnoses were grouped into 9 categories with the assistance of a pediatric neurologist to facilitate data analysis.

The categories were:

1. Epilepsy - all types
2. Cerebral Palsy - due to birth trauma only
3. Infection Sequelae - encephalitis, meningitis, tuberculosis, etc.
4. Degenerative Diseases - Muscular dystrophy, Friedrich's Ataxia, etc.
5. Vascular Accidents - mostly post infection cases, hemiplegia, monoplegia, etc.

6. Spinal Cord Diseases - such as Guillain Barre, poliomyelitis, Wernig - Hoffman
7. Neoplasms
8. Metabolic Diseases - hypoglycemia, aminoaciduria, metachromatic leucodystrophy Wilson's Disease
9. Miscellaneous - nystagmus, migraine, malnutrition, rickets, subdural collection, etc.

Results and Discussion

The results will be discussed in three main sections: Parents, patients, and diagnoses. Since it is the parents who bring the patients to the clinic, first we wanted to know which part of Turkey they came from, the size of their place of residence, their educational level and their occupations.

Table I shows the distribution of parents according to the area of residence.

TABLE I
THE DISTRIBUTION OF PARENTS ACCORDING TO THE AREA OF
RESIDENCE

	Number	Percentage
Ankara	128	38.9
Area 1*	80	24.3
Area 2*	55	16.7
Area 3* (includes Marmara region)	11	3.3
Area 4*	37	11.3
Area 5*	10	3.0
No information	8	2.4
Total	329	99.9

* 1 = Central Anatolia, 2 = Black Sea region, 3 = Aegean Sea region, 4 = Mediterranean region, 5 = Eastern Anatolia

About 80 % of the cases came from the area roughly 200 km around Ankara which is the major center of this area.

The distribution of the place of residence is presented in Table I.

As can be seen in the above table, very close to 75 percent of the population came from urban centers and small towns, and only a small percentage came from villages. These data suggest that this group is not a representative sample of the national population as around 60 percent of the total population lives in rural areas.¹

TABLE II
THE DISTRIBUTION OF PARENTS ACCORDING TO SIZE OF
RESIDENTIAL LOCATION

	Number	Percentage
City	183	55.6
Kaza*	63	19.1
Village	73	22.2
No information	10	3.0
Total	329	99.9

* Kaza is an administrative unit which is defined in Turkey as a town with a population of 2-20 thousand.

Table III presents the distribution of educational levels of the parents.

TABLE III
THE DISTRIBUTION OF PARENTS ACCORDING TO LEVEL OF
EDUCATION

Education level	Fathers		Mothers	
	Number	Percentage	Number	Percentage
No schooling	31	9.4	118	35.9
Elementary school	173	52.6	168	51.1
Secondary school	97	29.5	29	8.8
University	19	5.8	7	2.1
Post graduate	2	.6	0	0
No information	7	2.1	7	2.1
Total	329	100.0	329	100.0

When the educational levels of mothers and fathers were compared over fifty percent of both groups had elementary school education. The next highest percentage for the fathers is secondary school (29.5 %), whereas for the mothers it is the no schooling group (35 %). Thirty-five percent of the fathers had secondary and higher education as compared to only 10.9 % of the mothers.

The national statistics show an estimated 2.05 % of the male population and 0.78 % of the female population over 20 years of age to have lycee or higher education.

These data show that this group has higher than average education.

The distribution of the fathers' occupations and the number of working and non-working mothers are presented in Table IV.

TABLE IV
THE DISTRIBUTION OF PARENTS ACCORDING TO OCCUPATION

	Fathers		Mothers		
Conditions	No.	%	No.	%	
Skilled worker	88	26.7	Housewives	270	82.0
Government employee	87	26.4	Working	56	14.0
Farmers	40	12.2	(non-agri-		
Unskilled workers	26	7.9	cultural)		
Shopkeepers	25	7.6	No inf.	13	4.0
Teachers	14	4.3			
Workers abroad	13	4.0			
Others	28	8.5			
No information	8	2.4			
Total	329	100.0		329	100.0

The majority of fathers (53.1 %) either worked for the government or were employed as skilled laborers. The next highest percentage (12.2 %) worked as farmers.

Of the mothers 14 % were working in jobs other than agriculture. According to national statistics in the Ankara province 13.5 % of the women above the age of 15 held a non-agricultural occupation.² Thus our sample is typical of the Ankara province.

Table V presents the number of children per family.

TABLE V
THE DISTRIBUTION OF THE NUMBER OF CHILDREN PER FAMILY

Number of children in the family	No.	Percentage
1	45	13.7
2	70	21.3
3	85	25.8
4	62	18.8
5	37	11.2
6	14	4.3
7	6	1.8
8	6	1.8
9 and more	4	1.2
Total	329	99.9

The national average for the number of children per family in Turkey is 4.5.¹ The average number of children per family in our sample is 3.

The parents of the patients who contacted the out-patient clinic in Pediatric Neurology at Hacettepe Hospital tended to come from urban places, and had higher educational level than the average population. They represented a higher socio-economic status in terms of occupation, and tended to have smaller families than would be expected in Turkey.

Patients

During the three months that this study took place 329 patients were seen at the clinic. Of the 329 patients 206 (62.0%) were boys and 123 (37.4%) were girls. Table VI gives the age and sex distribution of the patients.

TABLE VI
THE DISTRIBUTION OF PATIENTS ACCORDING TO AGE AND SEX

Ages	Sex					
	No. of Male	%	No. of Female	%	Total	%
Under 1	11	5.3	4	3.3	15	4.6
1-4	60	29.1	36	29.3	96	28.2
5-9	66	32.1	48	39.1	114	34.7
10-14	56	27.2	29	23.6	85	25.9
15-19	13	6.3	6	4.7	19	5.7
Total	206	100.0	123	100.0	329	100.0

When we compare the ages of boys to girls, we see that slightly older boys are brought in. The mean age for boys is 8.2, whereas for girls it is 7.8.

As far as the ratio of boys to girls is concerned we can think of two explanations for the predominance of male patients: Either these are diseases that are sex specific (boys are more prone than girls) or parents value their sons more than girls. Except for the disease muscular dystrophy (in the degenerative category which is seen more frequently in boys, and of which there was only one patient in our study) there is no medical reason for this sex difference in the diseases we dealt with. Therefore the general impression we got from this result is that boys are more valued in the family than girls, thus more importance is given to boys' health than girls.' In spite of the higher than average social class of this group there is still a bias toward males.

Table VII presents the educational level of the patients.

Elementary school education is compulsory for all Turkish children between the ages 7 through 15. Out of the total 329 patients, 172

(52.3%) are of school age. Out of this number 150 (87.2% of school age children) were known to be attending school. There were 12 children who were of school age but not attending school either due to handicap or negligence.

TABLE VII
THE DISTRIBUTION OF PATIENTS ACCORDING TO THEIR
EDUCATION LEVEL

Educational level	Number	Percentage
Does not attend	171	52.0
Elementary School*	107	32.5
Left elementary school before graduating	5	1.5
Graduated from elementary school	5	1.5
Secondary school**	29	8.8
Left secondary school	4	1.2
No information	8	2.4
Total	329	99.9

* Grades 1-5

** Grades 6-11

As a national average 62.75% of the population ages six through 15 attend school, this shows that our sample is better educated than the national average.

In tables VIII and IX we give the ages of the patients at the onset of the disease and the ages at which the patients contacted the Pediatric Neurology Department of Hacettepe.

TABLE VIII
THE DISTRIBUTION OF PATIENTS ACCORDING TO AGE OF ONSET
OF DISEASE

Ages	Number	Percentage
Under-1	115	35.0
1-4	106	32.0
5-6	50	15.2
10-14	33	10.0
15-	1	.3
No information	24	7.3
Total	329	99.8

TABLE IX

THE DISTRIBUTION OF PATIENTS ACCORDING TO AGE AT WHICH
FIRST CONTACTED HACETTEPE

Ages	Number	Percentage
Under-1	37	11.0
1-4	113	34.3
5-9	88	26.8
10-14	66	20.1
15-	3	.9
No information	22	6.7
Total	329	99.8

The highest percentage in Table VIII is the 0 and 1 age group. This is the age at which the majority of patients in our sample first developed the disease. In Table IX the highest percentage is for the age group 1-4. There is a time gap between the age of the onset of the disease and the age of contacting Hacettepe. This may be due to the fact that 60% of the patients come from outside of Ankara. Thus the parents first try local physicians and clinics, and then when the disease persists they come to, or are referred to Hacettepe Hospital. Thus the Hacettepe clinic may be getting worse than average cases.

Our sample showed that the ratio of boys to girls is 1.67 to 1 the highest percentage of the patients falls into the 5-9 age group; and close to 90% of the school age children attend school.

The last part of our study focussed upon the various diagnoses, their distribution according to age, sex and their relationship to various physical and behavioral disorders.

Diagnoses and Defects. Of the 329 patients 218 had only one diagnosis, 84 had two different diagnoses. There were 27 patients for whom the information for their diagnoses was lacking.

The distribution of cases according to diagnoses is shown in Table X.

As can be seen in Table X over 50% of the cases carry the diagnosis of epilepsy. This finding is in accordance with the general trend seen in other pediatric neurology clinics.³ Epilepsy is the most common diagnosis. Another reason that we had a high percentage in our group is that since epileptic children are on anti-convulsant drugs they have to come back for regular check-ups, so even during as short a time as three months we encountered a large number of epileptics. Epileptics whose seizures are under control come for a check-up every six months to one year. Others, whose seizures are not under control come back once a month.

TABLE X
THE DISTRIBUTION OF CASES ACCORDING TO DIAGNOSES

Diagnoses*	Number	Percent
Epilepsy	216	52.30
Cerebral Palsy	62	15.01
Infection Sequelae	20	4.84
Degenerative Diseases	10	2.42
Vascular Accidents	28	6.77
Spinal Cord Diseases	4	.96
Neoplasm	3	.72
Metabolic Diseases	6	1.45
Miscellaneous	37	8.95
No information	27	6.53

*More than one diagnosis possible per case.

The next most common diagnosis for our group was Cerebral Palsy due to birth trauma.

The distribution for diagnoses by age and sex are given in Tables XI and XII.

According to Livingston the characteristic ages for the onset of epilepsy are 1. First two years of life, 2. 5-7 years of age 3. At the onset of puberty. In our sample 68.5% of the cases fell into 5-14 age group. Only 6% of the epileptics in our group fell into the age range of 15-19. The reason for this is that after the age of 15, cases usually go to adult neurology. (Table XI)

As mentioned above, the next most common diagnosis, after epilepsy was cerebral palsy (15.01). The highest percentage of the cases fell in the 1 - 4 age group (46.7%). After a case is diagnosed as having C.P. parents usually do not bring the child back. Thus most of the C.P. cases came only for diagnostic purposes.

TABLE XI
THE DISTRIBUTION OF AGE OF PATIENTS ACCORDING TO
DIAGNOSES

Age	Ep.	C.P.	I.S.	D.D.	V.A.	S.C.	N.	M.D.	MIS.	N.I.	T
Under-1	3	5	2	2	0	0	0	0	3	3	18
1-4	52	29	11	0	10	2	1	2	13	10	130
5-9	87	17	4	3	9	0	1	2	9	9	141
10-14	61	11	2	4	6	2	1	2	9	4	102
15-19	13	0	1	1	3	0	0	0	3	1	22
Total	216	62	20	10	28	4	3	6	37	27	413

TABLE XII

THE DISTRIBUTION OF SEX OF PATIENTS ACCORDING TO DIAGNOSES

Diagnoses	Boys	%	Girls	%	Total
Epilepsy	141	54.7	75	48.4	216
Cerebral Palsy	35	13.6	27	17.4	62
Infection S.	16	6.2	4	2.6	20
Degenerative D.	6	2.3	4	2.6	10
Vascular Acc.	17	6.6	11	7.1	28
Spinal Cord D.	4	1.6	0	0	4
Neoplasm	1	0.3	2	1.3	3
Metabolic D.	3	1.2	3	1.9	6
Miscellaneous	21	8.1	16	10.3	37
No information	14	5.4	13	8.4	27
	258	100.0	155	100.0	413

This is the reason that the number of C.P.'s decreased as the age advanced (Table XI).

For the diagnosis of infection sequelae, 55% of the cases in our study fell in the 1 - 4 age group. Most of these were between the ages 1 and 2.

There were a total of 10 cases in the degenerative diseases group (2.42% of all cases). This number may be inflated for this time span because many such patients who cannot get treatment elsewhere come to this clinic. Also, at the time our research took place a few of the patients were called in for an enzyme analysis as part of an on-going research.

Vascular accident cases represent 6.7% of all the cases. Patients usually came for a check-up and to be referred to physical therapy.

The other categories of diagnoses involved too few patients to give any sort of an interpretation.

Table XII shows the percentage of boys and girl within each diagnostic category. Difference between sexes did not exceed 4% except in infection sequelae and the spinal cord disease. Since neither one of these diseases is sex specific these findings can be interpreted as being the result of chance.

Aside from the diagnoses of patients, data were collected on the physical defects and the behavioral disorders. Ten categories were selected and items were marked as to the presence and absence of each defect. The results are given in Table XIII.

TABLE XIII
THE DISTRIBUTION OF PHYSICAL DEFECTS AND BEHAVIORAL
DISORDERS

Disorders	Number	%	
Behavior problems	160	48.6	
Motor defects	123	37.4	
Speech defect	123	37.4	(110 patients had no information as to their mental age)
Retardation	123	37.4	
Aggressiveness	76	23.1	
Learning problems	55	16.7	
Hyperactivity	54	16.4	
Discipline	44	13.4	
Visual defects	36	10.9	
Hearing defects	15	4.6	

Those categories with the highest percentages of incidence were selected and distributions by diagnoses were determined. Although the percentage for retardation was high, it was not included for further analysis because there were 110 patients out of the total 329 (33.4%) for whom this information was not available.

As can be seen in Table XIII, the most common complaint was behavior problems. The parents expressed this problem, over and over, with almost identical sentences as their child "constantly misbehaving", "disobeying", and "not doing as being told".

Discipline problem, in this study referred to school discipline. Parents whose children misbehaved in the classroom, and whose teachers complained about this behavior reported it as such.

Learning problem was taken crudely as lower than average school grades and failure to pass to the next class.

Under the group "hyperactive", those children who were unable to stay in one place, who were constantly running around in the room, pulling out drawers, taking objects from the desk, climbing over the bookshelves during the time of the interview were included. This group of children also had moderate to severe brain damage.

Aggressiveness referred to breaking objects, biting the parents or other children, and being physically destructive in other ways.

The distributions for behavior problems, motor defect, speech defect, aggressiveness, according to diagnoses are presented in Tables XIV, XV, XVI and XVII. It is necessary to bear in mind that some of the

diagnostic categories are overlapping i.e. a patient with epilepsy may also have had infection sequelae. Therefore one patient may have been counted twice.

Behavior problems were present in 50% or over of patients with epilepsy, cerebral palsy, vascular accident and metabolic diseases. (Table XIV).

For motor defects the highest percentages (67% - 83%) were in metabolic diseases, degenerative diseases, infection sequelae, and cerebral palsy. Motor defects would be expected to be present in a high percentage of the cases with these kinds of diseases.

TABLE XIV
THE DISTRIBUTION OF BEHAVIOR PROBLEM CASES ACCORDING TO
DIAGNOSES

Diagnoses	Number	Baseline*	Percentage
Epilepsy	110	(216)	50.9
Cerebral Palsy	33	(62)	53.2
Infection Sequelae	7	(20)	35.0
Degenerative Diseases	3	(10)	30.0
Vascular Accident	14	(28)	50.0
Spinal Cord Diseases	1	(4)	25.0
Neoplasm	1	(3)	33.3
Metabolic Diseases	3	(6)	50.0
Miscellaneous	14	(37)	37.8
No Information	11	(27)	40.7

* Number of cases for each diagnostic category.

TABLE XV
THE DISTRIBUTION OF MOTOR DEFECT CASES ACCORDING TO
DIAGNOSES

Diagnoses	Number	Baseline	Percentage
Epilepsy	56	(216)	25.9
Cerebral Palsy	42	(62)	67.7
Infection Sequelae	14	(20)	70.0
Degenerative Diseases	9	(10)	90.0
Vascular Accident	20	(28)	70.0
Spinal Cord Diseases	2	(4)	50.0
Neoplasm	1	(3)	33.3
Metabolic Diseases	5	(6)	83.3
Miscellaneous	18	(37)	46.6
No Information	10	(27)	37.0

TABLE XVI
SPEECH DEFECT
THE DISTRIBUTION OF CASES ACCORDING TO DIAGNOSES

Diagnoses	Number	Baseline	Percentages
Epilepsy	70	(216)	32.4
Cerebral Palsy	44	(62)	71.0
Infection Sequelae	17	(20)	85.0
Degenerative Diseases	3	(10)	30.0
Vascular Accidents	21	(28)	75.0
Spinal Cord Disease	0	(4)	—
Neoplasm	1	(3)	33.3
Metabolic Diseases	5	(6)	83.3
Miscellaneous	10	(37)	27.0
No Information	8	(27)	29.6

TABLE XVII
AGGRESSIVENESS
THE DISTRIBUTION OF CASES ACCORDING TO DIAGNOSES

Diagnoses	Number	Baseline	Percentage
Epilepsy	53	(216)	24.5
Cerebral Palsy	16	(62)	25.8
Infection Sequelae	3	(20)	15.0
Degenerative Diseases	1	(10)	10.0
Vascular accidents	9	(28)	32.1
Spinal Cord Disease	0	(4)	—
Neoplasm	1	(3)	33.3
Metabolic Disease	1	(6)	16.7
Miscellaneous	11	(37)	29.7
No Information	3	(27)	11.1

The highest percentages (71% - 85%) of speech defect was in infection sequelae, metabolic diseases, vascular accidents, and cerebral palsy (Table XVI). It should be noted there are various conditions related to speech defect but the most prominent one for our sample was considered to be mental retardation.

Aggressiveness was present in 23.1% of the total cases. This is low when compared to behavior problems (48.6%), motor defects and speech defects (37.4% each). As can be seen in Table XVII the percentages are more evenly distributed among the diagnostic categories than the other defects. The highest percentage of aggressiveness was seen in vascular accidents with 32.1% (we are discounting neoplasm which had

only 3 cases). For none of the diagnostic categories did the percentage of aggressiveness reach 50%. The next highest group was the miscellaneous one (29.7%). After that came cerebral palsy and epilepsy respectively.

After the above results were obtained, a count was taken of the patients who had physical defects versus patients with behavioral disorders, and those having behavioral disorders surpassed the physically defected. (There were altogether 187 with behavioral disorders and 147 with physical defects).

Patients with various physical defects, because of their inability to behave as other children, and also because people treat them differently, may develop behavior disorders. Consequently what starts out as a physical defect becomes an emotional one.

Another explanation for this may be connected to the result of a study done by Ozdirim.⁵ She compared a group of epileptic children taking diphenylhydantoin to those taking phenobarbital, with a placebo group as a control, and came up with the result that the group on phenobarbital showed some behavioral problems.⁴ Since 52% of our patients were epileptics and they were all on anti-convulsant drugs some of the behavioral problems we encountered may stem from the effects of drugs.

Summary

This study was conducted to obtain information about the patient population of the outpatient clinic at the Pediatric Neurology Department of the Hacettepe University Children's Hospital. Information was collected on the socio-economic level of the parents; age, sex, education level of the patients, and the kind of diseases, physical and behavioral defects the clinic dealt with.

This information was sought out for the purpose of aiding the psychological services, within the department, in what kind of test materials to select and in giving direction to the kind of research to be carried out.

Information obtained from the 329 patients indicated that our population does not represent the average general population. The parents of our patients came from urban places, had higher educational level, represented a higher socio-economic status in terms of occupation and tended to have smaller families than would be expected in the Ankara region. As for the patients themselves, 87.2% of the school age children were attending school as compared to 62.75% of the national average. There were more male patients than female, and this was attributed to the fact that boys are more important in the Turkish family than girls. Among the nine categories of diagnoses over 50% of the patients fell in

the epilepsy category. The next most common diagnosis was cerebral palsy. The data collected on the ten categories of physical and behavioral disorders showed behavioral problems, motor defects, speech defects, retardation, and aggressiveness to have the highest incidences. A cross tabulation of these disorders with the diagnoses (with the exception of retardation due to the reason explained above) showed expected relationships.

Considering the high proportion of patients having behavioral problems it was concluded that more emphasis should be placed upon developing better evaluation techniques and methods of dealing with these problems and providing services for directing parents.

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