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Evaluation of children with disabilities: BMI indicators and difficulties experienced by parents

Evaluation of disabled children

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Abstract
Aim: The aim of this study was to analyze the disability categories and sociodemographic characteristics of disabled children to stratify their risks in terms of body mass index (BMI), obesity and underweight, and to identify the problems of affected children and their families.
Material and Methods: A total of 1229 children younger than 7 years of age were identified to be surveyed with home visits by a dedicated team. BMI parameters were obtained for 330 children. Functional impairment was classified into six groups according to the ICD-10 (International Statistical Classification of Diseases and Related Health Problems) codes.
Results: Children with orthopedic disabilities accounted for 34.9%, with intellectual disability 34.1%, developmental disorders of speech and language 15.6%, autistic disorders 15.5%, hearing loss 8%, and visual disturbances and blindness 0.8%.
According to the BMI percentile curves of the 330 children, 25.8% were considered obese, 5.4% were overweight, and 18.5% were underweight. The risks for obesity and underweight were significantly increased in children with autistic disorders and orthopedic disabilities, respectively ($p<0.05$).
Discussion: Children with disabilities are at an increased risk for obesity and underweight, which requires the evaluation and close monitoring of nutritional problems and provision of nutritional support.

Keywords
Disability; Children; Body Mass Index

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Introduction

According to the UNICEF's 'The State of the World's Children 2006' report, there are approximately 150 million disabled children under the age of 18 worldwide (available at: https://www.unicef.org/reports/state-worlds-children-2006). In a later report by the Turkish Statistical Institute (TSI), ''Survey on Problems and Expectations of Disabled People 2010'', the proportion of disabled individuals for the age bracket of 0 to less than 14 years was 21.1%, with 4.9% falling in the age bracket of 0 to 6 years (available at: https://www.ailevecalisma.gov.tr/media/5602/ozurlulerin-sorun-ve-beklentileri-arastirmasi-2010.pdf). There are genetic, prenatal, natal and postnatal risk factors leading to the disability in children. Among genetic causes, consanguineous marriage represents an increased risk factor for giving birth to a disabled child. [1] The prevalence of consanguineous marriages in the world is between 20-25% [2], with a similar Turkish share of 23.2% (available at: https://tuikweb.tuik.gov.tr/HbPrint.do?id=24646). Congenital or acquired disabilities of children adversely affect themselves and their family members in in all aspects of life. Aside from the lack of policies to improve their quality of life, disabled children face many problems that limit their participation in society, including negative attitudes and behaviors towards them, lack of appropriate infrastructure for their living, and difficulties in access to health, education, communication, information and social services, all make it difficult for the child and their families to cope with the situation. [3,4] Moreover, difficulties in raising disabled children and preparing them for future life render family members of these children more susceptible to diseases, especially to mental disorders such as depression. [5,6]

On the other hand, nutrition is of paramount importance to maintain the growth and development of disabled children. Nutritional problems leading to inadequate nourishment are quite common among these children, such as difficulty in eating, chewing and swallowing, prolonged keeping of food particles in the mouth, reflux and vomiting. Thus, comorbidities associated with inadequate and unbalanced nutrition may be inevitable, especially in children with neurological disabilities, such as growth retardation, overweight, micronutrient deficiencies or osteopenia.

The aim of this study was to analyze the disability categories and sociodemographic characteristics of disabled children younger than 7 years of age, and to stratify their risks in terms of body mass index (BMI), obesity and underweight as well as identify the problems of affected children and their families.

Material and Methods

Study design

This study was conducted prospectively within the scope of the project implemented by the Istanbul Development Agency, titled 'Protective and Preventive Measures for Oral and Dental Health in Infants and Children with Disabilities in the 0-6 Age Group'. In the first instance, 2600 eligible children in the 0-6 age group, who received disability reports for various disabilities from community hospitals on the Anatolian side of Istanbul were identified to be surveyed with home visits. Of these, 1229 children were included in the study after obtaining parental consent for home visits. All participants were younger than 7 years of age at the time of home visits that were scheduled from January 1 to December 31, 2017. Home visits were conducted by a team including a dentist, psychologist, social worker, nurse and data entry clerk. A pediatrician was assigned to the project as a director and consultant. The study was approved by the ethics committee of the Kartal Kosuyolu Training and Research Hospital, Health Sciences University (No 2017/18; date 23/02/2017), and was conducted in accordance with the ethical principles of the Helsinki Declaration. Parental written informed consent was obtained for all the children.

Data collection

During the visits, a comprehensive survey of demographic characteristics such as age, gender, parental educational status, family economic status, consanguineous marriages, as well as nutritional status and financial, social and psychological needs of the family were carried out. Body mass index was calculated for 330 children whose weight and height measurements were made by the team.

Disability categories of children

Disability status was determined from the present disability reports given by health care institutions and the ICD-10 (International Statistical Classification of Diseases and Related Health Problems) codes assigned based on functional loss and impairment. Children were examined in six categories according to the ICD codes (Figure 1), including intellectual disability (F70-F79), motor disabilities (specific developmental disorder of motor function F82; primary disorders of muscles G71; myopathies G72; infantile cerebral palsy G80; hemiplegia and hemiparesis G81; paraplegia and quadriplegia G82; abnormalities of gait and mobility R26), developmental disorder of speech and language (F80, F81, R47), autistic disorder (F84), hearing loss (H90, H91), visual disturbances and blindness (H53-H54). In addition, children assigned to multiple ICD codes were identified.

BMI and percentile calculation

BMI was calculated in 330 children as body weight in kilograms divided by height in meters squared, and BMI percentile curves were constructed according to gender and age (in months). National BMI percentile curves were used for reference [7]. Percentile values at <5, 5 to <85, 85 to 95, and >95 were considered indicators of underweight, normal weight, overweight, and obesity, respectively.

Statistical analysis

The data were processed using NCSS (Number Cruncher Statistical System) 2007 Statistical Software (Kaysville, Utah, USA). Descriptive data were expressed as mean, standard deviation, median, frequency, percentage, and minimum-maximum. Categorical variables were compared using the chi-squared test. A P-value of less than 0.05 was considered statistically significant.

Results

Children with disabilities

Among 1229 participating children, 754 (61.4%) were girls. The mean age of the surveyed population was 4.5±1.5 years.

According to the ICD-10 codes, 34.9% (n=429) had motor disabilities, 34.1% (n=419) had intellectual disability, 15.6%

(n=192) had developmental disorders of speech and language, 15.5% (n=191) had autistic disorders, 8% (n=98) had hearing loss, and 0.8% (n=10) had visual disturbances and blindness (Fig. 1). Eighty-six and 12 children received two and three categories of disability, respectively.

Means of nutritional intake and BMI indices

While the great majority of children were fed by mouth (96.8%, n=1190), 3.2% (n=39) were fed through a percutaneous endoscopic gastrostomy tube. Nutritional intake was complicated in 36.1% (n=444) due to various problems such

Table 1. Distribution of BMI percentiles according to the ICD-10 disability codes

Disability types (N) Age (Months) Median (IQR) N	BMI (kg/m²) Mean±SD	<5th percentile N (%)	≥5 - ≤85th percentiles N (%)	>85-≤95th percentiles N (%)	>95th percentiles N (%)
Intellectual disability (125) 54 (39-70)	17.3±3.7	18 (14.4)	61 (48.8)	10 (8)	36 (28.8)
Autistic disorder (76) 55 (44-70)	17.2±3.3	9 (11.8)	30 (39.5)	9 (11.8)	28 (36.9)
Developmental disorder of speech and language (67) 53 (37-67)	16.4±2.9	10 (14.9)	36 (53.7)	7 (10.4)	14 (20.9)
Motor disabilities (115) 55 (37-70)	16.5±3.9	32 (27.8)	53 (46.1)	7 (6.1)	23 (20)
Hearing loss (29) 59 (36-70)	16.7±3.1	5 (17.2)	13 (44.9)	4 (13.8)	7 (24.1)
Visual disturbances and blindness (3) 34 (28-51)		0 (0)	3 (100)	0 (0)	0 (0)
Total (330) 54 (39-70)	16.8±3.6	61(18.5)	166 (50.3)	18 (5.4)	85 (25.8)

Table 2. Comparison of disability categories of 330 children with respect to BMI percentile thresholds of 5 and 95

Disability types	BMI Percentiles									
	≤ 95%		>95%		P	≥ 5%		<5%		p
	N	%	N	%		N	%	N	%	
Motor disabilities	92	30.0	23	21.3	0.083	83	24.3	32	43.2	0.001
Intellectual disability	89	29.0	36	33.3	0.397	107	31.4	18	24.3	0.231
Autistic disorder	48	15.6	28	25.9	0.017	67	19.6	9	12.2	0.131
Developmental disorder of speech and language	53	17.3	14	13.0	0.296	57	16.7	10	13.5	0.497
Hearing loss	22	7.2	7	6.5	0.810	24	7.0	5	6.8	0.931
Visual disturbances and blindness	3	1.0	0	0.0	0.303	3	0.9	0	0.0	0.418

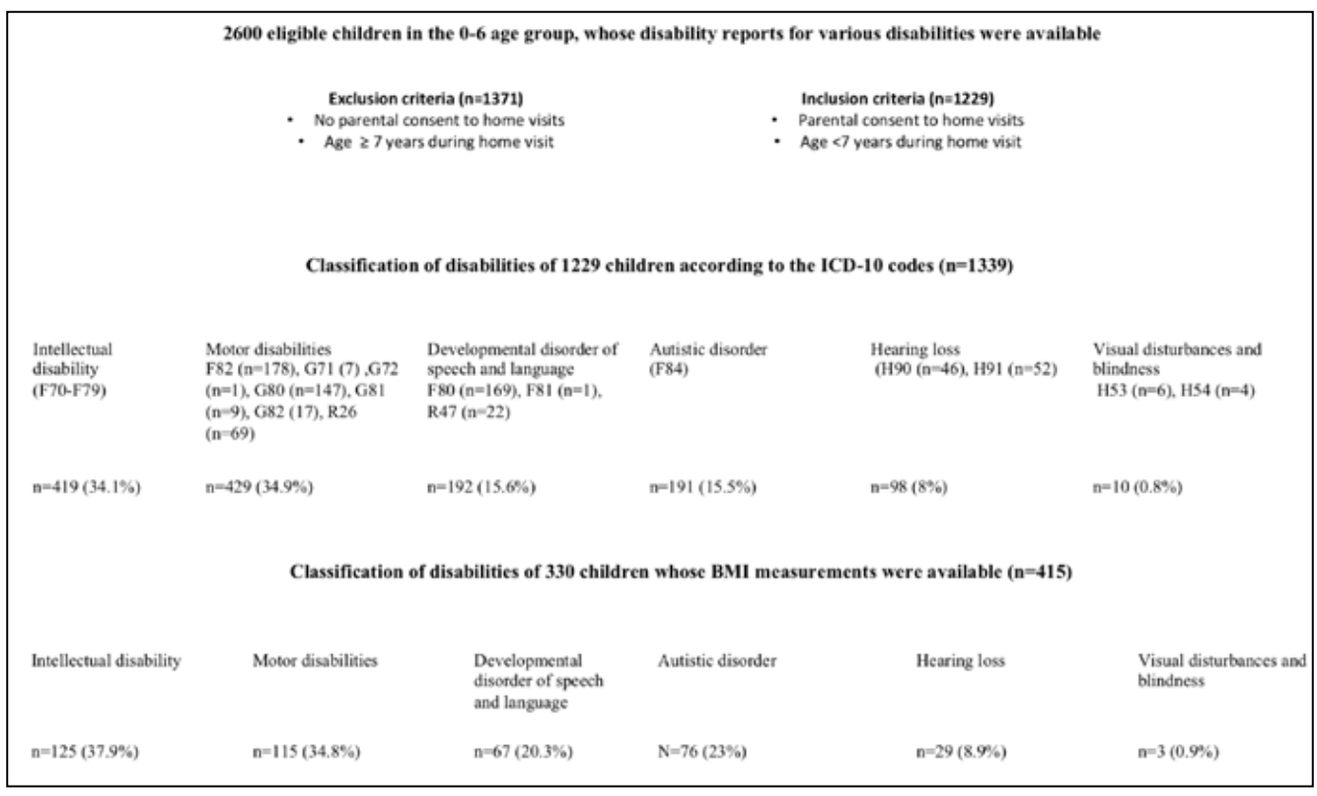

Figure 1. Classification of disabilities of children according to the ICD-10 codes

as difficulty in swallowing, chewing, prolonged keeping of food particles in the mouth, reflux, and vomiting.

Among the 330 children whose BMI measurements were available, 196 (59.4%) were boys and the median age was 55 months (interquartile range 37-70 months). BMI ranged from 10 to 39 kg/m2, with an average of 16.8±3.6 kg/m2. Eighty children had more than one type of disability, with 75 children falling in two disability categories, and five children in three categories.

According to the percentile curves of the 330 children, 50.3% were within the normal range, while 25.8% were considered obese, 5.4% were overweight, and 18.5% were underweight (Table 1).

The prevalence of obesity was highest (36.9%) among children with autistic disorders, and the prevalence of underweight was highest (27.8%) among children with motor disabilities. Similarly, in each disability category, comparison of children with reference to <5 and >95 percentiles showed that the risk of obesity was highest for autistic disorders (p=0.017), and the risk for underweight was highest for motor disabilities (p=0.001) (Table 2).

Parental socio-demographic characteristics

Levels of educational attainment of mothers vs. fathers were as follows: illiterate 6.9% vs. 2.8%; primary school or less 60.3% vs. 54.8%; high school or less 20.0% vs. 26.3%; and university degree 12.8% vs. 16.1%.

Consanguineous marriage was detected in 29.7% of the parents (n=365).

Self-reported economic profile was poor in 25.1% (n=308), moderate in 71.8% (n=883), and good in 3.1% (n=38).

The need for psychological support was identified in 329 (27%) parents, in particular for mothers, as was the need for financial support for 9.4% of the families.

Discussion

According to the WHO 2011 report, 0.7% to 5.1% of children aged 0 to 14 years, experience some form of disability (available at: https://www.who.int/disabilities/world_report/2011/report.pdf). TSI survey in 2002 reported the disability rate of 1.54% among children 0 to 9 years of age, with the highest share of motor disabilities (0.64%), followed by developmental speech and language disorders (0.46%), and intellectual disability (0.42%) (available at: http://kutuphane.tuik.gov.tr/pdf/0014899.pdf). In our study, motor disabilities were in first place with 34.9%, followed by intellectual disability with 34.1%, and developmental speech and language disorders with 15.6%.

Among genetic factors, consanguineous marriage represents an increased risk factor for giving birth to a disabled child. Among a randomly selected 708 individuals from a small town population in Turkey, the prevalence of disabilities was 23.3%, of which consanguineous marriage was detected in 44.5%. [8] Another study examined 655 disabled children and found a strikingly high rate of consanguineous marriage with 76.5%. [9] In our study, the prevalence of consanguineous parents was 29.7% for disabled children. As expected, these results were seen to be higher than the overall average of consanguineous marriages in Turkey. The discrepancies in reported rates of consanguineous marriages may have arisen from regional differences and/or may be due to the fact that our data were obtained about five years after the above-mentioned studies, during which time public awareness of the problem might have increased. In order to prevent genetic diseases arising from consanguineous marriages, it is highly beneficial for prospective spouses to undergo genetic screening before marriage and take precautions for possible risks [10].

There seems to be a close relationship between disabilities of children and parental education levels. The lower the educational level of the parents, the higher the likelihood that a child will be born with a disability, possibly due to a lack of awareness about the risks associated with consanguineous marriages and about the need for antenatal screening and care. This was evident in our study with an overall low educational level of the parents, with no or only primary school (or less) education in 67.2% of mothers and in 57.6% of fathers. A previous study from Turkey reported similarly low levels of parental education, with 4.6% and 1.7% of children having illiterate mothers and fathers, and 54% and 39.2% of children having mothers and fathers with an education degree of up to the primary level, respectively. [9] These rates are in striking contrast with the overall rates of maternal and paternal primary education levels, which, according to the TSI 2018 report, are 25% and 17% for women and men, respectively (available at: https://www.tuik.gov.tr).

Children with disabilities and their family members are adversely affected by a wide variety of factors, including mental and physical health problems, family relations, employment, and economic problems [11-14]. A previous study from the United Kingdom examined 72 mothers and 42 fathers with disabled children and found that 55.6% of mothers and 64.3% of fathers had mental health problems [15]. Another study from Canada examined 449 parents with disabled children aged 0-19 years and detected mild to severe psychiatric disorders in 42% of the parents [16]. A review from the USA drew attention to chronic stressors faced by parents of children with intellectual and developmental disabilities, particularly when their children are in need of extreme care [17]. Likewise, several studies from Turkey reported highly increased levels of chronic fatigue and depression among mothers of disabled children and emphasized the need for support in addressing these parental problems [6,18,19]. Likewise, in our study, 27% of the parents, especially mothers, were found to be in need of psychological support and were advised to seek help at rehabilitation centers. Unfortunately, only 25.5% of these parents could be integrated into rehabilitation programs, while the majority remained unaided for various reasons on the part of family members, such as having no one to look after their children, transportation difficulties, and time limitations. This shows us that providing psychological support to these families is best done at home rather than at institutional-based settings.

Children with disabilities are at increased risk of morbidity and mortality associated with malnutrition, leading to problems such as growth failure, overweight, micronutrient deficiencies and osteopenia. Therefore, careful evaluation and monitoring of these children for nutritional problems is of the utmost importance [20,21]. In our study, nutritional intake was complicated in a high proportion of children (36.1%) due to problems such as difficulty in swallowing, prolonged keeping

of food particles in the mouth, reflux, and vomiting. Nutritional assessments to ensure adequate growth and nutrient intake should be made at least once a year in older children, while younger children and infants need more frequent assessments including length, weight, BMI or weight for height [20]. We used BMI to evaluate these children. Percentile curves of 330 children whose BMI measurements were available showed that a significant proportion of the children were found to be obese (25.8%) or overweight (5.4%), or to lack adequate nutrition (18.5%). The risk for obesity was highest in children with autistic disorders, and underweight was more closely associated with motor disabilities. In a study involving 2,769 children with autistic disorders in the USA, 33.9% were found to be overweight and 18.2% were found to be obese [22]. In the present study, the prevalence of obesity was much higher with 36.9% among children with autistic disorders. Concerning the risk for overweight or obesity associated with motor disabilities, an Australian cohort study examined the BMI Z-scores of 587 children diagnosed with cerebral palsy and found that 19.4% were obese or overweight, and 7% were underweight [23]. Among the 330 children with BMI measurements, 34.9% had motor disabilities, with cerebral palsy being most common, a more pronounced distribution of overweight/obesity and underweight was noted, i.e. 26.1% and 27.8%, respectively.

Limitations

Although a considerable number of children with disabilities could be screened through home visits and inquired into a wide range of issues via face-to-face interviews, the study provided no data as to why more than half of the families (1371 of 2600) abstained from giving parental consent for home visits. Another limitation is the limited number of BMI assessments. The weight and height measurements of only 330 children could be made due to various reasons such as insufficient equipment that our visiting teams experienced from time to time, the fact that some children are very agitated and some parents do not want to take measurements. If more children were involved in our BMI measurements, our results on nutritional problems and obesity, as well as the association between BMI variables and disability types, would be more powerful. Another limitation is that our face-to-face interviews were confined to problem-based screening, which could have been combined with some form of referral to prespecified services or centers.

Conclusion

Our study provided instrumental data about the main characteristics and risk factors for disabilities seen in children in the 0-7 age group: motor disabilities and intellectual disability as the two most common impairments; high prevalence of consanguineous marriages among parents, and low educational level of the parents. Disabilities themselves, in particular motor disabilities and autistic disorders, predispose these children to an increased risk for the development of obesity and underweight, which requires close monitoring and the provision of appropriate nutritional support. Besides having a child with a disability and inherent problems, a significant number of parents experience psychosocial problems, for which access to psychological support services is unavailable or limited.

Scientific Responsibility Statement

The authors declare that they are responsible for the article's scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

Animal and human rights statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. No animal or human studies were carried out by the authors for this article.

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Conflict of interest

None of the authors received any type of financial support that could be considered potential conflict of interest regarding the manuscript or its submission.

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