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Demographic Characteristics and Health Problems Related to Disability of Children with a Disability and Their Families

Engelli Çocukların ve Ailelerinin Demografik Özellikleri ve Engelliliğe İlişkin Sağlık Problemleri

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ABSTRACT

Aim: The purpose of this study was to determine demographic characteristics and health problems related to disability of diabled children and their families living in the city center of Gaziantep.

Materials and Methods: This cross-sectional and descriptive study was conducted between 01.09.2012 and 24.02.2013. The study sample consisted of families with children with a disability, who were chosen by random sampling from those who attended private training and rehabilitation centers in the county of Şehitkamil, Gaziantep and accepted to participate in the study (n=239).

Results: It was found that 62.8% of the children were boys, 75.3% had mental disabilities, 27.6% of the mothers suffered from anxiety due to the burden of care. Also, it was determined that 77.8% of the children were dependent to on their parents for their personal needs; and health problems such as oral cavities (46.9%); lack of appetite (43.5%) and spasticity and restricted movement (35.6%) were common among disabled children.

Conclusion: It was found that most of the children had more than one disability and their disability was accompanied by oral, dental, eating problems, spasticity and other muscular disorders. Also, most of the caregivers were suffering from anxiety due to the burden of care. In light of these findings, we suggest that there is a need for providing increased support for children with a disability and their caregivers.

Keywords: Children with a disability, family, health problems, demographic characteristics

ÖZ

Amaç: Gaziantep'te yaşayan engelli çocukların ve ailelerinin demografik özellikleri ve engelliğe ilişkin sağlık problemlerini belirlemek amacıyla yapılmıştır.

Gereç ve Yöntemler: Kesitsel ve tanımlayıcı olan bu çalışma 01.09.2012 ve 24.02.2013 tarihleri arasında yapılmıştır. Çalışmanın örneklemini Gaziantep'te Şehitkamil ilçesinde bulunan rehabilitasyon merkezlerinden rastgele örnekleme yöntemiyle seçilen ve bu merkezlere devam eden çalışmaya katılmayı kabul eden (n=239) engelli çocuğun ailesiyle yapılmıştır.

Bulgular: Çocukların %62,8'inin erkek, %75,3'ünün zihinsel engelli olduğu, annelerin %27,6'sının bakım yüküne bağlı olarak anksiyete yaşadıkları, çocukların %77,8'inin kişisel bakımını gerçekleştirmede bağımlı olduğu, %46,9'unun ağız problemleri, %43,5'inin iştahsızlık, %35,6'sının spastite, hareket kısıtlılığı gibi sağlık sorunları yaşadıkları saptandı.

Sonuç: Çocukların çoğunun birden fazla engele sahip olduğu, engelli olmanın yanı sıra ağız, diş, yeme problemleri, spastite ve diğer kas sorunları bulunduğu saptandı. Bakım verenlerin çoğunun da bakım yüküne bağlı olarak anksiyete yaşadığı belirlendi. Bu sonuçlar doğrultusunda bakım verenlerin ve engelli çocukların desteklenmesi önerilebilir.

Anahtar Kelimeler: Engelli çocuk, aile, sağlık problemi, demografik özellikler

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Introduction

Humans are social beings and they realize themselves by participating in the community in which they live. However, in real life, because of their social conditions, cognitive or physical differences, some groups may not have a full level of participation. Individuals with a disability constitute a category within these groups and they are in need of information on subjects related to their professional development and social welfare in their daily lives (1). The concept of disability is a life condition to which affected individuals and their families are involuntarily exposed beyond their control and a state of functional limitation caused by physical, mental or sensory incapacity (1-5). In general, among children, disability may occur separately as physical, developmental, cognitive or sensory impairment or several types of disability may coexist in one individual (6). Disability in children leads to inadequacy in different areas such as self-care, speech, communication, learning, mobility, independent living and financial adequacy (7). Disability affects the quality of life of children and their parents. Multiple symptoms and complications present a range of physical, intellectual, orthopedic, auditory, visual, and communication impairments, with a wide range of severity, and are likely to influence quality of life (8). Therefore, individuals with chronic disabilities need long term care, treatment and rehabilitation (7). According to the Global Burden of Disease (2004) data; it is estimated that 15.3% of the world's population are "mild or severely" disabled, 2.9% are "heavily" disabled and that 0.7-3 5.1% of children between the ages of 0-14 are disabled (9). There is insufficient information on the number, percentage and the socioeconomic characteristics of individuals with disabilities or chronic illnesses in Turkey. According to the data of a survey on people with disabilities conducted by the Turkish Prime Ministry Administration for Disabled People in 2002, the percentage of disabled individuals in relation to the total population is 12.29% (10).

Individuals with intellectual and physical disabilities suffer also from motor disorders, mental retardation, convulsions and visual, auditory, speech, sensory and behavioral disorders (11-13). For example, although cerebral palsy is a motor abnormality, it is often accompanied by mental retardation as well as epilepsy, visual, auditory, speech and nutritional disorders (14-21). These disorders have an adverse effect on the development levels of children and their self-care (22). Children with limited motor and sensory coordination disorder need to their parents or caregivers (11). In recent years, the availability of care services in Turkey for individuals with disabilities has increased. Care insurance premiums of poor families who provide care for disabled individuals are covered by the government. Education services for the disabled are provided in official and private institutions by the Ministry of National Education. However, although some services exist, there are still many problems to be addressed. These include a lack of family participation in the programs offered, inadequate support services for families, and a lack of available counselling and guidance services in these caregiving institutions (17,22).

In Turkey, major considerations exist for disabled children, which should be improved, including their disability-related and general health problems, their access to health-care services, specifying the problems encountered in the provision of health-care services and exploring sustainable solutions. While there are studies which specifically focus on disabled persons, a limited number of studies have been conducted to investigate other coexisting health problems of individuals with disabilities in a generalized approach. Sociocultural-economical and demographical characteristics vary in the various regions of Turkey. Gaziantep is one of the most important industrial and agricultural major cities in the south-east; it has mixed socio-economic characteristics due to migration into the city. The purpose of this study was to determine demographic characteristics and health problems related to the disability of children and their families living in the city center of Gaziantep.

Materials and Methods

Procedures

This cross-sectional and descriptive study was conducted between 01.09.2012 and 24.02.2013. The study sample consisted of families with disabled children who were selected randomly from those who attended private training, and rehabilitation centers in the county of Şehitkamil, Gaziantep and accepted to participate in the study (n=239)

Inclusion Criteria of the Study

- Families with children who had mental, physical, auditory and/or visual and speech disabilities, and who were between the ages of 0-18,
- Families who agreed to participate in the study,
- Parents without mental, auditory and/or visual disabilities.

Measures

For the purposes of data collection, a questionnaire of 34 questions was used, which was generated by the investigators based on a review of the literature (12,15,22-27). The form had two sections. The first section included 17 questions on the socio-demographic characteristics of the children and their families; and the second section included 17 questions on the care burden and other coexisting health problems of the disabled children. Questionnaires were administered by the investigators during face-to-face interviews with parents while they were waiting for their children at the rehabilitation centers. Each questionnaire took approximately 15 minutes to

complete. After the questionnaires were completed, they were submitted to an expert for his opinion. Also, before the initiation of collecting study data, the questionnaire was administered to the families of 16 disabled children in an institution not related with the study, in order to test the comprehensibility of the questions. Incomprehensible questions were revised.

Data Analyses

The study data were analyzed with a computer using means, numbers and percentages.

Ethical Considerations

Before the initiation of the study, written approval was obtained from the relevant institutions and the Ethics Committee of Gaziantep University, and families gave oral informed consent.

Results

Socio-demographic Characteristics of Children with Disability and Their Families

The mean age of the children participating in the study was 8.63 ± 4.45 years; 62.8% of them were boys and 30.1% were second-born children. It was found that 94.1% of the children attended rehabilitation centers, 84.4% received rehabilitation service twice a week, mean years of attending a rehabilitation center was 3.46±2.52 and 58.6% did not attend school. When the socio-demographic characteristics of the families were examined, it was observed that the mean age of the mothers and fathers was 36.34±7.71 years and 40.24±8.33, respectively and 54.0% of the mothers and 50.6% of the fathers were primary school graduates, 93.7% of the mothers were housewives and 46% of the fathers were self-employed, 96.7% had social security, 46.4% had equivalent levels of income and expenses, 34.3% of the families had four or more children, 83.3% did not have any other disabled children (Table 1)

Disability Type, Health Condition of Children and Provision of Health-Care Services

When the disabilities of the children were examined, it was observed that 75.3% had mental disability, which was first noticed between 0-5 months of age for 48.6%. The cause of disability was genetic or hereditary for 34.4% of the children. It was determined that 21.7% of the children had convulsions, 27.1% were taking medication on a regular basis, and of those using medication 86.2% were taking anticonvulsants; 78.2% did not have any illness during the previous year and 78.6% had not been hospitalized. It was also reported that 79.5% of the children did not benefit from home-based health care services, 41.9% preferred state hospitals to obtain health services and of those preferring state hospitals, 58.6% stated that their preference was based on the fact that their physician was working in that institution, and 61.1% said that most of their health services were provided by physicians (Table 2).

Care-related Needs of Children

It was stated that the care-related needs of 95.8% of the children were being fulfilled by their mothers, and that 27.6% of the mothers suffered from anxiety due to the burden of care. Moreover, it was reported that 43.5% of the mothers needed assistance while providing hygiene and bathing care to their children (Table 3).

Characteristics of Children Related to Performing Daily Activities

It was also stated that 77.8% of the children were dependent on others for their personal care needs, 69.0% needed assistance in getting; dressed, 60.7% for their toilet needs, 54.4% for feeding and 46.4% for mobilization.

Health Problems Accompanying Child's Disability

A look at the health problems of children accompanying with their disability revealed that they had the following coexisting problems: Oral problems (lesions, halitosis, tooth decay, gum diseases) (46.9%), lack of appetite (43.5%), spasticity, restriction of movement and contracture, foot deformity (foot drop, defective shape, pes equinovarus, pes planus, inward or outward flexion of the feet) (35.6%), difficulty in breathing (31.8%), eating, swallowing and chewing (29.7%), vision problems (27.6%), salivation (20.5%), sleeping problems (19.7%), elimination problems (18.8%), hand deformity (%17.6), nasal discharge, congestion, bleeding (17.2%), ear discharge, infection (11.7%) and allergy (10.5%) (Table 4).

Discussion

Having a disabled child necessitates assuming more responsibility than having a child without any disabilities. The life of the family of a disabled child generally revolves around the needs of the child (28), because individuals with intellectual or physical disability usually require assistance from others in performing their daily life activities and taking care of their needs (11). Children with disabilities may be partially or wholly dependent on someone else to perform their daily care and activities, and this situation may cause difficulties for the families of these children (29). The mother is most often the primary caregiver for a disabled child. Many studies conducted in our country have shown that the care of the children with a disability is mostly provided by their mothers (25,28,30-32). Consistently, our study has found out that almost all the children with a disability, have their needs provided by their mothers (95.8%).

Disability is one of the most important issues affecting the society in terms of social life, economics, public health, and politics today (33). Having a disabled child also increases the responsibilities of the parents and the functional burden

Table I. Socio-demographic characteristics of children with disability and their families

Socio-demographic characteristics	n	%
Mean age of children	8.63±4.45	
Child's gender		
Female	89	37.2
Male	150	62.8
Child's birth order		
First-born	61	25.5
Second-born	72	30.1
Third-born	51	21.3
Fourth-born	55	23.1
Does the child attend a rehabilitation center?		
Yes	225	94.1
No	14	5.9
Frequency of child to attend a rehabilitation center		
Once a week	12	5.3
Twice a week	190	84.4
Three times a week	23	10.3
Mean years of child attend a rehabilitation center	3.46±2.52	
Is the child going to the school?		
Yes	99	41.4
No	140	58.6
Mean age of mothers	36.34±7.71	
Mean age of fathers	40.24±8.33	
Mather's education status		
Illiterate	59	24.7
Primary school	129	54.0
Secondary school	24	10.0
High school	15	6.3
University	12	5.0
Father's education status		
Illiterate	19	7.9
Primary school	121	50.6
Secondary school	44	18.4
High school	37	15.5
University	18	7.5
Mather's occupation		
Housewife	224	93.7
Worker	2	0.8
Civil Servant	13	5.4
Father's occupation		
Worker	104	43.5
Civil Servant	25	10.5
Self-Employed	110	46.0
Social security		
Yes	231	96.7
No	8	3.3
Income status		
Income more than expenses	18	7.5
Income equal to expenses	111	46.4
Income less than expenses	110	46.0
Number of children in the family		
1	16	6.7
2	62	25.9
3	79	33.1
4	82	34.3
Other children with any disability?		
Yes	40	16.7
No	199	83.3

on them, because an individual with a disability requires more attention with respect to satisfying their needs in several areas such as education, health, care, affection, being loved, leisure activities, and protection (31). The nurse plays a significant role in getting to know the child, the family and the difficulties encountered by them. Nurses can also determine the types of support families need. Because of the fact that children with a disability are in a dependent position and their needs for care are increased, their parents and especially mothers suffer from physical overload. Moreover, insufficient knowledge on how to deliver proper care for a disabled child, concerns for his/her future, social stigmata and economic problems may lead to an emotional overload (23,30,31). The increased burden of care imposed on the family naturally causes health problems as well as stress and anxiety between the parents (23,27,30,33). Several studies have confirmed that families with disabled children suffer from physical/physiological health problems as well as psychological problems while providing personal care and tending to other needs of their children (2,25,27,28,32-36). Similarly, our study has shown that parents experience physical problems like low back pain and psychological problems such as anxiety resulting from the burden of care.

Parents of children with a disability need assistance and support in several areas in order to provide care for their children, sustain their development and aid them in their daily lives. (21,25,32). A study by Üşenmez (37) found that parents of disabled children required assistance in satisfying the needs of their children while feeding, bathing and using the toilet. A study by Şen and Yurtsever (6) reported that parents of children with cerebral palsy were in need of greater assistance in meeting the needs of their children while feeding and using the toilet. A study by Bilsin (25) showed that parents of children with a disability required assistance in taking care of the needs of their children while bathing,and using the toilet and giving treatment. A study by Abelson (38)

Table II. Disability type, health condition of children and provision of health-care services		
Characteristics	**n**	**%**
Type of child's disability*		
Mentally	180	75.3
Physically	143	59.8
Visually	7	2.9
Hearing	3	1.3
Speech	74	31.0
Age when the disability was first noticed		
Between 0-5 months	116	48.6
Between 6-11 months	21	8.7
Between 1-3 years	62	25.9
4 years and over	40	16.8
Cause of child's disability*		
Genetic or hereditary causes	82	34.4
Birth-related causes (trauma, asphyxia)	75	31.3
Maternal reasons (illness, medication, nutrition, substance using)	23	9.6
Child-related causes	39	16.3
Unknown	58	24.3
Does the child have convulsions?		
Yes	52	21.7
No	187	78.3
Does the child take medications regularly?		
Yes	65	27.1
No	174	72.9
Type of medication (n=65)		
Inhaler	5	7.7
Anticonvulsant	56	86.2
Tranquilizer and antidepressant	4	6.1
Illnesses during the previous year		
Upper respiratory tract infection	33	13.9
Asthma/bronchitis	17	7.1
Urinary infection	1	0.4
Poisoning	1	0.4
None	187	78.2
Hospitalization during the previous year		
Yes	51	21.4
No	188	78.6
Provision of home-based health-care services		
Yes	49	20.5
No	190	79.5
First institution preferred for receiving health-care services		
State Hospital	100	41.9
University Hospital	8	3.4
Private Hospital	15	6.3
Family Physician	53	22.3
No response	55	23.1
Reason for preference (n=174)		
Economic	37	21.3
Treatment course of the child and his/her physician working there	102	58.6
Proximity	37	21.1
Health-care personnel from whom you received most of the services		
Nurse	30	12.6
Doctor	146	61.1
Physical therapy specialist	63	26.4
*More than one answer checked		

Table III. Care-related needs of the children		
Individuals contributing to the care of the child*	**n**	**%**
Mother	229	95.8
Father	113	47.3
Siblings	56	23.4
Relative	14	5.9
Friends/Neighbours	7	2.9
Association/Institution	20	8.4
Health problems experienced by the mothers because of difficulties in child care*		
Low back pain	33	13.8
Headache	4	1.7
Anxiety	66	27.6
Insomnia	2	0.8
Areas where assistance is needed when providing care to the child*		
Hygiene-Bathing	104	43.5
Treatment	49	20.5
Nutrition	46	19.2
Toilet	62	25.9
Exercise-Mobility	61	25.5
*More than one answer checked		

found that parents of disabled children required assistance with their children while giving their drugs, bathing, feeding, dressing them, taking them to the toilet and giving oral care. Consistently, our study has shown that parents required assistance primarily while helping their children with their bathing/toilet needs (43.5%) and during the mobilization/exercising of their children. The results of our study are consistent with the literature.

Like normally functioning children, those with a disability have biological and physiological needs such as eating, drinking, elimination and mobility (39). However, children with disabilities may be dependent on others in satisfying these needs as opposed to other children of the same age. Any number of disabilities may considerably impair the ability to meet their self-care needs (5,11,22,37,40). Self-care plays an integral role in the development of positive health behaviours and self-control as well as for increasing individual capacities and improving the level of quality of life (22).

Individuals with intellectual and physical disabilities constitute a risk group with regard to health problems. One of the two major reasons for this is that these individuals are more susceptible to health problems in comparison to the general population. Secondly, they may not sufficiently benefit from health-care services (41). Our study has shown that nearly half of the children had oral and dental problems such as bad breath, lesions in the oral cavity, tooth decay

Table IV. Health problems accompanying childs disability*

Health problems of children with disability	**Yes**		**No**		**Sometimes**	
	n	**%**	**n**	**%**	**n**	**%**
Oral and dental problems	112	46.9	120	50.2	7	2.9
Lack of appetite	104	43.5	92	38.5	43	18.0
Spasticity	85	35.6	154	64.4	0	0.0
Foot deformity	85	35.6	154	64.4	0	0.0
Breathing problems	76	31.8	123	51.5	40	16.7
Difficulty in eating, swallowing and chewing	71	29.7	157	65.7	11	4.6
Vision problems	66	27.6	159	66.5	14	5.9
Drooling	49	20.5	179	74.9	11	4.6
Sleeping problems	47	19.7	168	70.3	24	10.0
Foot deformity	42	17.6	197	82.4	0	0.0
Nasal discharge, congestion, bleeding	41	17.2	152	63.6	46	19.2
Ear discharge, infection	28	11.7	197	82.4	14	5.9
Allergy	25	10.5	194	81.2	20	8.3
Hand deformity	4	1.7	235	98.3	0	0.0
*More than one answer checked						

and salivation. A study by Bilsin (25) found that children with disabilties had salivation, tooth decay, bronchitis, asthma, epilepsy, constipation. Erdoğanoğlu and Günel's (42) study revealed that children with cerebral palsy had vision, speech and hearing problems, and epilepsy. A study by Durduran (43) showed that children with disabilities had asthma, bronchitis and epilepsy. According to a study by Chen et al. (11), children who required special health care (such as those with mental disabilities, or multiple disabilities) had more dental problems. A study by Ikeda et al. (21) showed that most of the children with physically disabilities had sleep disturbances. Specifically, oral hygiene and oral health is worse than their healthy peers (4,44). The reasons for the differences between healthy and disabled children with respect to the incidences of oral and dental problems include differences in the frequency of carbohydrate intake and differences in the saliva flow rate, impaired cooperation, medications used, lack of hygiene due to muscular or joint problems and difficulty of in chewing (44). Thus, health-care institutions should cooperate with institutions providing specialized education to individuals with a disability and their families in order to improve the oral and dental health of these individuals. Instead of waiting for these individuals to attend these centers, regular screening should be conducted in order to determine their health-care needs, and take preventative measures (12).

Healthcare professionals can identify the coping strategies of families and offer more effective coping and communication skills to help promote healthy family functioning. In Turkey, individuals with disability and their families experience difficulties in demanding health-care services and in expressing their health problems. Moreover, lack of laws or deficiencies in the enforcement of the laws for persons with a disability, and limitations in the number of appropriately trained professionals prevent their access to health-care and rehabilitation services and thus contribute to an increase in their coexisting problems. This poses an obstacle to gaining new psychomotor abilities by decreasing their quality of life (15). In individuals with a disability, motor disorders may occur in the form of spasticity, weakness, coordination disorder, involuntary movements, muscle stiffness, contracture and associated deformities and tremors (22). A study by Ones et al. (17) showed that most of the patients with cerebral palsy had spasticity and foot deformity. Our study has also found that the majority of the children had spasticity and foot deformation.

Study Limitations

Our study has some limitations: The study was conducted with only a small group of individuals attending the rehabilitation centers. We were unable to contact all of the children with a disability and their families and also the study period was short. In our country, there is a need for large-scale and multidisciplinary experimental studies in order to address the general health problems of the individuals with disabilities and to suggest solutions. Based on the results of future studies, disabled children and their families will be able to get more support for their specific needs.

Conclusions

In conclusion, our study found that most of the children had more than one type of disability, they needed assistance from others to carry out their daily needs, and their disability was often accompanied by oral, dental and eating problems, spasticity and other muscular problems. It was also observed that most of the caregiving mothers experienced physical and psychological problems. In the light of these findings, a multidisciplinary approach seems to be highly important in resolving the problems of individuals with disabilities. In addition to the efforts to increase the independence of the disabled, children and families should be supported in overcoming their problems of rehabilitation, social adaptation and health. Moreover, primary-care nurses and other health-care professionals should regard the child with a disability and his/her family as a whole, and provide education in the areas needed.

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Ethics

Ethics Committee Approval: The study were approved by the Süleyman Demirel University of Local Ethics Committee, Informed Consent: Consent form was filled out by all participants.

Peer-review: External peer-reviwed

Authorship Contributions

Surgical and Medical Practices: Gülendam Karadağ, Elif Bilsin, Concept: Gülendam Karadağ, Elif Bilsin, Design: Gülendam Karadağ, Elif Bilsin, Data Collection or Processing: Gülendam Karadağ, Elif Bilsin, Analysis or Interpretation: Gülendam Karadağ, Elif Bilsin, Literature Search: Gülendam Karadağ, Elif Bilsin, Writing: Gülendam Karadağ, Elif Bilsin.

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