

Family Burden Among Parents of Children With Intellectual Disability

Zihinsel Yetersiz Çocuğu Olan Ebeveynlerde Aile Yüğü

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SUMMARY

Objectives: This study aimed to assess family burden and associated factors among parents of children with intellectual disability.

Methods: The study was performed with 467 parents of children with intellectual disability aged between zero to 18 years at Akdeniz University, Department of Pediatric Neurology. The data was collected through face-to-face interviews via a "Family Questionnaire Form" which was composed in reference to the literature, and a "Family Burden Assessment Scale". Family Burden Assessment Scale an instrument comprised of 6 sub-factors and 43 items and measured with a five-point Likert-type (1-5) scale. Higher scores represented more severe family burden. The number and percentage distributions were used for characteristic of the children and parent, correlation analysis was used to determine the relationship between the scale sub-factors and characteristics of children with intellectual disability.

Results: All the participants were mothers and the mean score of the mothers in the Family Burden Assessment Scale was quite high (4.16±0.53). The sub-factors that have highest score were perceived inadequacy (4.62±0.53), time requirement (4.51±0.51), emotional burden (4.39±0.59). Physical burden (4.278±1.284), emotional burden (4.632±0.515), economic burden (3.942±1.073), social burden (4.130±0.619) and time requirement (4.788±0.219) of family increased with the intellectual disability level of children.

Conclusion: The care, treatment and rehabilitation of children with intellectual disability requires more manpower, cost and time than healthy children. Children who attend special education, depend on self-care or have severe intellectual disability, should support from health and psychosocial professionals in care and coping with. This situation is too important for both mother and family health.

Keywords: Child; family burden; intellectual disability; mother; nurse; parents.

ÖZET

Amaç: Çalışma, zihinsel yetersiz çocuğu olan ebeveynlerinaile yükünü ve etkileyen faktörleri incelemek amacıyla yapılmıştır.

Gereç ve Yöntem: Araştırmanın evrenini, Ocak-Mayıs 2014 tarihleri arasında Akdeniz Üniversitesi Hastanesinin Çocuk Nöroloji Polikliniği'ne başvuran, 0-18 yaş arası, psikometrik değerlendirmeler sonucu zihinsel yetersizliği olduğu belirlenen tüm çocukların ebeveynleri oluşturmuştur. Örneklem seçimine gidilmeyerek, araştırmanın amacı açıklandıktan sonra araştırmaya katılmayı kabul eden 467 ebeveyn araştırmanın örneklemini oluşturmuştur. Veriler, literatür bilgisi doğrultusunda oluşturulan "Aile Tanıtım Formu" ve "Aile Yüğü Değerlendirme Ölçeği" kullanılarak yüz-yüze görüşme yöntemi ile toplanmıştır. Aile Yüğü Değerlendirme Ölçeği; 6 alt ölçek, 43 maddeden oluşan 5'li likert tipinde (1-5 puan) bir değerlendirme aracıdır. Alt ölçekler; ekonomik, fiziksel, duygusal, sosyal yük, yetersizlik algısı ve zaman gereksinimidir. Puanların yüksek olması, aile yükünün fazla olduğunu göstermektedir. Araştırmanın yapılabilmesi için Akdeniz Üniversitesi Girişimsel Olmayan Klinik Araştırmalar Etik Kurulu'ndan yazılı onay, kurumdan yasal izin ve ebeveynlerden yazılı aydınlatılmış onam alınmıştır. Çocuk ve ebeveynlere ait özellikler için sayı ve yüzde dağılımı kullanılırken, ölçek alt faktörleri ile çocuğa ait özellikler arasındaki ilişkiyi incelemek için korelasyon analizi kullanılmıştır.

Bulgular: Araştırmada katılımcıların tamamının anne olduğu ve annelerin aile yükü değerlendirme ölçeği puan ortalamalarının yüksek olduğu görülmüştür (4.16±0.53). En yüksek puan ortalamasına sahip alt ölçekler; yetersizlik algısı (4.62±0.53), zaman gereksinimi (4.51±0.51) ve duygusal yüküdür (4.39±0.59). Araştırmada çocuğun zihinsel yetersizlik düzeyi arttıkça, ailenin fiziksel (4.278±1.284), duygusal (4.632±0.515), ekonomik (3.942±1.073), sosyal yükünün (4.130±0.619) ve zaman gereksiniminin (4.788±0.219) arttığı görülmüştür.

Sonuç: Zihinsel yetersizliği olan çocuğun bakımı, tedavisi ve rehabilitasyonu sağlıklı bir çocuğun bakımından daha fazla insan gücü, maliyet, zaman ve multidisipliner yaklaşım gerektirmektedir. Hemşire, ekipte zihinsel yetersiz birey ve ailesini bakımın merkezine alarak diğer ekip üyeleriyle koordinasyonu sağlayabilecek anahtar kişidir. Araştırma sonuçları ebeveynlerin yaşayabilecekleri yükü ve ruhsal sorunları hemşirenin öngörebilmesi, tanınması, onlara bu konuda eğitim ve danışmanlık vermesi açısından önemlidir.

Anahtar sözcükler: Çocuk; aile yükü; zihinsel yetersizlik; anne; hemşire; ebeveyn.

Introduction

Intellectual disability is the insufficient development of intellectual skills.^[1] It is a significant condition which causes

permanent deficiencies, affects all family members financially, socially, emotionally, behaviorally and cognitively, and requires lifelong observation, control, care, treatment and rehabilitation.^[2,3] The history of the term, children with intellectual disability, indicates that children with the condition were initially referred to as "children with personal differences," and later as: "abnormal children," "exceptional children," "disabled children," "individuals with disabilities," and "individuals with special needs." The history of the condition makes it clear that the following terms were used: individuals with special educational needs, children with special educational needs, individuals needing special education, disabled

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persons, disabled, exceptional children and individuals with special needs.^[4,5] The World Health Organization (WHO) classifies intellectual disability as mild (IQ: 52-69), moderate (IQ: 36-51), severe (IQ: 20-35) and deep (IQ: <20) following the psychometric assessments.^[6] This classification makes it possible to teach people according to their abilities and ensure that they live without being a burden to themselves, their families and society.^[1] The WHO reports that there are 650 million disabled people on the world, and approximately 200 million of them are children.^[6] The Turkish Statistical Institute (TSI) defines the group that faces a higher risk of poverty and exclusion than the general population as a precarious population and includes the disabled population in it. TSI data (2015) indicate that there are 482,361 intellectually-disabled people in Turkey, and children constitute 8.7% of the disabled population.^[7]

Recent studies of caregiving have focused on the term, burden. The term, family burden, was mentioned first by Grad and Sainsbury. They defined it as the negative expenditures created by the intellectually disabled children for their families.^[8] Intellectually disabled children significantly affect how their families live.^[9,10] Deficiency becomes the core of families' lives upon diagnosis and causes them many burdens. Family members' roles and responsibilities start to change. These changes may be seen in intrafamilial roles, private living spaces, social environments, expectations, plans and careers. Factors such as economic and educational status, profession, marital adjustment and cultures of the parents, lack of social support, difficulties in communication, severity of the disease, children's age, distortions of family routines, the level of need for medical aid and the financial burden caused by the disease all affect the stress levels of parents.^[11] Chronic stress causes families to have more perceived problems and raises their anxiety levels. It also causes serious problems with coping and worsens the family burden. Studies indicate that families face the most stress during the diagnoses, and families' energy levels are diminished as children's dependency on their parents increases. Family members start to lock themselves in the house, and their private lives are disturbed. Social isolation and loneliness can occur. This diminishes satisfaction with life and quality of life.^[12] This disease affects not only nuclear families, but also extended families.^[13]

Parents who have intellectually disabled children have problems in their marriages due to stress.^[14] A study suggests that couples who have intellectually disabled children do not spare time for each other, and problems such as blaming one another emerge.^[14] Couples who do not display the same level of coping feel that they are not supported by their partners and feel emotions such as anger, vexation and despair. In particular, mothers undertake the main responsibility to provide care and thus get angry more frequently. This anger also

affects families. The siblings of children with deficiencies are deprived of the attention of their parents when these children become the focus of attention. This causes tensions between the subsystems covering parents and siblings.^[15] Emotional problems, jealousy and competition may emerge between the siblings, and marriages may be negatively affected by this. However, there is parental feedback that suggests couples' adaptation to the disease can enhance their relationships and draw the family members closer to one another.^[16]

The care to be provided to intellectually disabled children and their parents requires an interdisciplinary team approach. This team should include professionals such as nurses, doctors, dietitians, physical therapists, psychologists and special education experts. A nurse is a key person who can position disabled persons and their families at the center of care and ensure coordination with other personnel. Nurses who provide care to intellectually disabled children and their parents should undertake a variety of distinct roles and act as educators, consultants, advocates and decision makers.

Determining the family burden of the parents of intellectually disabled children is important for providing professional support to families who suffer from burden and for identifying coping behaviors. The families of disabled children will feel that they are not alone and will be able to receive professional support for the issues that burden them. Doing so will make it possible to teach people according to their abilities and ensure that they can lead lives without causing stress and burden for their families and society. This study was conducted to examine the family burden of the parents with intellectually disabled children and the factors that affect it.

Materials and Method

Type and Sampling of the Research

This study is descriptive.

Study population consisted of the parents of children who were diagnosed with intellectual disability following the psychometric assessments, whose ages ranged between newborn and 18 and who visited the Department of Pediatric Neurology at Akdeniz University between January and May 2014. Sample selection was not performed for this study, and 467 parents who were informed about the study aim and agreed to participate constituted the sample.

Data Collection Tools and Activities

The data were collected in face-to-face interviews using the Family Introduction Form and the Family Burden Evaluation Scale, which were prepared by the researchers considering findings in the literature^[9,12] and expert opinions. Interviews with parents were conducted in a quiet environment in the pediatric neurology polyclinic. Ten parents with whom a

pilot test was conducted to evaluate the scales' comprehensibility were excluded from the sample. This study directed the following questions: What are the family burden and family burden subfactors of the parents with intellectually disabled children? and, Is there a relationship between the family burden and family burden subfactors, and sociodemographic characteristics and the children's characteristics?

The Family Introduction Form

This form consists of 20 open-ended multiple-choice questions regarding the intellectual deficiency and sociodemographic characteristics of the children and their parents.

The Family Burden Evaluation Scale: This scale has six subfactors. It was developed by Sarı and Başbakkal in 2008. It has 43 five-point Likert type items.^[9] Its subscales are economic burden, physical burden, emotional burden and social burden, inadequacy perception and time requirement. The options are scored 1=never, 2=seldom, 3=occasionally, 4=frequently and 5=always. Higher scores indicate heavier family burden. The breakpoint is 97 points. The Cronbach's alpha coefficient for this scale is 0.92.^[9]

Data Analysis

The study data were evaluated using SPSS 20.0, numbers, percentage distributions, t test in independent groups, variance analysis and Duncan's test. $P < 0.05$ was used as the threshold for statistical significance.

Dependent and Independent Variables of the Study

The Family Burden Evaluation Scale (FBES) and subscale scores constitute the dependent variables of the study. Its independent variables include various factors that may affect FBES and subscale scores such as children's age, gender, school attendance, level of intellectual disability, coexistence of another chronic disease, maternal details and economic status.

Ethical Dimension of the Research

Ethical approval was obtained from the Ethics Committee of Non-Interventional Clinical Studies at Akdeniz University, and written permission was obtained from the Pediatric Neurology Polyclinic of Akdeniz University Hospital. Written informed consent was obtained from the parents.

Results

The characteristics of the intellectually disabled children and their parents are shown in Table 1. All the participating parents were mothers, and their mean age was 35.1 ± 7.2 . Of the families, 49% had equal incomes and expenses. The children's mean age was found to be 8.4 ± 4.6 years, and the age of 39.4% ranged between 7 and 12. Of all the children, 54% had mild intellectual disability, 71.3% received special education, and 49.5% went to school. Furthermore, 84.4%

had another chronic disease (61.9% had epilepsy, 12.6% had cerebral palsy, and 9.9% had autism) (Table 1).

Table 2 shows the mothers' mean scores on the FBES and its subfactors. The mothers' mean FBES score was found to be 4.16 ± 0.53 .

Table 3 shows the difference between the mothers' mean scores on the FBES and its subfactors and the characteristics of the intellectually disabled children. A statistically significant difference was found between the mothers' mean FBES scores and intellectually disabled children's age, level of disability and the coexistence of another chronic disease. However, no statistically significant difference was found between

Table 1. The characteristics of the intellectually disabled children and their parents (n=467)

Characteristics	n	%	Mean±SD
Mothers' mean age (years)			35.1±7.2
Children's mean age (years)			8.4±4.6
Educational status of mother			
Not literate	25	5.4	
Completed elementary school	268	57.4	
High school graduate	114	24.4	
University graduate	60	12.8	
Mother's profession			
Housewife	400	85.7	
Civil servant	48	10.3	
Self-employed	17	3.6	
Retired	2	0.4	
Economic status			
Income>Expense	205	43.9	
Income=Expense	229	49.0	
Income<Expense	33	7.1	
Child's gender			
Female	212	45.4	
Male	255	54.6	
Child's age group			
0-11 years	3	0.6	
1-3 years	48	10.3	
4-6 years	80	17.1	
7-12 years	184	39.4	
13-18 years	152	32.5	
Level of child's intellectual disability			
Mild	252	54.0	
Moderate	192	41.1	
Severe	23	4.9	
Child's attendance to school			
Yes	231	49.5	
No	236	50.5	
Child's attendance to special education			
Yes	333	71.3	
No	134	28.7	
Existence of another chronic condition			
Yes	394	84.4	
No	73	15.6	
If yes, conditions			
Epilepsy	289	61.9	
Cerebral palsy	59	12.6	
Autism	46	9.9	

SD: Standard deviation.

the intellectually disabled children's gender and whether or not they go to a school or receive special education (Table 3). The children's characteristics that played a role in the differ-

ence between the subfactors were identified using Duncan's advanced statistical analysis method.

Family burden was found to vary by the existence of another chronic disease. The difference between the age groups resulted from the group of children less than a year old. Similarly, mothers whose children had another chronic disease (epilepsy, chronic disease or autism) were found to have heavier family burden. In addition, the difference between the intellectual disability levels of children resulted from the group including severely disabled children. The mean family burden scores of severely disabled children's mothers were found to be high, and this score was found to be low for the mothers of mildly disabled children (Table 3).

Economic burden was found to vary by age group and in-

Table 2. The mothers' mean scores on the FBES* and its subfactors (n=467)

Scale subfactors	Mean scores (Mean±SD)
F1. Economic burden	3.47 ± 1.28
F2. Perception of inadequacy	4.62 ± 0.53
F3. Social burden	3.63 ± 0.97
F4. Physical burden	3.92 ± 1.14
F5. Emotional burden	4.39 ± 0.59
F6. Time requirement	4.51 ± 0.51
Mean FBES score	4.16 ± 0.53

*FBES: Family Burden Evaluation Scale; SD: Standard deviation.

Table 3. Distribution of the mothers' mean scores on the FBES and its subfactors by the characteristics of the intellectually disabled children (n=467)

Characteristics	FBES*	Economic burden (F1)	Perception of inadequacy (F2)	Social burden (F3)	Physical burden (F4)	Emotional burden (F5)	Time requirement (F6)
	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD
Age groups							
0-11 months	4.441±0.162	3.333±1.527	4.916±0.144	4.055±0.693	4.600±0.400	4.697±0.277	4.666±0.459
1-3 age	4.273±0.320	2.979±1.359	4.700±0.225	4.090±0.717	4.233±1.004	4.541±0.358	4.657±0.264
4-6 age	4.182±0.344	3.287±1.367	4.728±0.286	3.614±1.022	3.972±1.157	4.443±0.402	4.551±0.316
7-12 age	4.146±0.629	3.587±1.245	4.557±0.671	3.638±0.950	3.953±1.120	4.302±0.758	4.483±0.564
13-19 age	4.145±0.562	3.587±1.235	4.622±0.510	3.493±1.018	3.744±1.208	4.426±0.516	4.480±0.595
	F=3.433 p=0.009	F=2.899 p=0.022	F=3.619 p=0.006	F=3.675 p=0.006	F=2.962 p=0.020	F=2.249 p=0.063	F=1.419 p=0.227
Gender							
Female	4.177±0.437	3.324±1.266	4.705±0.396	3.559±0.923	3.976±1.017	4.461±0.481	4.531±0.424
Male	4.158±0.611	3.594±1.294	4.557±0.618	3.700±1.006	3.876±1.247	4.338±0.678	4.498±0.584
	t=0.364 p=0.716	t=-2.274 p=0.023	t=2.994 p=0.003	t=-1.572 p=0.117	t=0.940 p=0.348	t=2.217 p=0.027	t=0.672 p=0.502
Child's attendance to school							
Yes	4.175±0.498	3.663±1.166	4.664±0.422	3.489±0.963	3.794±1.180	4.435±0.532	4.507±0.507
No	4.159±0.577	3.284±1.372	4.586±0.622	3.780±0.959	4.045±1.105	4.354±0.657	4.519±0.529
	t=0.325 p=0.745	t=3.208 p=0.001	t=1.572 p=0.116	t=-3.272 p=0.001	t=-2.372 p=0.018	t=1.465 p=0.144	t=-0.255 p=0.799
Child's attendance to special education							
Yes	4.191±0.555	3.382±1.332	4.616±0.581	3.755±0.965	4.052±1.064	4.412±0.620	4.523±0.507
No	4.106±0.492	3.692±1.143	4.645±0.394	3.340±0.926	3.595±1.283	4.348±0.545	4.487±0.543
	t=1.536 p=0.125	t=-2.365 p=0.018	t=-0.533 p=0.594	t=4.246 p=0.000	t=3.952 p=0.000	t=1.040 p=0.299	t=0.690 p=0.490
Level of child's intellectual disability							
Hafif	4.083±0.525	3.323±1.270	4.592±0.492	3.487±0.991	3.790±1.199	4.342±0.562	4.464±0.539
Orta	4.242±0.554	3.610±1.309	4.661±0.602	3.772±0.943	4.051±1.040	4.433±0.647	4.544±0.503
Ağır	4.457±0.332	3.942±1.073	4.668±0.309	4.130±0.619	4.278±1.284	4.632±0.515	4.788±0.219
	F=8.523 p=0.000	F=4.381 p=0.013	F=0.983 p=0.375	F=8.060 p=0.000	F=4.020 p=0.019	F=3.201 p=0.042	F=4.809 p=0.009
Existence of another chronic condition							
Yes	4.194±0.541	3.583±1.231	4.641±0.540	3.641±0.965	3.978±1.128	4.413±0.615	4.493±0.550
No	4.016±0.501	2.869±1.417	4.532±0.493	3.609±1.009	3.613±1.218	4.287±0.499	4.622±0.267
	t=2.607 p=0.009	t=4.436 p=0.000	t=1.609 p=0.108	t=0.256 p=0.798	t=2.507 p=0.013	t=1.655 p=0.099	t=-1.963 p=0.050

FBES: Family Burden Evaluation Scale; SD: Standart sapma.

tellecual degree of disability. The difference between the age groups resulted from the group of 7-19-year-old children. For the economic burden group, the difference between the levels of children's intellectual disability resulted from severe intellectual disability, and the mean economic burden scores of mothers whose children have severe intellectual disability were found to be high (Table 3). Similarly, mothers whose male children had another chronic disease (epilepsy, chronic disease or autism) and did not receive special education were found to have heavier family burden (Table 3).

Perception of inadequacy was found to vary by age group and gender. The difference between the age groups resulted from the group consisting of children who were less than a year old. The perception of inadequacy of mothers with children who were less than a year old and with female children was found to be higher (Table 3).

Social burden was found to vary by age group and degree of intellectual disability. The difference between the age groups resulted from the group of children who were less than three years old, and the difference between the levels of intellectual disability resulted from the group with severe intellectual disability (Table 3). The social burden of the mothers of children who received special education was heavier and was milder for those whose children went to school (Table 3).

Physical burden was found to vary by age group and degree of intellectual disability. The difference between the age groups resulted from the group of children who were less than a year old, and the difference between the levels of intellectual disability resulted from the group with severe intellectual disability (Table 3). Similarly, the physical burden of those whose children had another chronic disease and received special education was heavier, and this burden was not as heavy for those whose children went to school.

Emotional burden was found to vary by degree of intellectual disability. This difference resulted from the group with severe intellectual disability. The mothers of intellectually disabled female children had heavier emotional burden (Table 3).

Time requirement: Time requirement was found to vary by degree of intellectual disability and the existence of another chronic disease. This difference resulted from the group with severe intellectual disability. The time requirement of mothers increased for intellectually disabled children with another chronic disease (Table 3).

Discussion

The family system is a whole. The difficulties of one member affect the other people in this system. Continuous inadequacy that cannot be altered frequently affects not only the child, but also the family and relatives physically, emotion-

ally and socially, leading to multiple problems.^[17] This study examined the family burden and the factors that affect this burden. Perception of inadequacy score was at the highest level in the family burden. Children's characteristics affected all mean subscale scores, but parents' characteristics did not affect at all.

The fact that the study sample consists of only mothers is remarkable. This study indicated that the majority of those who provided care to intellectually disabled children were mothers.^[18-20] This is an expected result considering the roles women are assigned by society and their social status.^[20] This result indicated that Turkish family structures are based on gender roles and cultural characteristics that assign the primary responsibility for childcare to mothers. Mothers undertake the primary role in providing care to intellectually disabled children. Mothers are thus forced to leave their jobs and provide care at home or hospitals. Thus, mothers with intellectually disabled children have heavier economic, physical and emotional burden, and their lives are restricted.

This study also examined the factors that affected the sub-factors (economic burden, perception of inadequacy, social burden, physical burden, emotional burden and time requirement) of the Family Burden Evaluation Scale.

Economic burden: This study found that the mothers of children who go to school and have another chronic disease have heavier economic burden. These findings are similar to studies that indicate that intellectually disabled children's needs for therapy, special education and special tools put an economic burden on the shoulders of their families.^[20-24] The finding that mothers of severely disabled children have heavier burden is like the studies that identify a significant relationship between the level of intellectual disability and economic difficulty.^[22-25] As the disability worsens, children's independence level drops, which increases expenses for nutrition, transportation and hygienic care.

Perception of inadequacy indicates the sorrowful incidents families experience and concerns about the future of intellectually disabled children. As understood from the answers provided to the questions evaluating the perception of inadequacy within family burden, families get upset when their children acquire skills such as talking or walking later than their peers, complete their developmental skills later, fail to fully perform their daily activities and have communicational difficulties. This causes families to feel inadequate. Another study similarly reported that having disabled children, living with them, planning a future for them, setting goals and having concerns about whether or not goals will be achieved increases perception of inadequacy.^[26] Furthermore, considering the statements of the families, attitudes of acquaintances and social reactions (questions and glances

towards the families) were found to worsen the perception of inadequacy. Among the family burden subdimensions, perceptions of inadequacy by mothers who have intellectually disabled children less than a year old was found to be high. Perception of inadequacy is expected to be high during the early childhood since children's mental-motor development takes place rapidly, and care responsibilities are many in this period. Another study^[14] also indicated the same finding.

Social burden: The social interactions of the families are restricted since care responsibilities for the children are plenty during early childhood.^[14,27] Thus, it is expected that mothers of intellectually disabled children whose ages range between one and three have severe social burden. However, there are studies that claim the social burden of mothers worsens as their intellectually disabled children grow up. As the gap between the chronological age and mental age becomes more distinct, inadequacy becomes clearer, and this increases the perception of stigmatization. Thus, families become more socially timid.^[28] The fact that mothers of severely disabled children and children with another chronic disease have heavier social burden is similar to this finding. The family has to spare more time for the children as the intellectual disability worsens, thus the social life of the family is interrupted. The picture gets darker once another chronic disease emerges. The care provided to the children increases, and the family is restricted more.

This study found that children's attendance to school lowered mother's social burden. However, special education was found to increase this burden. The literature, on the other hand, suggests that family burden may be effectively relieved in the event that sufficient (in amount and quality) day care centers provide care to these children at certain hours of the day.^[29] There are similar results in the literature. It reports that families are disturbed by glances towards them or their intellectually disabled children, thus they restrict their social relationships to preserve themselves from the reactions and experience less problems by disregarding these attitudes and reactions.^[14,24,29-31] In another study of the social restrictions and social support scores of care providers by gender, the social support scores of female care providers were found to be lower than those of male care providers.^[32]

Physical burden is evaluated by comparing self-care and daily activities. Families experience physical burden due to care responsibilities for their intellectually disabled children. Studies have highlighted that families had difficulties and needed assistance with these specific activities: preparing meals and feeding their children, providing personal care to the children, using medicines, maintaining hygiene, protecting children from danger and preventing threatening situations, dressing their children, ensuring dental health, taking their children to the toilet, changing diapers, helping during

tantrums, and assisting their children while climbing stairs and using wheelchairs.^[33,34] Although it is expected that the physical needs of children who have severe intellectual disability and whose motor development is inferior to that of their peers will increase as they age, self-care and daily activities of small children are hard to perform since these children cannot yet care for themselves. The physical burden of families will be reduced when their children begin to meet their needs such as eating, going to the toilet, dressing and cleaning themselves. As seen in age groups, children's level of disability is among the most significant factors that affect when they can meet their self-care needs on their own. Mothers' statements and children's experiences indicate that the independence level of children with severe mental deficiency drops, meaning that their families have to meet their self-care needs. This situation worsens the physical burden of families. The coexistence of another chronic disease (epilepsy, cerebral palsy or autism) can make the situation more complicated. It can make it difficult or even impossible for children to meet their own self-care needs. Thus, the physical burden of the family increases.

Emotional burden: Considering that mothers feel overwhelmed by the idea that their intellectually disabled children will die, it is not surprising that emotional burden is too heavy for mothers with severely disabled children. Severe mental deficiency decreases children's independence and complicates child care. This causes additional physical burden. Many studies conducted with the families of intellectually disabled children suggested that the stress levels of the parents of intellectually disabled children are higher than those of the parents of normal, healthy children.^[21,35,36] One study^[37] reported that the mothers of intellectually disabled children have two or three times more mental problems than society at large. Another study^[38] indicated that 22% of the mothers visited a doctor for mental problems arising from situations related to their children.

Time requirement: As the intellectual disability level worsens, families need more time to care for their children. The reason for this may be that intellectually disabled children cannot perform self-care in their independence and daily activities on their own. The case is similar when another chronic disease exists. The situation will get worse with another chronic disease along with the mental deficiency, it will be harder to provide care, and mothers will need more time. Studies have reported that mothers plan their daily activities around their intellectually disabled children and cannot take a rest and spare time for their husbands and other children.^[14,23,39-42]

Conclusion

The fact that the study sample consists of only moth-

ers, and families have heavy family burden is remarkable. It is a well-known fact that mothers are primarily responsible for the childcare. This study shows that mothers undertake the primary role in providing care to intellectually disabled children. As the mental deficiency level gets worse, families' physical, emotional, economic and social burden gets heavier, and the time requirement for care increases. Care, treatment and rehabilitation for intellectually disabled children require more manpower, expense and time than those of healthy children. Support from health professionals and psychosocial experts for providing care to intellectually disabled children who depend on other people for meeting their self-care needs, continue their special education or have severe intellectual disability, and for helping them cope with their disease is important for both mothers and family health. Educating intellectually disabled children and their families about providing care and coping with the disease requires a multidisciplinary approach. A nurse is a key person who can position disabled persons and their families at the center of care and ensure coordination with other personnel. Nurses who work with intellectually disabled people and their parents provide primary, secondary and tertiary care in hospitals and society, and they undertake distinct roles as educators, consultants, advocates and decision makers. The outcomes of the study are important for helping pediatric nurses to recognize family burden and mental problems mothers may face and for training care providers about these subjects. This study provided data about the family burden of intellectually disabled people and can serve as a guide for future studies.

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