



The Psychosocial Status of Physically and/or Mentally Retarded Children's Siblings

Fiziksel ve/veya Zihinsel Engelli Çocukların Kardeşlerinin Psikososyal Durumu

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Abstract

Objective: In this study, we aimed to evaluate psychosocial status, the relationship between socio-demographic factors, to support the psychosocial development of physically and/or mentally disabled children's siblings that can be often overlooked, we also aim to plan new projects, researches and education that will support families and children in the light of our findings.

Method: This study was planned as a one centered, a cross-sectional study with prospectively recruited participants. The children aged 6-17 years who had physical and/or mental retarded siblings, admitted to University of Health Sciences Turkey, Şişli Hamidiye Etfal Training and Research Hospital, Family Medicine Clinic and Pediatric Neurology Clinic were included in the study. Children's psychosocial status and depression levels were questioned face to face interview with children-adolescent's depression inventory (CDI) and the results were analyzed using frequency, chi-square and t-test.

Results: Most of the participants of 51 children in the study, were girl (60.8%) and mean age was 11.25 ± 3.14 . The average CDI score was 11.76 ± 6.56 for the healthy siblings. 15.7% of children were depressed and 75% of them were girls. Average CDI scores of children with depression was found as 22.87 ± 3.90 . Mean CDI scores of girls (12.03 ± 6.32) compared with boys (11.35 ± 7.06) was higher, however, this relationship was not statistically significantly. The average CDI scores (13.5 ± 7.21) of subjects whose siblings do not get education were higher than those who get education (11.23 ± 6.35) While 12.8% of children whose siblings got education, had depression; 25.0% of siblings who have not educated were depressed ($p > 0.05$).

Öz

Amaç: Bu çalışmada, çoğu kez göz ardı edilebilen fiziksel ve/veya zihinsel engelli çocukların kardeşlerinin psikososyal durumlarını ve sosyo-demografik özellikleriyle ilişkisini değerlendirmeyi, çocukların psikososyal gelişimlerinin desteklenmesini; elde ettiğimiz bulgular ışığında aileye ve çocuklarına destek olacak yeni projeler oluşturulmasını amaçladık.

Yöntem: Çalışma katılımcıların prospektif olarak alındığı kesitsel, tek merkezli, tanımlayıcı ve analitik nitelikte bir çalışma olarak planlandı. Sağlık Bilimleri Üniversitesi, Şişli Hamidiye Etfal Eğitim ve Araştırma Hastanesi, Aile Hekimliği Polikliniği ve Çocuk Nörolojisi Polikliniği'ne başvuran, fiziksel ve/veya mental retarde çocukları olan ailelerin 6-17 yaş arası sağlıklı çocukları dahil edildi. Çocukların psikososyal durumu ve depresyon düzeyleri çocuk-ergen depresyon ölçeği (ÇDÖ) uygulanarak, yüzyüze görüşmeyle değerlendirildi. Analizlerde frekans, ki-kare, t-testi kullanıldı; $p < 0,05$ anlamlı kabul edildi.

Bulgular: Çalışmaya katılan 51 çocuğun çoğu kız (%60,8) ve yaş ortalaması $11,25 \pm 3,14$ idi. Sağlıklı kardeşlerin ortalama ÇDÖ puanı $11,76 \pm 6,56$ idi. %15,7'sinin depresyonda olduğu; depresyonda olanların %75'inin kız çocuk olduğu belirlendi. Depresyonda olan çocukların ortalama ÇDÖ puanı $22,87 \pm 3,90$ olarak bulundu. Kız çocukların ortalama ÇDÖ puanının ($12,03 \pm 6,32$), erkek çocuklara göre ($11,35 \pm 7,06$) daha yüksek olduğu ancak aralarında anlamlı bir ilişki olmadığı saptandı. Gruplar arasında anlamlı bir ilişki saptanmasa da, kardeşi eğitim almayan çocukların ortalama ÇDÖ puanı ($13,5 \pm 7,21$), kardeşi eğitim alanlara göre ($11,23 \pm 6,35$) daha yüksekti. Bununla birlikte kardeşi eğitim alanların %12,8'inin, kardeşi eğitim almayanların ise %25,0'ının depresyonda olduğu saptandı ($p > 0,05$).

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Abstract

Conclusion: This study showed that siblings of disabled children may experience psychosocial problems and are at risk of developing depression. The developmental period of children with disabled siblings is of great importance and should not be overlooked.

Keywords: Children, depression, disabled, psychosocial development, sibling

Öz

Sonuç: Bu çalışma, engelli çocukların kardeşlerinin psikososyal gelişimleriyle ilgili problemler yaşayabileceklerini, depresyona meyilli ya da depresyonda olabileceklerini göstermiştir. Engelli çocukların sağlıklı kardeşlerinin gelişim süreci göz ardı edilemeyecek kadar büyük önem taşımaktadır.

Anahtar kelimeler: Çocuklar, depresyon, engelli, kardeş, psikososyal gelişim

Introduction

The needs of siblings often compete with those of their ill brothers or sisters, which increases the risk that they may suppress or neglect their own needs (1). Research indicates that siblings of children with chronic illnesses experience both positive and negative consequences related to their family situation (2). Negative outcomes include increased emotional and behavioral difficulties, as well as feelings of fear, anxiety, sadness, anger, guilt, helplessness, and uncertainty. Additional challenges may involve family disruptions, limited parental support, school difficulties, changes in friendships, unmet needs, and a reduced health-related quality of life (2-5).

Erik H. Erikson proposed a theory of psychosocial development (6) based on the "principle of gradual formation (epigenetics)" (7,8). According to Erikson, personality development occurs in eight overlapping stages in which conflicts between positive and negative elements (such as basic trust and mistrust) emerges at each stage evolve and mature. The tension between these opposing forces defines the stage-specific crisis and ultimately determines which emotion will predominate (9).

Erikson's eight psychosocial developmental stages are as follows:

1. Basic trust versus distrust (0-1 years)
2. Autonomy versus doubt and shame (2-3 years)
3. Initiative versus guilt (3-5 years)
4. Industry (success) versus inferiority (6-11 years)
5. Identity versus role confusion (11-20 years)
6. Intimacy versus isolation (young adulthood)
7. Generativity versus stagnation (adulthood)
8. Ego integrity versus despair (old age) (10).

Depression in Children

The term "depression" refers to a persistent state of low mood. Depressive disorders in children and adolescents

represent a significant public health concern because of their high prevalence and persistent negative effects on cognitive, social, and psychological development. These disorders affect approximately 2-3% of children and 8% of adolescents (11).

Symptoms and Diagnostic Criteria of Depression in Children

Depression in children can be difficult to detect because its onset is often vague. Depressive symptoms in children can present differently and present with different clinical manifestations. In early childhood, symptoms are particularly variable and are often misinterpreted as behavioral issues. These may include hyperactivity, irritability, self-harm or environmental damage, introversion, emotional instability, and sudden mood swings (12).

Among school-aged children, depression may present as persistent sadness or irritability, diminished interest in previously enjoyable activities, changes in appetite (resulting in weight fluctuations), insomnia or hypersomnia, psychomotor agitation or retardation, fatigue, feelings of worthlessness or guilt, reduced attention span, and in severe cases, suicidal ideation (13).

According to the diagnostic and statistical manual of mental disorders-5, a diagnosis of major depressive disorder requires the presence of at least five symptoms lasting for a minimum of two weeks. One of these must be a depressed mood, an irritable mood, or a loss of interest or pleasure (14).

Additional symptoms may include:

1. Lack of expected weight gain
2. Insomnia or excessive sleep
3. Psychomotor agitation or retardation
4. Fatigue or loss of energy
5. Feelings of worthlessness or excessive guilt
6. Reduced ability to think or concentrate
7. Recurring thoughts of death.

These symptoms must cause clinically significant impairment in social or academic functioning (11).

This study aims to evaluate the psychosocial status of siblings of children with physical and/or mental disabilities—an often overlooked group—and to propose projects, research, and educational initiatives to support these families and their children.

Materials and Methods

This study was performed with the approval of the University of Health Sciences Turkey, Şişli Hamidiye Etfal Training and Research Hospital Clinical Research Ethics Committee (date: 15/03/2016; approval number: 1125).

Characteristics of the Study

This study was planned as a single-center, descriptive and analytical cross-sectional study with prospectively recruited participants. The study population included patients who visited the family medicine and pediatric neurology outpatient clinics at the training and research hospital between March 30 and June 10, 2016. Sample size was calculated using the Yamane formula. Statistical calculations indicated that at least 40 children must be included in the study. A total of 51 healthy children (aged 6-17 years) who met the inclusion criteria and consented to participate, from families of children with physical and/or mental disabilities, were included (n=51).

Prior to participation, both the children and their parents were informed in detail about the study's objectives. Parents completed a socio-demographic questionnaire, while the child-adolescent depression inventory (CDI) was administered to children via face-to-face interviews. The obtained CDI scores were subsequently analyzed.

CDI and Evaluation

The children's depression scale was developed by Kovacs (15) on the basis of Beck's depression inventory, through the addition of depression-specific relations. The validity and reliability study for the Turkish population was carried out by Öy (16).

Children's psychosocial development and depression levels were assessed using the CDI, a self-assessment tool suitable for children aged 6-17 years. The CDI consists of 27 items written in simple language to ensure understanding by this age group. The inventory can be completed by the child independently or with assistance and offers three response options for each item.

For example:

1. "I feel sad from time to time"
2. "I often feel sad"
3. "I always feel sad".

Each item is scored based on symptom severity: 0, 1, or 2 points. Children are asked to reflect on their feelings over the past two weeks and select the most appropriate statement. The maximum possible score is 54 with a cut-off point of 19. Compared with 19, the higher the obtained score is, the more severe the depression can be considered (16).

Statistical Analysis

The data were analyzed using SPSS (Statistical Package for the Social Sciences) version 20.0. Descriptive statistics included mean, standard deviation, median, minimum, maximum, frequency, and ratios. The distributions of the variables were assessed using the Kolmogorov-Smirnov test. Kruskal-Wallis and Mann-Whitney U tests were used in the analysis of quantitative data. The chi-square test was used to analyze qualitative data, and Spearman correlation analysis was used to assess correlations. Significance was evaluated at the $p < 0.05$ level.

Results

A total of 51 children who had siblings with physical and/or mental disabilities were included in the study; the majority were female (60.8%, n=31). The ages of the participants ranged from 6 to 17 years, with a mean age of 11.25 ± 3.14 years. By age group, 26 children (51%) were aged 6-11 years and 25 (49%) were aged 11-17 years. Sixteen children (31.4%) had one sibling, 19 children (37.3%) had two siblings, and 16 children (31.4%) had three or more siblings. Among the disabled siblings, ages ranged from 1 to 24 years; the mean duration of illness was 7 years, and the mean age at treatment initiation was 1 year.

Most parents were married (94.1%; n=48). Mothers' educational levels were as follows: Primary school graduates, 56.9% (n=29); university graduates, 11.8% (n=6); literate, 3.9% (n=2); and illiterate 2% (n=1). Fathers' educational levels were as follows: Primary school graduates, 56.9% (n=29); university graduates, 11.8% (n=6); and illiterate, 2% (n=1). Similarly, 2% (n=1) of the fathers were illiterate. While 92.2% (n=47) of mothers were not working, 98.2% (n=50) of fathers were working. The average CDI scores of children, stratified by socio-demographic characteristics, are presented in Table 1. 7.8% (n=4) of the children had

a family history of psychiatric illness, and their rates of depression were significantly higher than those without a family history (Table 2).

Among the children, 47% (n=24) had difficulty sleeping, 41.2% (n=21) had a poor appetite, and 33.3% (n=17) often worried that something terrible would happen. Additionally, 37.3% (n=19) often worried about aches and pains, and 68.6% (n=35) believed that they were responsible for negative events. In terms of social interactions, 19.6% (n=10) did not like being around people most or all of the time; 41.2% (n=21) often felt lonely; and 47.0% (n=24) reported having few or no friends. School performance was another area of concern: 54.9% (n=28) showed poor or deteriorating academic performance.

Among siblings with disabilities, 9.8% (n=5) had physical disabilities only, 43.1% (n=22) had mental disabilities only, and 47.1% (n=24) had both physical and mental disabilities. The breakdown of disability types is shown in Graphic 1. When the educational status of the disabled siblings was evaluated, 76.5% (n=39) were receiving an education, while 23.5% (n=12) were not (Graphic 2). Although no statistically

significant relationship was found between CDI scores and sibling education status ($p=0.225$), children with siblings not receiving an education had higher average CDI scores (13.5 ± 7.21) than those with siblings receiving an education (11.23 ± 6.35). Among children with disabled siblings who were educated, 12.8% were depressed, compared with 25.0% of children whose disabled siblings were not receiving an education ($p=0.310$), as shown in Table 3.

The overall mean CDI score among participants was 11.76 ± 6.56 , with 15.7% (n=8) meeting the criteria for depression. Among the depressed children, 75% (n=6) were girls. The average CDI score was 22.87 ± 3.90 in depressed children and 9.69 ± 4.56 in non-depressed children. Analysis by age showed that 6-year-olds had the highest mean CDI score (19.66 ± 9.29), while 11-year-olds had the lowest (8.0 ± 5.14). When examining scores by age group and gender, children aged 12 to 17 and girls had higher CDI scores than younger children and boys, although these differences were not statistically significant.

The mean score of children with physically disabled siblings was 10.20 ± 6.83 ; the mean score of children with mentally disabled siblings was 11.77 ± 6.09 . Although children with

Table 1. Mean CDI scores according to socio-demographic factors

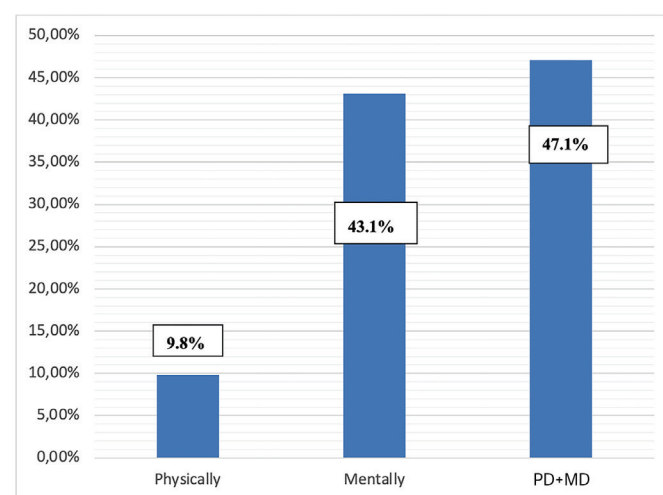
	n	Mean CDI score	p-value
Gender			
Girl	31	12.03 ± 6.32	0.463
Boy	20	11.35 ± 7.06	
Age			
6-11 years	26	10.92 ± 6.64	0.294
12-17 years	25	12.64 ± 6.49	
Number of siblings			
Has 1 sibling	16	10.43 ± 6.21	0.223
Has 2 siblings	19	12.31 ± 6.78	
Has 3 and more siblings	16	12.43 ± 6.85	
Mother's education level			
Uneducated, primary or secondary school	34	12.14 ± 6.65	0.371
High school or university	17	11.0 ± 6.50	
Father's education level			
Uneducated, primary or secondary school	35	12.42 ± 6.74	0.358
High school or university	16	10.31 ± 6.10	
Mother's working status			
Works	4	16.25 ± 1.89	0.221
Does not work	47	11.38 ± 6.68	

Mann-Whitney U test, Kruskal-Wallis H test, CDI: Children-adolescent's depression inventory

Table 2. The relationship between the family history of psychiatric illness and children's depression status

Family history of psychiatric illness	Depression status		p-value
	Yes	No	
	Yes	No	
Yes	50.0% (n=2)	50.0% (n=2)	0.049
No	12.8% (n=6)	87.2% (n=41)	

chi-square test



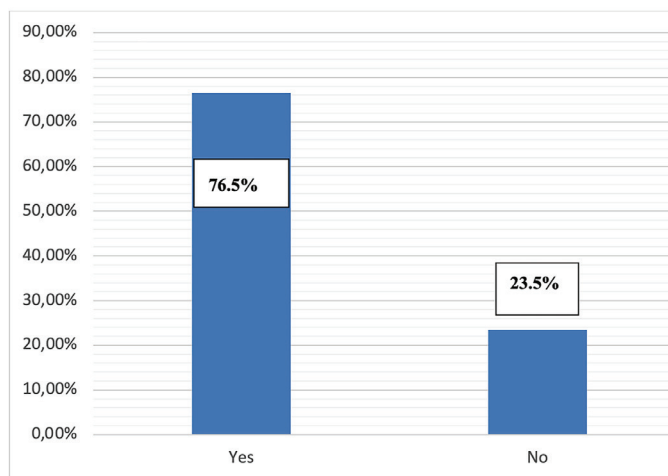
Graphic 1. Distribution of disability type of the disabled siblings

PD+MD: Physically and mentally disability

siblings who had both physical and mental disabilities recorded the highest mean scores (12.08 ± 7.13), there was no statistically significant difference in CDI scores by sibling disability type.

When the children's answers were evaluated, 8.8% sometimes feared that something bad would happen and felt sad, and 4.7% sometimes wanted to cry and felt sad all the time. As shown in Table 4, a significant correlation was found between these groups ($p=0.049$; $p=0.014$).

All children who were self-loathing also felt ugly ($p=0.002$). Among children who reported being "always bored", 50.0% described themselves as "bad" children, as did 42.9% of those who often felt tired, 22.7% of those experiencing academic decline, and 22.2% of those frequently in conflict with others; the associations were statistically significant ($p=0.018$, 0.002, 0.026, and 0.044, respectively).



Graphic 2. Education status of disabled siblings

Table 3. The relationship between the educational status of the disabled siblings of children and the depression status of non-disabled children

		Depression status		p-value
		Yes	No	
Disabled sibling's education status	Having education	12.8% (n=5)	87.2% (n=34)	0.310
	Not having education	25.0% (n=3)	75.0% (n=9)	

chi-square test

Table 4. The relationship between frequency of thinking something bad will happen and feeling sad of children

	Those who feel sad from time to time	Those who often feel sad	Those who always feel sad	p-value
Those who think that something bad will happen to them from time to time	88.2% (n=30)	8.8% (n=3)	2.9% (n=1)	0.049
Those who cry from time to time	79.1% (n=34)	16.3% (n=7)	4.7% (n=2)	0.014

chi-square test

Discussion

Few studies have focused on siblings' well-being (17). This study aims to assess the psychosocial development and depressive symptoms of siblings of children with disabilities. A proportion of participants scored above the CDI cut-off, suggesting that they may be at an increased risk of depressive symptoms. Siblings of children with disabilities represent an at-risk group (18). Recent reviews and meta-analyses have shown that siblings have an increased risk of mental health problems and decreased well-being compared with their peers (18-20).

When CDI scores were analyzed by age, six-year-old children exhibited the highest mean scores. Younger children have heightened developmental needs for love, attention, play, and shared time with their parents. This finding suggests that depressive symptoms in healthy siblings may be more pronounced when these fundamental needs are not met, particularly during early childhood. Supporting this conclusion, studies by Powell and Ogle (21), Valdivieso et al. (22) Bayhan and Yükselen (23) show that younger siblings may have difficulty interpreting events realistically. They noted that non-disabled siblings may perceive the time and attention given to their disabled siblings as a form of parental rejection, which may lead to feelings of resentment and anger. In addition, they may wonder why their parents favor their disabled siblings and even imitate their siblings' physical or behavioral characteristics (21-23).

Our study found no significant difference in CDI scores between boys and girls, which is consistent with Senel's (24) findings. In Senel's (24) study titled "Comparison of the Attitudes towards Disability and Anxiety Levels

of Those Who Have and Do Not Have Siblings with Disabilities", which involved 30 healthy siblings and 30 siblings diagnosed with intellectual disabilities, autism, or Down syndrome, no significant differences in anxiety levels were found according to gender, family size, or parental education level.

Although there was no statistically significant correlation between CDI scores and the type of disability (physical, mental, or both), siblings of children with both physical and mental disabilities had the highest average CDI scores. Having a sibling with a disability increases the need for care and support, affects the educational, social, and personal needs of the healthy sibling, consequently affecting his/her psychosocial development.

Regarding the educational status of disabled siblings, children whose disabled siblings did not receive education had higher average CDI scores than children whose disabled siblings received education. Depression rates were approximately twice as high among children whose siblings with disabilities did not receive an education. Ertürk (25) found significant differences in "Sibling Problems Questionnaire" scores between siblings of disabled and non-disabled children in a study of siblings in integrated education programs.

In our study, nearly half of the children had sleep disturbances and loss of appetite, and more than half experienced decreased academic success.

Similarly, Sloper (26) found that siblings of children with chronic illnesses often experienced significant eating and sleep disturbances following the child diagnosis. In their study of depressive symptoms among siblings of children with disabilities, Martinez et al. (18) reported that siblings of children with chronic health problems were at greater risk of symptoms suggestive of depression than siblings of healthy children.

Dinkelbach et al. (2) reported decreased physical and psychological well-being and lower self-esteem among siblings of children and adolescents with life-limiting conditions who were receiving pediatric palliative care at home. Siblings of disabled or chronically ill children are often overlooked members of the family, and their needs for support may go unmet (27). Siblings often have little knowledge about disabilities and may feel ostracised (28). In one study, many participants, who were healthy siblings of people with additional or complex needs, reported a disparity in attention received between themselves and their sibling. As we can see below, this often came from

immediate or extended family members or other adults they knew, even during difficult times such as the death of a family member:

"Nobody really asked me anything." When my mum died, everyone just kept asking me how my sister was coping with my mum's death; they asked me how my dad was or how my sister was, but nobody actually asked me how I was (27). Additionally, Wawrzynski et al. (29) found that siblings often experience differential treatment by parents, friends, and others, and consequently feel more isolated and restricted in their interactions.

Most studies have reported that a sibling's disability negatively affects sibling functioning, causing increased anxiety and depression, social withdrawal, conduct disorders, and other behavioral problems (17).

In studies examining emotional and behavioral adjustment, the primary internalizing and externalizing symptoms identified were hyperactivity, hostility, anxiety, and somatic and emotional problems (30-36). In one study, more than 50% of siblings of individuals with disabilities reported feelings of guilt, described their sibling relationships as poor, exhibited elevated levels of depressive symptoms, and demonstrated reduced overall well-being (37).

It is crucial not to neglect the health needs of my siblings. Supporting the psychosocial development of these children is essential for their future well-being. Studies have shown that adult siblings of individuals with intellectual and developmental disabilities often report higher levels of depression and anxiety, poorer sibling relationships, and lower life satisfaction (38).

Study Limitations

In our study, the cases were evaluated only once. More data can be obtained from studies that include larger numbers of participants and that regularly evaluate healthy siblings with psychosocial support. It would be more useful to evaluate developmental processes comparatively in follow-up assessments during childhood, adolescence, and adulthood.

Conclusion

Our study indicates that siblings of children with disabilities may experience challenges in their psychosocial development and be prone to depressive symptoms or clinical depression. In particular, depressive symptoms were apparent in very young children, possibly because parents were unable to fully meet the healthy sibling's needs.

When educating parents on caring for children with disabilities, practitioners should also focus on the psychosocial well-being of healthy siblings by providing them with concrete, practical guidance. Considering that siblings' anxiety levels may decrease following support programs, it is recommended to provide psychological support to siblings of children with disabilities and to establish structured support programs.

The needs of siblings of children with disabilities remain under-researched in current medical practice, with limited scientific studies addressing this issue. More research and interventions are needed to support these families by recognizing siblings as essential family members and future contributors to society. In light of these findings, new projects, research, and educational programs should be developed to ensure that these children do not feel excluded.

Ethics

Ethics Committee Approval: This study was performed with the approval of the University of Health Sciences Turkey, Şişli Hamidiye Etfal Training and Research Hospital Clinical Research Ethics Committee (date: 15/03/2016; approval number: 1125).

Informed Consent: Written informed consent was obtained from all parents.

Footnotes

The study was presented at 22nd WONCA Europe Conference Prague, Czech Republic, June 28-July, 2017 (poster presentation).

Authorship Contributions

Concept: D.Y., D.T., G.K., Design: D.Y., D.T., G.K., Data Collection or Processing: D.Y., D.T., G.K., Analysis or Interpretation: D.Y., D.T., G.K., Literature Search: D.Y., D.T., G.K., Writing: D.Y., D.T., G.K.

Conflict of Interest: No conflict of interest was declared by the authors.

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