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Research Article

Comparison of the Quality of Life of Mentally and Physically Disabled Children and Their Healthy Siblings

Zihinsel ve Bedensel Engelli Çocuklar ile Sağlıklı Kardeşlerinin Yaşam Kalitelerinin Karşılaştırılması

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ABSTRACT

Purpose: It is known that the health-related quality of life of children with neurological problems is adversely affected. But these problems also have a negative impact on the whole family. This study was conducted to examine the quality of life of children with mental and physical disabilities and their healthy siblings. **Material and Methods:** 82 children with mental and physical disabilities between the ages of 2-18 and their healthy siblings were included in the study. The sociodemographic data of the participants were recorded. The Pediatric Quality of Life Inventory was used to measure health-related quality of life, and the Gross Motor Function Classification System was used to evaluate the gross motor functions of children with disabilities. **Results:** 82 (48 boys, 34 girls) mentally and physically disabled children with a mean age of 9.87±5.06 years and 82 (34 boys, 48 girls) healthy siblings with a mean age of 12.68±3.65 were included in the study. When the quality of life of mentally and physically disabled children was examined, it was seen that there was no significant difference between the two groups (p>0.05). There was no significant difference between the quality of life of the healthy siblings of mentally and physically disabled children (p>0.05). **Discussion:** It was observed that the quality of life of healthy siblings of mentally and physically disabled children was similarly affected. It should not be forgotten that the quality of life of their families and healthy siblings will also be adversely affected during the treatment process of disabled children.

Keywords: Mental; Physical; Siblings; life Quality.

ÖZ

Amaç: Nörolojik sorunu olan çocukların sağlıkla ilgili yaşam kalitelerinin olumsuz etkilendiği bilinmektedir. Ancak bu sorunlar aynı zamanda tüm aileyi de olumsuz etkilemektedir. Bu çalışma, zihinsel ve bedensel engelli çocuklar ile sağlıklı kardeşlerinin yaşam kalitesini incelemek amacıyla yapılmıştır. **Gereç ve Yöntem:** Çalışmaya 2-18 yaş arası zihinsel ve bedensel engelli 82 çocuk ve onların sağlıklı kardeşleri dahil edildi. Katılımcıların sosyodemografik verileri kaydedildi. Sağlıkla ilişkili yaşam kalitesini ölçmek için Pediatrik Yaşam Kalitesi Envanteri, engelli çocukların kaba motor fonksiyonlarını değerlendirmek için Kaba Motor Fonksiyon Sınıflandırma Sistemi kullanıldı. **Sonuçlar:** Araştırmaya yaş ortalaması 9,87±5,06 yıl olan 82 (48 erkek, 34 kız) zihinsel ve bedensel engelli çocuk ve yaş ortalaması 12,68±3,65 olan 82 (34 erkek, 48 kız) sağlıklı kardeş dahil edildi. Zihinsel ve bedensel engelli çocukların yaşam kalitesi incelendiğinde iki grup arasında anlamlı bir fark olmadığı görüldü (p>0,05). Zihinsel ve bedensel engelli çocukların sağlıklı kardeşlerinin de yaşam kaliteleri arasında anlamlı bir fark yoktu (p>0,05). **Tartışma:** Zihinsel ve bedensel engelli çocuklar gibi sağlıklı kardeşlerin yaşam kalitesinin de benzer şekilde etkilendiği gözlendi. Engelli çocukların tedavi sürecinde ailelerinin ve sağlıklı kardeşlerinin yaşam kalitesinin de olumsuz etkileneceği unutulmamalıdır.

Anahtar Kelimeler: Zihinsel; Fiziksel; Kardeş; Yaşam kalitesi.

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Quality of life has been defined as a way of perceiving one's own situation within the culture and value system (Öztürk and Ayar, 2013). Chronic neurological disorders that cause physical and mental disability include many problems that begin in the developmental period and often continue throughout life (Rana and Mishra, 2015). According to the World Health Organization (WHO), these disorders are one of the most important causes of deterioration in health-related quality of life in the world (WHO, 2006). Many studies have examined the impact on the health-related quality of life of children with disabilities (Malhi and Singhi, 2005). It is known that the health-related quality of life of children with physical or mental chronic problems is affected, as well as the effects of these problems on all family members (Juneja, Jain, Singhal et al., 2012). These neurological disorders not only affect the lifestyle of parents, but also affect the quality of life of healthy siblings of these children and all members of their families (Dinleyici and Dagli, 2018). Siblings in the family have an important place in each other's lives. As siblings are each other's playmates, they also acquire different roles such as being a teacher, protector, competitor and model to each other as time progresses (Barlow and Ellard, 2006). It is stated that the siblings of these children are exposed to a lot of stress. Situations such as being ashamed of their peers, being jealous of their parents' spending time for their siblings, communication problems with their siblings, being exposed to their siblings' aggression, and trying to make up for their siblings' deficiencies can cause stress in healthy siblings. In addition, the stress experienced by his parents and the role he will assume in caring for his disabled sibling in the future may reveal the anxiety about the future of the healthy sibling (Rana and Mishra, 2015).

When family members take care of the special needs of their disabled children, healthy siblings feel neglected (Ali and Sarullah, 2010). Knowing the quality of life of healthy children and examining the factors affecting them is important before any intervention is made to improve the quality of life of all members of the family (Rana and Mishra, 2015). Studies examining the quality of life of healthy siblings of children with disabilities are scarce in the literature. This study was conducted to compare the quality of life of healthy siblings of mentally and physically disabled children.

METHODS

A total of 164 children, including children aged 2-18 with physical or mental disabilities and their healthy siblings, were included in our study. Ethics committee approval was approved by Pamukkale University Non-Interventional Clinical Research Medical Ethics Committee with the decision dated 03.03.2020 and numbered 05. Voluntary informed consent was obtained from the participants. The personal information of the participants was recorded in the sociodemographic data form. The Gross Motor Function Classification System (GMFCS) was used to evaluate the gross motor functions of physically and mentally handicapped children, and the Pediatric Quality of Life Inventory (PedsQL) was used to measure the health-related quality of life of all children. Criteria for inclusion in the study were determined as having a physically or mentally disabled sibling, living in the same environment, and not having any health problems. Face-to-face interviews with healthy siblings were held in the units where disabled siblings received treatment.

Sociodemographic Data Form

Information such as gender, age, clinic type, and type of disability were recorded on a sociodemographic data form.

Gross Motor Function Classification System (GMFCS)

It is a five levels scale that assesses gross motor functions such as sitting, walking and moving that the child with cerebral palsy initiates by himself (Arıkan, Mutlu, and Livanelioğlu, 2020).

•Level 1: there is no problem in walking

•Level 2: Her/his walking is somewhat restricted.

•Level 3: Can walk with assistive devices that can be used with hands

•Level 4: Self-mobility is limited. It can provide mobility with motor vehicles

•Level 5: Mobilization is severely limited even when assistive devices are used

The Pediatric Quality of Life Inventory (PedsQL)

It is a scale with patient and parent versions used to determine health-related quality of life among children and adolescents aged 2-18 years. While there are four parent forms, 2-4, 5-7, 8-12, 13-18 years old, there are three for children and adolescents, 5-7, 8-12 and 13-18 years old. It has four components: physical, emotional, social and school. Responses with five options are scored 100 if marked as never, 75 if rarely, 50 if sometimes, 25 if frequently, 0 if almost always. The higher the overall score, the higher the health-related quality of life is considered (Çakın-Memik, Ağaoğlu, Coşkun et al., 2007).

Statistical analysis

Data were analyzed with SPSS 22.0 (IBM SPSS

Statistics 22 software (Armonk, NY: IBM Corp.) package program. Mean±standard deviation was used for continuous variables, and numbers and percentages were used for categorical variables. Relationships between continuous variables were evaluated with Spearman or Pearson correlation analysis according to their suitability. The differences between regression models and categorical variables were analyzed by Chi-square analysis, and the significance level was accepted as p≤0.05.

RESULTS

43 (24 boys, 19 girls) mentally disabled children with an average age of 10.66±4.32, 39 (24 boys, 15 girls) physically disabled children with an average age of 13.60±3.69 and 82 healthy siblings (34 boys, 48 girls) with an average age of 12.68±3.65 were included in the study. Demographic data and clinical conditions of children with mentally and physical disabilities are shown in Table 1.

When the quality of life of mentally and physically disabled children and healthy siblings of mentally and physically disabled children was examined, no significant difference was found between the two groups (Table 2, p>0.05). When the relationship between the quality of life of healthy siblings and the physical data of the chronically disabled sibling was examined, no significant relationship was found. When the relationship between the quality of life of mentally and physically disabled and their healthy siblings was examined, no significant difference was found between the groups. The results are given in table 2 and table 3.

Table 1. Data on mentally and physically disabled children and their siblings

	N(%)		
Physically Disabled	39(%47.6)		
Mentally Disabled	43(%52.4)		
Clinical Diagnosis of Children with Physical Disabilities	**N(%)**		
Cerebral Palsy	25(%64.1)		
Spina Bifida	5(%12.8)		
Down Syndrome	1 (%2.6)		
Brachial Plexus	3(%7.7)		
Neuromuscular disease	3(%7.7)		
Chromosome anomaly	1(%2.6)		
Other	1(%2.6)		
GMFCS			
Level I	18(%22.0)		
Level II	28(%34.1)		
Level III	16(%19.5)		
Level IV	3(%3.7)		
Level V	17(%20.7)		
Total	82(%100.0)		
	Physically Disabled	**Mentally Disabled**	**Total**
Gender			
Female	15(%38.5)	19(%44.2)	34(%41.5)
Male	24(%61.5)	24(%55.8)	48(%58.5)
Type of Birth			
Normal	20(%51.3)	29(%67.4)	49(%59.8)
Caesarean section	19(%48.7)	14(%32.6)	33(%40.2)
Risk factors			
Consanguineous marriage			
yes	20(%51.3)	7(%16,3.	26(31.7)
no	19(%48.7)	36(%83.7)	56(68.3)
Blood incompatibility			
yes	2(%5.1)	2(%4.7)	4(4.9)
no	37(%94.9)	41(%95.3)	78(95.1)
Trauma			
yes	0(%0)	1(%2.3)	11(13.4)
no	39(%100)	42(97.7)	71(86.6)
Difficult birth			
yes	13(%33.3)	18(%41.9)	31(37.8)
no	26(%66.7)	25(%58.1)	51(62.2)

Table 1. Data on mentally and physically disabled children and their siblings

	X±SD	X±SD	X±SD
Age	10.66±4.32	9.16±5.60	9.87±5.06
Birth weight	3215.12±616.04	2888.25±802.94	3043.71±734.38
Data on healthy siblings	**N(%)**		
Gender			
Female	48(%58.5)		
Male	34(%41.5)		
	X±SD		
Age	12.68±3.65		

X: Mean, SD: Standard Deviation

Table 2. Comparison of the quality of life

	Mentally Disabled Children	**Physically Disabled Children**	**p**
	X±SD	**X±SD**	
PedsQL – total	1960.12±279.61	1962.69±428.52	0.974
	Siblings of Mentally Disabled Children	**Siblings of Physically Disabled Children**	**p**
	X±SD	**X±SD**	
PedsQL - total	1961.28±285,021	1987.69±401.144	0.730
	Mentally Disabled Children	**Healthy Siblings**	
	X±SD	**X±SD**	**p**
PedsQL - physically	598.26±192.56	600.35±198.22	0.901
PedsQL - psychosocial	1361.86±93.61	1360.93±94.11	0.906
PedsQL - total	1960.12±279.61	1961.28±285.02	0.958
	Physically Disabled Children	**Healthy Siblings**	
	X±SD	**X±SD**	**p**
PedsQL - physically	601.67 ± 257.41	623.08 ± 250.69	0.721
PedsQL - psychosocial	1361.03 ± 226.69	1364.62 ± 157.210	0.931
PedsQL - total	1962.69 ± 428.53	1987.69 ± 401.14	0.791

X: mean, SD: standard deviation, p<0.05:significant difference; PedsQL: Pediatric Quality of Life Inventory

When the quality of life of the healthy siblings of children with physical disabilities is examined according to the functional levels, there is a negative significant relationship between the functional level and the quality of life (Table 3, p<0.05).

Table 3. Factors associated with the quality of life of healthy siblings

	PedsQL	
	R	**p**
Age	-0.156	0.16
Gender	0.032	0.77
Visual	0.047	0.67
Speech	0.115	0.30
Hearing	0.108	0.33
GMFCS	-0.346	0.001

PedsQL: Pediatric Quality of Life Inventory; GMFCS: Gross Motor Function Classification System; p<0.05:significant difference

DISCUSSION

In our study, the quality of life of mentally retarded children and healthy siblings of physically disabled children was investigated. It was determined that there was no significant difference between the quality of life of mentally retarded children and their healthy siblings, and between physically disabled children and healthy siblings. At the same time, no

significant difference was found in the quality of life of mentally disabled children and physically disabled children. In addition, it has been observed that there is a negative significant relationship between the functional levels of physically disabled children according to GMFCS and the quality of life of their healthy siblings.

Family relationships that form the basis of individuals; It is a condition that determines the personality and identity of individuals from childhood to adolescence and even adulthood (Knecht, Hellmers and Metzing, 2015). Having a chronic illness in one of the siblings in the family creates a risk for the mental, social and psychological well-being of healthy siblings and creates negative effects. It has been stated that these negative effects such as anxiety, depression, stress symptoms, low quality of life values and peer problems persist in the later stages of healthy siblings' lives (Barlow and Ellard, 2006; Bellin and Kovacs, 2006; Stoneman, 2005). It has been reported that healthy siblings are psychologically affected more intensely, especially in cases where the chronic disease is severe and poses a life threat (Vermaes, van Susante, and van Bakel, 2012).

It has been reported that the type of chronic disease of disabled children affects the quality of life of the healthy sibling. However, while some of the studies in the literature evaluated the disabled children as a whole and evaluated their healthy siblings, some studies made evaluations for a specific disease (Taylor Fuggle and Charman, 2001). For example, one study reported that parents reported that behavioral problems were more common in healthy siblings of children with chronic disabilities than in the normal population (Giallo and Gavidia-Payne, 2006). In addition, in a meta-analysis in which children with various chronic diseases such as cancer and diabetes were evaluated together, it was reported that healthy siblings had high levels of anxiety and depression. Cognitive development, peer effectiveness and functional results of these siblings were also found to be low (Sharpe and Rossiter, 2002). In our study, the quality of life of healthy siblings of children with physical and mental disabilities was examined and it was seen that the quality of life of healthy children with physically and mentally disabled siblings was affected in accordance with the literature. However, in our study, no significant difference was found between siblings of mentally retarded and physically disabled children in terms of quality of life. According to our study, it was concluded that the type of disability had no effect on the quality of life of the healthy sibling.

It was stated that apart from the type of the disease, the level of involvement and functional status may also have an effect on the quality of life of the healthy sibling. In a study involving children with muscular dystrophy, a difference was observed between the psychological findings of healthy siblings of children with and without wheelchair requirements. This study showed that the worsening of the functional status of the patient and the increase in the severity of the disease increase the psychological impact of healthy siblings, since wheelchair use is an indicator of advanced stage of the disease or functional status (Read, Kinali, Muntoni et al., 2011). In our study, it was observed that as the functional level of physically disabled children deteriorated, the quality of life of their healthy siblings decreased. When the literature is examined, factors such as the type and severity of the chronic disease, age and gender of the healthy sibling have been shown among the factors affecting the quality of life outcomes (Alderfer et al., 2010). In our study, it was observed that the functional level of the physically disabled child affected the quality of life of healthy siblings to different degrees. In addition, it was determined that vision, speech and hearing problems, age and gender of the disabled sibling did not affect the quality of life of the healthy sibling.

This situation has been interpreted as that the additional problems of the disabled children do not affect the quality of life of the healthy sibling as long as they do not change the functional level.

In studies on quality of life evaluating healthy siblings of children with chronic disease, it is stated that all siblings are generally affected (Sharpe and Rossiter, 2002). Wolfe et al. showed in their study that the lives of healthy siblings of mentally retarded children were greatly affected in adulthood and their psychosocial stress burden was high (Wolfe, Song, Greenberg et al., 2014). In addition, there are studies showing that siblings of chronically disabled children have better empathy skills and are more successful in personal relationships (Hall and Rossetti, 2018). In our study, when the quality of life of mentally retarded children and their healthy siblings was compared, no significant difference was found. This shows that the quality of life of healthy siblings is affected in the same way as their mentally retarded siblings.

As a result, the quality of life of healthy siblings such as both physically and mentally disabled children is affected similarly, and the severity of exposure (motor function, mental function severity,

etc.) in physically and mentally disabled children causes the quality of life of healthy siblings to be affected differently. It should be kept in mind that during the treatment process of chronically disabled children, the quality of life of their families and healthy siblings will also be adversely affected, and this may affect the treatment of children with disabilities in different ways.

Ethical Approval

All methods were performed in accordance with the ethical standards of the institutional and/or national research committee and the Declaration of Helsinki. Ethics committee approval was approved by Pamukkale University Non-Interventional Clinical Research Medical Ethics Committee with the decision dated 03.03.2020 and numbered 05. Written informed consent was obtained from the participant included in the study.

Authors' Contribution

Erdoğan Kavlak, Design, Analysis, Manuscript writing, Control, Server Erdoğmuş, Data collection, Article writing, Literature review, Ebru Kavlak, Data collection, Article Writing, literature review, Gülay Yalçın, Data collection, Article Writing

Conflicts of Interest Statement

All authors who contributed to the study declare that there is no conflict of interest regarding the article and that they did not receive financial support.

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