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Assessment of Functional Status and Quality of Life in Children with Spina Bifida

Spina Bifidalı Çocuklarda Yaşam Kalitesi ve Fonksiyonel Durumun Değerlendirilmesi

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Abstract

Objective: The aim of this study was to determine functional status and QoL of children with spina bifida (SB) by using the Functional Independence Measure for Children (WeeFIM) and the Child Health Questionnaire PF-50 (CHQPF-50) and to compare the functional status data of pediatric SB patients with those of healthy children.
Material and Methods: Forty children with SB and 40 healthy children aged between 36 and 143 months were enrolled in the study. Both pediatric SB patients and healthy children were divided into three age groups: Group 1: 36-71 months, Group 2: 72-107 months, and Group 3: 108-143 months. The WeeFIM and CHQPF-50 were completed for children with SB, whereas the WeeFIM was completed only for healthy children.
Results: In both assessments, the total score and subscale scores were lower than normal values in children with SB. However, improvement was found in self-care; communication; social, emotional, and mental status; and family factors with increasing age. On the other hand, there was no improvement in physical score, transfer, mobility, and sphincter control with increasing age. Functional status of children with SB was significantly lower compared to healthy children.
Conclusion: There was progress in self-care, communication, family factors, and social, emotional and mental status in children with SB with increasing age.
Key Words: Spina bifida, functional status, quality of life

Özet

Amaç: Bu çalışmanın amacı, spina bifidalı (SB) çocuklarda fonksiyonel bağımsızlık indeksi (WeeFIM) ile çocukluk çağı sağlık değerlendirme sorgu formu PF-50 (CHQPF-50) kullanılarak fonksiyonel durumu ve yaşam kalitesini belirlemek ve fonksiyonel durum açısından elde edilen sonuçları sağlıklı çocuklarla karşılaştırmaktır.
Gereç ve Yöntemler: Yaşları 36-143 ay arasındaki, 40 SB'li ve 40 sağlıklı çocuk çalışmaya alındı. Pediatrik SB hastaları ve sağlıklı çocuklar yaşlarına göre 3 gruba ayrıldı: Grup 1: 36-71 ay, Grup 2: 72-107 ay, Grup 3: 108-143 ay idi. Spina bifidalı çocuklarda WeeFIM ve CHQPF-50; sağlıklı çocuklarda ise WeeFIM doldurduldu.
Bulgular: Her iki değerlendirmede toplam skor ve alt grupların skorları SB'li çocuklarda normal değerlerden daha düşüktü. Ancak kendine bakım, iletişim, sosyal, ruhsal ve mental durum ve ailesel faktörlerin yaşla birlikte iyileştiği tespit edildi. Öte yandan fiziksel skor, transfer, mobilite ve sfinkter kontrolünde yaş artışıyla birlikte iyileşme saptanmadı. Sağlıklı çocuklara göre, SB'li çocukların fonksiyonel durumunda anlamlı bir düşüklük elde edildi.
Sonuç: Sonuçta SB'li çocuklarda kendine bakım, iletişim, ailesel faktörler ile sosyal, ruhsal ve mental durumlarda yaş arttıkça ilerleme olmaktadır.
Anahtar Kelimeler: Spina bifida, yaşam kalitesi, fonksiyonel durum

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Introduction

Spina bifida (SB) is a congenital disorder caused by the incomplete closing of the embryonic neural tube during development of the spinal cord. It is an anomaly of the central nervous system associated with considerably high morbidity and mortality rates (1,2). Its average incidence is 4.7 in 10,000 live births worldwide, showing great variability between countries and between different geographic regions within a single country (3). Before 1960, only a small percentage of children with SB could survive (10%), since most of them were dying due to reasons, such as infection and hydrocephaly (4). Today, the life expectancy and percentage of surviving babies are much higher owing to improvements in treatment methods (5).

Spina bifida falls into two categories, including SB occulta, with a mild disease course, and SB aperta, which is clinically more significant and has a more severe course (6). SB is a demanding condition that requires a lifelong struggle with various health problems to keep children alive, especially those with SB aperta. Children with SB face many motor, sensory, cognitive, and metabolic defects and disabilities as a result of complex manifestations. The most important problems are the deficits in fine motor control, and they may cause impairments in daily activities, such as sitting, standing, walking, and voluntary bowel and bladder control. All of these problems affect the patient's quality of life (QoL) adversely. Thus, several studies have been performed in order to assess the QoL of patients with SB (7-9).

The ability of patients to perform daily life activities is very important in terms of the arrangement of a rehabilitation program and the evaluation of treatment response. However, there are few assessment methods available to evaluate functional status and QoL in these children. One of these measures is the Functional Independence Measure for Children (WeeFIM), which was generated from the adult FIM, and it is frequently used in order to assess the functional status of pediatric patients (10,11). Another measure that is used to evaluate the QoL of these patients is the Child Health Questionnaire PF-50 (CHQPF- 50) scale (12).

The aim of this study was to determine the functional status and QoL of children with SB by using the WeeFIM and CHQPF-50 and to compare the functional status data of pediatric SB patients with those of healthy children.

Material and Methods

This was an prospective, hospital-based study, including a control group of healthy children.

Sample

For this study, we enrolled 40 patients aged between 36-143 months who were diagnosed with SB aperta and followed in our pediatric rehabilitation unit and 40 healthy children with similar age, gender, sociocultural, and economic characteristics. Families of all children were informed about the study and signed parental informed consent forms; also, ethics committee approval was received for this study from the ethics committee of Necmettin Erbakan University, Meram Faculty of Medicine.

Both pediatric SB patients and healthy children were divided into three age groups: Group 1: 36-71 months, Group 2: 72-107 months, and Group 3: 108-143 months.

Evaluation criteria

Demographic characteristics of all children and their families were questioned. A single physician assessed the functional status and daily life activities of children with SB using WeeFIM and CHQPF-50. The same physician used the WeeFIM for healthy children. Assistance from their mothers or caregivers was requested when required.

The WeeFIM was used to evaluate the functional status of patients. The WeeFIM contains a total of 18 measurement items that are divided into 6 areas: self-care (6 items), sphincter control (2 items), transfers (3 items), locomotion (2 items), communication (2 items), and social cognition (3 items). Each item is assigned a score between 1 and 7, where 1 indicates 'total assistance' and 7 is 'complete independence.' The total WeeFIM score ranges between a minimum of 18 points (completely dependent in all activities) and a maximum of 126 points (completely independent in all activities). Its reliability and validity have been previously shown in children with SB patients and healthy children (10,11,13,14).

The CHQPF-50 scale was used to assess the QoL of patients. This scale consists of 50 items questioning the overall health status of patients, and it is a fast and easy-to-use scale for measuring disease-related QoL. Subcategories of this measure include physical functioning (PF), role/social-physical (RP), general health perceptions (GH), bodily pain (BP), family activities (FA), role/social-emotional/behavioral (REB), parent impact-time (PT), parent impact-emotion (PE), self-esteem (SE), mental health (MH), behavior (BE), and family cohesion (FC). The scores are combined in two main scores: physical summary (PhS) and psychosocial summary (PsS). Higher scores (0-100) show healthier states. Very low scores for PhS indicate severe physical dysfunction, distressful bodily pain, frequent tiredness, and unfavorable health status. Very low scores for PsS indicate psychological distress and severe social and role disability due to emotional problems. The reliability and validity of this scale have been shown in children (12).

Statistical analysis

Statistical analyses were performed by using the Statistical Package for the Social Sciences (SPSS Inc., Chicago, IL, USA), version 11.5 statistical package. The demographic data of both groups were assessed using chi-square test. The mean subsection and total scores for WeeFIM and CHQPF-50 obtained in children with SB and healthy children were evaluated by Mann-Whitney U test. The correlation between the two measures was assessed with Pearson's correlation test, since the variables showed a normal distribution when analyzed by tests for conformance to normal distribution. P values lower than 0.05 were considered statistically significant.

Results

There were no statistically significant differences between children with SB and healthy children in terms of age, gender, parental educational status, and occupation (Table 1).

Table 1. The characteristics of children with spina bifida (SB) and healthy children and their parents

	Children with SB (n:40)	Healthy controls (n:40)	p
Age (months)	36-143	36-143	>0.05
Sex (girl/boy)	15/25	15/25	>0.05
Mother's educational status			>0.05
No education	2	0	
Primary school graduates	11	10	
High school or university graduate	27	30	
Father's educational status			>0.05
No education	0	0	
Primary school graduate	5	3	
High school or university graduate	35	37	
Mother's occupational status			>0.05
Unemployed	15	12	
Employed	25	28	
Father's occupational status			>0.05
Unemployed	2	1	
Employed	38	39	

Table 2. Characteristics of children with spina bifida

	n (%)
Type	
Meningomyelocele	34 (85)
Meningocele	6 (15)
Anatomic location	
Thoracic	3 (7.5)
Thoracolumbar	10 (25)
Lumbar	13 (32.5)
Lumbosacral	12 (30)
Sacral	2 (5)
Scoliosis	18 (45)
Kyphosis	6 (15)
Urinary incontinence	38 (95)

Of the children with SB, 34 were followed due to a diagnosis of meningomyelocele, and 6 were followed due to a diagnosis of meningocele (Table 2). Thirty-four patients with meningomyelocele had undergone surgical operation after birth. The anatomical lesion was localized in the thorax in 3, thoracolumbar region in 10, lumbar region in 13, lumbosacral region in 12, and sacrum in 2 patients (Table 2). Analysis of the motor functional status of patients by spinal defect showed that 27 patients were independently ambulatory, 10 patients were dependently ambulatory, and 3 patients were non-ambulatory. Scoliosis deformities with different grades were detected in 18 patients, and a kyphosis deformity was detected in 6 patients during the clinical examination (Table 2).

Spina bifida patients were under follow-up with a home exercise program, including range-of-motion exercise; isometric, isotonic, and stretching exercises; and ambulation training, which were designed on the basis of the patient' s condition. Patients were not given any special training for micturition and defecation. Two patients had no urinary problems, whereas 38 patients showed urinary incontinence (Table 2). Thirty-five patients had received bladder training, and 3 patients were using diapers. In children with SB, both WeeFIM and CHQPF-50 scores were remarkably low compared to normal values. However, when the WeeFIM subsection scores were compared within the three groups based on age among children with SB, a statistically significant improvement was found in self-care, communication, and social status with increasing age ($p<0.05$). On the other hand, there was no significant change in sphincter control, locomotion, and transfers ($p>0.05$). In these three groups, there was no statistically significant change in total WeeFIM score with increasing age ($p>0.05$) (Tables 3, 4). In the CHQPF-50 measure, significant progress was observed in all subscales (GH, BP, FA, REB, PT, PE, SE, BE, FC) ($p<0.05$) except for PF, RP, and PhS ($p>0.05$), with increasing age among children with SB (Table 5). A correlation was found between total PhS score of the CHQPF-50 and total WeeFIM score ($p<0.001$, $r=0.640$).

When healthy children were assessed as a separate group, a statistically significant improvement was detected in all three age groups in self-care, transfers, locomotion, communication, and social status with increasing age ($p<0.001$). However, there was no statistically significant change in sphincter control with increasing age ($p>0.05$) (Table 3). A significant increase in total WeeFIM scores was detected in these three groups by increasing age ($p<0.01$), and higher scores were found compared to children with SB.

Discussion

In this study, which aimed to evaluate the functional status and QoL of children with SB, we found that the functional status and QoL of these children were poor compared to healthy children, but there was an improvement in self-care, communication, family factors, and social, emotional, and mental status with increasing age.

In SB patients, who are being increasingly diagnosed in our country, rehabilitation requirements during infancy, childhood, and adulthood are increasing. Assessment of QoL in children with SB is important in terms of designing a suitable rehabilitation program. Functional status and QoL are affected by many factors, such as age, environmental factors, socio-cultural level of the family, depression, pain, and economic status, in both disabled and healthy children (15-17). Therefore, studies have been performed in order to demonstrate QoL and functional status in SB. In their study on 26 children with myelomeningocele, Börjeson and Lagergren (18) found that 23 of them were able to perform cleaning, dressing, and bathing independently. Buran et al. (19) assessed 66 adolescents with SB using WeeFIM

Table 3. The Functional Independence Measure for Children (WeeFIM) subscale scores and total WeeFIM scores in children with spina bifida

	Age			
	36-71 mo	72-107 mo	108-143 mo	
WeeFIM subset scores	n:13 mean (SD)	n:14 mean (SD)	n:13 mean (SD)	p
Self-care*	9.8 (4.5)	14.7 (4.8)	19.4 (5.7)	0.036
Sphincter control	5.1 (5.4)	8.4 (5.6)	11.2 (5.1)	0.346
Transfers	8.7 (6.1)	11.4 (7.1)	13.7 (7.9)	0.479
Locomotion	9.2 (6.5)	12.7 (6.9)	14.4 (6.9)	0.756
Communication*	16.9 (6.8)	22.3 (8.5)	28.1 (8.3)	0.021
Social cognition*	17.6 (7.2)	23.4 (8.5)	29.3 (9.4)	0.032
Total score	67.3 (23.6)	92.9 (22.4)	116.1 (22.9)	0.285

mo: months; *: p<0.05. SD: standard deviation

Table 4. The Functional Independence Measure of Children (WeeFIM) subscale scores and total WeeFIM scores in healthy children

	Age			
	36-71 mo	72-107 mo	108-143 mo	
WeeFIM subscale scores	n:13 mean (SD)	n:14 mean (SD)	n:13 mean (SD)	p
Self-care*	20.4 (7.9)	32.1 (5.4)	40.2 (3.2)	0.000
Sphincter control	12.1 (5.1)	12.9 (1.6)	13.1 (1.1)	0.328
Transfers*	28.5 (6.1)	35.1 (3.1)	36.3 (1.2)	0.000
Locomotion*	30.2 (5.1)	36.3 (2.2)	36.8 (1.1)	0.000
Communication*	28.6 (5.2)	34.3 (1.5)	36.1 (1.1)	0.000
Social cognition*	27.5 (4.3)	34.2 (0.5)	35.3 (0.8)	0.000
Total score*	89.9 (13.6)	114.9 (5.4)	125.5 (3.8)	0.000

mo: months; *: p<0.05. SD: standard deviation

Table 5. The Child Health Questionnaire PF-50 (CHQPF-50) subscale scores in children with spina bifida

	Age			
	36-71 mo	72-107 mo	108-143 mo	
Scores	n:13 mean (SD)	n:14 mean (SD)	n:13 mean (SD)	p
Physical functioning	26.9 (21.9)	28.4 (28.9)	28.5 (21.4)	0.347
Role/social-physical	36.5 (39.1)	37.9 (38.7)	38.8 (39.5)	0.468
General health perceptions*	40.7 (20.5)	47.1 (23.7)	54.7 (22.5)	0.026
Bodily pain	38.4 (34.6)	38.6 (35.6)	39.3 (35.6)	0.726
Family activities*	55.2 (32.4)	61.7 (34.6)	65.2 (33.4)	0.032
Role/social-emotional/behavior*	30.8 (38.9)	36.9 (39.9)	41.8 (37.1)	0.036
Parent impact-time*	45.2 (36.7)	52.6 (36.9)	55.4 (38.7)	0.026
Parent impact-emotion*	45.6 (31.4)	51.7 (34.5)	54.6 (32.6)	0.033
Self-esteem*	36.3 (20.5)	40.5 (21.0)	46.5 (20.3)	0.035
Mental health*	47.5 (36.9)	54.6 (35.8)	58.3 (37.9)	0.041
Behavior*	45.3 (33.6)	52.7 (34.8)	55.7 (36.4)	0.045
Family cohesion*	42.5 (31.5)	46.8 (37.4)	52.6 (32.7)	0.034
Psychosocial summary*	35.1 (20.2)	41.5 (23.5)	48.3 (21.6)	0.021
Physical summary	20.5 (23.7)	20.9 (24.5)	22.5 (24.3)	0.289

mo: months; *: p<0.05. SD: standard deviation

and reported that most of them were independent in the areas of eating, cleaning, dressing, mobility, and transfers. In a study in which they evaluated 20 adults with SB using WeeFIM, Andren and Grimby (20) found that most of them were independent in the areas of eating, social function, and cognition and partially dependent in other activities. Some studies were also performed in healthy children to show QoL and functional status. In a study performed in Turkey, Erkin et al. (21) evaluated the functional status of 41 healthy children aged between 24-120 months using WeeFIM and found that independence in activities increased with advanced age, except sphincter control. Also, Aybay et al. (22) found that the WeeFIM total score was 125 in 116 non-disabled children aged between 63-92 months. In our study, significantly low scores for functional status and QoL were observed among children with SB, and there was progress in self-care; communication; social, emotional, and mental status; and family factors with increasing age. However, there were no changes in sphincter control, transfers, mobility, and other physical scores. Furthermore, we compared total WeeFIM scores of healthy children and children with SB, and we found higher scores in healthy children.

Since bathroom transfer is difficult because of motor dysfunction, which is the most significant symptom of SB, called paraplegia, all children with SB have to spend too much time to fulfill their needs, regardless of whether they have sphincter problems or not. This highly affects the QoL of these children in an unfavorable way. Lavinge and Faier-Routman (23) reported that physical disorders (e.g., paraplegia) reduce QoL, particularly self-esteem levels. Padua et al. (24) have shown in a study that urinary/fecal incontinence is one of the major causes of disability and affects QoL adversely, both mentally and emotionally. Furthermore, sphincter control is an important indicator of social activity, independence, and development (25,26). Urinary and fecal incontinence results in major social problems (27-30). These studies suggest that physical problems may negatively affect physicosocial status. Some studies showed lower scores in the physical domain of the HRQOL measure in individuals with SB in comparison to healthy children (31-33). At the end of our study, we observed that there was no improvement in sphincter control, mobility, transfers, and other physical function problems with increasing age, but there was significant progress in the SE, REB, BE, and MH sub-scales. Consequently, in this study, physical functions were found to be poorer than psychosocial functions in children with SB. Thus, the mobility, transfer, and incontinence problems did not negatively affect the SE, BE, REB, and MH sub-scales of the CHQPF-50 in children with SB. Although our patients had incontinence, mobility, and transfer problems, there was positive improvement in social status, self-esteem, emotional status, mental status, and communication over time. The reason for this was that most patients reduced these problems down to a minimum by having bladder, bowel, mobility, and transfer rehabilitation training. Another reason is that many factors affect the social status, self-esteem, emotional status, and mental health areas of QoL in children with SB. Furthermore, some studies have shown that certain factors, other than the type and severity of the disability, may affect QoL among children with SB (34).

Conclusion

This study showed that physical problems were more pronounced than psychosocial problems in children with SB. Therefore, the fundamental concerns of these patients may possibly be determined better by further studies evaluating and comparing the functional status and QoL in SB patients receiving rehabilitation with those who do not.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Necmettin Erbakan University Faculty of Medicine.

Informed Consent: Written informed consent was obtained from patients who participated in this study.

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