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Participation and its Correlation with Upper Extremity Strength in Individuals with Spina Bifida: Correlation Study

Spina Bifidalı Bireylerde Katılım ve Üst Ekstremite Kuvveti ile İlişkisi: Korelasyon Çalışması

Hatice EKİNALAN KAYHAN[a], Bahar KÜLÜNKOĞLU[b]

[a]Program of Radiotherapy, Ankara University Vocational School of Health Services, Ankara Türkiye
[b]Department of Physiotherapy and Rehabilitation, Yıldırım Beyazıt University Faculty of Health Sciences, Ankara, Türkiye

ABSTRACT Objective: The aim of this study was to compare participation and upper extremity muscle strength in individuals with spina bifida (SB) and their normally developing peers, and to investigate the correlation between participation and upper extremity muscle strength in individuals with SB. **Material and Methods:** Twenty three individuals with SB (SB group) and twenty three normally developing individuals (control group) aged 6-12 years were included in the study. Participation was evaluated with "Child and Adolescent Participation Scale", muscle strength with "Hand Held Dynamometer", grip strength with "Hand Dynamometer", pinch strength with "Pinchmeter". **Results:** Participation, shoulder flexion, shoulder abduction, elbow flexion and elbow extension muscle strength, dominant side grip strength and lateral, palmar and finger tip pinch strength were significantly lower in individuals with SB compared to their normally developing peers ($p<0.05$). In addition, there was a positive correlation between participation and upper extremity muscle strength, grip strength and pinch strength in individuals with SB ($p<0.05$). **Conclusion:** Upper extremity muscle strength, grip strength and pinch strength are related to participation in individuals with SB. Increasing upper extremity muscle strength may contribute to increased participation. Upper extremity muscle strength should be evaluated in individuals with SB and included in the rehabilitation program.

Keywords: Spinal dysraphism; participation; upper extremity; muscle strength; grip strength; pinch strength

ÖZET Amaç: Bu çalışmanın amacı, spina bifidalı (SB) bireylerde ve normal gelişim gösteren akranlarında katılım ve üst ekstremite kuvvetinin karşılaştırılması ve SB'li bireylerde katılım ve üst ekstremite kas kuvveti ile ilişkisinin incelenmesidir. **Gereç ve Yöntemler:** Çalışmaya 6-12 yaş arası 23 SB'li birey (SB grubu) ve 23 normal gelişim gösteren birey (kontrol grubu) dâhil edildi. Katılım "Çocuk ve Ergen Katılım Ölçeği", kas kuvveti "İzometrik Dinamometre", kavrama kuvveti "El Dinamometresi", parmak kavrama kuvveti "Pinçmetre" ile değerlendirildi. **Bulgular:** SB'li bireylerde katılım, omuz fleksiyon, omuz abdüksiyon, dirsek fleksiyon ve dirsek ekstansiyon kas kuvveti, dominant taraf kavrama kuvveti ve lateral, palmar ve parmak ucu kavrama kuvveti normal gelişim gösteren akranlarına göre anlamlı derecede düşüktü ($p<0,05$). Ayrıca SB'li bireylerde katılım ile üst ekstremite kas kuvveti, kavrama kuvveti ve parmak kavrama kuvveti arasında pozitif korelasyon vardı ($p<0,05$). **Sonuç:** SB'li bireylerde üst ekstremite kas kuvveti, kavrama kuvveti ve parmak kavrama kuvveti katılım ile ilişkilidir. SB'li bireylerde üst ekstremite kas kuvvetinin artırılması katılımın artmasına katkı sağlayabilir. SB'li bireylerde üst ekstremite kas kuvveti değerlendirilmeli ve rehabilitasyon programına dâhil edilmelidir.

Anahtar Kelimeler: Omurga disrafisi; katılım; üst ekstremite; kas kuvveti; kavrama kuvveti; sıkma kuvveti

Spina bifida (SB) is a condition that requires lifelong management of multiple system comorbidities.[1] With advances in treatment methods, technologies and medical knowledge, the majority of children born with SB survive to adulthood. Increasing life expectancy has led researchers and therapists to not only ensure the child's survival but also promote maximum well-being, functioning, independence and participation throughout the entire lifespan.[2]

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Correspondence: Hatice EKİNALAN KAYHAN
Program of Radiotherapy, Ankara University Vocational School of Health Services, Ankara Türkiye
E-mail: hekayhan@ankara.edu.tr

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The World Health Organization defines participation as "involvement in all life situations including home life, school and various recreational activities as an important consequence of being healthy".[3] The International Classification of Functioning, Disability and Health model defines participation as a complicated condition and states that participation can change over time as body structure and body functions interact with personal and environmental factors. Participation is a fundamental human right and an important outcome of the rehabilitation process. Participation in children is important. It directly affects the behavioral, mental and physical health of children.[2-4] It was stated that children with disabilities involvement less in school, social, recreational and leusire activities when compared to children of the same age without disabilities. Moreover, as the age of children with disabilities increases, the diversity of participation decreases. It has been reported that children with SB involvement in less and low intense activities than their normal developmental peers and children with other physical disabilities.[2,5] Children with paraplegia after spinal cord injury (SCI) and children with SB have similar physical functions, but children with SB have lower frequency and intensity of participation than children with paraplegia after SCI.[2,6]

It has been reported that muscle strength and grip strength are decreased in children with SB compared to their peers.[7-9] Decreased grip and finger grip strength have been associated with hydrocephalus, damage to the cortical and corticospinal tracts, Chiari II malformation, syringomyelia, and cognitive status. In addition, studies have reported that causes other than hydrocephalus and lesion level may adversely affect upper extremity functions in patients with meningomyelocele.[10,11]

There are few studies in the literature on the upper extremity in individuals with SB. SB management mostly includes interventions for the lower extremities and trunk, and the upper extremities are neglected. The aim of this study is to examine participation and its relation with upper extremity strength in individuals with SB.

MATERIAL AND METHODS

The study started with the permission of Yıldırım Beyazıt University Health Sciences Ethics Committee, dated December 9, 2021 and decision number 33. Informed consent was obtained from the participants and their families. The study was conducted in accordance with the principles of the Helsinki Declaration.

PASS 11 (Power analysis sample size/NCSS Statistical Software/USA) program was used to determine the number of participants. In order to conduct the study with 81.99% power, 5% margin of error and 0.49 effect width, the sample size was found to be 22 people in each group and 44 people in total. Our study was completed with 46 participants.

Inclusion criteria for the study: being between 6-12 years old, diagnosed with SB aperta (meningomyelocele) by a specialist, having an IQ level of 70 and above, hydrocephalus with shunt if hydrocephalus, not having a shunt infection and shunt revision, not having tethered cord syndrome, having lesions below the T4 level, not having spasticity and contracture in the upper extremity and not having visual and hearing deficits that affect understanding, responding and application to test instructions. The control group consists of individuals between the ages of 6-12 and showing typical development.

Demographic information of the participants was recorded. Ambulation levels of individuals with SB were determined using the Hoffer classification system.[8,12] The estimated cognitive levels of the children were determined by the SPARCLE project cognitive evaluation form completed by the families of the children.[13,14]

PARTICIPATION

Children's participation was evaluated with the Child and Adolescent Participation Scale (CAPS). CAPS is a scale that evaluates the level of involvement of children in home, school and community activities compared to their peers, based on family or caregiver reports. CAPS consists of 20 items and 4 subsections. Twenty items are evaluated on a 4-point scale.[15-17]

UPPER EXTREMITY MUSCLE STRENGTH, GRIP STRENGTH AND PINCH STRENGTH

Upper extremity muscle strength of the participants was measured with a digital hand held dynamometer (Power track II commander, JTECH Medical, Utah, USA). Shoulder abduction, shoulder flexion, elbow extension and elbow flexion were measured. After the participants were brought to the appropriate position for each muscle, the desired movement was explained to the participants and they were asked to do the movement actively. Resistance to active movement was applied with a hand dynamometer and the participant was asked to maintain his position against resistance for 5 seconds. The value at which the participant resisted the resistance was recorded in "Newtons". Two measurements were made for each muscle. The value higher than the measurements was used in the evaluation.[18,19]

Grip strength was evaluated with a hydraulic hand dynamometer (Saehan Corp. Masan, Korea). Participants were positioned in line with the recommendations of the American Association of Hand Therapists. Three repetitions were made for each measurement. It was recorded in "pounds" by taking the average of 3 trials.[20,21]

Pinch strength was evaluated with pinchmeter (Jamar, Sammons Preston Rolyan, Bolingbrook, USA). Participants were positioned in line with the recommendations of the American Association of Hand Therapists. Fingertip, lateral and palmar grip strength were evaluated. Three repetitions were made for each measurement. It was recorded in "pounds" by taking the average of 3 trials.[21,22]

STATISTICAL ANALYSIS

All data were analyzed with SPSS v.25 (IBM Corp., New York, USA). The normality of the distribution of the variables was evaluated via the Shapiro-Wilk test. Independent two samples t-test was used for normally distributed data and Mann-Whitney U test was used for non-normally distributed data in intergroup comparisons. The relationship between the 2 numerical variables was evaluated with the Spearman rho coefficient. Statistical significance level was determined as $p<0.05$.

RESULTS

The ages of individuals with and without SB were statistically similar. 11 (42.3%) of the individuals with SB and 15 (57.7%) of the healthy individuals were women, and the groups were not statistically different ($p>0.05$). The average height of individuals with SB was lower than healthy individuals ($p<0.05$). The groups showed similar distribution in terms of weight. The number of individuals with a right dominant hand was 22 (52.4%) in individuals with SB and 20 (47.6%) in healthy individuals ($p>0.05$) (Table 1).

Home participation, community participation, school participation, home community participation and CAPS total score were statistically lower in individuals with SB ($p<0.05$) (Table 2).

TABLE 1: Demographic characteristics of participants.

	Groups		Test statistics	
	SB group n=23	Non SB group n=23	Test value	p value
Age M (minimum-maximum)	9 (6-12)	8.5 (6-12)	z=2.180	0.336
Gender. n (%)				
Female	11 (42.3)	15 (57.7)	χ^2=3.225	0.183
Male	12 (60.0)	8 (40.0)		
Height $\bar{X}$±SD	120.13±10.78	133.09±9.53	t=4.265	**<0.001**
Weight $\bar{X}$±SD	30.32±10.04	31.08±6.03	t=0.306	0.761
Dominant hand, n (%)				
Right	22 (52.4)	20 (47.6)	11.052	0.051
Left	1 (25.0)	3 (75.0)		

%: Percentage in total; χ^2: Fisher exact test; t: Independent two sample t-test; z: Standardized Mann-Whitney U test; SB group: Individuals with spina bifida; Non SB group: Normally developing individuals; $\bar{X}$: Mean; SD: Standard deviation.

TABLE 2: CAPS scores.

	Groups		Test statistics	
	SB group M (IQR)	Non SB group M (IQR)	z value	p value
Home participation	91.6 (8.3)	100 (4.1)	23.116	**<0.001**
Community participation	81.2 (6.2)	100 (12.5)	16.276	**<0.001**
School participation	85 (20)	100 (0)	21.088	**<0.001**
Home community participation	90 (10)	90 (10)	3.652	**<0.001**
CAPS total score	87.5 (7.5)	96.2 (6.2)	23.653	**<0.001**

M: Median; IQR: Interquartile range; z: Standardized Mann-Whitney U test; CAPS: Child and Adolescent Participation scale; SB group: Individuals with spina bifida; Non SB group: Normally developing individuals.

Dominant and non-dominant side shoulder abduction, shoulder flexion, elbow extension and elbow flexion muscle strength were statistically lower in the SB group ($p<0.05$) (Table 3).

The grip strength of the non-dominant side was similar between the groups, while the grip strength of the dominant side was statistically lower in the SB group ($p<0.05$) (Table 4).

TABLE 3: Comparison of grip strength and muscle strength between groups.

	Groups		Test statistics	
	SB group $\bar{X}$±SD	Non SB group $\bar{X}$±SD	Test value	p value
Dominant				
Grip strength (P)	17,32±10,78	23,18±6,66	2,216	**0,032**
Shoulder flexion (N)	34,30±15,24	64,45±14,27	t=6,924	**<0,001**
Shoulder abduction (N)	34,80±16,70	52,70±9,43	t=4,474	**<0,001**
Elbow flexion (N)	37,73±18,51	54,91±12,53	t=3,686	**0,001**
Elbow extension M (IQR)	35,2 (17,8)	61,6 (18,6)	z=4,731	**<0,001**
Non-dominant				
Grip strength (P)	16,82±10,84	21,19±6,89	3,613	**0,110**
Shoulder flexion (N)	34,37±15,35	59,60±14,50	t=5,730	**<0,001**
Shoulder abduction (N)	34,70±18,17	49,80±10,45	t=3,453	**0,001**
Elbow flexion (N)	34,71±16,51	52,87±12,25	t=4,236	**<0,001**
Elbow extension (N)	36,82±16,65	58,96±13,58	t=4,490	**0,001**

N: Newton; $\bar{X}$: Mean; SD: Standard deviation; M: Median; IQR: Interquartile range; P: Pounds; t: Independent Two Samples t-test; z: Standardized Mann-Whitney U test; SB group: Individuals with spina bifida; Non SB group: Normally developing individuals.

TABLE 4: Comparison of pinch strength between groups.

	Groups		Test statistics	
	SB group	Non SB group	Test value	p value
Dominant				
Lateral grip strength M (IQR) (P)	1.33 (2.40)	5.30 (1.40)	z=5.238	**<0.001**
Fingertip grip strength $\bar{X}$±SD (P)	3.20±2.12	7.12±1.74	t=6.681	**<0.001**
Palmar grip strength $\bar{X}$±SD (P)	2.71±1.78	7.01±1.84	t=8.026	**<0.001**
Non-dominant				
Lateral grip strength M (IQR) (P)	1.16 (2.30)	5.0 (1.70)	z=4.994	**<0.001**
Fingertip grip strength $\bar{X}$±SD (P)	3.07±2.23	6.46±1.83	t=5.634	**<0.001**
Palmar grip strength M (IQR) (P)	2.0 (2.64)	6.30 (3.10)	z=4.846	**<0.001**

t: Independent two-sample t-test; z: Standardized Mann-Whitney U test; SB group: Individuals with spina bifida; Non SB group: Normally developing individuals; IQR: Interquartile range; SD: Standard deviation.

Dominant and non-dominant side lateral, palmar and fingertip grip strengths were statistically lower in SB group ($p<0.05$) (Table 4).

Dominant and non-dominant upper extremity muscle strength had a statistically significant relationship with home participation, community participation, home community participation and CAPS total score ($p<0.05$) (Table 5). There was a statistically significant relationship between dominant and non-dominant side grip strength and CAPS total score, community participation and home community participation sub-parameters. There was a statistically significant relationship between dominant and non-dominant side lateral pinch strength and CAPS total score, home participation and home community participation sub-parameters ($p<0.05$) (Table 6).

TABLE 5: Correlation of upper extremity muscle strength with CAPS in spina bifida group.

		CAPS total score	Home participation	Community participation	School participation	Home community participation
Dominant shoulder flexion MS	rho	0.478	0.491	0.471	0.108	0.425
	p value	**0.021**	**0.017**	**0.023**	0.622	**0.043**
Dominant shoulder abduction MS	rho	0.498	0.246	0.490	0.236	0.617
	p value	**0.016**	0.258	**0.018**	0.279	**0.002**
Dominant elbow flexion MS	rho	0.682	0.407	0.599	0.398	0.632
	p value	**<0.001**	0.054	**0.003**	0.060	**0.001**
Dominant elbow extension MS	rho	0.414	0.464	0.327	0.234	0.250
	p value	**0.049**	**0.026**	0.127	0.083	0.249
Non-dominant shoulder flexion MS	rho	0.558	0.490	0.668	0.134	0.553
	p value	**0.006**	**0.018**	**0.000**	0.542	**0.006**
Non-dominant shoulder abduction MS	rho	0.543	0.295	0.519	0.269	0.631
	p value	**0.007**	0.171	**0.011**	0.214	**0.001**
Non-dominant elbow flexion MS	rho	0.702	0.627	0.522	0.349	0.589
	p value	**<0.001**	**0.001**	**0.011**	0.103	**0.003**
Non-dominant elbow extension MS	rho	0.647	0.552	0.649	0.344	0.501
	p value	**0.001**	**0.006**	**0.001**	0.108	**0.015**

rho: Spearman correlation coefficient; CAPS: Child and Adolescent Participation Scale; MS: Muscle strength.

TABLE 6: Correlation of grip strength and finger grip strength with CAPS in spina bifida group.

		CAPS total score	Home participation	Community participation	School participation	Home community participation
Dominant grip strength	rho	0.601	0.376	0.695	0.239	0.703
	p value	**0.002**	0.077	**<0.001**	0.273	**<0.001**
Non-dominant grip strength	rho	0.571	0.386	0.670	0.200	0.629
	p value	**0.004**	0.069	**<0.001**	0.360	0.001
Dominant fingertip pinch strength	rho	0.293	0.287	0.196	0.064	0.332
	p value	0.175	0.184	0.369	0.772	0.121
Dominant lateral pinch strength	rho	0.526	0.491	0.406	0.176	0.486
	p value	**0.010**	**0.017**	0.055	0.421	**0.019**
Dominant palmar pinch strength	rho	0.344	0.233	0.195	0.152	0.506
	p value	0.108	0.284	0.372	0.488	**0.014**
Non-dominant fingertip pinch strength	rho	0.392	0.375	0.291	0.099	0.326
	p value	0.065	0.078	0.178	0.653	0.130
Non-dominant lateral pinch strength	rho	0.508	0.456	0.313	0.222	0.428
	p value	**0.013**	**0.029**	0.146	0.308	**0.041**
Non-dominant palmar pinch strength	rho	0.277	0.219	0.178	0.041	0.412
	p value	0.201	0.315	0.417	0.854	0.051

rho: Spearman correlation coefficient; CAPS: Child and Adolescent Participation Scale.

DISCUSSION

In this study, participation, shoulder abduction, shoulder flexion, elbow extension and elbow flexion muscle strength, dominant side grip strength, and lateral, palmar and fingertip pinch strength were found to be lower in individuals with SB compared to their peers with normal development. In addition, there was a positive correlation between participation and muscle strength, grip strength and finger grip strength in individuals with SB.

It was stated that children with disabilities involvement less in school, social, recreational and leusire activities when compared to children of the same age without disabilities. Moreover, as the age of children with disabilities increases, the diversity of participation decreases. It has been reported that children with SB involvement in less and low intense activities than their normal developmental peers and children with other physical disabilities.[2,5] Our study also shows parallelism with the information in the literature that home participation, school participation, community participation and home community participation are low compared to healthy peers of individuals with SB.

Children with paraplegia after SCI and children with SB have similar physical functions, but children with SB have lower frequency and intensity of participation than children with paraplegia after SCI.[2,6] Children born with disabilities are viewed by their parents as more vulnerable than their healthy peers. Families exhibit overprotective attitudes towards children. Such an attitude prevents the child with SB from being aware of and revealing his/her abilities and capacities. It has been reported that parents of children with SB are more protective than parents of children with normal development.[2,23,24] Overprotected children have poor socialization, self-determination and interaction with people outside of school. They have a high dependence on adults for guidance. The difference in participation between individuals with SB and SCI may be due to the age of onset of pathology (congenital or acquired), individuals with SCI being less affected by overprotection and its consequences, the presence of hydrocephalus in individuals with SB, and cognitive dysfunction.[23,24] Studies have highlighted that the most important and widespread obstacle to participation is low motivation. Motivation can be affected by a variety of factors, including insufficient experience, restricted peer interaction, learned helplessness and neurological impairment. Children with disabilities who have not experienced participation and peer interaction may not know an different way to participate in social activities or may not dare. In addition, overprotection by parents and neurological impairment can lead to decreased targeted behavior and participation in children. Children should be intervened at a young age before negative environmental effects occur and behavior patterns occur. The intervention should be according to the interests of each child and should aim to increase their motivation level.[2,25,26]

It has been reported that children and adolescents with SB participate more in activities in the home environment such as family interactive activities and screen time, unlike school preparation and housework. It has been stated that the participation of children with SB in the pre-school/school environment is more limited and they prefer to receive education at home.[5,27,28] In a study of disabled and non-disabled children, it was found that children with disabilities had low participation in school clubs, organizations and social activities with friends outside of school. This situation may cause social isolation in children.[29,30] It has been reported that children with SB show lower levels of community involvement compared to their normally developing peers and even children with other disabilities such as acquired SCI or learning difficulties.[2,5] In our study, home participation, school participation, community participation and home community participation were statistically lower in individuals with SB compared to their healthy peers. While children with SB show the highest home participation, the lowest community participation confirms the literature. When the relationship between upper extremity strength and participation in individuals with SB was evaluated, dominant and non-dominant side shoulder abductor, shoulder flexor, elbow extensor and elbow flexor muscles, grip strength and especially lateral pinch strength were found to be related.

It has been reported that participation decreases with increasing age in individuals with physical disabilities. With the expectation that children with SB will grow up to become independent adolescents and adults, the process of developing self-management skills is a process that needs to be addressed early and should be practiced at home, at school, and in the community. In order to manage the difficulties of the SB, targeted planning should be done that evaluates the needs of the children, covers the strengths and interests of the child, and supports the development of self-management skills.[31-33]

The study has limitations. The first is that only individuals with SB aperta were included in the study. Moreover, the study included individuals with SB with lesions below the T_4 level and evaluated this group as a whole. More studies are needed examining upper extremity strength and participation in individuals with different lesion levels. The number of participants in the study is small and only includes individuals between the ages of 6-12. There is a need for studies with more participants and examining different age groups.

CONCLUSION

SB is a neurological birth defect that requires lifelong management of multiple system comorbidities. SB management is a versatile and variable process that includes education, prevention, medical treatment, surgical treatment and habilitation. Upper extremity muscle strength, grip strength and pinch strength are related to participation in individuals with SB. Increasing upper extremity muscle strength may contribute to increased participation. Upper extremity muscle strength should be evaluated in individuals with SB and included in the rehabilitation program.

Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct connection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

Idea/Concept: *Hatice Ekinalan Kayhan, Bahar Külünkoğlu;* ***Design:*** *Hatice Ekinalan Kayhan, Bahar Külünkoğlu;* ***Control/Supervision:*** *Hatice Ekinalan Kayhan, Bahar Külünkoğlu;* ***Data Collection and/or Processing:*** *Hatice Ekinalan Kayhan, Bahar Külünkoğlu;* ***Analysis and/or Interpretation:*** *Hatice Ekinalan Kayhan;* ***Literature Review:*** *Hatice Ekinalan Kayhan;* ***Writing the Article:*** *Hatice Ekinalan Kayhan;* ***Critical Review:*** *Hatice Ekinalan Kayhan, Bahar Külünkoğlu;* ***References and Fundings:*** *Hatice Ekinalan Kayhan, Bahar Külünkoğlu;* ***Materials:*** *Hatice Ekinalan Kayhan.*

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