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Original Article

Investigation of occupational balance and quality of life in mothers of children with acquired brain injury: A prospective comparative study

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ABSTRACT

Objectives: This study aims to investigate differences in occupational balance and quality of life between mothers of children with acquired brain injury (ABI) and healthy children.

Patients and methods: Forty mothers (mean age: 37.6±7.8 years; range, 24 to 52 years) of children with ABI (27 males, 13 females; mean age: 9.6±4.7 years; range, 2 to 16 years) and 40 mothers (mean age: 42.1±7.1 years; range, 32 to 58 years) of healthy children participated in the cross-sectional experimental study between May 2022 and December 2022. The occupational balance levels of the mothers in the study and control group were evaluated with the Occupational Balance Questionnaire 11-T, and the quality of life of the mothers was evaluated with the Nottingham Health Profile.

Results: Total Occupational Balance Questionnaire 11-T scores and items "having sufficient things to do during a regular week," "balance between doing things for others and for oneself," "balance between work, home, family, leisure, rest, and sleep," "having sufficient time for doing obligatory occupations," "balance between physical, social, mental, and restful occupations," "balance between energy-giving/energy-taking activities," and "satisfaction with time spent in rest, recovery, and sleep" were found to be statistically significantly lower in the mothers of children with ABI compared to the control group. The Nottingham Health Profile scores were found to be statistically significantly lower for the mothers of children with ABI compared to the control group.

Conclusion: The study revealed that the occupational balance and quality of life of mothers of children with ABI were adversely affected. In the rehabilitation process of children with ABI, the focus should be on the mother's occupational balance as well as the functional status of the children.

Keywords: Acquired brain injury, children, occupational balance.

Pediatric acquired brain injury (ABI) leads to physical issues such as loss of motor skills, spasticity, muscle weakness, and problems with balance and coordination.[1] In addition to physical problems, it often results in a wide range of persistent cognitive, behavioral, social, and functional difficulties for the child. Symptoms are highly variable, and problems can persist for years.[2,3] Children with ABI have a major impact on their families and this situation is extremely stressful for the entire family.[4] The burden and emotional exhaustion experienced by parents as caregivers vary according to the severity of the disability.[5] There are more apparent and lasting effects on the functioning of the family when the level of disability is severe, such as in the case of children who are fully dependent in activities of daily living.[6,7] Families may struggle with financial difficulties, social isolation, and lack of support, or may experience stress, anxiety, low mood, and sometimes feel guilty for not being able to protect their child.[8] Families of children with acquired disabilities cannot easily adapt to the new situation, and the process of acceptance takes longer than for families of individuals with congenital disabilities. When an individual has a congenital disability, families accept the situation more easily, and the

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transition between stages is faster. However, there are findings indicating that the family impact is similar for children with congenital and acquired brain damage.[9]

Occupational balance (OB) is defined as the ability to establish and maintain a meaningful equilibrium among various domains of daily life, such as work, family, leisure, rest, and social activities.[10] This balance is critical for addressing individuals' physical, mental, social, and emotional needs. Quality of life (QoL) is a multidimensional concept encompassing health, social relationships, environmental conditions, and personal satisfaction. Research has consistently highlighted the significant impact of OB on QoL. An imbalance in daily activities can lead to physical and emotional exhaustion, chronic stress, and reduced satisfaction with life.[11] Conversely, achieving harmony among activities enhances individuals' sense of self-efficacy, life satisfaction, and overall well-being. In high-stress situations, such as caregiving roles that demand substantial time and energy, occupational imbalance has been identified as a major risk factor adversely affecting QoL. Therefore, OB emerges as a critical component not only for maintaining daily functionality but also for promoting and sustaining overall QoL.

It is known that achieving OB and ideal QoL is difficult for parents of children with disabilities due to the high demands of the disability-related caregiving role.[12] Mothers of children with ABI are emotionally and physically worn out, just like mothers of other disabled children. However, there is not enough data in the literature about what changes occur in the OB of these individuals and the relationship between OB and QoL. The extent to which these emotional states in caregiving mothers affect their OB and QoL are questions awaiting answers in the literature.

Therefore, this study aimed to examine the OB and QoL in mothers of children with ABI by comparing them with mothers of healthy children. The results of the study are expected to guide intervention programs planned for the families of children with ABI.

PATIENTS AND METHODS

A cross-sectional experimental design was undertaken to compare the OB and QoL of mothers of children with ABI and mothers of healthy developing children. The study was conducted between May 2022 and December 2022 and included 40 mothers (mean age: 37.6±7.8 years; range, 24 to 52 years) of children with ABI (27 males, 13 females; mean age: 9.6±4.7 years; range, 2 to 16 years) who underwent an inpatient rehabilitation program in the pediatric rehabilitation clinic of the Ankara Bilkent City Hospital. Additionally, 40 healthy control subjects (mean age: 42.1±7.1 years; range, 32 to 58 years) matched for age, place of residence, employment, and marital status were included in the study. Mothers aged 18 to 65 years who had children with ABI for traumatic or nontraumatic reasons after normal typical development between the ages 2 and 16 years were included in the study. Mothers with any physical, neurological, or psychological disease and children with additional physical or neurological diseases (e.g., autism or mental retardation) before the brain injury were excluded from the study. Written informed consent was obtained from all the mothers. The study protocol was approved by the Ankara Bilkent City Hospital Ethics Committee (Date: 13.04.2022, No: E2-22-1643). The study was conducted in accordance with the principles of the Declaration of Helsinki.

Demographic and clinical characteristics (age, sex, etiology, passed time since the injury, length of stay in the intensive care unit, presence of percutaneous endoscopic gastrostomy [PEG], presence of tracheotomy, history of rehabilitation, cooperation, and functional status) and complications (contracture, spasticity, pressure ulcers, visual-hearing impairment, respiratory impairment, agitation, epilepsy, sleeping problems, depression, drooling, and incontinence) of all the children with ABI were recorded. The characteristics of the mothers in both groups were recorded, including age, marital status, marriage duration, number of children, daily childcare duration, daily sleep duration, employment status, income-expense balance, chronic disorders, musculoskeletal pain, presence of care assistance and physical activities.

The modified Rankin Scale, which is a scale used to evaluate the disability level of people after brain injury, was used to determine the disability level of the children with ABI in this study. Items in the scale are scored from 0 to 6, with 0 points indicating the absence of disability, 5 points indicating being bedridden and in need of constant care, and 6 points indicating death.[13]

The functional status of the patients was categorized at five different levels. *(i)* fully dependent patients and can partially perform in-bed activities

at bed level; *(ii)* patients at wheelchair level, with sitting balance with minimal support, and able to be mobilized by wheelchair; *(iii)* patients with therapeutic ambulation, able to sit independently and stand with assistive devices; *(iv)* indoor ambulation, patients who can stand and walk a short distance with assistive devices but cannot walk for long periods or on uneven surfaces or climb stairs; *(v)* community ambulation, patients who can walk long distances independently in public.

The Occupational Balance Questionnaire 11-T (OBQ11-T) was used to examine the OB levels of the mothers in the study and control groups. This questionnaire was first developed in 2014 and later modified as OBQ11 by Håkansson et al.[14] It is a self-rating scale that measures OB in different dimensions. The purpose of the scale is to measure satisfaction according to the amount and variety of daily activities of the person and to define the OB according to the results obtained. The validity and reliability of OBQ11-T was demonstrated by Günal et al.[15] in 2020. Each item in the scale is scored on a 4-point Likert-type scale ranging from "strongly disagree" (0) to "strongly agree".[3] A total score ranging from 0 to 33 is obtained by adding the scores of all the items, with higher scores indicating better OB.

The QoL of the mothers in the study and control group was evaluated with the Nottingham Health Profile (NHP). This is an overall patient-reported outcome that aims to measure subjective health status. The questionnaire is designed to measure a patient's view of their health status in various domains. The NHP consists of two parts. The first section focuses on health and consists of 38 items dealing with pain, energy, sleep, mobility, emotional response, and social isolation. The second part focuses on the affected parts of life and consists of seven items that address issues related to occupation, household chores, social life, family life, sexual function, hobbies, and holidays. The responses to all the questions are yes or no, and the maximum score in each section is 100. A higher score indicates an increased number and severity of problems. The validity and reliability of the Turkish version of this scale was demonstrated by Küçükdeveci et al.[16]

Statistical analysis

The required sample size was calculated using G*Power version 3.1 statistical software (Heinrich Heine University, Düsseldorf, Germany). The number of patients to be included in the study was calculated as 40 for each group, with a medium effect size, type 1 error of 0.05, and 95% power.[17]

Data analysis was performed using IBM SPSS version 20.0 software (IBM Corp., Armonk, NY, USA). Descriptive statistics were expressed as mean and standard deviation (SD) for continuous variables and as numbers and percentages for discrete variables. The conformity of the data to normal distribution was measured with the Shapiro-Wilk test. The Mann-Whitney U test was used for the comparisons of numerical variables and the chi-square test for categorical variables. Correlations between OBQ11-T and NHP, as well

TABLE 1
Demographic and clinical features of children with ABI

	Children with ABI (n=40)		
	n	%	Mean±SD
Age (year)*			9.6±4.7
Sex			
Male	27	67.5	
Female	13	32.5	
Etiology			
Traumatic brain injury	20	50	
Anoxic brain injury	11	27.5	
Stroke	3	7.5	
Tumors	2	5.0	
Encephalitis	4	10.0	
Time since injury (mo)			13.2±10.1
Duration of intensive care unit (day)			35.3±30.4
Coma duration (day)			8.5±11.5
Presence of PEG	9	22.5	
Presence of tracheotomy	11	27.5	
History of rehabilitation	14	35.0	
Cooperation status	0	0.0	
None	17	42.5	
Partial	4	10.0	
Fully	19	47.5	
Modified Rankin Scale			
2	5	12.5	
3	11	27.5	
4	8	20.0	
5	16	40.0	
Functional status			
At bed level	13	32.5	
Wheelchair level	3	7.5	
Therapeutic ambulation level	7	17.5	
In-home ambulation level	14	35.0	
Community ambulation level	3	7.5	

ABI: Acquired brain injury; SD: Standard deviation; PEG: Percutaneous endoscopic gastrostomy.

TABLE 2
Complications of children with ABI

	Children with ABI (n=40)	
	n	%
Spasticity	29	72.5
Incontinence	24	60.0
Visual impairment	20	50.0
Epilepsy	19	47.5
Aphasia	18	45.0
Pressure ulcers	10	25.0
Contracture	10	25.0
Drooling	10	25.0
Agitation	8	20.0
Respiratory impairment	7	17.5
Hearing impairment	6	15.0
Sleeping problems	6	15.0
Depression	6	15.0

ABI: Acquired brain injury.

as demographic and clinical characteristics, were examined with the Spearman correlation analysis. A p-value <0.05 was considered statistically significant.

RESULTS

All the demographic and clinical characteristics and the complications of the children are presented in Table 1 and Table 2. No statistically significant difference was found between the mothers in the study and control groups in respect of age, marital status, marriage duration, number of children, daily sleep duration, employment status, income-expense balance, chronic disorders, musculoskeletal pain, presence of care assistance, and physical activities (p>0.05). There was a significant difference between the groups in terms of daily childcare duration of the mothers (9.1±1.75 h *vs.* 2.9±1.3 h; Table 3).

TABLE 3
Demographic characteristic of mothers of children with ABI and typically developing children

	Mothers of children with ABI (n=40)					Mothers of typically developing children (n=40)					
	n	%	Mean±SD	Median	Min-Max	n	%	Mean±SD	Median	Min-Max	*p*
Age (year)			37.6±7.8	36.0	24-52			42.1±7.1	40.0	32-58	0.378
Marriage status											0.456
Married	37	92.5				35	87.5				
Divorced	3	7.5				5	12.5				
Marriage duration (year)			15.9±3.9					15.0±4.4			0.631
Numbers of children			2.2±0.4					1.7±0.3			0.268
Daily childcare duration (h)			9.1±1.75					2.9±1.3			**<0.001**
Daily sleep duration (h)			6.5±0.9					7.0±0.8			0.234
Employment stats											0.112
Working	20	50.0				13	32.5				
Housewife	20	50.0				27	67.5				
Income expense balance											0.054
Income < expense	6	15.0				3	7.5				
Income = expense	11	27.5				17	42.5				
Income > expense	23	57.5				20	50.0				
Chronic disorders											0.143
Yes	10	25.0				15	37.5				
Musculoskeletal pain											0.117
Yes	23	57.5				16	40.0				
Care assistance											0.715*
None	11	27.5				14	35.0				
Husband	22	55.0				18	45.0				
Close relatives	4	10.0				6	15.0				
Caregiver	3	7.5				2	5.0				
Regular physical activity											0.121
Yes	7	17.5				13	32.5				
Hobby											0.084
Yes	8	20.0				15	37.5				

ABI: Acquired brain injury; SD: Standard deviation; * Fisher's Exact test; Chi-square test (group), Mann-Whitney-U test (quantitative) p<0.05 statistically significant (bold).

TABLE 4
Comparisons of OBQ11-T scores across the groups

	Mothers of children with ABI			Mothers of typically developing children			
	Mean±SD	Median	Min-Max	Mean±SD	Median	Min-Max	*p*
Item 1 (having sufficient things to do during a regular week)	2.02±0.53	2	1-3	2.60±0.54	3	1-3	**<0.001**
Item 2 (balance between doing things for others/for oneself)	1.12±1.52	1	0-3	1.55±0.81	2	0-3	**0.003**
Item 3 (time for doing things wanted)	1.30±0.79	1	0-3	1.50±0.67	2	0-3	0.143
Item 4 (balance between work, home, family, leisure, rest, and sleep)	0.95±0.78	1	0-3	1.77±0.76	2	0-3	**<0.001**
Item 5 (have sufficient time for doing obligatory occupations)	1.22±0.52	1	0-3	1.62±0.89	2	0-3	**0.009**
Item 6 (balance between physical, social, mental, and restful occupations)	0.87±0.53	1	0-3	1.55±0.74	2	0-3	**<0.001**
Item 7 (satisfaction with how time is spent in everyday life)	1.25±0.70	1	0-3	1.57±0.78	1	0-3	0.076
Item 8 (satisfaction with the number of activities during a regular week)	1.37±0.80	1	0-3	1.40±0.59	1	0-3	0.890
Item 9 (balance between obligatory/voluntary occupations)	1.02±0.86	1	0-3	1.20±0.68	1	0-3	0.326
Item 10 (balance between energy-giving/energy-taking activities)	1.05±0.64	1	0-3	1.70±0.75	2	0-3	**<0.001**
Item 11 (satisfaction with time spent in rest, recovery, and sleep)	1.42±0.59	1	0-3	1.77±0.80	2	0-3	**0.021**
Total score	12.45±6.12	12	1-27	18.52±4.76	18	6-27	**<0.001**

OBQ11-T: Occupational Balance Questionnaire 11-T; ABI: Acquired brain injury; SD: Standard deviation; Mann-Whitney-U test, p<0.05 statistically significant (bold).

The total scores of the OBQ11-T and the scores for each item were evaluated separately. The scores for Item 1 (having sufficient things to do during a regular week), Item 2 (balance between doing things for others and for oneself), Item 4 (balance between work, home, family, leisure, rest, and sleep), Item 5 (having sufficient time for doing obligatory occupations), Item 6 (balance between physical, social, mental, and restful occupations), Item 10 (balance between energy-giving/energy-taking activities), Item 11 (satisfaction with time spent in rest, recovery, and sleep), and the total OBQ11-T

TABLE 5
Comparisons of NHP scores across the groups

	Mothers of children with ABI			Mothers of typically developing children			
	Mean±SD	Median	Min-Max	Mean±SD	Median	Min-Max	*p*
Part 1 Pain	25.35±25.19	16	0-87	12.10±14.55	9	0-52	**0.015**
Part 1 Physical mobility	23.15±20.49	22	0-88	10.10±12.31	10	0-42	**0.004**
Part 1 Emotional reactions	44.57±24.33	43	0-100	12.80±17.42	0	0-70	**<0.001**
Part 1 Energy levels	71.80±26.76	69	24-100	37.52±40.69	24	0-100	**<0.001**
Part 1 Social isolation	41.97±29.58	42	0-100	8.05±16.18	0	0-77	**<0.001**
Part 1 Sleep	42.90±23.24	49	0-77	14.12±20.45	0	0-65	**<0.001**
Part 1 Total score	248.45±110.04	246	24-444	93.97±91.11	66	0-275	**<0.001**
Part 2 Total score	3.57±1.63	4	0-6	0.72±0.98	0	0-3	**<0.001**

NHP: Nottingham health profile; ABI: Acquired brain injury; SD: Standard deviation; Mann-Whitney-U test, p<0.05 statistically significant (bold).

TABLE 6
Correlation between OBQ11-T and NPH scores of mothers of children with ABI

	OBQ11-T	
NHP	r	*p*
Part 1 Pain	−0.605	**<0.001**
Part 1 Physical mobility	−0.530	**0.004**
Part 1 Emotional reactions	−0.717	**<0.001**
Part 1 Energy levels	−0.635	**<0.001**
Part 1 Social isolation	−0.512	**<0.001**
Part 1 Sleep	−0.623	**<0.001**
Part 1 Total score	−0.751	**<0.001**
Part 2 Total score	−0.697	**<0.001**

OBQ11-T: Occupational Balance Questionnaire 11-T; NHP: Nottingham health profile; Spearman correlation analysis p<0.05 statistically significant (bold).

scores were found to be statistically significantly lower in the mothers of children with ABI compared to the control group (Table 4). The NHP scores in all sections of Part 1 (pain, physical mobility, emotional reactions, energy levels, and social isolation) and Part 2 were found to be statistically significantly lower for the mothers of children with ABI compared to the control group (Table 5).

In the correlation analysis of the OBQ11-T and NHP scores of the mothers of children with ABI, a moderate to strong negative correlation was found between all sections of the NHP and OBQ11-T (Table 6). In the correlation of the OBQ11-T with demographic and clinical characteristics of mothers and children in the study group, a weak to moderate negative correlation was determined between maternal-related factors such as age, chronic disorder, musculoskeletal pain, and daily childcare duration (r=−0.337, r=−0.353, r=−0.375, and r=−0.465, respectively) and a moderate positive correlation with daily sleep duration (r=+0.592). The OBQ11-T was also determined to have a weak to moderate negative correlation with child-related factors such as age, modified Rankin Scale, presence of PEG, tracheotomy, contracture, and respiratory impairment (r=−0.356, r=−0.692, r=−0.420, r=−0.545, r=−0.343, and r=−0.480, respectively), a moderate positive correlation with cooperation status (r=0.471), and a strong positive correlation with functional status (r=0.608).

A post hoc power analysis conducted for the study using the total OBQ-11-T score, with an alpha of 0.05, revealed a power of 0.99, indicating a very high probability of detecting a true effect given the observed sample size and effect size.

DISCUSSION

This study was conducted to examine the OB and QoL in mothers of children with ABI. It was determined that the mothers with ABI provided more daily care to their children compared to the mothers of healthy children, and their OB and QoL was found to be lower. The concepts of QoL and OB were found to be correlated, and when the QoL of the mothers decreased, OB also decreased. When the OBQ11-T subdata were examined, it was understood that mothers with children with ABI spent less time on themselves, did not have sufficient time, and experienced imbalance between the time they spared for themselves and the time they spared for others. In addition, it was concluded that there was no balance between various occupations in life, they could not spare time for social, intellectual, and relaxing activities, and that they devoted a large part of their energy to their children. Furthermore, the OB level of the mothers of the children with ABI was associated with the mother's age, the presence of maternal chronic disease and musculoskeletal pain, daily childcare duration time, daily sleep time, the child's age, disability level, communication and functional status, the presence of child's PEG, tracheostomy, contracture, and respiratory issues.

Caregiving is a natural and fundamental part of parenting, but if the child has a chronic disability, parents may need to devote a large part of the day to helping the child with basic tasks such as feeding, hygiene, dressing, play, and communication. These children may depend on their parent's help throughout their lives.[18] In the care of children with disabilities, mothers are generally unpaid caregivers. In many cases, the mother quits her job to focus on the child's care, which requires more time and has a major impact on her daily life.[19] In the present study, it was determined that the daily childcare duration for children with ABI was longer than for healthy developing children. The duration of daily care given by mothers was longer in the ABI diagnosed children group in this study. In a study on cerebral palsy, it was stated that there was a need for continuous care for the child beyond the planned time for the family, and this meant extra pressure on the mother.[20] This pressure on the mother also caused an imbalance in her use of time, and

therefore, her life quality could be affected much more than a mother with healthy children.

The use of time is a concept associated with OB. In a study examining the time use of mothers with and without children with disabilities such as cerebral palsy, autism, developmental delay and Down syndrome, it was shown that there was a significant difference in the time spent on childcare and leisure activities among the mothers of children with disabilities.[21] Inal et al.[9] examined the families of children with brain damage and determined that the daily care duration of children with ABI was 9 h or more at a rate of 77.3%. In another study that examined mothers with children with CP, it was found that the mothers cared for their children for 6 h every day on weekdays and 8.3 h a day at weekends.[22] The results of the present study are also similar to the literature, and the mean time spent by the mothers of children with ABI on daily care was 9.1±1.75 h, while it was 2.9±1.3 h for the mothers of healthy children. Another study conducted on the mothers of children with autism reported that the mothers experienced occupational instability and self-sacrifice when they stopped participating in activities for themselves by taking time to attend professional services and travel.[23] This situation can be considered an important factor in the finding that the OB of the mothers of children with ABI was found to be lower than the mothers of healthy children in the current study.

The present study revealed that mothers of children with ABI experienced significant disruptions in OB and had lower QoL compared to mothers of healthy children. These findings highlight that ABI not only affects the child but also deeply impacts the primary caregiver's daily life. Mothers were found to struggle with balancing domains such as work, home, family, leisure, rest, and sleep. They reported insufficient time for mandatory and voluntary activities, dissatisfaction with the time allocated for rest, recovery, and sleep, and a disrupted balance between energy-giving and energy-taking activities. This aligns with previous research indicating that caregivers often face physical, emotional, and social challenges due to their caregiving roles.[24] The correlation analysis demonstrated a relationship between OB and QoL, which is consistent with findings from Backman,[25] who emphasized the role of daily activity balance in promoting overall well-being and life satisfaction. Particularly, a disrupted balance between energy-giving and energy-draining activities can lead to emotional exhaustion and reduced motivation among caregivers, perpetuating a cycle of declining QoL. Moreover, the inability of mothers to allocate sufficient time even for mandatory activities can contribute to social isolation and a decline in individual well-being. This issue reflects not only the inadequacy of social support mechanisms but also the challenges of caregiver overload and time management difficulties. The literature indicates that such imbalances can reduce caregivers' psychological resilience, leading to increased levels of stress and burnout.[26]

This study had some limitations. First, there was a risk of subjective bias due to the self-reported nature of the outcome measures used in the study. Second, most of the children in the study group were traumatic and anoxic brain injury patients. The patient population was heterogeneous because the study was conducted at one of the largest centres in Türkiye, where generally moderate to severe patients are accepted. Third, the fact that the children included in the study were in a wide range such as subacute-chronic period may have affected the results regarding the OBQ and QoL status of the families. Nonetheless, the presence of a control group and the examination of many maternal and pediatric factors affecting OB can be considered strengths of the study.

In conclusion, the results of this study revealed that the OB and QoL of mothers with ABI children were adversely affected. In this context, it is important to carry out intervention studies to increase OB and QoL in mothers of children with ABI. Role satisfaction and spousal support may be possible targets of intervention to improve OB and thereby improve the family's QoL.

Data Sharing Statement: The data that support the findings of this study are available from the corresponding author upon reasonable request.

Author Contributions: Idea/concept, design, analysis and/or interpretation, writing the article: B.A., Ö.İ.Ö.; Control/supervision, critical review: S.G.A., C.Ç.; Data collection and/or processing: B.T.; Literature review: B.A., Ö.İ.Ö., B.T.

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