



## Fatigue and depression in mothers caring for children with spina bifida: Examining the role of child's functionality

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### Abstract

Spina bifida (SB) has a significant impact on factors such as stress, depression and fatigue in mothers. The purpose of this study was to examine the relationship between depression and fatigue in mothers of children diagnosed with SB and the functional status of their children. The research was conducted with 75 children (53.3% girls; 46.7% boys) with SB (5.3% meningocele, 94.7% myelomeningocele) aged between 1 and 16 years (mean 6.34 ± SD 3.64) and their mothers aged between 22 and 55 years (mean 33.76 ± SD 7.06). Functional levels of the children were assessed using the Gross Motor Function Classification System (GMFCS), and depression and fatigue levels of the mothers were assessed using the Beck Depression Inventory and the Fatigue Impact Scale, respectively. No significant correlation was found between maternal fatigue and depression levels and GMFCS levels in children with SB ( $p>0.05$ ). However, 25.33% of the mothers had minimal, 64% mild, 8% moderate and 2.67% severe depression. It was found that 6.67% of the mothers had some, 45.33% moderate, 44% significant and 4% very significant problems with fatigue. Moderate to severe fatigue is reported by approximately 9 out of 10 parents of children with SB, whereas moderate to severe depression is reported by approximately 1 out of 10. Rehabilitation practices for children with SB should include psychological support for their mothers, regardless of their functional status.

**Keywords:** caregiver, depression, fatigue, functionality, spina bifida

### 1. Introduction

Spina bifida (SB) is a congenital birth defect that occurs when the neural tube fails to close in the first weeks of pregnancy. It is the second most common birth defect in the world, affecting about 18.6 out of every 10,000 live births (1, 2). An estimated 3% of live births in Turkey are affected by SB (3). There are two main types of SB: occulta and cystica. SB occulta is the mildest form and is often not diagnosed until later in life. SB cystica is a more severe form characterized by a sac-like protrusion of the meninges or spinal sac through defects in the vertebral arches. There are three types of SB cystica: meningocele, myelomeningocele, and myeloschisis. The most severely affected type is without myelocele, and the mildest type is meningocele (4, 5). Motor and sensory neurological disorders are common in people with SB. According to the International Classification of Functioning, Disability and Health (ICF) framework (6), SB-related disorders (such as neuromuscular weakness, neurogenic bladder or bowel, hydrocephalus, cognitive impairment, bone or joint deformity, sensory loss) can cause functional limitation. SB is a multiple-affected disease characterized by tethered cord, syringomyelia, degenerative musculoskeletal problems, osteoporosis, cardiopulmonary disease, obesity, and latex sensitivity. Long-term problems associated with SB include walking difficulties, bowel and bladder incontinence, hydrocephalus and shunt disorder, skin deterioration and learning difficulties (7). SB

requires specialised, multidisciplinary and often intensive management customised for children and their parents. This leads to an increase in the physical, psychological and social needs of the child and the family, as well as the need for health and social resources (8).

Despite the health problems associated with the condition, biomedical advances have increased the life expectancy of people with SB (9). However, there is a need for approaches to the improvement of the psychosocial status of patients (10). There is a relationship between the care of a child with chronic illnesses and parental mental health (11). In addition, parents with a child with SB report pessimism (12), uncertainty in family roles (13) and less family adjustment (14). The majority of studies on parents of children with chronic illnesses have focused on the psychological adjustment of mothers (15, 16).

Parents of children with SB experience more psychological problems than parents of healthy children (17, 18). The causes of stress among these parents include immediate situations (e.g. during diagnosis and surgery) and recurrent, daily problems (e.g. walking and incontinence problems). These parents are faced with the challenge of understanding and managing their child's medical condition while also adjusting to the practical and emotional demands of caring for a disabled child (19).

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As a consequence of having a child with SB, parents experience more stress, poorer parental psychosocial adaptation, and lower marriage satisfaction (20). SB has a significant impact on parental adaptability, stress, depression, sleep and quality of life, especially for mothers (17). Single-parent families and the need for clean intermittent catheterization in children have been shown to be among the factors that increase stress levels in mothers (8). There have also been reports that maternal age is another factor that can have an impact on stress levels (21).

In the literature, there are some studies evaluating fatigue, depression, quality of life and sleep quality in mothers of children diagnosed with SB (4, 22). One of these studies reported that those who had a child with SB felt significantly more tired and depressed than those who did not (22). This variability in the psychological adjustment of parents of children with SB may be related to many factors, including the severity of the child's illness, developmental delays and functionality. This study focuses on parental psychological state and fatigue, which have the potential to improve treatment outcomes, and examines the relationships between maternal depression and fatigue and child functional status. In this study, we hypothesised a significant correlation between the functional levels of children with SB and the fatigue and depression experienced by their mothers.

## 2. Materials and Methods

### 2.1. Participants and Setting

This study was conducted in the Pediatric Rehabilitation Unit of the Physiotherapy and Rehabilitation Department of Gisbir Hospital. The study included 75 children with SB (5.3% meningocele, 94.7% myelomeningocele) aged between 1 and 16 years (mean  $6.34 \pm SD 3.64$ ) and their mothers (53.3% girls; 46.7% boys) aged between 22 and 55 years (mean  $33.76 \pm SD 7.06$ ). The mothers were all housewives who were the primary carers, spending most of their time with their children. Demographic information and clinical data such as birth history, type of SB, presence of hydrocephalus and presence of maternal chronic diseases were obtained from medical records. Inclusion criteria for mothers were the following: Having and living with a child with SB, not having a severe or chronic disease (e.g. diabetes mellitus, chronic hypertension, stroke), and not having a severe chronic psychological disease.

The study was conducted using a face-to-face questionnaire method, and the functionality of the children was identified by clinical assessment. Mothers were asked to complete two questionnaires: The Beck Depression Inventory and the Fatigue Impact Scale. Furthermore, the functionality of the children was assessed by a physiotherapist with ten years of experience in pediatric rehabilitation.

### 2.2. Data Collection Tools

#### 2.2.1. Gross Motor Classification System (GMFCS)

The Gross Motor Classification System was first developed in 1997 to classify gross motor functions of children with cerebral

palsy and extended in 2007. It is a standardized system. It categories children's gross motor function into five levels. Level I refers to walking without restriction; level V refers to being carried in a wheelchair pushed by hand. At level 1, the child walks independently with limitations in advanced gross motor functions. At level 2, the child walks without an assistive device and has limitations while walking. At level 3, the child walks using an assistive device and has limitations while walking. At level 4, the child has limitations, cannot walk independently, and needs support or a wheelchair for mobility. Level 5 has limited mobilization despite the use of assistive devices (23, 24). Our study assessed children's functional level with SB using the GMFCS, a standardized system for classifying gross motor function in children that is also used in children with SB (25). This classification system is valid and reliable in the Turkish language (26).

#### 2.2.2. Fatigue Impact Scale

Developed in 1994 by a Canadian group, the Fatigue Impact Scale includes 40 items ranging from 0 to 160, each scored from 0 (no problem) to 4 (extreme problem) (27). It consists of three subscales describing the impact of fatigue on cognitive (10 items), physical (10 items) and psychosocial functioning (10 items) (28). A Turkish validity and reliability study was conducted by Armutlu et al. in 2007 (29). The scale determines the fatigue status of the individuals in the last 1 month. The effect of fatigue is interpreted as no (0-32) / some (33-64) / moderate (65-96) / significant (97-128) / very significant (129-160) problem (28).

#### 2.2.3. Beck Depression Inventory

In the Beck Depression Inventory (BDI), each item has a score from 0 to 3, with 21 items in total (30). The maximum possible score on the BDI is 63, while the minimum is 0. A person scoring 0-9 is not depressed, a person scoring 10-16 is mildly depressed, a person scoring 17-29 is moderately depressed, and a person scoring 30-63 has severe depressive symptoms. The scale is valid and reliable in the Turkish language (31).

### 2.3. Ethical Considerations

The participants were fully informed about the study and voluntarily agreed to participate. The study protocol was approved by the Üsküdar University Non-Interventional Research Ethics Board on 26/04/2022 with decision number 61351342. The study adhered to the World Medical Association's Declaration of Helsinki.

### 2.4. Statistical Analysis

The conformity of the variables to normal distribution was analysed visually (histogram and probability graphs) and analytically (Kolmogorov-Smirnov test). Descriptive data were presented as mean  $\pm$  standard deviation (SD), minimum-maximum (min-max) and, number (n) and percentage (%) for categorical variables. The functional status of children and fatigue and depression levels of mothers were analysed by the Spearman correlation test. According to the Spearman correlation coefficients, the degree of relationship was

interpreted according to the classification: no relationship (0-0.19), weak (0.20-0.39), moderate (0.40-0.69), strong (0.70-0.89), very strong (0.90-1) (32). The Mann-Whitney U test was used to compare two independent groups. IBM SPSS Statistics 20.0 was used for statistical analyses and calculations. Statistical significance was accepted as  $p < 0.05$ .

### 3. Results

Table 1 shows the sociodemographic and clinical data. According to GMFCS, 12% (n=9) of the children were level 2, 38.7% (n=29) were level 3, 44% (n=33) were level 4, and 5.3% (n=4) were level 5.

**Table 1.** Sociodemographic and clinical information about the children and their mothers

Child's		Mean±SD (min-max)
Age(year)		6.34±3.59 (1-16)
BMI (kg/m <sup>2</sup> )		18.29±4.28 (11.24-40.47)
		n(%)
Gender	Girl	40(53.33)
	Boy	35(46.7)
Type of SB	Meningocele	4(5.3)
	Myelomeningocele	71(94.7)
Hydrocephaly	Yes	73(97.3)
	No	2(2.7)
GMFCS	Level I	0(0)
	Level II	9(12)
	Level III	29(38.7)
	Level IV	33(44)
	Level V	4(5.3)
Mother's		Mean±SD (min-max)
Age(year)		33.76±7.06 (22-55)
		n(%)
Education Level	Primary School	36(48)
	High School	24(32)
	Undergraduate	3(4)
	Graduate	12(16)
Chronic disease	Yes	9(12)
	No	66(88)

SD: standard deviation, min: minimum, max: maximum, n: number of individuals, %: percentage, SB: Spina Bifida, BMI: Body Mass Index kg: kilogram, m: meter, GMFCS: Gross Motor Function Classification System

**Table 4.** Comparing levels of depression and fatigue in mothers of high and low functioning children

	High Functional SB (GMFCS I II III) n=38	Low Functional SB GMFCS (IV V) n=37	p	Cohen's d
	Mean±SD (min-max)	Mean±SD (min-max)		
Fatigue	91.16±18.45 (52-139)	95.78±16.42 (64-114)	0.387	0.264
Depression	12.84±5.59 (6-36)	12.16±5.44 (7-40)	0.569	0.123

SB: Spina Bifida, GMFCS: Gross Motor Function Classification System

### 4. Discussion

Our study showed that although the depression and fatigue levels of the mothers were not related to the functioning of the children, some of the mothers had moderate to severe depression, and most of them had moderate to very significant fatigue.

Depression was found to be minimal in 25.33%, mild in 64%, moderate in 8%, and severe in 2.67% of the mothers. It was found that 6.67% of the mothers had some, 45.33% had moderate, 44% had significant, and 4% had very significant problems related to fatigue (Table 2).

**Table 2.** Depression and fatigue levels of mothers

	Levels	n(%)	Mean±SD (min-max)
Depression	Minimum	19(25.33)	12.51±5.49 (6-40)
	Mildly	48(64)	
	Moderately	6(8)	
	Severe	2(2.67)	
Total BDI Score			12.51±5.49 (6-40)
Fatigue	Some	5(6.67)	93.44±17.51 (52-144)
	Moderate	34(45.33)	
	Significant	33(44)	
	Very significant	3(4)	
Total FIS Score			93.44±17.51 (52-144)

SD: standard deviation, min: minimum, max: maximum, n: number of individuals, %: percentage, BDI: Beck Depression Inventory, FIS: Fatigue Impact Scale

No significant relationship was found between fatigue and depression levels of mothers and GMFCS levels of children with SB ( $p > 0.05$ ) (Table 3).

**Table 3.** The relationship between fatigue and depression levels of mothers and GMFCS levels of children

	GMFCS Level
	rho (p)
Depression	-0.067(0.57)
Fatigue	0.078 (0.50)

GMFCS: Gross Motor Function Classification System, rho: Spearman's correlation coefficient;  $p < 0.05$  statistical significance

When depression and fatigue levels were compared between mothers of high-functioning and low-functioning children, no significant difference was found between the groups for either parameter ( $p > 0.05$ ) (Table 4).

Depression is a prevalent symptom in mothers of children with chronic diseases. Similar to our findings, in a study in which no relationship was found between functional levels of children with CP and depression levels of mothers, depression was found in 61.2% of mothers of children with CP. (33). Another study evaluating depression levels in mothers with CP

using the Beck Depression Scale found parental stress levels similar to our study (34). On the other hand, 10.2% of the mothers of children with spina bifida in our study had depression, whereas this rate was higher (62.8%) in a study of mothers of children with asthma (35). The rate of parental depression was found to be 36.7% in a study of children with a range of special needs (36). The rate of moderate-severe depression among mothers of children with mental and physical disabilities was reported to be 69% (37). The rate of maternal depression in our study was lower than in studies that included children with intellectual disabilities.

Parental depression is a severe mental health condition. It can considerably impact the health of the parent, child and family. Parents of children with disabilities are primarily at risk of depression because of the demands of high levels of parental care and participation. SB is a complex chronic health condition that can lead to a variety of physical and learning disabilities. Parents of children with SB often face a long and complex journey, which can be emotionally and physically draining. In addition to the above, children with SB may experience learning difficulties. These challenges can significantly influence the child's independence and social integration, which can add to the stress of raising a child with SB (11, 38).

In a study investigating the relationship between functional independence and parental depression and family dynamics in children with SB, no relationship was found between WeeFIM scores of children and the depression levels of the mother or father (39). Studies have focused on parameters such as the size of the defect, functional mobility and the number of shunt revisions to investigate the relationship between the level of disability of the child and the psychological health of the parents (17, 40, 41). These studies found that children's level of physical disability was not associated with parental stress and psychological adjustment. In a study of children with different impairments (e.g. SB, cerebral palsy and limb deficiency), the functional status of the child was assessed using the Vineland Adaptive Behaviour Scales, and no relationship was found between the degree of the child's disability and the level of parental distress (42). Consistent with previous research, the current study's results show that there is no relationship between maternal fatigue and depression and the functional status of children with SB. This suggests that the deterioration in maternal psychological status may be independent of the functional level of children with SB. This suggests that the deterioration in maternal psychological status may be independent of the functional level of children with SB. The reasons for determining the levels of depression and fatigue of parents with a disabled child are multidimensional. At the beginning of the study, we hypothesised that children with lower functioning may have more complex disease management and require more intensive medical care, which may increase parental concern about medical issues and affect depression and fatigue. However, it

has been shown that attitudes of relatives and the social environment towards the family, social isolation of parents, concerns about the child's social adaptation (e.g. difficulties in making friends), lack of adequate social opportunities for children with disabilities, concerns about the child's future and wellbeing are common among parents of children with disabilities (43). Although the average depression and fatigue levels of the mothers in our sample were moderate, we believe that the fact that there was no difference in depression and fatigue levels between mothers of children with good and poor functioning may be due to other social factors.

High fatigue was reported in 27% of mothers of children with CP (44). In our study, 48% of the mothers of children with SB had significant-very significant fatigue. Maternal fatigue has been the subject of research in a number of neurodevelopmental disorders. Fatigue level was found to be significantly higher among mothers of children with autism and cerebral palsy than in healthy children's mothers (34, 44, 45, 46). Increased fatigue in mothers of children with cerebral palsy was not correlated with any clinical indicators in the children, but this was not associated with any clinical parameter in the children (34). Another study carried out among the mothers of children with cerebral palsy found that fatigue in the mothers was associated with all of the parameters of quality of life (44). There are insufficient studies on maternal fatigue (39). To the best of our knowledge, our study is the first in the literature to assess fatigue and its association with child functioning. Our findings are in line with studies of other neurodevelopmental disorders. We found that levels of maternal fatigue were not associated with child functioning. Regardless of disease severity, psychological symptoms in parents of children with chronic illness have been reported to be negatively associated with the parents' quality of life (47). In our experience, there is a widespread belief in clinical practice that parents of more functional children can cope better with this process. The results of our current study may be significant in that they show that parents of children with SB who have a high level of functioning may also be in need of psychological and social support.

Rehabilitation for spina bifida patients begins in the neonatal period and continues throughout life. Since the people who will be with and care for the patients during this period are usually the patients' families, rehabilitation should be family-centred and planned, taking into account the characteristics of the family (48). Depression and fatigue in mothers may play a role in the effective progress of the rehabilitation process in children.

One of the limitations of this study is that there were no child participants with functional level 1. Another limitation is the wide range of ages of the children with spina bifida included in the study. The length of time a woman has been a mother of a child with spina bifida may also be a factor that affects the results. Another limitation of the study is the lack of

a control group. A control group of mothers with healthy children should be included in future studies.

The findings of the study lead to the conclusion that the functional level of children with SB is not a determinant of maternal depression and fatigue symptoms. In addition, mothers may experience fatigue and depression, although this is independent of children's functioning. Given that the functional level of the child does not determine the psychological status of the mother, all mothers of children with SB should be assessed for the need for psychological support. Studies are needed to determine other factors affecting depression and fatigue levels in mothers.

### Conflict of interest

The authors declared no conflict of interest.

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### Authors' contributions

Concept: P.G., B.D.H., Design: P.G., B.D.H., B.K., Data Collection or Processing: P.G., Analysis or Interpretation: B.K., T.A., Literature Search: B.K., B.D.H., T.A., P.G., Writing: B.K., B.D.H., T.A., P.G.

### Ethical Statement

Approval was obtained from Üsküdar University Non-Interventional Research Ethics Board, the study started. The ethics committee decision date is 26/04/2022 and the number of ethical committee decisions is 2022/59.

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