

Maternal Psychological Distress and Coping Strategies in Mothers of Children with Myelomeningocele Aged 1-72 months

Research Article

Running Title: Maternal Distress and Coping Strategies in Mothers of Children with MMC

Hatice Altun^{1*} and İdiris Altun²

¹ Department of Child and Adolescent Psychiatry, Kahramanmaraş Sutcu Imam University, Turkey

² Istanbul Rumeli University, Istanbul, Turkey

***Corresponding author**

Hatice Altun,
Department of Child and Adolescent Psychiatry, Faculty of Medicine, Kahramanmaraş Sutcu Imam University, Kahramanmaraş, Turkey, Tel: +903443003374; Fax: +903443003409; Email: drhaticealtun@gmail.com

Article Information

Received: 25-October-2023;
Accepted: 26-November-2023;
Published: 02-December-2023.

Abstract

Background: The aim of the study was to evaluate the difficulties experienced, maternal distress and coping strategies of mothers of children with myelomeningocele (MMC) aged 1-72 months.

Methods: The study included 40 mothers with a child aged 1-72 months with MMC and a control group of 40 mothers of age and gender-matched healthy children. All mothers were asked to complete the sociodemographic form, the Symptom Check List-90-Revised (SCL-90-R), and the Coping Strategies with Stress Inventory (COPE) forms.

Results: The SCL-90-R subscales points of somatization, depression, anxiety, hostility, phobic anxiety, psychotic, additional items and GSI were determined to be significantly higher for the mothers of the MMC children compared to the control group mothers ($p < 0.05$). All of the MMC patients had at least one urological, neurosurgical or orthopaedic problems and difficulties experienced. The denial and behavioural disengagement subscale points of the COPE were determined to be statistically significantly higher and the points of active coping, planning and focus on and venting of emotions were lower in the mothers of the MMC children compared with the control group ($p < 0.05$). There was a negative correlation between the maternal age and the somatization, obsession, anxiety and paranoid thought subscales and GSI of the SCL-90-R. There was a positive correlation between all the SCL-90-R subscales and GSI and the behavioural disengagement subscale points of the COPE.

Conclusion: The results of this study showed that mothers of children diagnosed with MMC had a higher level of maternal distress, more dysfunctional coping strategies and less problem-focussed coping strategies. It was also determined that the mothers experienced several difficulties in areas related to the biopsychosocial functionality of the disease.

Keywords: Myelomeningocele; Children; Coping strategies; Maternal distress; Depression; Anxiety.

Introduction

Spina Bifida (SB) is a congenital malformation in which the spinal column is split as a result of failed closure of the embryonic neural tube. Myelomeningocele (MMC), the most common and most severe form of SB, has a pervasive impact on the physical, neurocognitive, psychological and social functioning of affected individuals [1,2]. Although the prognosis for children born with MMC was poor before 1970, up to 70–80% of children with MMC

survive to adolescence due to advances in the management of Chiari II malformation, hydrocephalus and infections in nowadays [3-5]. Understanding pathways to measure and enhance the quality of life and psychiatric problems of both the child and the family is important because of the increasing number of these children living longer.

It is known that children and adolescents with chronic health conditions require special attention and rehabilitation. The

parents must supervise, observe and care for the child according to needs, which are mostly determined by the health condition and the fact that they are still developing. The birth of a child with a chronic health condition changes the dynamics and the daily lives of family members, especially the mother, due to the new demands of the child and there can be a negative impact on many aspects of the parents' lives [6]. The parents of these children often have difficulty balancing caring for their child with other responsibilities including work and social life, financial management and other home affairs. Therefore, they may feel overwhelmed or incompetent and experience more stress and worry [7].

SB is a chronic condition that can affect both physical and cognitive functioning, and the severity of deficits in functioning has an impact on parental stress. One study found that the severity of physical dysfunctions, but not cognitive deficits, was associated with increased parental stress in mothers of children with SB [8]. Given the heterogeneity of impairments associated with SB, it is likely that SB-specific parental stress is not uniform across all parents of children with SB. However, when the negative impact of general parental stress on the outcome of the child is considered, it can be hypothesized that increased SB-specific parental stress may also lead to poorer outcomes for the child, including quality of life [5,8-11]. Family relationships are particularly important for children with MMC, since they tend to be more socially isolated from their peers than healthy children and the majority of children with MMC complete multiple daily medical routines with at least some assistance from a parent or other caregiver [1,12]. Thus, children with MMC are especially reliant on their parents, and may thus be more affected by parental adjustment and behaviors than healthy children. Parental functioning is of great importance for children with severe disabilities who depend for a large part of their functioning on the parent or caregiver. Research has shown impairments in the family functioning and the psychosocial adjustment of families of children with MMC [3-16]. Parental distress is defined as the psychosocial functioning or degree of extreme anxiety, sorrow, or pain experienced by a parent. Some parents of children with MMC have been found to experience clinical levels of global psychological distress (e.g., depressive symptoms, anxiety, somatic complaints) [13,17-19]. As the care of a child with MMC is usually the responsibility of the mother, maternal stress is very important in respect of family functions, family adaptation and the care and mental health of the child.

The concept of coping can be defined as all the cognitive, emotional and behavioural reactions displayed by an individual to control and reduce stress to remove the difficulties created in the internal and external world and to resist the event and effects causing the stress. The coping attitudes used by the individual in these circumstances are qualities specific to the individual and can vary depending on several factors such as the age, gender, culture and the disease [20-22]. Psychological adaptation is an important factor. Coping strategies are separated into 3 forms as those directed at solving the problem, those which are emotionally focussed and those which are dysfunctional [23]. Parental coping skills are a significant marker of the adaptation of both the family and the child, and it has been determined that parents who use

active/adaptive coping methods experience fewer psychiatric problems and the children have better psychosocial adaptability [24-26].

To the best of our knowledge, there have been not a study on the parental distress and the coping strategies of parents of children with MMC in Turkey. Due to the differences in roles in respect of care and work, mothers are at greater risk of parental stress than fathers, so this study was conducted on the mothers of children with MMC. The aim of the study was to identify and evaluate the problems experienced, maternal distress and the coping strategies of mothers of children with MMC aged 1-72 months.

Material and Methods

Sampling and Procedures

The study included 40 mothers with a child aged 1-72 months (preschool age) with MMC and a control group of 40 mothers of age and gender-matched healthy children. Informed consent for participation in the study was obtained from all the mothers. Exclusion criteria for the mothers of the MMC children were not having completed primary school education, the presence of a chronic disease or receiving treatment for an ongoing psychiatric disorder. The control group was formed of mothers with at least a primary school level of education with no known chronic, neurological or psychiatric disease with a healthy child with no chronic, physical or psychiatric disease, age and gender-matched to the study group. All the mothers were requested to complete a sociodemographic form prepared by the researchers, The Symptom Checklist-90-Revised (SCL-90-R) and the Coping Strategies with Stress Inventory (COPE) forms. The study protocol was reviewed and approved by the Ethics Committee of Kahramanmaraş Sutcu Imam University, Faculty of Medicine.

Instruments / Assessment

The sociodemographic form: This form included questions to identify the descriptive characteristics of the mother and child, including age, gender, maternal educational level, maternal history of previous psychiatric disease, family economic status, number of children in the family, marital consanguinity status, drugs taken during pregnancy and difficulties experienced.

The Symptom Checklist-90-Revised (SCL-90-R): This scale was developed to assess psychopathological symptoms and mental problems [27]. It can be applied to a healthy or patient population aged >13 years who have received at least 6 years of education. It is formed of 90 items based on personal reporting to measure the general psychopathological level and the level of difficulty in respect of mental symptoms. Each item is scored from 0-4 with Likert-type responses (never/very little/moderate/extremely/advanced degree). The scale has 9 subscales reflecting 9 separate groups of symptoms (somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid thoughts and psychoticism) and an additional scale evaluating feelings of guilt, eating disorders and sleeping disorders. The scale also has 3 indexes of the Global Severity Index (GSI) measuring total mental distress, the Positive Symptom Total (PST) which gives the number of self-reported symptoms and the Positive Symptom Distress Index (PSDI), which measures the intensity of the symptoms. The total of the points obtained for each

item was divided by 90 to obtain the GSI. For university students a mean GSI of 1.00 has been accepted as the base. An increase in scale points shows an increase in symptoms. Scores above 1 in GSI indicate that the symptoms are at a psychopathological level. Cronbach alpha value (internal consistency coefficient) of the scale was found to be 0.97 [28].

The Coping Strategies with Stress Inventory (COPE): This scale was developed by Carver et al to identify the coping strategies used in stressful situations [29]. The validity and reliability of the form in Turkish was proven by Ağargün et al. The scale showed high internal consistency [20]. It is a self-reporting scale of 60 items which are answered with 4 options of i) I never do this, ii) I very occasionally do this, iii) I sometimes do this, and iv) I usually do this. The COPE has 15 subscales of 1) active coping, 2) planning, 3) restraint, 4) use of instrumental social support, 5) suppression of competing activities, 6) positive reinterpretation and growth, 7) religious coping, 8) humor, 9) use of emotional social support, 10) acceptance, 11) behavioural disengagement, 12) substance use, 13) denial, 14) mental disengagement, 15) focus on and venting of emotions. A total of 4-16 points can be obtained for each subscale. The total points of subscales 1-5 are problem-focussed coping points, the total points of subscales 6-10 are the emotion-focussed coping points and the total points of subscales 11-15 are the dysfunctional coping points Cronbach alpha value (internal consistency coefficient) of the scale was found to be 0.79.

Statistical Analyses

The statistical analyses of the study data were performed using SPSS vn 22.0 software. The conformity of the data to normal distribution was assessed with the Kolmogorov-Smirnov test. In the comparisons of categorical data, the Chi-square test was used and for numerical data, the t-test was used when parametric test assumptions were met, otherwise the MannWhitney U-test was applied. To evaluate the correlations of data, Spearman Correlation analysis was used. A value of $p < 0.05$ was accepted as statistically significant.

Results

The MMC cases comprised 25 (62.5%) females and 15 (37.5%) males aged 33.92 ± 22.52 months and the control group children were 22 (55%) females and 18 (45%) males aged 32.57 ± 20.63 months. The mean age of the mothers was 30.27 ± 5.37 years (range, 26-43 years) in the MMC group and 32.35 ± 5.76 years (range, 21-38 years) in the control group. No statistically significant difference was determined between the two groups in respect of age of the mother, father and child, gender of the child, socioeconomic level, maternal educational level, previous history of parents psychiatric illness, family structure and number of children in the family. The sociodemographic characteristics of the MMC children are shown in Table 1, All the mothers of the MMC children in the current study reported on the sociodemographic form related to the child's disease that they had experienced one or more problems related to psychological, social and family problems and the disease. Concomitant problems and difficulties experienced by the mothers are shown in Table 2.

Table 1: Demographic and clinical data of groups.

	MMC group n=40	Controls group n=40	p
Age (months)	33.92 ± 22.52	32.57 ± 20.63	0.781
Gender (male/female)	15 /25	18/22	0.496
Maternal age (mean±sd)	30.27 ± 5.38	32.75 ± 5.76	0.100
Paternal age (mean±sd)	34.07 ± 6.30	36.25 ± 6.12	0.122
Previous history of maternal psychiatric illness			0.187
Yes	8 (20%)	2 (5%)	
No	32 (80%)	38 (95%)	
Previous history of paternal psychiatric illness			0.209
Yes	6 (15%)	3 (7.5%)	
No	34 (85%)	37 (92.5%)	
Use of folic acid in pregnancy			0.019
Yes	21 (52.5%)	31 (77.5%)	
No	19 (47.5%)	9 (22.5%)	
Walking			0.000
Yes	4 (10%)	33 (82.5%)	
No	36 (90%)	7 (17.5%)	
Speech			0.327
Yes	22 (55%)	25 (62.5%)	
No	18 (45%)	15 (37.5%)	
Toilet training			0.003
Yes	5 (12.5%)	19 (47.5%)	
No	35 (87.5%)	21 (52.5%)	

The GSI points of the SCL-90-R of the MMC group mothers were determined to be statistically significantly higher than those of the control group mothers (median (min-max) 0.77 (0.08-2.11), 0.36 (0.07-1.86) respectively, $p < 0.05$). The points of the SCL-90-R subscales of somatization, depression, anxiety, hostility, phobic anxiety, psychotic and additional items were determined to be significantly higher for the mothers of the MMC children compared to the control group mothers ($p < 0.05$) (Table 3).

Table 2: Concomitant problems in patients with MMC and difficulties experienced by family.

	Yes	No
Concomitant problems		
Urological problems	12 (30%)	28 (70%)
Hydrocephalus	17 (42.5%)	23 (52.5%)
Orthopedic	15 (37.5%)	25 (62.5%)
Difficulties experienced		
Disappointment	20 (50%)	20 (50%)
Sense of guilt	9 (22.5%)	31 (77.5%)
Being uncomfortable by people's point of view	11 (27.5%)	29 (72.5%)
Explanation the child's situation to the around people		
Difficulties in social communication	9 (22.5%)	31 (77.5%)
Worries about the future of the child	29 (72.5%)	11 (27.5%)
Inadequate wife support	9 (22.5%)	31 (77.5%)
Inadequate social support	21 (52.5%)	19 (47.5%)
Having a family problem	10 (25%)	30 (75%)
Adjustment difficulties between brothers	11 (27.5%)	29 (72.5%)
Neglecting other children	15 (37.5%)	25 (62.5%)
Bringing additional cost to the family	12 (30%)	28 (70%)
Difficulties during treatment	29 (72.5%)	11 (27.5%)

MMC: Myelomeningocele, $p < 0.05$: Statistically significant

Table 3: The SCL-90-R subscale scores of the mothers of children with MMC and healthy controls.

Subscales	MMC group (n=40) median (min-max)	Controls grubu (n=40) median (min-max)	z	p
Somatization	0.54 (0.08-2.00)	0.37 (0.00-1.92)	- 2.435	0.015
Obsessive-compulsive	0.70 (0.00-2.20)	0.70 (0.00-2.80)	-0.975	0.330
Interpersonal sensitivity	0.83 (0.00-2.89)	0.55 (0.00-2.22)	-1.786	0.074
Depression	1.11 (0.08-2.54)	0.61 (0.00-2.38)	-2.906	0.004
Anxiety	0.75 (0.00-2.10)	0.20 (0.00-1.70)	-3.591	0.000
Hostility	0.75 (0.00-2.33)	0.33 (0.00-2.17)	-3.461	0.001
Phobic anxiety	0.50 (0.00-2.17)	0.00 (0.00-1.43)	-3.955	0.000
Paranoid thoughts	0.66 (0.00-1.67)	0.50 (0.17-2.50)	-0.997	0.319
Psychotism	0.20 (0.00-1.70)	0.00 (0.00-0.90)	-2.929	0.003
Additional scale (eating and sleeping disorders)	0.78 (0.00-2.43)	0.14 (0.00-1.579)	-3.595	0.000
Global Severity Index	0.77 (0.08-2.11)	0.36 (0.07-1.86)	-3.109	0.002

SCL-90-R: The Symptom Checklist-90-Revised, MMC: Myelomeningocele, p<0.05: Statistically significant.

Table 4: The COPE subscale scores of the mothers of children with MMC and healthy controls.

Subscales	MMC group (n=40) median (min-max)	Controls grubu (n=40) median (min-max)	z	p
Active coping	13 (7-16)	15 (8-16)	-2.963	0.003
Planning	10 (7-16)	14 (5-16)	14 (5-16)	0.000
Restraint	1(0-10)	1(0-10)	-1.507	0.132
Use of instrumental social support	13.5 (6-16)	13 (9-16)	-0.408	0.683
Suppression of competing activities	11 (5-16)	10 (6-14)	-1.268	0.205
The problem-focussed coping points (total)	51 (34-64)	54 (31-62)	-1.644	0.100
Positive reinterpretation and growth	13 (5-16)	14 (9-16)	-0.738	0.461
Religious coping	15 (4-16)	15 (9-16)	-0.327	0.743
Humor	6 (4-13)	6 (4-14)	-0.983	0.325
Use of emotional social support	13 (5-16)	13 (4-16)	-0.029	0.977
Acceptance	12 (4-16)	11.5 (8-15)	-1.568	0.118
The emotion-focussed coping points (total)	59 (33-76)	59 (44-72)	-0.487	0.626
Behavioural disengagement	3 (0-10)	2 (0-10)	- 2.017	0.044
Substance use	4 (3-13)	4 (4-8)	-1.209	0.227
Denial	7.5 (3-16)	4 (4-9)	-4.020	0.000
Mental disengagement	9 (4-15)	9 (6-11)	-0.015	0.988
Focus on and venting of emotions	11(6-16)	12 (9-16)	-3.083	0.002
The dysfunctional coping points (total)	35 (19-56)	33(28-45)	-1.651	0.099

MMC: Myelomeningocele, COPE: The Coping Strategies with Stress Inventory, p<0.05: Statistically significant

When a GSI cutoff point of 1.00 was taken for the mothers of the children diagnosed with MMC, 10 (28.6%) of the mothers in this group were seen to have higher points, compatible with psychopathology. In the control group, 4 (10%) mothers had points higher than the cutoff point. In the comparison of the two groups, points higher than the cutoff point and compatible with psychopathology were determined to have been obtained at a statistically significantly higher rate in the MMC group than the control group (p<0.05). In the comparison of the coping strategies between the groups, the denial and behavioural disengagement

subscale points of the COPE were determined to be statistically significantly higher and the points of active coping, planning and focus on and venting of emotions were lower in the mothers of the MMC children compared with the control group. The points of the other subscales of the COPE were similar in both groups (Table 4). According to the results of the Spearman Correlation analysis, there was a negative correlation between the maternal age and the somatization, obsessive-compulsive, anxiety and paranoid thoughts subscales and the GSI. There was a positive correlation between all the SCL-90-R subscales and GSI and the behavioural disengagement subscale points of the COPE. The correlation values of the SCL-90-R, maternal age, the child's age and the COPE results are shown in Table 5.

Table 5: Correlations between child and parent age, the COPE subscales and the SCL-R-90 subscales in mother of children with MMC.

	Som	O-C	Inter-sen	Dep	Anx	Host	Phobic	Paran	Psych	Add-sc	GSI
Child	r	.087	.315	.183	.111	.301	.065	.212	.316	.167	.153
Age	p	.594	.048	.257	.496	.059	.692	.189	.047	.302	.347
Maternal	r	-.526	-.407	-.308	-.300	-.496	-.205	-.361	-.238	-.272	-.423
Age	p	.000	.009	.053	.060	.001	.204	.339	.022	.140	.090
COPE 1	r	-.313	.049	-.302	-.350	-.211	-.278	-.118	-.283	-.118	-.282
	p	.049	.093	.058	.027	.192	.083	.469	.077	.468	.078
COPE 2	r	-.397	-.317	-.055	-.186	-.390	-.165	-.133	-.227	-.265	-.308
	p	.011	.046	.734	.250	.013	.308	.412	.158	.098	.053
COPE 11	r	.730	.810	.693	.584	.697	.734	.578	.823	.740	.703
	p	.000	.000	.000	.000	.000	.000	.000	.000	.000	.000
COPE 13	r	.091	.060	.187	.124	.271	.287	.421	.198	.291	.125
	p	.578	.715	.247	.882	.090	.072	.007	.220	.068	.443
COPE 15	r	.078	.151	.358	.417	.137	.272	.206	.447	.162	.145
	p	.634	.325	.023	.002	.401	.090	.203	.004	.318	.371

SCL-90-R: The Symptom Checklist-90-Revised, Som: Somatization, O-C:Obsessive-compulsive Inter-sen: Interpersonal sensitivity Dep: Depression, Anx: Anxiety, host: Hostility, Phobic: Phobic anxiety, Paran: Paranoid thoughts, Psych:Psychotism, Add-sc: Additional scale, GSI: Global Severity Index, COPE: The Coping Strategies with Stress Inventory, COPE1: Active coping, COPE 2: Planning COPE11: Behavioural disengagement, COPE13: Denial, COPE 15: Focus on and venting of emotions, MMC: Myelomeningocele, p<0.05: Statistically significant

Discussion

In this study, an examination was made of the psychiatric symptoms and stress coping strategies of the mothers of children with MMC and the mothers of healthy children. This is the first study in Turkey to evaluate the strategies for coping with psychiatric symptoms of mothers of children aged 1-72 months, diagnosed with MMC. The results of the study determined the level of psychiatric symptoms in the mothers of children diagnosed with MMC to be higher than those of the mothers of the healthy peers. Moreover, the points of the SCL-90-R subscales of somatization, depression, anxiety, hostility, phobic anxiety, psychotic additional items and GSI were determined to be higher for the mothers of the MMC children compared to the control group mothers. In addition, all the mothers of the MMC children reported that they had experienced one or more problems related to psychological, social and family problems and the disease. Parents of children with a chronic health condition, who require a high level of parental care and involvement, may be particularly at risk of parental depressive symptoms. MMC, a complex chronic health condition with multi-system involvement, is such a condition. Similar to the results of the current study, it has been previously reported that psychiatric problems such as anxiety and depression are seen more often in the mothers of

disabled children or those with a chronic disease, compared to the mothers of healthy children [30-35]. While there is a limited number of studies in review of parental depressive symptoms in the parents of children with SB, it has been reported that up to 48% of parents experience depressive symptoms. In addition, this review of the literature of parental depressive symptoms revealed that 32%-67% of psychological distress and parental depressive symptoms were explained by similar contextual factors (demographic factors, presence and severity of SB, and child-related factors) and process factors (family functioning and parent-related factors such as stress and coping). However, while these context variables are important they are not sufficient alone to explain depressive symptoms. The process variables (family functioning, parental stress and coping) have been reported to contribute a greater amount of variance in parental depressive symptoms [36]. In addition to depression and anxiety symptoms, our study showed that the mothers of children with MMC have been found to experience clinical levels of global psychological distress such as somatization, hostility, phobic anxiety, psychotic additional items. These results support previous studies evaluating the mothers of children with MMC [13,17-19].

Demographic factors that contribute to the experience of anxiety and depression in the parents of children with MMC include caregiver and child age, employment status/income, illness-specific factors, such as lesion level (a proxy for illness severity) and shunt status [36-38]. In a study, it was shown that an older parental age was related to fewer parental depressive symptoms [37]. On the contrary, another study reported that there was no relationship between maternal age and depression and anxiety symptoms [39]. In the current study, a negative correlation was determined between the maternal age and the somatization, obsessive-compulsive, anxiety and paranoid thoughts subscales and the GSI points in the mothers of children with MMC. Psychiatric problems were seen at a higher rate in younger mothers.

One study found a relationship between the child's age and parental depressive symptoms where parents of children 0-6 years old (but not those 7-17 years of age) reported "feeling blue more than a little of the time" [38]. In another study, parents with adolescent/young adults with MMC experienced the highest prevalence of parental depressive symptoms (48%) [19]. A pattern of lower rates of depressive symptoms (14%-25%) has been reported in the few studies which have examined the parents of children younger than 9 years old. Most studies have been limited by a wide age range (2months-18 years) and generally have not reported the relationship of age of the child to parental depressive symptoms [36]. In the current study, no relationship was seen between the age of the child and the SCL-90-R depression subscale points in the mothers of the 1- 72 months MMC children. However, it was determined in the current study that the obsessive-compulsive and paranoid thoughts subscale points increased as age increased. This suggests that there could be greater problems for the family when the patient is of school age, adolescent or adult.

Studies of mothers of children with MMC have found that more than one third of these mothers experience clinically

significant levels of parenting stress [9]. Parenting stress is associated with both parenting behaviors and child adjustment. Parenting stress decreases the quality of the parent-child relationship and is predictive of non-optimal social-emotional and cognitive outcomes for children and adolescents [10,18,40]. All the mothers of the MMC children in the current study reported on the sociodemographic form related to the child's disease that they had experienced one or more problems related to psychological, social and family problems and the disease. This suggests that the disease created stress for the family in many areas of life and that the experience and perceptions of stress could be important in respect of psychiatric diseases. Furthermore, it was also determined in the current study that all of the MMC patients had at least one urological, neurosurgery or orthopaedic problem, which was consistent with the findings of previous studies [1]. Higher rates of psychiatric disease have been reported to be seen in the families of children with MMC who have urological problems in particular. In the management of bladder dysfunction in children with MMC, the use of clean intermittent catheterisation which has to be applied once every 4-6 hours every day, is a significant source of stress for mothers [9] However, in the current study, despite the higher levels of depression and anxiety in the mothers of MMC children with urological problems compared to the control group, the difference was not statistically significant. This could be attributed to the small sample size. Moreover, incontinence is accepted as normal in children under the age of 5 years, and as the current study group patients were in the 1-72 months age group, this could be related to the families seeing this as less of a problem. It is thought that urological problems in particular could cause greater problems in later adolescence and adulthood. Therefore, there is a need for further studies of more extensive samples to evaluate different age groups.

Children with hydrocephalus are often in need of neurosurgical treatment, which may involve the insertion of a shunt or creation of a bypass within the brain to allow drainage of cerebrospinal fluid. Shunts are prone to infections, which can be life threatening. For children with both MMC and hydrocephalus, such shunt dependency has been associated with higher levels of parental anxiety and depression [37]. In the current study, the most common pathology accompanying MMC was hydrocephalus. However no difference was determined between the mothers of MMC children with and without hydrocephalus in respect of mental pathologies. This result could be attributed to the young age of the patient group and the small sample size. Another factor found to affect parental stress in MMC is the ambulatory status of the child. Parents of children with MMC who are able to walk independently report lower parental stress than the parents of children who are wheelchair bound [41]. In the current study, the majority of the patients could not walk and 37.5% of the patients had an orthopaedic problem. However, just as for hydrocephalus and urological problems, no difference was determined in respect of mental pathologies between the mothers of MMC children with and without orthopaedic problems.

Levels of parental distress may influence parenting behaviors. High emotional distress and high levels of parental stress may

impair the abilities of the parents to manage the demands of complex medical treatments, make medical decisions, and may also affect the individual behavior that a parent demonstrates towards their child. For example, personal distress and high levels of parental stress have been found to decrease parental warmth and provoke harsh, reactive caregiving [7,10]. Both maternal and paternal depression have been found to be associated with more child problems, such as behavioral issues and internalizing symptoms and family system adjustment [15,18,40]. Therefore, the evaluation of psychiatric problems of the families together with children with MMC in particular is important for both the child and the family members.

In another finding of our study, compared to the control group, it was found that the mothers of the MMC children used less active coping and planning from the problem-focussed strategies. This suggests that the mothers of the children with MMC were forced to find and implement suitable approaches directed to resolving problems. There was no difference between the groups in respect of the skills for resolving emotionally-focussed problems. Problem-focussed coping strategies directly resolve or prevent the problems, whereas emotionally-focussed coping is used to cope with negative emotions originating from problems [42]. It has been reported that emotion-focussed, problem-focussed and the use of the two methods together are useful in the resolution of problems [43]. In this study, it was also shown that of the dysfunctional coping strategies, denial and behavioural disengagement were used more and focus on and venting of emotions were used less by the mothers of the MCC children. These findings were seen to be in parallel with the increased psychiatric problems in the mothers of the children with MMC. Dysfunctional coping strategies have been reported to cause a negative stress reaction, to conceptualise the solution as difficult or impossible and consequently to cause an increase in psychiatric problems [29,44-46]. The use of dysfunctional strategies by the mothers in the current study can be considered to have impaired psychological adaptation by making resolution of the problem more difficult and thus, psychiatric diseases emerged.

In a study by Durukan et al of ADHD children with chronic diseases and their mothers, the suppression of competing activities, focus on and venting of emotions and denial subscales of the COPE and the total scores of dysfunctional coping strategies in COPE were determined to be statistically significantly higher in the ADHD group than in the control group, while no difference was determined between the groups in respect of the children's age and gender and the age and educational level of the mothers [34]. In a study which evaluated the mothers of children with chronic neurological disease, the psychiatric problems of the mothers were determined at a high rate and their coping capabilities were seen to be insufficient for the problems created by the chronic disease [47].

The use of behavioural disengagement and substance use of the coping strategies that impaired adaptation by the mothers of children with chronic diseases were found to be related to psychiatric symptoms in both the mothers and the children [44]. Evaluation of the coping ability of the parents is important as

the coping skills of the parent define the adaptation of the child and the family to the disease [26]. The use of appropriate coping methods is important in increasing the quality of life. Previous studies have shown that by increasing the family ability to cope and the quality of life, family interventions have decreased depressive symptoms, increased sharing between parents and child related to the disease, and increased the efficacy of the parent [48,49]. Therefore, evaluation of the family system is just as important as evaluation of the psychosocial functionality of the child.

Limitations of this study are that the sample size was small, the psychopathology of the mothers was not determined in a structured psychiatric interview and it was cross-sectional in nature. While the scales used in the study are long and allow the evaluation of many different problems, it is difficult for those who fill the scale. In addition, the fact that the measurement tools used are based on self-report may be considered a limitation in this study, as in all studies where this method is used, as it may reveal the tendency of respondents to give false answers (e.g. making themselves look good or worse than they are). Nevertheless, this was the first report on the problems experienced, maternal distress and the coping strategies of mothers of children with MMC aged 1-72 months, which, we believe, will form a basis for further prospective, large-scale studies in which the psychiatric evaluation of the MMC group is made and all age groups are evaluated.

Conclusion

In conclusion, the results of this study showed that mothers of children diagnosed with MMC had a higher level of maternal distress (e.g somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety and paranoid thoughts) and that more denial and behavioural disengagement and less focus on and venting of emotions from dysfunctional coping strategies and less active coping and planning from problem-focussed coping strategies were used. It was also determined that the mothers experienced several difficulties in areas related to the biopsychosocial functionality of the disease. In the treatment process of children with MMC, screening the parents for psychiatric problems, providing the family with psychosocial support and developing appropriate coping skills in the mother could provide a positive contribution to the quality of life of both the child and the family. There is a need in Turkey for further studies including parents of all age groups to be able to develop the area of providing social support for the mothers and other family members of these children.

Acknowledgment: None.

Conflict of interest: The authors declare no conflict of interests.

References

1. Copp AJ, et al. (2015). Spina bifida. Nature reviews. Disease primers. 1: 15007.
2. Sawin KJ, Bellin MH. (2010). Quality of life in individuals with spina bifida: a research update. Developmental disabilities research reviews. 16: 47-59.
3. Talamonti G, D'Aliberti G, Collice M. (2007). Myelomeningocele: long-term neurosurgical treatment and follow-up in 202 patients.

4. Okurowska-Zawada B, Kułak W, Otapowicz D, Sienkiewicz D, Paszko-Patej G, et al. (2011). Quality of life in children and adolescents with cerebral palsy and myelomeningocele. *Pediatric neurology*. 45: 163-168.
5. Bakaniene I, Prasauskiene A, Vaiciene-Magistris N. (2016). Health-related quality of life in children with myelomeningocele: a systematic review of the literature. *Child: care, health and development*. 42: 625-643.
6. Barlow JH, Ellard DR. (2006). The psychosocial well-being of children with chronic disease, their parents and siblings: An overview of the research evidence base. *Child: care, health and development*. 32: 19-31.
7. Power N, Franck L. (2008). Parent participation in the care of hospitalized children: a systematic review. *Journal of advanced nursing*. 62: 622-641.
8. Vermaes I, J M Ajanssens MAM, Mullaart RA, Vinck A, Gerris JRM, et al. (2008). Parents' personality and parenting stress in families of children with spina bifida. *Child: care, health and development*. 34: 665-674.
9. Kanaheswari Y, Razak NNA, Chandran V, Ong LC. (2011). Predictors of parenting stress in mothers of children with spina bifida. *Spinal cord*. 49: 376-380.
10. Deater-Deckard K, Scarr S. (1996). Parenting stress among dual-earner mothers and fathers: Are there gender differences? *Journal of Family Psychology*. 10: 45.
11. Bannink F, Van Hove G, Idro R. (2016). Parental stress and support of parents of children with spina bifida in Uganda. *African Journal of Disability*. 5: 1-10.
12. Holmbeck GN, Westhoven VC, Phillips WS, Bowers R, Gruse C, et al. (2003). A multimethod, multi-informant, and multidimensional perspective on psychosocial adjustment in preadolescents with spina bifida. *Journal of consulting and clinical psychology*. 71: 782.
13. Holmbeck GN, Gorey-Ferguson L, Hudson T, Seefeldt T, Shapera W, et al. (1997). Maternal, paternal, and marital functioning in families of preadolescents with spina bifida. *Journal of Pediatric Psychology*. 22: 167-181.
14. Holmbeck GN, Devine KA. (2010). Psychosocial and family functioning in spina bifida. *Developmental disabilities research reviews*. 16: 40-46.
15. Vermaes IPR, Janssens JM, Bosman AMT, Gerris JRM. (2005). Parents' psychological adjustment in families of children with spina bifida: a meta-analysis. *BMC pediatrics*. 5: 32.
16. Vermaes IP, Gerris JR, Janssens JM. (2007). Parents' social adjustment in families of children with spina bifida: a theory-driven review. *Journal of Pediatric Psychology*. 32: 1214-1226.
17. Friedman D, Holmbeck GN, Jandasek B, Zukerman J, Abad M. (2004). Parent functioning in families of preadolescents with spina bifida: longitudinal implications for child adjustment. *Journal of Family Psychology*. 18: 609.
18. Bechtel CF. (2016). Parenting-related stress, parental distress, and youth health-related quality of life in families of youth with spina bifida: Parenting behaviors as mediators. *Loyola University Chicago*.
19. Brei TJ, Woodrome SE, Fastenau PS, Buran CF, Sawin KJ. (2014). Depressive symptoms in parents of adolescents with myelomeningocele: The association of clinical, adolescent neuropsychological functioning, and family protective factors. *Journal of pediatric rehabilitation medicine*. 7: 341-352.
20. Ağargün MY, Besiroglu L, Kiran UK, Kara H. (2005). COPE (Coping attitudes assessment scale): A preliminary study on psychometric properties. *Anatolian Journal of Psychiatry*. 6: 221-226.
21. Folkman S. (1984). Personal control and stress and coping processes: A theoretical analysis. *Journal of personality and social psychology*. 46: 839.
22. Folkman S, Lazarus RS, Gruen RJ, A DeLongis A. (1986). Appraisal, coping, health status, and psychological symptoms. *Journal of personality and social psychology*. 50: 571.
23. Folkman S, Lazarus RS. (1980). An analysis of coping in a middle-aged community sample. *Journal of health and social behavior*: 219-239.
24. Rao P, Pradhan PV, Shah H. (2004). Psychopathology and coping in parents of chronically ill children. *Indian journal of pediatrics*. 71: 695-699.
25. Thompson RJ, Gil KM, Burbach DJ, Keith BR, Kinney TR. (1993). Role of child and maternal processes in the psychological adjustment of children with sickle cell disease. *Journal of consulting and clinical psychology*. 61: 468.
26. Melnyk BM, Feinstein NF, Moldenhouer Z, Small L. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric nursing*. 27: 548.
27. Derogatis L. (1977). *SCL-90-R: Administration, Scoring and Procedures Manual for the Revised Version* (Baltimore, MD: John Hopkins University).
28. Mountain I. (1991). Reliability and validity of the Symptom Screening List (Scl-90-R) for University Students. *Turkish Journal of Psychiatry*. 2: 5-12.
29. Carver CS, Scheier MF, Weintraub JK. (1989). Assessing coping strategies: a theoretically based approach. *Journal of personality and social psychology*. 56: 267.
30. Uğuz Ş, Fevziye T, Yazgan BI, Oguzhan C. (2004). Determination of Anxiety, Depression and Stress Levels of Mothers of Mentally and/or Physically Disabled Children. *Klinik Psikiyatri*. 7: 42-47.
31. Hanson MJ, Hanline MF. (1990). Parenting a child with a disability: A longitudinal study of parental stress and adaptation. *Journal of Early Intervention*. 14: 234-248.
32. Miller AC, Gordon RM, Daniele RJ, Diller L. (1992). Stress, appraisal, and coping in mothers of disabled and nondisabled children. *Journal of Pediatric Psychology*. 17: 587-605.
33. Ashkani H, Dehbozorgi GR, Tahamtan A. (2015). Depression among parents of children with chronic and disabling disease. *Iranian Journal of Medical Sciences*. 29: 90-93.
34. Durukan İ, Murat E, Evren TA, Ayhan C, Ozgur Y, et al. (2008). Depression and anxiety levels and coping methods used in mothers of children with ADHD: A preliminary study. *Anatolian Journal of Psychiatry*. 9: 217-223.
35. Şengül S, Baykan H. (2013). Attitudes of Coping with Depression, Anxiety and Stress in Mothers of Mentally Disabled Children. *Kocatepe Tıp Dergisi*. 14.
36. Ridosh MM, Sawin KJ, Klein-Tasman BP, Holmbeck GN. (2017). Depressive symptoms in parents of children with spina bifida: A review of the literature. *Comprehensive Child and Adolescent Nursing*. 40: 71-110.
37. Malm-Buatsi E, Aston CE, Ryan J, Tao Y, Palmer BW, et al. (2015). Mental health and parenting characteristics of caregivers of children with spina bifida. *Journal of pediatric urology*. 11: 65.

38. Grosse SD, Alina FL, Lijing O, James RM, John TM. (2009). Impact of spina bifida on parental caregivers: findings from a survey of Arkansas families. *Journal of Child and Family Studies*. 18: 574-581.
39. Civilibal M, Suman M, Elevli M, Duru NS.. (2014). The quality of life of mothers of children with spina bifida. *Journal of Pediatric Orthopaedics B*. 23: 319-321.
40. Ringoot AP, Tiemeier H, Jaddoe VWV, So P, Hofman A, et al. (2015). Parental depression and child well-being: young children's self-reports helped addressing biases in parent reports. *Journal of clinical epidemiology*. 68: 928-938.
41. Antiel RM, Adzick NS, Thom EA, Burrows PK, Farmer DL, et al. (2016). Impact on family and parental stress of prenatal vs postnatal repair of myelomeningocele. *American journal of obstetrics and gynecology*. 215: 522.
42. Association AP, Lazarus RS, Folkman S. (1984). *Coping Strategies and Perceived Support in Adolescents and Young Adults: Predictive Model of Self-Reported Cognitive and Mood Problems Stress, appraisal and coping*. New York: Springer. *Psychology*. 7: 14.
43. Peyrot M, McMurry JF Jr, Kruger DF. (1999). A biopsychosocial model of glycemic control in diabetes: stress, coping and regimen adherence. *Journal of health and social behavior*. 141-158.
44. Esra Ç, Dinç GŞ, Kültür SEÇ, The Relationship between Coping Skills and Psychiatric Symptoms in Mothers of Children with Chronic Diseases: A Preliminary Study.
45. Rohde P, Lewinsohn PM, Tilson M, Seeley JR. (1990). Dimensionality of coping and its relation to depression. *Journal of personality and social psychology*. 58: 499.
46. Compas BE, Connor-Smith JK, Saltzman H, Thomsen AH, Wadsworth ME. (2001). Coping with stress during childhood and adolescence: problems, progress, and potential in theory and research. *Psychological bulletin*. 127: 87-127.
47. Katip I. (2017) Examination of Psychological Symptom Levels and Coping Skills of Mothers Having Children with Chronic Neurological Diseases.
48. Kieckhefer GM, Trahms CM, Churchill SS, Kartz L, Uding N, et al. (2014). A randomized clinical trial of the building on family strengths program: an education program for parents of children with chronic health conditions. *Maternal and child health journal*. 18: 563-574.
49. Barlow JH, Ellard DR. (2004). Psycho-educational interventions for children with chronic disease, parents and siblings: An overview of the research evidence base. *Child: care, health and development*. 30: 637-645.