

Pain, Anxiety, Depression, Fatigue, Sleep Quality, and Health-Related Quality of Life in the Mothers of Children with Autism Spectrum Disorder and the Mothers of Typically Developing Children: A Case-Control Study

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Abstract

BACKGROUND/AIMS: The special needs for children with autism spectrum disorder (ASD) increase the burden of caregiving, which may cause several negative effects on the caregiver. The aim of this study was to compare the care burden, pain, anxiety, depression, fatigue, sleep quality, and health-related quality of life (HRQOL) in the mothers of children with ASD against those with typically developing children.

MATERIALS AND METHODS: Children with ASD (n=35) and their mothers (n=35), and typically developing children (n=35) and their mothers (n=35) were recruited into this case-control study. The pain, anxiety/depression, fatigue, sleep quality, and HRQOL of the mothers were assessed.

RESULTS: There was no significant difference in most of the demographic characteristics of the children and their mothers ($p>0.05$). The mothers of those children with ASD had a significantly greater care burden and anxiety levels, and more impaired sleep quality and HRQOL ($p<0.05$). A non-significant difference was observed in depression, fatigue, and pain between the mothers of children with ASD and those with typically developing children ($p>0.05$).

CONCLUSION: It was found that the mothers of children with ASD had a higher care burden and anxiety levels, and lower sleep quality and HRQOL compared to the mothers of typically developing children. However, there was no significant difference between the two groups in terms of pain, fatigue, or depression levels.

Keywords: Autism spectrum disorder, mother, caregiver, children, pain, quality of life

INTRODUCTION

Developmental disabilities include various cognitive and physical disorders which occur in early childhood and remain throughout life.¹ Developmental disabilities such as autism spectrum disorder (ASD)

have an increasing prevalence.² These children with developmental disabilities commonly require significant help while performing many activities of daily living.² These elevated special needs generate significant changes in family dynamics and increase the burden on caregiving which is commonly given by their biological mothers.³⁻⁵

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The caregiver's problems can affect the continuous interaction between them and their children.⁶ Therefore, it is important to know a caregiver's health status in order to provide better treatment to an impaired child. Previous studies showed that the caregivers of children with intellectual and developmental disabilities have higher levels of anxiety and depression compared to the caregivers of children without such disabilities or the general population.^{1,7-9} There is cumulative evidence that the caregivers of such children have a lower health-related quality of life (HRQOL).^{2,4,5,10}

Chronic pain is commonly co-morbid with a depressive or anxiety disorder which can exacerbate the pain perception.^{11,12} Although it is known that the caregivers of children with developmental disabilities experience more anxiety and depression,^{1,7-9} the interaction between these problems and other related issues such as pain, fatigue, and sleep quality is not clear. A previous study investigated the HRQOL in the caregivers of children with intellectual disability using the 5-level EQ-5D which includes five dimensions related to the level of perceived problems, including pain/discomfort and anxiety/depression.¹⁰ It was reported that 49.7% of the caregivers had pain/discomfort problems and 54.3% of them had anxiety/depression problems.¹⁰ However, that study focused on pain/discomfort and anxiety/depression problems related to HRQOL without assessing them directly.¹⁰ However, direct assessments are required in order to obtain a better understanding. For example, a recent study reported that having intellectual disability in children with cerebral palsy increases pain and disability related to the lower back and neck in the caregivers.¹³ Our study aimed to compare the care burden, pain, anxiety, depression, fatigue, sleep quality, and HRQOL in those mothers of children with ASD and the mothers of typically developing children. We hypothesized that the mothers of children with ASD would have significantly greater levels of care burden, pain, anxiety, depression, and fatigue; and lower levels of sleep quality and HRQOL compared to the mothers of typically developing children.

MATERIALS AND METHODS

Study Design and Participants

This study had a case-control design. Children diagnosed as having an ASD according to the fifth edition of Diagnostic and Statistical Manual of Mental Disorders-5¹⁴ and their primary caregivers were recruited from a special education and rehabilitation center located in Nicosia, The Turkish Republic of North Cyprus. Typically developing children (without a physician-diagnosed chronic disease) and their primary caregivers living in the same city were recruited from the friends, families, and neighborhoods of the researchers. The inclusion criteria for the caregivers were being the biological mother and primary caregiver of the child. We included only the mothers since mothers are generally the primary caregivers of the children due to certain cultural considerations. Those mothers with a physician-diagnosed chronic disease (neurological, systemic, metabolic, etc.), a history of operation within the prior 6 months, or those who were pregnant were excluded.

The required sample size was calculated as 54 participants with their children (27 for each group) in order to achieve an effect size of 0.78, a power of 80%, and an alpha error probability of 0.05 using G*Power (Ver. 3.1.9.4, Dusseldorf University, Germany).^{15,16}

This study was approved by the Ethics Review Board of Near East University (approval number: 2019/65-715, date: 22.01.2019) and performed in accordance with the ethical standards as laid down in the

1964 Declaration of Helsinki (as revised in Brazil, 2013). All mothers gave informed consent for themselves and their children before entering this study.

Outcome Measures

Demographic characteristics [gender, body mass index (BMI), education level, and the number of children] of the mothers and their children were obtained.

The Zarit Burden Interview (ZBI) was used to assess the distress experienced by the caregivers due to caring for their children. The ZBI consists of 22 items having a 5-point scale, where higher scores indicate a higher burden. The ZBI was found to be a valid and reliable scale to be used within the Turkish population.¹⁷

The McGill Pain Questionnaire (MPQ) was used to assess the pain experience of the caregivers.¹⁸ The MPQ includes three parts. In the first part, the participants mark their painful sites. The second part is a verbal descriptive scale related to the intensity level of their current pain. The third part consists of 72 descriptive adjectives related to pain. A cumulative total score is calculated, and higher scores indicate more pain experience. The Turkish version of the MPQ was found to be a reliable and valid measure.¹⁹

The Nordic Musculoskeletal Questionnaire (NMQ) was used to determine the prevalence of pain in different body regions within the prior year and week. The NMQ has a dichotomous option for each body part and gives a prevalence rate for each body region rather than a cumulative score.^{20,21} The NMQ was translated into Turkish, and this version was found to be reliable and valid.²⁰

The Fatigue Severity Scale (FSS) was used to assess fatigue severity.²² The FSS includes 9 items with a 7-point scale and higher scores represent greater fatigue severity. The Turkish version of FSS was found to be reliable and valid.²² A cut-off score of 4 or more is considered indicative of problematic fatigue.²³

The Hospital Anxiety and Depression Scale (HADS) was used to assess the level of anxiety and depressive symptoms. It consists of two subscales: HADS-Anxiety and HADS-Depression with each subscale having 7 items with a response-scale with four alternatives (from 0 to 3).^{24,25} The Turkish version of the HADS was also found to be a valid and reliable measure.²⁶ The cut-off points of the Turkish version were 10 for HADS-Anxiety and 7 for HADS-Depression.²⁶

The Pittsburgh Sleep Quality Index (PSQI) was used to assess sleep quality.²⁷ The PSQI has 19 items with a 0-3 interval scale and lower scores indicate healthier sleep quality. The Turkish version of the PSQI was found to be valid and reliable.²⁸

The Nottingham Health Profile (NHP) was used to assess HRQOL.²⁹ The NHP consists of 38 items with yes/no answer options and each section score is weighted. The NHP has 6 different subscale scores and the higher the score, the lower the HRQOL. The Turkish version of the NHP was found to be valid and reliable.³⁰

Statistical Analysis

The Kolmogorov-Smirnov test and histograms were used to investigate the normal distribution of data. Mann-Whitney U test and chi-squared test were conducted to compare differences between the study groups.

Effect sizes were calculated as Cohen's d .³¹ Statistical significance was set at $p < 0.05$. Statistical analyses were conducted using the IBM SPSS Statistics for Windows (Version 24.0. Armonk, NY: IBM Corp.).

RESULTS

In total, 70 mothers and 70 children participated in this study. No significant differences were observed in age, BMI, number of children, and education levels between the mothers of children with ASD and those with typically developing children ($p > 0.05$) (Table 1). There were significantly more males in those children with ASD ($p < 0.05$). No significant difference was observed in age, BMI, and education level between those children with ASD and the typically developing children ($p > 0.05$) (Table 2).

The mothers of children with ASD had significantly greater ZBI, PSQI, HADS-Anxiety, NHP-Energy, NHP-Emotional reaction, and NHP-Social isolation scores compared to the mothers of the typically developing children ($p < 0.05$). No significant differences were observed in the remaining study variables ($p > 0.05$). Table 3 presents the comparison statistics of care burden, pain, fatigue, sleep quality, anxiety, depression, and HRQOL between the mothers of children with ASD and those with typically developing children.

The most common musculoskeletal pain sites during the prior year and prior week were the upper back and neck in both the mothers of children with ASD and those with typically developing children. No significant difference was observed in the presence of musculoskeletal pain sites during the prior year or prior week between the mothers of

children with ASD and those with typically developing children ($p > 0.05$). The details are presented in Table 4.

DISCUSSION

The study hypothesis was that the mothers of children with ASD would have significantly greater levels of care burden, pain, anxiety, depression, and fatigue; and lower levels of sleep quality and HRQOL compared to the mothers of typically developing children. The main findings were that the mothers of children with ASD had greater care burden, greater anxiety levels, lower sleep quality, and lower HRQOL.

Although the mothers of children with ASD had greater anxiety levels, there was no significant difference between the number of individuals with anxiety determined by published cut-off values between the mothers of children with ASD and the mother of typically developing children.²⁶ This finding should be interpreted with caution. The mothers of children with ASD had relatively high anxiety (14.3%) and depression (42.9%) prevalence in our study. However, mothers with typically developing children also had relatively high anxiety (8.6%) and depression (37.1%) prevalence. Almansour et al.³² found that the caregivers of children with ASD had significantly more anxiety/depression disorders compared to controls; with 32% of the caregivers of children with ASD having anxiety/depression, whereas the controls had 2%. Ingersoll et al.³³ reported similar results that 44% of the mothers of children with ASD had depression and this ratio was 30% in their control subjects. Similarly, other studies also reported significant differences between the caregivers of children with ASD and controls in terms of depression/anxiety.^{34,35} The depression/anxiety rates in the mothers of children with

Table 1. The demographic characteristics of the mothers of children with ASD and typically developing children

	Mothers of children with ASD (n=35)	Mothers of typically developing children (n=35)	p
Age (years) ^a	35 (31-41)	34 (29-41)	0.879
BMI (kg/m ²) ^a	22.4 (20.8-25.5)	23 (20.8-28.7)	0.385
Number of children ^a	2 (1-2)	2 (1-2)	0.497
Education level			
Secondary school ^b	17 (48.6)	6 (17.1)	0.775
High school ^b	10 (28.6)	13 (37.1)	
University ^b	8 (22.9)	16 (45.7)	

^aMedian (interquartile range), analyzed with Mann-Whitney U test. ^bNumber of participants, analyzed with chi-squared test. ASD: autism spectrum disorder, BMI: body mass index.

Table 2. The demographic characteristics of the children with ASD and typically developing children

	Children with ASD (n=35)	Typically developing children (n=35)	p
Age (years) ^a	7 (5-9)	8 (4-12)	0.331
Gender			
Female ^b	9 (25.7)	17 (48.6)	0.048*
Male ^b	26 (74.3)	18 (51.4)	
BMI (kg/m ²) ^a	19.0 (16.6-24.1)	18.5 (15-21.6)	0.312
Education level			
Preschool ^b	17 (48.6)	11 (31.4)	0.054
Primary school ^b	15 (42.9)	15 (42.9)	
Secondary school ^b	3 (8.6)	8 (22.9)	
High school ^b	0	1 (2.9)	

* $p < 0.05$. ^aMedian (interquartile range), analyzed with Mann-Whitney U test. ^bNumber of participants, analyzed with chi-squared test. ASD: autism spectrum disorder, BMI: body mass index.

Table 3. Comparison of care burden, pain, fatigue, sleep quality, anxiety, depression, and health-related quality of life between the mothers of children with ASD and those with typically developing children

	Mothers of children with ASD (n=35)	Mothers of typically developing children (n=35)	p	U/ χ^2	d
ZBI ^a	25 (18-31)	12 (6-22)	<0.001*	292.5	1.0
MPQ ^a	44 (27-65)	38 (30-50)	0.250	514.5	0.29
FSS ^a	40 (23-50)	30 (14-44)	0.113	477.5	0.39
Presence of problematic fatigue ^b	19 (54.3)	14 (40.0)	0.231	1.433	0.29
HADS-Anxiety ^a	7 (5-8)	5 (3-7)	0.014*	403.5	0.61
Presence of anxiety ^b	5 (14.3)	3 (8.6)	0.452	0.565	0.18
HADS-depression ^a	6 (4-8)	6 (4-8)	0.763	587.0	0.07
Presence of depression ^b	15 (42.9)	13 (37.1)	0.626	0.238	0.11
PSQI ^a	13 (11-14)	12 (10-13)	0.019*	414.0	0.58
NHP					
Pain ^a	18.7 (9-33.8)	17.1 (0-36)	0.582	566.0	0.13
Energy ^a	37 (0-61)	0 (0-39.2)	0.049*	454.0	0.46
Sleep ^a	12.6 (0-27.3)	0 (0-12.6)	0.071	476.5	0.39
Mobility ^a	0 (0-21.4)	0 (0-22)	0.877	600.5	0.04
Emotional reaction ^a	16.8 (10.5-24.4)	0 (0-14)	<0.001*	315.0	0.92
Social isolation ^a	0 (0-22)	0 (0-0)	0.011*	439.0	0.50

*p<0.05. ^aMedian (interquartile range), analyzed with Mann-Whitney U test. ^bNumber of participants, analyzed with chi-squared test. ASD: autism spectrum disorder, ZBI: Zarit Burden Interview, MPQ: McGill Pain Questionnaire, FSS: Fatigue Severity Scale, HADS: Hospital Anxiety and Depression Scale, PSQI: Pittsburgh Sleep Quality Index, NHP: Nottingham Health Profile.

Table 4. Comparison of the presence of musculoskeletal pain sites during the prior year and prior week between the mothers of children with ASD and those with typically developing children

Anatomical region	Musculoskeletal pain sites during the prior year						Musculoskeletal pain sites during the prior week							
	Mothers of children with ASD (n=35)		Mothers of typically developing children (n=35)		p	χ^2	d	Mothers of children with ASD (n=35)		Mothers of typically developing children (n=35)		p	χ^2	d
n	%	n	%	n				%	n	%				
Neck	18	51.4	22	62.9	0.334	0.933	0.23	13	37.1	12	34.3	0.803	0.062	0.06
Shoulders	16	45.7	17	48.6	0.811	0.057	0.06	6	17.1	11	31.4	0.163	1.942	0.34
Elbows	4	11.4	2	5.7	0.393	0.729	0.21	3	8.6	1	2.9	0.303	1.061	0.25
Wrists/hands	11	31.4	6	17.1	0.163	1.942	0.34	5	14.3	4	11.4	0.721	0.128	0.09
Upper back	22	62.9	23	65.7	0.803	0.062	0.06	14	40	18	51.4	0.337	0.921	0.23
Lower back	16	45.7	19	54.3	0.473	0.541	0.18	10	28.6	9	25.7	0.788	0.072	0.06
Hips/thighs	7	20	4	11.4	0.324	0.971	0.24	1	2.9	2	5.7	0.555	0.348	0.14
Knees	9	25.7	10	28.6	0.788	0.072	0.06	1	2.9	5	14.3	0.088	2.917	0.42
Ankles/feet	10	28.6	9	25.7	0.788	0.072	0.06	7	20	7	20	>0.999	<0.001	<0.001

ASD: autism spectrum disorder.

ASD in our study were similar to previous studies. However, due to the high rate of depression/anxiety in the mothers of typically developing children, this difference did not reach a significance level. This difference might be related to outcome measures, cut-off values, and sample sizes. In addition, cultural differences can also play a notable role on this difference as the aforementioned studies were conducted in China, Singapore, Saudi Arabia, and the USA.³²⁻³⁵ On the other hand, a study conducted in Iran reported no significant difference between the mothers of children with ASD and controls in terms of depression levels, whereas anxiety/insomnia levels were significantly different.³⁶ We also found that anxiety and sleep quality were significantly different, whereas depression levels were not. We believe that these similar results

can be attributed to the similarities between the two studies, such as similar geography and a similar study sample (32 mothers of children with ASD and 29 mothers of children without ASD).³⁶

We expected that if the mothers of children with ASD had greater anxiety/depression, they would have greater pain experience. However, since there was no large difference in anxiety/depression, the pain scores (direct assessment and related to HRQOL) were not significantly different. In addition, no significant difference was observed in the musculoskeletal pain sites between the mothers of children with ASD and those with typically developing children. However, one should keep in mind that this finding does not mean that these problems are non-

significant in this population as, in our study, 62.9% of the mothers of children with ASD reported upper back pain, 51.4% reported neck pain, and 45.7% reported lower back and shoulder pain. In a previous study, although pain symptoms were not directly assessed, it was reported that 49.7% of the caregivers of children with intellectual disability had pain/discomfort problems.¹⁰ Health professionals working with children with ASD should consider referring their mothers for further assessment and rehabilitation programs for musculoskeletal pain management.

There is cumulative evidence that the caregivers of children with developmental disorders have lower HRQOL.^{2,4,5,10} Our results are consistent with these previous reports. We found that most of the subdomains of HRQOL (energy, emotional reaction, and social isolation) were significantly lower in the mothers of children with ASD compared to the mothers of typically developing children. On the other hand, there was a non-significant difference in the pain, sleep, and mobility subdomains of HRQOL. Indeed, one could expect this due to the observed significant difference in sleep quality, the mothers of children with ASD would have an impaired sleep sub-domain of HRQOL. The median of the sleep sub-domain was 12.6 in the mothers of children with ASD, whereas it was 0 in the mothers of typically developing children. This non-significant difference might be related to the small sample size. However, the observed small effect size suggests that this non-significant difference would be similar in a large sample size. Therefore, the results show that statistically significant sleep quality impairment does not cause a significant decrease in the sleep subdomain of HRQOL in the mothers of children with ASD.

Study Limitations

There are many limitations to our study. Firstly, although we conducted a priori sample size calculation, our sample size was relatively small. Secondly, we only included mothers, which diminishes the generalizability of our findings. The inclusion of other family members such as fathers, grandmothers, grandfathers, and siblings would reflect the family impact better. Lastly, due to the cross-sectional design of our study, we cannot give information about changes over time or show possible factors contributing towards the assessed variables which are mostly time-dependent and context-dependent conditions. Therefore, future longitudinal studies are required. Despite these limitations, our study had strength in assessing pain, fatigue, and sleep quality directly.

CONCLUSION

Our results may provide valuable information regarding sample size calculations for future studies.

The mothers of children with ASD had a greater care burden, higher anxiety levels, lower sleep quality and lower HRQOL related to energy, emotional reaction, and social isolation compared to the mothers of typically developing children. However, the mothers of children with ASD did not have significantly different pain, fatigue, or depression levels compared to the mothers of typically developing children. However, one should keep in mind that these problems were relatively high in both groups.

MAIN POINTS

- The special needs for children with ASD increase the burden of caregiving.

- The mothers of children with ASD have a greater care burden and higher anxiety levels, lower sleep quality, and lower HRQOL.

- The levels of pain, fatigue, and depressive symptoms are not significantly different between the mothers of those children with and those without ASD.

ETHICS

Ethics Committee Approval: This study was approved by the Ethics Review Board of Near East University (approval number: 2019/65-715, date: 22.01.2019) and performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki (as revised in Brazil, 2013).

Informed Consent: All mothers gave informed consent for themselves and their children before entering this study.

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Authorship Contributions

Concept: E.S., T.K., A.G., Design: E.S., T.K., A.G., Supervision: T.K., A.G., Data Collection and/or Processing: E.S., T.K., A.G., Analysis and/or Interpretation: E.S., T.K., A.G., Literature Search: E.S., T.K., A.G., Writing: E.S., T.K., A.G., Critical Review: E.S., T.K., A.G.

DISCLOSURES

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