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RESEARCH ARTICLE

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CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER QUALITY OF LIFE AND SPIRITUAL REQUIREMENTS IN THE COVID-19 PANDEMIC

Otizm Spektrum Bozukluğu Olan Çocuklara Bakımverenlerin COVİD-19 Pandemisinde Yaşam Kalitesi ve Manevi Gereksinimleri

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ABSTRACT

Purpose: This study aimed to assess the quality of life and spirituality of caregivers of children with “Autism Spectrum Disorder” during the COVID-19 pandemic and to explore the relationship between these factors. Additionally, it seeks to identify the socio-demographic factors that contribute to variations in caregivers' quality of life and levels of spiritual needs.

Methods: Descriptive, cross-sectional study. The population of the study consisted of caregivers (n=230) of autistic children registered in two public rehabilitation centers. 187 caregivers were reached using the convenience sampling method. The data were collected Version," and "Spirituality Scale" were evaluated with descriptive statistics, independent t-tests, one-way ANOVA, and correlation analysis. Post-hoc Bonferroni correction was applied ($p < 0.05$).

Results: The quality of life of caregivers of children with Autism Spectrum Disorder was above average (QoLA-Part A=85.66±17.27; QoLA-Part B=54.30±16.07) and their levels of spirituality were high (100.94±14.80). The relationship between the quality of life and spirituality levels of caregivers was weak ($r = 0.378$, $p=0.00$ for Quala A, $r =-0.243$, $p=0.01$ for Quala B). Quality of life scores varied based on age, gender, educational status, occupation, income level, proximity to the autistic child, chronic disease status, and age of the autistic child. Spirituality scores varied based on the gender of the caregiver and their level of closeness to the autistic child.

Conclusions: As a result, although spirituality scores were found to be high, the quality of life among caregivers remains at a level that could be improved. Significant differences were determined in the quality of life and spirituality scores of caregivers based on sociodemographic factors such as age, education level, and income. To address these disparities and enhance overall quality of life, it is recommended to develop and implement targeted support programs that are specifically tailored to the sociodemographic characteristics and unique needs of caregivers.

Keywords: Autism spectrum disorder, caregiver, Covid-19 pandemic, spirituality, quality of life (QoL)

ÖZET

Amaç: Bu çalışmanın amacı, otizm spektrum bozukluğu olan çocuklara bakım verenlerin yaşam kalitesi ve manevi ihtiyaç düzeylerini belirlemek ve iki değişken arasındaki ilişkiyi ve değişkenleri etkileyebilecek sosyodemografik özellikleri incelemektir.

Yöntem: Tanımlayıcı, kesitsel bir çalışmadır. Araştırmanın evrenini iki kamu rehabilitasyon merkezine kayıtlı olan otistik çocukların bakım verenleri (n=230) oluşturmuştur. Çalışmada amaçlı örnekleme yöntemi kullanılarak 187 bakım verene ulaşılmıştır. Veriler 30 Eylül 2021-30 Ağustos 2022 tarihleri arasında "Google Forms" aracılığıyla çevrimiçi olarak toplanmıştır. "Sosyodemografik Veri Formu", "Otizmde Yaşam Kalitesi Anketi-Ebeveyn Sürümü" ve "Maneviyat Ölçeği" kullanılarak toplanan veriler tanımlayıcı istatistikler, bağımsız t-testi, tek yönlü ANOVA ve korelasyon analizi ile değerlendirilmiştir. Post-hoc Bonferroni düzeltmesi uygulanmıştır ($p < 0.05$).

Bulgular: Otizm spektrum bozukluğu olan çocuklara bakım verenlerin yaşam kalitesi ortalamanın üzerindeydi (QoLA-Part A=85.66±17.27; QoLA-Part B=54.30±16.07) ve maneviyat düzeyleri yüksekti (100.94±14.80). Bakım verenlerin yaşam kalitesi ve maneviyat düzeyleri arasındaki ilişki zayıftı ($r = 0.378$, $p=0.00$ for Quala A, $r =-0.243$, $p=0.01$ for Quala B). Yaşam kalitesi puanları yaş, cinsiyet, eğitim durumu, meslek, gelir düzeyi, otistik çocuğa yakınlık, kronik hastalık durumu ve otistik çocuğun yaşına göre değişmektedir. Maneviyat puanları ise bakım verenin cinsiyetine ve otistik çocuğa yakınlık düzeyine bağlı olarak değişmiştir.

Sonuçlar: Sonuç olarak pandemi sırasında ölçülen maneviyat puanları yüksek yaşam kalitesi ise geliştirilebilir düzeydedir. Bakım verenlerin yaşam kalitesi ve maneviyat puanlarında sosyodemografik değişkenlere (yaş, eğitim düzeyi, gelir düzeyi vb.) göre anlamlı farklılıklar belirlenmiştir. Bu farklılıkları gidermek ve genel yaşam kalitesini artırmak için, bakım verenlerin sosyodemografik özelliklerine ve bireysel ihtiyaçlarına özel olarak tasarlanmış destek programlarının geliştirilmesi ve uygulanması önerilmektedir.

Anahtar Kelimeler: Otizm spektrum bozukluğu (osb), bakım veren, Covid-19 pandemisi, maneviyat, yaşam kalitesi

INTRODUCTION

The global prevalence of Autism Spectrum Disorder (ASD) is estimated to be between 1-2% (American Psychiatric Association [APA], 2013). According to the APA, ASD is a neurodevelopmental disorder characterized by stereotypic movements that result in social and communicative difficulties (APA, 2013). These symptoms typically appear in early childhood and persist throughout an individual's life. In some cases, ASD is also associated with language and intellectual disabilities (Borilli, Germano, de Avó, Pilotto, & Melo, 2022; Kreysa et al., 2022). For caregivers —whether mothers, fathers, or other family members— the primary concerns include managing the care, mobility, social interaction, communication, daily living activities, education, rehabilitation, group interactions, productivity, and school activities of individuals with ASD (Beheshti, Hosseini, Maroufzadeh, & Almasi-Hashiani, 2022). However, the onset of the pandemic has intensified existing challenges and disrupted caregivers' routines (Abolkheirian, Sadeghi, & Shojaeizadeh, 2022).

To curb the spread of the virus measures such as curfews, quarantine practices, school closures, special rehabilitation center closures, and the enforcement of mask-wearing, hygiene, and social distancing were implemented (Isensee, Schmid, Marschik, Zhang, & Poustka, 2022; Karabulut, 2020). These measures led to significant changes in learning methods, including a shift to virtual or hybrid formats, interruptions in professional support and services, increased reliance on electronic communication, and more time spent at home (Hurwitz, Garman-McClaine, & Carlock, 2022; Isensee et al., 2022; Kreysa et al., 2022). As a result, the responsibility for child care and education largely shifted from educators to caregivers (Isensee et al., 2022). This abrupt transition placed additional stress and challenges on caregivers. Educators from special education centers highlight the importance of collaborating with caregivers to address developmental needs in the home environment, utilizing technology to bridge educational gaps, and monitoring individual progress. However, the limited competencies of caregivers further compounded these difficulties (Hurwitz, Garman-McClaine & Carlock, 2022).

During the distance education period, caregivers faced increased burdens, including managing disruptive and repetitive behaviors and emotional outbursts of individuals with ASD, heightened anxiety about the future, and a lack of cooperation from educational institutions (Borilli et al., 2022). Given the extensive medical, educational, social, and behavioral support required by individuals with ASD, it is believed that the quality of life for caregivers has been negatively impacted during the COVID-19 pandemic (Stadheim et al., 2022).

The quality of life for caregivers of children with ASD is influenced by a multitude of factors, including marital conflicts, conflicts between parents and other children, interaction problems with neighbors, time spent on daily tasks, child care, education, sleep deprivation, engagement in social activities, physical health challenges, spiritual concerns, as well as medical, financial, social stigma, and legal issues (Abolkheirian et al., 2022). Quality of life is a multifaceted, subjective concept that encompasses physical health, psychological well-being, independence, social relationships, personal beliefs, and environmental factors (World Health Organization, 1998). In recent years, numerous scientific articles have been published rapidly, focusing on the psychosocial and behavioral impacts of the COVID-19 pandemic on children with autism and their families. However, much of this research has focused on practical guidance for individuals with autism, their parents, caregivers, or therapists, or has presented case studies (Kreysa et al., 2022). There is a notable gap in research specifically addressing the effects of the pandemic on caregivers (Isensee et al., 2022). To better address the needs of individuals with ASD during future emergencies, it is crucial to understand the challenges faced by caregivers and provide them with adequate support and resources. While some studies have explored the quality of life of families with ASD (Aoki et al., 2022; Borilli et al., 2022), there is a limited assessment of caregiver quality of life in low- and middle-income countries (Aoki et al., 2022). Additionally, caregivers often rely on spiritual resources to cope with these challenges, yet their spiritual well-being is frequently overlooked.

In the existing literature, recent studies on the families of individuals with autism examine the effects of cultural differences on the family, coping strategies, sources of stress, and levels of social support (Yassıbaş, Şahin, Çolak, & Toprak, 2019). Researches on spiritual needs has predominantly focused on elderly individuals (Uçar, 2017), cancer patients (Bostancı Daştan & Buzlu, 2010), and healthcare professionals (Eğlence & Şimşek, 2014). Research on the spiritual needs of families and parents in unique fields like autism is quite limited, including in our country. It has been primarily assessed within the realm of developmental disorders, children with disabilities, or solely spiritual coping (Aslan, Kant, & Gül Can, 2023; Hatun, Yavuz-Birben, İnce, & Kalkan-Yeni, 2016; Karaca & Konuk Şener, 2021).

This study aimed to assess the quality of life and spirituality of caregivers of children with ASD during the COVID-19 pandemic and to explore the relationship between these factors. Additionally, it seeks to identify the socio-demographic factors that contribute to variations in caregivers' quality of life and levels of spiritual needs.

METHODS

Design

The study is descriptive and cross-sectional in design.

Place and Time of the Study

The research, which was conducted between August 2021 and March 2023, took place at the "X Autism Education & Life Center" and "Y Special Education and Rehabilitation Center" in a province in southeastern Turkey.

Population and Sample of the Study

The population of the study consisted of caregivers of autistic individuals registered in two centers (n=230). Caregivers whose children attended one of these two centers and who voluntarily agreed to participate in the study were included in the research sample. The study utilized the convenience sampling method, which is one of the non-probability sampling techniques. According to the sampling calculation in the power analysis using the G Power 3.1.9.4 program, the aim was to reach 156 parents with 80% power, 95% reliability, 5% margin of error, and 0.2 effect size value. The study was completed with 187 parents (Faul et al., 2007).

Data Collection Tools

The Sociodemographic Data Form, Quality of Life in Autism Questionnaire-Parent Version, and Spirituality scale were used to collect the data.

Sociodemographic data form

The form was designed by the researchers to include nine questions aimed at determining the socio-demographic characteristics of the sample, drawing on sources from the literature (Bülbül & Giray, 2011; Özabacı, 2001; Şirin, 2014).

The quality of life in autism questionnaire (QoLA)

The Turkish validity and reliability of the scale developed by Eapen, Črnčec, Walter, and Tay (2014) to assess quality of life was conducted (Özgür et al., 2017). The scale consists of two parts: A and B. Section A includes 28 questions (with items 2, 4, 17, and 22 reversed) measuring parents' general perceptions of their quality of life. The questions are five-point Likert-type (1=not at all; 5=very much). The score for Section A ranges from 28 to 140, and the higher the score, the better the quality of life. Part B assesses the parents' perception of the extent to which their children's autism-specific difficulties pose a problem for them. For this, there are 20 assessment questions about the challenges faced by children diagnosed with ASD. In the five-point Likert-type assessment measure, which evaluates the extent to which these situations are problematic for parents, '1=it was too much of a problem for me' and '5=it was not a problem for me at all'. There are no return items in Section B. Scores in Section B range from 20 to 100, with higher scores indicating that parents perceive fewer problems with their children's ASD-related behaviors. The total QoLA score ranges from 48 to 240. The developers of the scale suggest that a total score can be calculated for general comparisons; however, since the sections in the instrument reflect separate subscales, it is recommended that sections A and B be scored separately. The Cronbach's alpha coefficient of the original scale was found to be 0.94 for Section A and 0.92 for Section B (Özgür et al., 2017). In this study, the Cronbach's Alpha value of the scale was found to be 0.97 for Section A and 0.94 for Section B. The skewness for QoLA is-0.395 (SE = 0.178) and the kurtosis is 0.248 (SE = 0.354).

Spirituality scale

The development, validity, and reliability of the scale were tested by Turgay Şirin (2018). The scale consists of seven sub-dimensions: spiritual coping, transcendence, spiritual experience, search for meaning, spiritual contentment, connection, and harmony with nature, totaling 27 items, including three negative and 24 positive items. The scale items were prepared using a 5-point Likert scale with the following options: (1) Not at All Suitable for Me, (2) Not Suitable for Me, (3) Somewhat Suitable for Me, (4) Quite Suitable for Me, (5) Completely Suitable for Me. The total score on the scale ranges from 27 to 135. The high score obtained from each sub-dimension of the scale indicates that the individual possesses that characteristic. The scale also provides a total spirituality score. A high score on the scale indicates that the individual has a high level of spirituality. In the results of the reliability study of the scale, Cronbach's Alpha was found to be 0.90 (Şirin, 2018). In this study, the Cronbach's Alpha value of the scale was found to be 0.92. The skewness for the spirituality scale is-0.787 (SE = 0.178) and the kurtosis is 0.998 (SE = 0.354).

Data Collection and Evaluation

Data were collected online via "Google Forms" from September 30, 2021, to August 30, 2022. After creating the data collection forms on the platform, the link to participate in the study was shared in

WhatsApp groups that were commonly used by families. Before starting online marking, caregivers were informed about the purpose of the study, obtained informed consent, and were informed that participation in the study was voluntary. Caregivers who agreed to participate in the study were able to continue filling out the data collection forms. The data obtained in the study were analyzed using the Statistical Package for the Social Sciences (SPSS) version 25.0 for the Windows program. Descriptive statistics (number, percentage, mean, standard deviation), independent t-test, one-way ANOVA, and correlation analysis were used to evaluate the data (Schober, Boer, C., & Schwarte, 2018). Post-hoc Bonferroni correction was applied ***p<0.05***).

FINDINGS

Information on the sociodemographic characteristics of the caregivers of individuals with autism, who are studying in the institutions where the research was conducted, is presented in Table 1.

Table 1. Sociodemographic Characteristics of Caregivers

Characteristics	Category	n	%
Caregiver's age (x̄=35.90±7.58)	20-29 years	39	20.9
	30-39 years	91	48.7
	Over 40 years	57	30.4
Caregiver's Gender	Female	105	56.1
	Male	82	43.9
Caregiver's Education	Primary or secondary school	43	23.0
	High school	48	25.7
	Undergraduate and above	96	51.3
Caregiver's Profession	Not working	12	6.4
	Housewife	65	34.8
	Public/private sector	78	41.7
	Self-employed	32	17.1
Caregiver's Income	No income	36	19.3
	<Wage salary	26	13.9
	Wage salary	7	3.7
	> Wage salary	118	63.1
Familiarity with Autistic Children	Mother	95	50.8
	Father	74	39.6
	Other	18	9.6
Age of the Autistic Child (x̄=5.77±2.63)	Less than 5 years	65	34.8
	5-6 years	66	35.3
	More than 7 years	56	29.9

Gender of the Autistic Child	Female	80	42.8
	Male	107	57.2
Chronic Illness of the Caregiver	Yes	38	20.3
	No	149	79.7
Total		187	100

Of the caregivers who participated in the study, 56.1% were female, 43.9% were male, and the mean age was 35.90 ± 7.58 years. Of the caregivers, 51.3% had a bachelor's degree or higher, 41.7% worked in the private or public sector, and 63.1% had an income higher than the minimum wage. While the majority of caregivers were mothers (50.8%), the age range of the autistic children was mostly (35.3%) between 5-6 years, and 57.2% were male. 20.3% of caregivers reported having a chronic disease (Table 1).

The perceptions of "quality of life" and levels of "spiritual need" among caregivers of children diagnosed with ASD during the COVID-19 pandemic are presented in Table 2.

Table 2. Caregivers' Levels of "Quality of Life" and "Spiritual Needs"

Scales and Subdimentions	Minimum	Maksimum	Mean±Std. Deviation
QoLA – Part A	42.00	120.00	85.66±17.27
QoLA – Part B	21.00	100.00	54.30±16.07
Spirituality Scale	45.00	132.00	100.94±14.80
Spiritual Coping	5.00	20.00	15.59±2.77
Transcendence	2.00	10.00	8.77±1.39
Spiritual Life	5.00	25.00	16.35±3.71
The Search for Meaning	4.00	20.00	15.95±2.58
Spiritual Contentment	4.00	20.00	14.13±3.01
Connection	4.00	20.00	16.96±2.93
Harmony with Nature	4.00	15.00	9.10±2.36

The mean QoLA-Part A score of caregivers was 85.66 ± 17.27, while the mean QoLA-Part B score was 54.30 ± 16.07. When the spiritual scores of the caregivers were analyzed, it was found to be 100.94 ± 14.80. It was found that caregivers had a mean score of 15.59 ± 2.7 in the "spiritual coping" sub-dimension, 8.77 ± 1.39 in the "transcendence" sub-dimension, 16.35 ± 3.71 in the "spiritual life" sub-dimension, 15.95 ± 2.58 in the "the search for meaning" sub-dimension, 14.13 ± 3.01 in the "spiritual contentment" sub-dimension, 9.10 ± 2.36 in the "connection" sub-dimension, and "harmony with nature" sub-dimension (Table 2).

Table 3 compares the scale scores and sociodemographic characteristics of caregivers of children with ASD (Table 3).

Table 3. Comparison of Scale Scores of Caregivers with Sociodemographic Characteristics

Variables		QoLA Scale						Spirituality Scale		
	QoLA–Part A			QoLA–Part B						
	x̄±SS	Test	Bonferroni	x̄±SS	Test	Bonferroni	x̄±SS	Test	Bonferroni	
Age	20-29 years (1) 30-39 years (2) >=40 yaş ve (3)	89.44±17.37 89.05±17.77 77.65±13.58	F=9.644*	1>3 2>3	56.90±18.84 51.56±14.56 56.89±15.88	F=2.619		103.67±15.05 100.80±15.75 99.28±12.94	F=1.024	
Sex	Female Male	82.92±17.87 89.16±15.90	t=-2.484*		55.90±15.87 52.24±16.19	t=-1.551		103.57±13.51 97.56±15.76	t=-2.805*	
Education	Primary school (1) Secondary school (2) High school (3) Undergraduate and above (4)	69.65±15.35 74.62±15.99 82.90±14.65 92.86±15.33	F=18.448*	3>1 4>1 4>2 4>3	60.53±18.33 55.54±13.24 54.42±16.36 52.80±16.15	F=1.185		102.00±13.63 99.38±15.20 101.44±12.93 100.92±15.91	F=0.141	
Profession	Not working (1) Housewife (2) Public/private sector (3) Self-employed (4)	87.08±22.16 77.52±15.70 94.06± 14.64 83.18±14.59	F=15.356*	3>2 3>4	59.33±20.96 57.30±15.38 52.28±16.62 51.21±13.02	F=1.984		102.50±19.59 103.90±13.99 99.92±15.70 96.78± 11.03	F=1.907	
Income	No income (1) <Wage salary (2) = Wage salary (3) > Wage salary (4)	76.61±17.12 79.19±20.47 76.14±9.12 90.41±15.17	F=9.285*	4>1 4>2	60.25±17.69 59.69±15.63 53.57±8.46 51.34±15.33	F=4.162*	1>4	103.33±14.46 93.62±17.43 99.43±6.80 101.91±14.28	F=2.699	
Familiarity	Mother (1) Father (2) Other (3)	82.11±17.86 87.91±14.87 95.17±19.02	F=5.633*	3>1	56.12±16.34 52.14±15.18 53.61±17.94	F=1.298		102.66±13.70 97.16±14.74 107.33±17.43	F=4.932*	1>2 3>2
Age of the autistic child	<5 years (1) 5-6 years (2) >=7 years and above (3)	91.46±16.64 86.00±15.83 78.52±17.28	F=9.219*	1>3 2>3	50.55±15.20 52.88±14.84 60.32±16.99	F=6.293*	3 > 1 3>2	101.98±13.89 100.35±14.68 100.41±16.12	F=0.248 -	
Sex of the autistic child	Female Male	84.14±16.59 86.79±17.75	t=-1.041		55.59±15.24 53.34±16.67	t=-0.947		98.80±15.19 102.53±14.37	t=-1.715	
Chronic illness of the caregiver	Yes No	76.18±14.92 88.07±17.04	t=-3.933*		55.03±14.80 54.11±16.42	t=-0.312		95.61±13.03 102.30±14.96	t=--2.522	

***Test value is significant at $p<0.05$ level.**

As a result of the analysis, it was found that there was a statistically significant difference between the QoLA-A scores of the participants and the age, gender, educational status, occupation, income level, proximity to the autistic child, chronic disease status and age of the autistic child (p<0.05). A statistically significant difference was found between QoLA-B scores and the income level of the caregiver and the age of the autistic child (p<0.05) (Table 3).

A statistically significant difference was found between the spirituality scale scores and the variables of caregivers' gender and closeness to the autistic child (p<0.05) (Table 3). In Table 4, the relationship between the perceptions of quality of life and spiritual needs of caregivers of children with ASD is analyzed (Table 4).

Table 4. Relationship between Parents' Perceptions of Quality of Life and Spiritual Needs (n=187)

Scales and subscales		1	2	3	4	5	6	7	8	9	10
1- QoLA–Part A	r	1.000	-0.528*	0.378*	0.254*	0.225*	0.040	0.299*	0.690*	0.296*	0.231*
2- QoLA–Part B	r		1.000	-0.243*	-0.179*	-0.147*	-0.008	-0.194*	-0.363*	-0.270*	-0.147*
3-Spirituality Scale	r			1.000	0.869*	0.820*	0.802*	0.801*	0.497*	0.847*	0.686*
4- Spiritual coping	r				1.000	0.789*	0.614*	0.665*	0.273*	0.800*	0.496*
5- Transcendence	r					1.000	0.580*	0.659*	0.188*	0.790*	0.506*
6- Spiritual life	r						1.000	0.548*	0.256*	0.574*	0.581*
7- The Search for meaning	r							1.000	0.308*	0.626*	0.540*
8- Spiritual contentment	r								1.000	0.324*	0.212*
9- Connection	r									1.000	0.404*
10- Harmony with nature	r										1.000

Test value is significant at p<0.05 level.

There is a statistically significant, positive and weak (r=0.38, p<0.05) relationship between the quality of life scores of caregivers of children diagnosed with ASD from the QoLA-A section and their spirituality levels. Caregivers' perceptions of quality of life were found to have a statistically significant, positive and moderate level relationship (r=0.690, p<0.05) only with "spiritual contentment" among the sub-dimensions of the spirituality scale. There was a statistically significant, negative and very low correlation between the QoLA-B section scores of caregivers of children with ASD and spirituality scores and all subscales of the scale (Table 4).

DISCUSSION

Quality of Life

In this study, the quality of life and spiritual needs of parents with children diagnosed with ASD were examined.

In a study comparing the quality of life of parents caring for autistic children across countries (Australia, Hungary, Malaysia, Romania, Romania, Singapore, Spain, and the United Kingdom), it was shown that the mean QoLA-Part A score ranged from 90.69±24.08 to 103.98±18.04 and the mean QoLA-Part

B score ranged from 48.93±16.33 to 71.61±18.99 (p<0.01) (Eapen et al., 2023). In this study, although QoLA-Part A score was lower than other countries, caregivers scored above the middle value. Findings from QoLA-Part B were similar to those from Malaysia, Romania, and Spain but lower than those from Australia and the United Kingdom (Eapen et al., 2023). This shows that the caregivers who participated in our study perceived the symptoms of the child with ASD as a problem to a great extent. Volgyesi-Molnar et al. (2024) showed that the mean score of parents was 93.88 in QoLA-Part A and 48.86 in QoLA-Part B (p<0.01). According to the results of a study examining the quality of life of caregivers of children with ASD in Turkey, the participants scored lower in Part A (62.89±15.03) and higher in Part B (64.43±19.94) than in this study (Çoban et al., 2021). It is thought that this may be related to the sample characteristics, family experiences, and environmental factors (Cardon & Marshall, 2021). The quality of life of caregivers is associated with many variables, such as the health system in countries, treatment practices, social and professional support differences, income level, and the psychological well-being of families (Cardon & Marshall, 2021; Volgyesi-Molnar et al., 2024). A study showed that many variables, such as the severity of autism, the presence of psychiatric disorders in the parents, the child's school attendance, the time since the diagnosis of autism, and the child's use of medication, affect the quality of life of the family (Özgür, Aksu, & Eser, 2018).

In the study, there was a difference between QoLA-A scores and the caregiver's age, gender, educational status, occupation, income level, proximity to the autistic child, chronic disease status, and age of the autistic child, and between QoLA-B scores and the caregiver's income level and age of the autistic child. Caregivers aged 40 years and younger had a difference in QoLA-A scores. No studies evaluating the age of the parents were found in the literature reviewed. However, in one study, it was stated that the duration of illness was associated with low quality of life (Alenazi, Hammad, & Mohamed, 2020). Considering this situation, it is considered that the longer exposure of the older caregiver to the disease may lead to these results.

The study showed that male participants had higher QoLA-A scores than female participants. The Volgyesi-Molnar et al. (2024) study showed that caregiver gender had a determinant effect on quality of life.

Similarly, Ten Hoopen et al. (2022) found that having a male gender (p = 0.016) was associated with a higher quality of life. In the study of Alenazi et al. (2020), it was determined that female gender was associated with poor quality of life but was not statistically significant. In the study, it was found that the QoLA-A scores of the mother caring for an autistic child were also lower. Volgyesi-Molnar et al. stated that fathers had higher scores than mothers on the QOLA-A scale and that fathers had a better quality of life. Mothers perceived the impact of ASD on their quality of life significantly more than fathers (Vernhet et al., 2022). It is thought that women may have a lower quality of life due to their social roles and the burden of motherhood and caregiving.

The results of the study show that, especially, the QoLA-A scores of university graduate caregivers are higher. Research results in the literature show that education level is a related and predictive factor for quality of life (Hsiao, 2018; Ten Hoopen et al., 2022; Volgyesi-Molnar et al., 2024). One of the protective factors for parental quality of life is parental education level (Turnage & Conner 2022).

In this study, it was found that private/public-sector employed caregivers had higher QoLA-A scores than housewives and self-employed participants. In the literature reviewed, only one study reported that occupation was associated with quality of life but was not a statistically significant variable (Alenazi et al., 2020). However, it may be necessary to interpret the findings together with income level. The QoLA-A scores of participants with an income level above the minimum wage were higher than those of participants with no income and participants with an income below the minimum wage. Many studies indicate that income level is an important predictor of quality of life (Alenazi et al., 2020; Alhazmi, Petersen, & Donald, 2018; Hsiao, 2018; Vasilopoulou & Nisbet, 2016). The caregiver's unemployment may make it easier to receive social support, but it could negatively impact income and quality of life. On the other hand, higher income levels could improve access to health and education services for child care, potentially enhancing the caregiver's quality of life. To tackle these issues, systems should be established to provide part-time or flexible work options for caregivers. Moreover, targeted financial assistance programs could enhance caregivers' financial security.

In this study, it was determined that the QoLA-A scores of caregivers of autistic children under the age of seven were higher than those of caregivers with children aged seven years and older. Unlike this study, Eapen et al. (2023) found no statistically significant difference between the age of the child with autism and QoLA-A scores. The researchers think that caregivers may have difficulties in terms of increasing needs with the growth of the child. Given the increasing demands related to aging, the establishment of state-supported mechanisms, such as guidance and counseling services, aimed at supporting caregivers emotionally, socially, and physically, could greatly improve their quality of life.

In addition, in this study, it was observed that the QoLA-A scores of caregivers without chronic illness were higher than those of participants without chronic illness. The history of chronic illness in mothers of children with autism was found to be associated with quality of life (Shu, 2009). No other findings evaluating caregivers' chronic diseases were found in the literature. However, it is estimated that perceived stress may increase in parents who are ill and may affect their quality of life (Hsiao, 2018). To better understand this relationship, future research could investigate the specific impacts of chronic illness on caregivers' stress levels and quality of life, and explore potential interventions to mitigate these effects.

When we evaluate the QoLA-B scores, it is seen that the QoLA-B scores of caregivers with no income are higher than the participants whose income is above the minimum wage, and the QoLA-B scores of the participants whose autistic child is seven years old and above are higher than the other groups. This is in line with the QoLA-A measurement results because these groups have a lower quality of life as they perceive the symptoms of the child with ASD as a problem to a great extent. Additional research could focus on identifying effective coping mechanisms and support systems for caregivers experiencing low income and those with older children, to better address their unique challenges and improve their overall quality of life.

Spirituality

In this study, the spirituality scores of caregivers are high. This shows that caregivers have the characteristics of spiritual coping, transcendence, spiritual life the search for meaning, spiritual contentment, and connection. Compared to other sub-dimensions, the dimension with the lowest score was found to be "harmony with nature".

Similar to the studies in the literature, the spiritual scores of families are high, and the positive thinking levels of families are an important predictor of spirituality (Ekas, Lauren Tidman, Lisa Timmons, 2019; Halki et al., 2024). In another study conducted with families of individuals with disabilities (n = 227), it was observed that families had a mean score of 106.20 ± 8.20 out of 120 full points (Alemdar, Yilmaz, & Günaydin, 2022). A qualitative study revealed that parents considered the child with ASL as a blessing from God, explained it as a reason for gratitude, and thought that special children have special families (Salkas, Magaña, Marques, & Mirza, 2016). It is thought that high spirituality scores may be related to the explained situations. In addition, Heydari, Shahidi, and Mohammadpour (2015) defined the spiritual journey in mothers as a process consisting of descent, connecting to deity, and ascent stages. In other words, although this process starts with painful stories, it continues with surrender and acceptance. Therefore, the scores obtained may also indicate that caregivers accept the disease and live a hopeful life. Building on these insights, future research could focus on evaluating the impact of spiritual acceptance on caregivers' mental health and resilience, and explore how fostering these aspects can enhance coping effectiveness.

In the study, the mean scores of the spirituality scale showed a difference according to the variables of gender of the caregiver and closeness to the autistic child. Due to the sociocultural structure of Turkey, mothers play an active role in raising children and are held responsible for the care of family members by society (Alemdar et al., 2022). In addition, mothers of children with ASD use more social support, problem-focused coping, and spiritual coping strategies than fathers, while fathers use more emotional coping (e.g., suppressing frustrations and avoiding family problems by going to work) (Lai & Oei, 2016). This may explain the higher mean spirituality scores of female caregivers and mothers in the study

Finally, a weak correlation was found between QoLA-A and the spirituality scores of caregivers of children with ASD. A moderate correlation was found only in the QoLA-A "spiritual contentment" sub-dimension. No correlational study evaluating the two variables together was found in the reviewed literature. However, in a study on parental well-being/stress, it was reported that spirituality was not an effective factor (Davis & Kiang 2020). In another study, on the contrary, a statistically significant positive relationship was found between effective coping with stress and spiritual coping ($p < 0.001$)

(Alemdar et al., 2022). Considering that stress is associated with quality of life (Parsaei, Roohafza, Feizi, Sadeghi, & Sarrafzadegan, 2020), it is thought that not the stress itself but the coping methods used to manage stress may be related to spirituality.

Limitations of the Study

While interpreting the results, it is important to consider the limitations associated with convenience sampling, such as potential selection bias. This study's limitation is its reliance on a sample of caregivers from only two rehabilitation centers who volunteered to participate. Future research could benefit from employing random sampling techniques to mitigate these biases and enhance the generalizability of the findings.

CONCLUSIONS AND RECOMMENDATIONS

As a result; while the quality of life of caregivers of children with ASD is above the middle level and could be improved, their spirituality levels are high. The relationship between the quality of life and spirituality levels of caregivers is weak. Quality of life scores differed according to variables such as age, gender, educational status, occupation, income level, proximity to the autistic child, chronic disease status, and age of the autistic child. To address these disparities and enhance the overall quality of life, it is recommended to develop and implement targeted support programs that are specifically tailored to the sociodemographic characteristics and unique needs of caregivers.

Sociocultural and economic initiatives/policies are needed to support caregivers who are female, older, have a low level of education, and especially those who do not have an income and/or are housewives, considering the variables that impact the quality of life scores.

Spirituality scores differed according to the gender of the caregiver and closeness to the autistic child. There is a need to empower men in terms of the coping strategies they employ.

The quality of life of caregivers of children diagnosed with ASD is at an improvable level. However, considering the weak relationship between spirituality and quality of life, it is recommended that the corrections to be made be evaluated in this direction. In future studies, the factors affecting the high spirituality levels of caregivers with children diagnosed with ASD can be investigated.

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Conflict of Interest

No conflict of interest has been declared by the authors

Ethical Approval

Institutional permission was obtained from Muğla Sıtkı Koçman University Health Sciences Ethics Committee (Protocol No: 210004, Decision No: 7, Date: 05.11.2021), as well as from the scale owners and two rehabilitation centers to conduct the study. Before collecting the study data, parents were briefly informed about the purpose and scope of the study. Those who voluntarily agreed to participate could proceed to fill out the questionnaires, while the study was terminated for those who did not.

Authorship Contribution Statement

MY: Conceptualization, Data analysis, Supervision, Writing-original draft, Writing-review & editing. RA and SK: Conceptualization, Data collection, Writing-original draft. All authors contributed to the drafting and finalizing of the manuscript preparation.

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