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Research Article / *Özgün Araştırma*

Investigating The Relationship Between Some Socio-Demographic Variables and Internalized Stigmatization and Care Burden of Primary Caregivers of Children with Autism Spectrum Disorder

Otizm Spektrum Bozukluğu Olan Çocukların Primer Bakım Vericilerinin Bazı Sosyo-Demografik Değişkenler ile İçselleştirilmiş Damgalama ve Bakım Yükü Arasındaki İlişkinin İncelenmesi

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ABSTRACT

***Purpose**: The study was conducted to examine the relationship between internalized stigma and care burden of primary caregivers of children with Autism Spectrum Disorder.*
***Method**: The study was conducted with 124 primary caregivers of children's who were diagnosed with Autism Spectrum Disorder. between April 1 and May 1. The Personal Information Form, Internalized stigmatization of Parents in Psychological Illness Scale, and Caregiver's Burden Scale were used to collect the data for the study. Pearson Correlation Analysis and Linear Regression Analysis were used in the analysis of the data.*
***Results**: A total of 88.0% of the caregivers of the children who had autism and who participated in the study were women and 31.2% were in the 35-40 age range. The result of the Regression Analysis made to determine the cause-effect relationship between the Internalized stigmatization of Parents in Psychological Illness Scale total score and the care burden was found to be significant (F=58.593; p=0.000<0.05). The total change in the level of caregiving burden was explained by the sum of Internalized stigmatization of Parents in Psychological Illness Scale at a rate of 31.7% (R2=0.317). Internalized stigmatization of Parents in Psychological Illness Scale increases the total care burden (ß=0.499). The result of the Regression Analysis made to determine the cause-effect relationship between the sub-dimensions of alienation, approval of stereotypes, perceived discrimination, social withdrawal, resistance to stigmatization and caregiving burden was found to be significant (F=11.424; p=0.000<0.05). The total change in the level of caregiving burden was explained by alienation, approval of stereotypes, perceived discrimination, social withdrawal, and resistance to stigmatization by 29.6% (R2=0.296). Among these, perceived discrimination (ß=0.621) and social withdrawal (ß=1.181) increase the level of caregiver burden (ß=1.181).*
***Conclusion**: Internalized stigmatization increases the care burden of caregivers of individuals with Autism Spectrum Disorder. It is recommended to repeat these variables in future studies with larger samples and studies with different designs.*

***Keywords:** Autism spectrum disorder, caregiver burden, primary caregiver, socio-demographical variables*

ÖZ

***Amaç**: Çalışma, Otizm Spektrum Bozukluğu olan çocuklara primer bakım verenlerin içselleştirilmiş damgalama ve bakım yükü arasındaki ilişkinin incelenmesi amacıyla yapılmıştır.*
***Yöntem**: Çalışma, 1 Nisan-1 Mayıs 2022 tarihleri arasında Otizm Spectrum Bozukluğu tanısı konulmuş çocukların 124 primer bakım verenleri ile gerçekleştirildi. Verilerin toplanmasında Kişisel Bilgi Formu, Ebeveynlerin Ruhsal Hastalıklarda İçselleştirilmiş Damgalanma Ölçeği ve Bakım Verme Yükü Ölçeği kullanıldı. Verilerin analizinde Pearson korelasyon analizi ve Lineer regresyon analizi kullanılmıştır.*

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***Bulgular**: Araştırmaya katılan otizmli çocuğa bakım verenlerin %88,0 kadın,%31,2'si 35-40 yaş aralığındadır. Ebeveynlerin Ruhsal Hastalıklarda İçselleştirilmiş Damgalanma Ölçeği toplam puanı ile bakım verme yükü arasındaki neden sonuç ilişkisini belirlemek üzere yapılan regresyon analizi anlamlı bulunmuştur (F=58,593; p=0,000<0.05). Bakım verme yükü düzeyindeki toplam değişim %31.7 oranında Ebeveynlerin Ruhsal Hastalıklarda İçselleştirilmiş Damgalanma Ölçeği toplamı tarafından açıklanmaktadır (R^2=0,317). Ebeveynlerin Ruhsal Hastalıklarda İçselleştirilmiş Damgalanma Ölçeği toplam bakım verme yükü düzeyini arttırmaktadır (ß=0,499). Ebeveynlerin Ruhsal Hastalıklarda İçselleştirilmiş Damgalanma ölçeğinin alt boyutları yabancılaşma, kalıp yargıların onaylanması, algılanan ayrımcılık, sosyal geri çekilme, damgalanmaya karşı direnç ile bakım verme yükü arasındaki neden sonuç ilişkisini belirlemek üzere yapılan regresyon analizi anlamlı bulunmuştur (F=11,424; p=0,000<0.05). Bakım verme yükü düzeyindeki toplam değişim %29.6 oranında yabancılaşma, kalıp yargıların onaylanması, algılanan ayrımcılık, sosyal geri çekilme, damgalanmaya karşı direnç tarafından açıklanmaktadır(R^2=0,296). Bunlardan algılanan ayrımcılık (ß=0,621), sosyal geri çekilme (ß=1,181) bakım verme yükü düzeyini arttırmaktadır (ß=1,181).*

***Sonuç**: Otizm Spektrum Bozukluğu olan bireylere bakım verenlerinde içselleştirilmiş damgalama bakım yükünü arttırmaktadır. Bu değişkenlerin daha geniş örneklem ve farklı desenlerdeki çalışmalarla tekrar edilmesi önerilir.*

***Anahtar kelimeler:** Otizm spektrum bozukluğu, bakım yükü, primer bakım veren, sosyo demografik değişkenler*

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder that appears in early childhood affecting social interaction and communication skills negatively (1,2). Although the exact cause of ASD is not known, it is a common disorder that requires the help of others and cannot be ignored (3,4). Some inappropriate behaviors can be observed in children who are diagnosed with autism when they are in social environments, such as aggression, crying fits, self-harming, damaging things and people, and taking things without asking permission, and are behaviors that caregivers have difficulty in overcoming (5).

The abilities and needs of individuals who have autism may change over time, some individuals can live independently, and some need lifelong care and support because of a serious disability (6). In this lifelong disorder, both individuals with ASD and their families who take care of them face many problems because of the inability to control obsessive and repetitive behaviors limiting their participation in social life (7). Parents mostly feel threatened and experience psychological problems because they do not know what to do (8). For this reason, being the parent of a child with ASD requires many correct moves from the birth of the child; responsibilities such as providing personal care for the child, meeting special needs, helping achieve various tasks, and ensuring that school life is not interrupted, and developing social life skills belong to the caregiver. In this respect, the parents, who are mostly in the caregiver position, consider this upbringing process of the child as a heavy burden and become open to encountering stress, depression, and anxiety disorders when they think that they can no longer support their children. Also, previous studies highlighted possible factors related to increased stress levels among parents of children with ASD, behavioral problems of the child, inadequate speech and language skills affecting communication, and academic difficulties of the child with ASD (9-11). The health of the parent of a child with ASD is important because of the role that the parent plays in terms of the psychological development of the child, aside from their own health (12). Because, it was reported that only 5-17% of individuals with autism who reach adulthood can continue their lives independently. In this context, there is a common point that parents are concerned about; "*When my child becomes an adult, will s/he be able to live as a free individual?*" For this reason, the caregiver may also be concerned about the social isolation of their children when they become adults. The scarce social assistance that individuals who struggle with autism in childhood can receive when they become adults, their inability to achieve economic independence, and the inability to engage in a full-time job are considered among the reasons directly increasing the care burden of the caregivers (13).

Another problem as important as the difficulties faced by families who have children with ASD is their exposure to stigmatization or their perception of stigmatization (14,15). In a previous study in which stigmatization was evaluated in families who had children with ASD, it was found that behavioral patterns specific to ASD were perceived as "weird" in society and reflected on the individual with ASD and their families with hurtful words and glances, which limited the social life of individuals with ASD and their families. Families also stated that they preferred to meet only with their close relatives and families with a disabled child whom they believed would understand and not judge themselves to avoid the judgment of society (16). The social and cognitive disabilities of children diagnosed with ASD can cause humiliation, social exclusion, isolation, and stigmatization for parents. In the Comprehensive Psychological Health Action Plan in Geneva on 19-24 May 2014, the World Health Organization aimed to eliminate the stigmatization, isolation, and discrimination that people with ASD and their families were exposed to and ensure their equal participation in life like other members of the society and decisions were taken in this regard. Parents blame themselves for their situation, isolate themselves from society, and can not show help-seeking behaviors. Stigmatization attitudes towards caregivers of individuals diagnosed with psychological illness cause worsening of the symptoms of the patient, poor disease management, depression, anxiety, burnout, and decreased quality of life in caregivers because of delayed medical support and decreased compliance with treatments (14,17-21).

In the light of this information, it can be argued that caregivers of individuals with ASD have perceptions of stigmatization and care burden, and this affects the health of caregivers negatively. In the present study, an answer was sought to the question of how the stigmatization perceived by caregivers affected the care burden because there has been an increase in the number of studies on the stigmatization of child and adolescent caregivers in recent years (11,16,20). However, studies examining the relationship between the internalized stigmatization of caregivers of children with ASD and the care burden are limited.

The study was conducted to determine the relationship between some sociodemographic variables and internalized stigmatization and the care burden of primary caregivers of individuals with Autism Spectrum Disorder (ASD).

METHODS

Research Design, Target Population, and the Sample

The study had a cross-sectional and correlational design examining the relationship between the internalized stigmatization of caregivers of children with ASD and the care burden. The population of the study consisted of the caregivers of children diagnosed with Autism Spectrum Disorder, who came to two special rehabilitation centers at the Directorate of National Education in XXXX in the Central Black Sea Region of Turkey in the 2021-2022 academic year. There were 250 caregivers with children with autism in both institutions. For this population, which was not homogeneous, the required sample size was calculated as N = 250 (1.96)2 (0.2) (0.8) / (0.5) with a sampling error of ± 5% at a 95% confidence interval by using the known sampling formula n = $250 (1,96)^2 (0,2) (0,8) / (0,5)^2 (250-1) + (1,96)^2 (0,2) (0,8)$ = 124 (22). The individuals who would constitute the sample were required to care for the child with ASD for at least one year and not have any diagnosed psychological disorders. The data were collected by using the face-to-face interview technique. The participants consisted of individuals who came to the institution on the dates of the study and agreed to participate in the study. A total of 23 people invited to the study said that they did not want to participate and were excluded from the study. The interviews were held in a special training room in the institution during the hours when the caregivers brought their children to the institution for education. Each interview lasted approximately 15-20 minutes.

Data Collection

The data were collected by using the Personal Information Form, Parents' Internalized stigmatization in Psychological Illness Scale (*ISPIMIS*), and Caregiver's Burden Scale (CBS).

Personal Information Form: This form consists of descriptive information about the caregiver and the patient in line with the literature data (11,23,24). The gender, age, educational level, marital status, gender of the person cared for, profession, age of the person cared for, the degree of closeness to the person with autism, the duration of caregiving, the status of receiving support in care with 18 questions, including 11 descriptive questions such as having a diagnosed disease status and one (1) open-ended question in which "*difficult situations in providing care*" are determined and five (5) questions on the child with ASD. These are the age and gender of the child with ASD, the closeness of the individual with autism, the presence of another chronic disease in an individual with autism, and the use of drugs for autism.

***Parents' Internalized stigmatization in Psychological Illness Scale (ISPIMIS)*:** Developed by Dikeç et al. (2020), the Parents' Internalized stigmatization in Psychological Illness Scale was used in the study (23). The scale consisted of 29 items in a 4-point Likert design, based on self-reporting. The scale has the following 5 subscales; "*alienation* (Items: 1,5,8,16,17,21)", "approval of stereotypes" (Items: 26,10,18,19,23,29)", "*perceived discrimination*" (Items: 3,15, 22,25,28)", "social withdrawal" (Items:

4,9,11,12,13,20)", "resistance to stigmatization" (Items: 7,14,24,26,27)". The items on the scale are answered as "I strongly disagree" (1 point), "I disagree" (2 points), "I agree" (3 points), and "I strongly agree" (4 points). The items of the resistance to stigmatization subscale (7,14,24-26) are reversely coded. The total ISMI score obtained by adding the five subscales ranges from 29 to 116 and there is no cut-off score for the scale. Higher scores indicate that the individual's internalized stigmatization is more severe in the negative direction. In this study, the total Cronbach Alpha value of the scale was calculated as 0.853.

The Caregiver's Burden Scale (CBS): The Caregiver's Burden Scale is a data collection tool that was developed by Zarit, Reever, and Bach-Peterson (1980) to evaluate the difficulties faced by caregivers and to uncover this situation. The adaptation studies of the scale into Turkish were conducted by Inci (2006) (27). The Caregiver's Burden Scale consists of 22 items applied without a time limit. The scale has a Likert-type rating that ranged between 0-4 as "never", "rarely", "sometimes", "often" and "almost always". A minimum score of "0" and a maximum score of "88" can be obtained from the scale, and a high score means a high level of distress (25). The version of the scale adapted to Turkish consisted of one dimension. The internal consistency coefficient of the scale was found to be 0.95. In the present study, the total Cronbach Alpha value of the scale was calculated as 0.875.

Statistical Analyses

The data obtained in the study were analyzed by using the SPSS (Statistical Package for Social Sciences) for Windows 22.0 program. The relationships between the dimensions of the scales of caregivers were examined through correlation and regression analyses. The T-Test, One-Way Analysis of Variance (ANOVA), and Post-Hoc (Tukey, LSD) analyzes were used to examine the differences in scale levels according to the descriptive characteristics of the caregivers. Numbers, percentages, mean values, and standard deviations were used as descriptive statistical methods. The kurtosis and skewness values were examined to determine whether the study variables had a normal distribution

Study Ethics

The study adhered to the principles of the Declaration of Helsinki. Written permission was obtained from the authors of the scales used in the study before the study was initiated. To conduct the study, the ethics committee approval was received with the decision number 2022-KAEK-32 on 23.03.2022 from the Clinical Research Ethics Committee of XXXX University Training and Research Hospital and written permission from the institutions where the study was conducted (12.03.2022\99923507-410-07/16 and 12.03.2022\999496851700/58). Oral and written informed consent was obtained from caregivers who agreed to participate in the present study.

RESULTS

A total of 88.0% of the caregivers of children with autism who participated in the study were female, 31.2% were in the 36-40 age range, 47.2% were primary school graduates, 96.0% were married, 65.6% were housewives, 65.6% had moderate income, 12.8% had someone else they cared for, 42.4% provided care for 1-5 years, 45.6% had not received information about autism, 14.4% of them had a diagnosed chronic disease, 28.8% of them had "*problems in social environments*", 23.2% of them had "*having trouble with approach*", 23.2% of them had "*Self-care issues and problem behaviors*" and 24.8% of them "*had problems in three areas*" (Table 1). When the sociodemographic characteristics of caregivers were evaluated, it was found that 76.8% were male, 48.8% were between the ages of 6-10, 48.8% had a moderate autism degree, 16.8% had a diagnosed chronic disease, and 51.2% did not use medication for autism (Table 1).

A positive and moderate correlation was detected between ISPIMIS and CBS total scores (r: 0.568, $p=0.000<0.05$). The mean, standard deviation, and minimum-maximum levels of the ISPIMIS and CBS scales are given in Table 2. The mean "ISPIMIS total of the caregivers was found to be 95.568±14.983 (Min=54; Max=130), and the mean CBS was 54.248±13.150 (Min=18; Max=80) (Table 2).

The result of the Regression Analysis made to determine the cause-effect relationship between the ISPIMIS total score and the care burden was found to be significant (F=58.593; $p=0.000<0.05$). The total change in the level of caregiving burden was explained by the total ISPIMIS of 31.7% ($R^2=0.317$). ISPIMIS increased the total care burden (ß=0.499). The result of the Regression Analysis made to determine the cause-effect relationship between the sub-dimensions of alienation, approval of stereotypes,

Table 1. The Differentiation of the Internalized Stigma and Care Burden Scores of the Caregivers According to Socio-Demographical Variables (N=125)

Groups	Frequency (n)	Percentage (%)	ISPMIS Total	CBS
Gender				
Female	110	88.0	95.29±15.13	54.65±13.30
Male	15	12.0	97.60±14.20	51.33±11.96
		Statistics / p	t: -0.558 p: 0.578	t:0.915 p:0.362
The age of the caregiver				
35 and below (smallest 24)	35	28.0	93.14±13.20	50.80±12.48
36-40	39	31.2	93.92±16.63	51.21±11.55
41-45	14	11.2	94.21±14.21	53.07±11.72
46-50	15	12.0	95.40±17.48	48.93±13.04
51 and above	22	17.6	103.32±11.62	69.50±5.23
		Statistics / p	F:1.901 p: 0.115 PostHoc= 3>1. 5>1. 3>2. 5>2. 3>4 (p<0.05)	F:12.589 p:0.000 PostHoc= 5>1. 5>2. 5>3. 5>4 (p<0.05)
Educational status				
Illiterate	8	6.4	98.63±19.51	52.00±4.57
Primary school	59	47.2	97.17±13.18	55.17±14.35
High school	43	34.4	94.86±15.38	56.42±12.00
University	15	12.0	89.67±17.70	45.60±11.59
		Statistics / p	F:1.147 p:0.333	F:2.850 p:0.040 PostHoc= 2>4. 3>4 (p<0.05)
Marital status				
Married	120	96.0	95.45±14.70	54.28±13.35
Separated/single	5	4.0	98.40±22.79	53.40±7.44
		Statistics / p	t:-0.430 p:0.668	t:0.147 p:0.884
Profession				
Housewife	82	65.6	96.34±14.40	56.55±13.02
Officer	25	20.0	96.56±15.65	49.12±12.40
Self-employed	9	7.2	87.33±15.18	49.11±15.30
Employee	9	7.2	94.00±18.05	52.67±9.97
		Statistics / p	F:1.050 p:0.373	F:2.713 p:0.048 PostHoc: 1>2 (p<0.05)

**All: 1,2,3. *All (1,2,3). F: Anova Test; t: Independent Groups T-Test; PostHoc: Tukey, LSD*

Table 1. Continued

Groups	Frequency (n)	Percentage (%)	ISPMIS Total	CBS
Economic situation				
Good	30	24.0	95.60±14.63	53.63±12.96
Moderate	82	65.6	94.63±14.93	54.27±13.56
Bad	13	10.4	101.38±15.95	55.54±11.67
		Statistics / p	F:1.142 p:0.323	F:0.094 p:0.910
The degree of proximity				
Son	88	70.4	94.98±15.50	54.33±12.56
Daughter	18	14.4	91.56±11.84	51.78±15.04
Grandson/Granddaughter	14	11.2	100.93±13.68	55.71±16.05
Niece/Nephew	5	4.0	105.40±15.13	57.60±9.21
		Statistics / p	F:1.827 p:0.146	F:0.373 p:0.772
Presence of another person cared for in the family				
Yes	16	12.8	97.88±14.17	56.56±11.07
No	109	87.2	95.23±15.13	53.91±13.44
		Statistics / p	t:0.658 p:0.512	t:0.753 p:0.453
Duration of care for a person diagnosed with autism (years)				
1-5	53	42.4	98.72±14.66	55.94±12.25
6-10	38	30.4	91.26±17.66	48.82±12.42
11 and above	34	27.2	95.47±10.85	57.68±13.77
		Statistics / p	F:2.820 p: 0.063	F:5.164 p: 0.007 PostHoc: 1>2. 3>2 (p<0.05)
Getting support from someone else in care giving				
Yes	14	11.2	100.71±18.13	52.86±14.88
No	111	88.8	94.92±14.51	54.42±12.98
		Statistics / p	t:1.369 p:0.174	t:-0.419 p:0.676
Receiving information on autism				
Yes	68	54.4	92.62±13.70	53.53±12.66
No	57	45.6	99.09±15.79	55.11±13.78
		Statistics / p	t:-2.453 p:0.016	t:-0.666 p:0.507

**All: 1,2,3. *All (1,2,3). F: Anova Test; t: Independent Groups T-Test; PostHoc: Tukey, LSD*

Table 1. Continued

Groups	Frequency (n)	Percentage (%)	ISPMIS Total	CBS
Difficulty in care giving				
Having problems in social settings[1]	36	28.8	93.94±16.40	50.19±10.57
Having approach problems[2]	29	23.2	89.34±16.17	49.55±12.80
Self-care problems and problematic behaviors[3]	29	23.2	97.03±12.03	51.38±13.42
All*(1,2,3)	31	24.8	101.90±12.29	66.03±8.43
		Statistics / p	F:4.023 p:0.009 PostHoc: 4>1. 3>2. 4>2 (p<0.05)	F:14.867 p:0.000 PostHoc: 4>1. 4>2. 4>3 (p<0.05)
The caregiver's diagnosed disease status				
Yes	18	14.4	102.22±15.36	64.33±11.93
No	107	85.6	94.45±14.70	52.55±12.62
		Statistics / p	t:2.063 p: 0.041	t:3.692 p: 0.000
Gender of the individual diagnosed with autism				
Female	29	23.2	100.41±12.87	56.28±11.87
Male	96	76.8	94.10±15.32	53.64±13.51
		Statistics / p	t:2.012 p:0.046	t:0.947 p:0.345
Age of the individual diagnosed with autism				
1-5	14	11.2	95.43±15.81	54.43±14.51
6-10	61	48.8	96.39±15.52	53.54±11.82
11 and above	50	40.0	94.60±14.33	55.06±14.47
		Statistics / p	F:0.195 p:0.823	F:0.182 p:0.834
Proximity of the individual with autism				
Mild	37	29.6	98.03±14.52	54.92±12.11
Moderate	61	48.8	94.72±15.74	53.07±14.49
Severe	27	21.6	94.11±13.96	56.00±11.41
		Statistics / p	F:0.720 p:0.489	F:0.530 p:0.590
Presence of another chronic disease in an individual diagnosed with autism				
Yes	21	16.8	101.95±13.89	63.43±11.55
No	104	83.2	94.28±14.93	52.39±12.71
		Statistics / p	t:2.173 p:0.032	t:3.681 p:0.000

**All: 1,2,3. *All (1,2,3). F: Anova Test; t: Independent Groups T-Test; PostHoc: Tukey, LSD*

Table 1. Continued

Groups	Frequency (n)	Percentage (%)	ISPMIS Total	CBS
Using drugs for autism				
Yes	61	48.8	97.00±15.43	55.64±13.50
No	64	51.2	94.20±14.54	52.92±12.77
Statistics / p			t:1.044 p:0.299	t:1.156 p:0.250

**All: 1,2,3. *All (1,2,3). F: Anova Test; t: Independent Groups T-Test; PostHoc: Tukey, LSD*

Table 2. The Mean ISPMIS and Caregiving Burden Scores

	Mean	SD	Min.	Max.	Kurtosis	Skewness
ISPMIS Total	95.568	14.983	54.000	130.000	-0.360	-0.316
Alienation	15.448	3.330	8.000	23.000	-0.831	-0.312
Confirming stereotypes	16.904	3.432	8.000	23.000	-0.402	-0.331
Perceived discrimination	14.096	2.638	8.000	20.000	-0.350	0.010
Social withdrawal	16.176	3.908	7.000	24.000	-0.431	-0.157
Resistance to stigmatization	14.664	2.652	6.000	20.000	0.535	-0.674
Burden of Caregiving (CBS)	54.248	13.150	18.000	80.000	-0.268	-0.541

Table 3. The Effect of Internalized Stigmatization on Burden of Caregiving

Dependent Variable	Independent Variable	ß	t	p	F	Model (p)	R^2
Burden of Caregiving	Constant	6.605	1.048	0.297	58.593	0.000	0.317
	ISPMIS Total	0.499	7.655	0.000			
Burden of Caregiving	Constant	10.701	1.462	0.146	11.424	0.000	0.296
	Alienation	0.505	1.117	0.266			
	Confirming Stereotypes	0.152	0.332	0.741			
	Perceived Discrimination	0.621	2.945	0.008			
	Social withdrawal	1.181	3.137	0.002			
	Resistance to Stigmatization	0.363	0.887	0.377			

Linear Regression Analysis, R2

perceived discrimination, social withdrawal, resistance to stigmatization and caregiving burden was found to be significant (F=11.424; p=0.000<0.05). The total change in the level of caregiving burden was explained by alienation, approval of stereotypes, perceived discrimination, social withdrawal, and resistance to stigmatization by 29.6% (R^2=0.296). Among these, perceived discrimination (ß=0,621) and social withdrawal (ß=1.181) increased the level of caregiver burden (ß=1.181) (Table 3).

DISCUSSION

Individuals with ASD live with their families, who become their primary caregivers. Families play important roles in the management of the disease processes of individuals with psychological illnesses, such as taking care of patients and participating in the treatment and rehabilitation processes. Because of these roles, people with psychological disorders are affected by stigmatization, they internalize the stigmatization, and their already difficult care burden increases even more (26). The data of the study, which was conducted to determine the relationship between some sociodemographic variables and internalized stigmatization and care burden of primary caregivers of individuals with ASD, were discussed in the light of the literature.

The majority of the caregivers of children with autism who participated in this study were female, under 40 years old, primary school graduates, married, housewives had moderate income levels, 12.8% had someone else they cared for, 42.4% had lived for 1-5 years with the individual cared for, 45.6% had not received information about autism, 14.4% of caregivers had a diagnosed chronic disease, 28.8% had “problems in social environments”, 23.2% had “approach problems”, 23.2% had “self-care problems and problematic behaviors”, and 24.8% “experienced problems in three areas”. In the study conducted by Khan et al. (28), it was reported that the caregivers of children with ASD were mostly female, between the ages of 31-40. In a previous study that investigated the needs of the parents of individuals with psychological disorders, it was reported that the parents were mostly married and had high school or higher education (29). In the study that was conducted by Dikeç et al. (23), it was reported that the majority of adolescents’ parents were married, female, and primary school graduates. It was reported in another study that the fathers of children diagnosed with ASD did not accept the diagnosis and did not participate in the care process of their children despite their physical presence, and women were left alone in the care of their children (30). As a result of traditional culture, women are given the responsibility of giving care and they have adopted this role based on the fact that they are mothers. For this reason, the burden of childcare generally falls on mothers in our country, not fathers. It can be argued that the descriptive characteristics of the participants in this study are similar to the descriptive characteristics of the participants in the other study.

In the present study, the majority of children with ASD were males, aged 6-10 years, had a moderate autism degree, 16.8% had a diagnosed chronic disease, and more than half did not use drugs for autism. ASD is a neuro-developmental disorder in early childhood affecting a lifetime (2). In the study that was conducted by Öz et al. (14), 58 (84%) of the 69 patients were boys and 11 (16%) were girls, and the mean age was 4.5±1.3. In previous studies that were conducted with adolescents, it was determined that adolescents were mostly males and more than half of them used their medications regularly (23,24). In a previous study that was conducted with parents, it was reported that their children were generally in the 10-16 age group, the physical health of their children was good, but their psychological health was moderate or below, and children were mostly diagnosed with two or more concomitant diseases (29). It was reported in the literature that ASD is more common in girls than boys (9,14). and 40.6% of adolescents do not fully comply with treatment (31). In line with these data, it can be argued that our findings are compatible with the literature data.

It was determined in the present study that the participants perceived internalized stigmatization above the average levels. Also, no significant differences were found between the sociodemographic variables of the caregivers of the autistic child, such as gender, educational status, marital status, occupation, economic status, having another caregiver in the family, duration of care, receiving support in caregiving, and total internalized stigmatization scores and subscale scores. There is no consensus in the literature on these variables. In the study of Kinnear et al. (32) conducted with the parents of 502 children with ASD, almost all parents reported stigmatization, and most of them experienced feelings of isolation and exclusion from their friends and families. There is a consensus in the literature that parents of individuals with ASD perceive moderate and higher stigmatization (14,33-42). Internalized stigmatization perception was also high in the majority of primary caregivers in the present study, supporting the findings of other studies reporting that stigmatization continues to be an important problem. In a previous study conducted by Minichil et al. (26) to evaluate the prevalence of perceived stigmatization and related factors among the primary caregivers of 408 children and adolescents with psychological diseases, it was determined that the participants faced stigmatization and that this stigmatization was significantly associated with being a mother, lack of another caregiver, poor social support, and depression symptoms. It was reported in the study conducted by Dikeç et al. that there were no significant differences in terms of internalized stigmatization scores between the variables of gender, educational status, economic status, and employment status of the adolescents and their parents who participated (23). In another study conducted by Öz et al. (14) with

69 mothers of children with ASD, it was reported that stigmatization scores decreased as the education level of the mother increased. Parents have key roles in children's access to psychological healthcare services (43). Stigmatization is an obstacle to help-seeking behavior (21). In addition to dealing with the symptoms and consequent difficulties of a child in academic and interpersonal functioning, parents face pressures to cope with or avoid stigmatization reactions from others. For such parents, dealing with stigmatization can be more troublesome than dealing with the difficulties of the disorder itself (44). For this reason, it has vital importance to diagnose the stigmatization faced by these individuals and to determine strategies to cope with stigmatization.

It was determined in the present study that the participants perceived a care burden above the average level. Also, there were significant differences between the caregiver burden of those with a pre-existing disease, the caregiver burden scores of caregivers who had chronic illnesses in their children with autism, the caregiver burden scores, the caregiver's age of 51 and above, the educational level of high school and below, those who were housewives, the duration of caregiving being 11 or more years, the response of "all" to all three areas determined as the field that had difficulty in caregiving. It was reported in the literature that caregivers of children with ASD have a moderate or higher care burden (28,30,45-50). In their study conducted to determine the perceived care burden of primary caregivers of children or adolescents with ASD, Jain et al. (46) found that caregiver's burden was affected by the caregiver's place of residence, family type, socioeconomic status, age at diagnosis, the severity of autism, and level of knowledge about autism. In another study, it was determined that maternal age, income status, health problems, the time elapsed after the diagnosis of autism, having a disease other than autism, and the child's autism level increased the care burden in mothers of children followed up with autism diagnosis, but the mother's education and employment status, marital status, presence of social security and health perception, family type, education about autism, and being a helper in care did not affect the care burden (8). In this study, it was reported that housewife caregivers and those whose education level was high school or below had a higher care burden. Vilanov et al. (30) reported that housewife mothers who cared for individuals with ASD perceived a higher care burden than mothers who worked outside the home. Datta et al. (51) reported in their study that as the education level of caregivers decreased, their perception of burden increased. It is already known that the majority of university graduates work outside the home in a job that generates income, and women with high school or lower education were mostly housewives. Working outside the home can make the individual feel productive and efficient, moving away from the patient and the environment during the day can make the individual feel better, and because going to work allows the individual to earn money, the needs of the individual being cared for can also be covered more easily. In this context, it is considered that it is understandable that the burden perceived by housewives is higher. Similar to the results of the present study, Nagaraju and Wilson (52) reported that the care burden increased as the age of the mother increased.

As the individual grows old, health issues increase and energy decreases. For this reason, it can be argued that the increasing age of the caregiver aggravates the care burden. In the present study, it was found that the care burden increased in those with a caregiving period of 11 years or more. It was determined in a previous study conducted with palliative care patients that the caregiver's care burden and age, the degree of closeness to the patient, the time involved in the care of the patient, receiving support from someone in giving care, the area of difficulty while giving care, and the daily care duration were found to be important. Also, the uninterrupted attention of the caregivers to the patient may cause them to postpone their responsibilities and needs (53). In the literature, this finding was studied as the age of diagnosis of the individual with ASD. The care burden was found to be higher in mothers whose children were diagnosed with early ASD because every parent may want that his/her child whom s/he sees as the work s/he will leave to this world to be perfect (47). Such individuals experience emotional burdens when a disorder develops in their children. Especially when this disorder occurs at an early age, parents face negative feelings about their children such as hopelessness. For this reason, it can be argued that the earlier the diagnosis is made, the greater the burden is. Unlike the present study, in another study, it was reported that the perceived care burden increased as ASD symptoms increased (50). Similar results were obtained in the present study. It was found that children with autism increased the caregiving burden scores of those with chronic disease. ASD is a lifelong neurodevelopmental condition characterized by social and communication disorders (54). In the literature, it is reported that Autism Spectrum Disorder is often accompanied by other medical conditions such as cognitive deficits, gastrointestinal disorders, attention deficit and hyperactivity disorder, sleep disorder, epilepsy, etc (29,55-57). These diseases aggravate the conditions and impose additional burdens on the caregiver. On the other hand, the presence of chronic diseases also increases perceived stigmatization. This can be considered the caregiver's thought that the probability of being well for the individual with ASD is low, and hopelessness replaces expectations for the future. One of the other results of the present study was that the female gender of the individual with ASD increased internalized stigmatization, but the care burden did not change. In traditional cultures, the idea of "healing when married" is dominant and the individual is married to "heal". In our country, in marriage, the choice of spouse generally belongs to the male side. The male side can choose a spouse for their child despite the illness, but when girls are diagnosed with a psychological illness while they are already weak in our society, where the status of women is inferior to that of men, and because of the prevailing opinion in our society that they will never be able to marry or work, and that they are lifelong caregivers, there is a greater concern for stigmatization. In this context, to reduce the perceived burden on the families, it is important to inform the families correctly so that caregivers can reach the treatment and get the maximum benefit from the treatment. Because having insufficient knowledge of ASD affects parental approaches toward children negatively. In short, there is no complete consensus in the literature on descriptive variables. For this reason, studies must be increased in terms of quality and quantity for more accurate results.

In the present study, it was found that there is a relationship between internalized stigmatization and care burden, and stigmatization increases the care burden. It was especially determined that the perceived discrimination and social withdrawal sub-dimensions of the ISPMIS were related to the care burden and increased the care burden. In the literature, stigmatization and care burden were studied separately in studies conducted with children of families with ASD, and no study that examined these two variables together could be found. In the literature, in a previous study conducted with individuals who had chronic psychological disorders, it was found that internalized stigmatization increases the care burden (20). In the study by Mehra et al. (58) conducted with 116 caregivers of individuals with psychological diseases, it was found that internalized stigmatization increases the care burden. It is also stated in the literature that the high care burden of children who develop differently causes social isolation in the family, and this causes low motivation for individuals to express their feelings Children and their families are exposed to stigmatization and socially isolate themselves because of ASD symptoms (44). Since parents cannot control their children's behaviors such as shouting and crying in public, they withdraw from social life by staying at home. Also, parents sometimes tend to hide the disease to protect their children and themselves from stigmatization (42) because parents with autistic children are overwhelmed by their stigmatization reactions, and feel pressure and want to avoid supportive groups and programs (59). Also, when parents direct these negative emotions to their children with psychological disorders, this can be even more devastating for individuals who have psychological disorders than social exclusion or stigmatization (23,24). In the light of these data, it is important to reduce or eliminate stigmatization in every attempt to alleviate the burden of the caregiver (58), support the individual and family to maintain functionality in society, and educate the society to empathize with the differences (60).

Strengths and Limitations

The limitation of the study was that the results cannot be generalized because the study was conducted in one single city and only in two centers. The strength of the study was that both internalized stigmatization and the care burden were evaluated together for caregivers of individuals with ASD.

CONCLUSION AND RECOMMENDATIONS

In the present study, the caregivers of children who had autism and who participated in the study were mostly female, mothers of the children, under 40 years old, primary school graduates, married, housewives, middle-income individuals, and individuals with ASD were mostly male, between the ages of 6-10, with a moderate-high autism degree and did not use drugs for autism. It was found that the participants' care burden and perceived and internalized stigmatization increased the care burden, especially perceived discrimination and social withdrawal increased the level of caregiving burden.

The stigmatization perceived by adolescents and parents must be determined at the start of treatment and during the continuation of the treatment because stigmatization is among the biggest obstacles to treatment. Untreated psychological illness in adolescence can cause social, behavioral, and academic problems, worsening of symptoms or impairments, other health comorbidities, suicidal behaviors, and chronic disease onset in adults Today, adolescents and their families still need psychological healthcare, and adolescents and their families cannot effectively benefit from such healthcare services, especially because of stigmatization even in developed and rich countries. It was reported in previous studies that adolescents and their families express their need for counseling, knowledge, and skills training more than drug treatment. These services must be expanded in the healthcare system and included in treatment guidelines. It is recommended to repeat these variables in future studies to be conducted with larger samples and different designs.

Recommendations for Further Research

Autism Spectrum Disorder is a frequent and chronic disorder in children and adolescents. Since the disorder affects the younger age group, it causes disability and is a chronic, internalized stigmatization and care burden on families. In parents, stigmatization delays the initiation of medical treatment and increases the severity of symptoms. This also increases the burden of stigmatization and care, affecting the health of caregivers negatively. Psychological health and psychiatric nurses have an important position in improving the health of the individual, family, and society. To reduce the care burden for children with ASD and their families and improve their health, they must develop and implement programs based on knowledge and skills in combating stigmatization, evaluate their effectiveness and make necessary revisions..

Author contribution

Research idea and design: HK, FG; data collection: HK; analysis and interpretation of results: HK, FG; research manuscript preparation: FG, HK. All authors reviewed the research results and approved the final version of the research.

Ethical approval

The study was approved by the Kastamonu University Clinical Research Ethics Committee (Protocol no. 2022-KAEK-32/23.03.2022).

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Conflict of interest

The authors declare that there is no conflict of interest.

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