Original Research / Orijinal Araştırma

Turkish Adaptation of the Family Stigma Stress Scale for Caregivers of Individuals with Neurodegenerative Diseases: A Validity and Reliability Study

Nörodejeneratif Hastalığı Olan Bireylerin Bakım Verenlerinde Aile Damgalanma Stresi Ölçeği'nin Türkçe Uyarlaması: Geçerlik ve Güvenirlik Çalışması

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Abstract

Objective: Family caregivers of individuals with neurodegenerative diseases such as Alzheimer's, dementia, and Parkinson's often face stigma stress, which adversely affects their mental health. This study aimed to adapt the Family Stigma Stress Scale (FSSS) into Turkish and evaluate its validity and reliability.

Materials and Methods: This methodological study recruited 87 family caregivers online between March and August 2025. Sociodemographic data were collected, and the Turkish version of the FSSS was applied following translation, back-translation, expert review, and pilot testing. Construct validity was evaluated using Confirmatory Factor Analysis (CFA). Reliability was tested through Cronbach's alpha, item–total correlations, test–retest, and split-half methods.

Results: The Turkish FSSS preserved the original two-factor and eight-item structure. Confirmatory factor analysis indicated good model fit. Reliability analyses, including Cronbach's alpha, item–total correlations, and test–retest (r=0.92, p≤0.001), demonstrated high internal consistency and stability.

Conclusion: The Turkish version of the FSSS is a valid and reliable tool for assessing stigma stress in family caregivers of individuals with Alzheimer's, dementia, and Parkinson's disease. It can also help identify psychosocial risks, evaluate resilience, and guide community-based interventions to reduce stigma.

Keywords: Caregivers, stress, stigma, neurodegenerative diseases

Özet

Amaç: Alzheimer, demans ve Parkinson gibi nörodejeneratif hastalıklara sahip bireylerin aile bakım verenleri, genellikle ruhsal sağlıklarını olumsuz etkileyen damgalanma stresine maruz kalabilmektedir. Bu çalışma, Aile Damgalanma Stresi Ölçeği'nin (FSSS) Türkçe'ye uyarlanmasını ve geçerlik-güvenirliğinin değerlendirilmesini amaçlamıştır.

Gereç ve Yöntem: Bu metodolojik çalışma, Mart–Ağustos 2025 tarihleri arasında çevrim içi olarak ulaşılan 87 aile bakım vereni ile yürütülmüştür. Sosyodemografik veriler toplanmış, FSSS'nin Türkçe formu çeviri, geri çeviri, uzman görüşü ve pilot uygulama aşamalarından sonra uygulanmıştır. Yapı geçerliği, Doğrulayıcı Faktör Analizi (DFA) ile test edilmiştir. Güvenirlik ise Cronbach alfa, madde–toplam korelasyonları, test–tekrar test ve iki yarım yöntemleri ile değerlendirilmiştir.

Bulgular: Türkçe FSSS, orijinaldeki iki faktörlü ve sekiz maddelik yapıyı korumuştur. DFA iyi uyum göstermiştir. Cronbach alfa, madde–toplam korelasyonları ve test–tekrar test (r=0,92, p≤0,001) sonuçları ölçeğin yüksek iç tutarlılık ve kararlılığa sahip olduğunu göstermiştir.

Sonuç: FSSS'nin Türkçe formu, Alzheimer, demans ve Parkinson hastalarının aile bakım verenlerinde damgalanma stresini değerlendirmek için geçerli ve güvenilir bir ölçme aracıdır. Ölçek, psikososyal risklerin belirlenmesine, bakım verenlerin dayanıklılık ve baş etme stratejilerinin değerlendirilmesine ve damgalanmayla mücadeleye yönelik toplum temelli girişimlerin geliştirilmesine katkı sağlayabilir.

Anahtar Kelimeler: Aile bakım verenleri, damgalanma stresi, nörodejeneratif hastalıklar

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Introduction

Dementia, Alzheimer's, and Parkinson's are neurodegenerative diseases that are distinguished by their progressive cognitive decline, loss of motor function, and reliance on daily living activities. These diseases have a profound effect not only on the patients, but also on their family caregivers. According to reports, the global prevalence of dementia was approximately 57 million in 2021, and it is anticipated that this figure will surpass 139 million by 2050. It is estimated that Alzheimer's disease is responsible for 60–70% of these cases.[1] According to the Global Burden of Disease Collaborative Network report, the global prevalence of Parkinson's disease increased by 274% between 1990 and 2021, reaching approximately 11.8 million cases as of 2021.[2] Family members are subjected to severe psychosocial stress, burnout, and poor mental health hazards as a result of the long-term and multidimensional care that is necessary to treat these diseases.[3] Stigmatization is the term used to describe the process by which society subjects individuals or their relatives to negative judgments, exclusion, and discrimination. This can result in caregivers enduring depression, social isolation, and a decrease in their quality of life.[4,5,6]

Studies in different countries have recently revealed that caregivers are exposed to both the exclusionary attitudes of society and the stigma they themselves internalize.[7,8] Stigma is particularly pronounced in neurodegenerative diseases, and in Parkinson's and Alzheimer's care, this situation is associated with weakened social relationships, mental distress, and delays in accessing health services.[9,10] Global reports also emphasize that stigma continues to be a significant barrier in dementia care.[11,12] These results reveal that reliably measuring the stigma-related stress experienced by family caregivers is critical for supporting both individual mental health needs and policy development processes. Chang et al. (2017) identified this gap and created the Family Stigma Stress Scale (FSSS), a quick and useful tool for identifying stigma-related stress in family caregivers. The FSSS was developed based on Rüsch et al.'s (2009) stress-coping model of mental illness stigma, which posits that stigma stress arises when the perceived harm of stigma exceeds one's coping resources. The scale enables early recognition of stigma-induced psychological strain and supports the planning of caregiver-focused interventions. It has demonstrated good psychometric properties in Taiwanese samples (Cronbach's α = 0.85; test–retest r = 0.66) and has been used internationally to assess caregivers' experiences of stigma-related stress.[13] However, there is no valid and reliable measurement tool in Turkey to meet this need. Therefore, this study was conducted to evaluate the validity and reliability of the Turkish version of the FSSS.

Methods

Study Design

This study was conducted using a methodological design to adapt the FSSS to Turkish and evaluate its validity and reliability.

Study Process and Sample

The study was conducted online between March 5 and August 10, 2025. The population consisted of relatives of individuals with Alzheimer's disease, dementia, or Parkinson's who were members of a disease-specific social media platform. Participants were recruited through a research invitation posted on the platform, and voluntary respondents were included.

Inclusion criteria were: being ≥18 years, actively involved in caregiving, and having no mental or communication disabilities. The sample size was determined according to recommendations of 5–10 participants per item. As the FSSS has 8 items, at least 40–80 participants were required. The study was completed with 87 caregivers, meeting the adequacy for factor analysis.

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Table 1. *Sociodemographic Characteristics of Family Caregivers (n = 87)*

Variables		N	%
Gender	Female	57	65.5
	Male	30	34.5
Educational Status	Primary School	7	8.0
	Middle School	11	12.6
	High School	42	48.3
	University	24	27.6
	Postgraduate	3	3.4
Marital Status	Single	19	21.8
	Married	63	72.4
	Divorced/Widowed	5	5.7
Occupation	Unemployed	17	19.5
	Student	11	12.6
	Public Sector Employee	14	16.1
	Private Sector Employee	4	4.6
	Self-employed	15	17.2
	Retired	26	29.9
Income Level	Income less than expenses	28	32.2
	Income equal to expenses	46	52.9
	Income more than expenses	13	14.9
Place of Residence	Village	7	8.0
	District	28	32.2
	Province/City	52	59.8
Age	Mean±SD	47.19±14.60	
	Min-Max	19.00-79.00	

Table 2. *Characteristics of Caregivers Related to Caregiving (N=87)*

Variables		N	%
Relationship with the Care Recipient	Parent	49	56.3
	Spouse	11	12.6
	Sibling	15	17.2
	Child	4	4.6
	Other	8	9.2
Diagnosis of the Care Recipient	Alzheimer's	59	67.8
	Dementia	15	17.2
	Parkinson's	13	14.9
Duration of the Care Recipient's	0-6 months	24	27.6
	6 months-1 year	15	17.2
	1-3 years	15	17.2
	3-5 years	13	14.9
	5 years and above	20	23.0
Duration of Caregiving	1-3 hours	32	36.8
	4-6 hours	17	19.5
	7-9 hours	10	11.5
	10 hours and above	28	32.2
Most Challenging Area During Caregiving	Behavioral problems	27	31.0
	Assistance with daily living activities	26	29.9
	Need for constant supervision	22	25.3
	Providing psychological support	12	13.8
Main Reason for the Decision to Provide Care During the Illness Process	No other support within the family	34	39.1
	Feeling responsible	44	50.6
	Feeling ashamed by others	9	10.3
Status of Experiencing Stigma During Caregiving	Yes	30	34.5
	No	57	65.5
Status of Receiving Support from Family or Social Circle	Yes	54	62.1
	No	33	37.9
Status of Receiving Professional Support During Caregiving	Yes	26	29.9
	No	61	70.1

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Table 2(continued). *Characteristics of Caregivers Related to Caregiving (N=87)*

Status of Ensuring Patient Supervision During Caregiving	I provide constant supervision	42	48.3
	I have taken safety measures at home	19	21.8
	I do not take any special safety measures	14	16.1
	I sometimes have to leave them alone	12	13.8
Impact of the Caregiving Process on Work, Social Life and Personal Time	Completely affects negatively	33	37.9
	Partially affects	43	49.4
	Does not affect	11	12.6
Condition of the Care Recipient's Illness Process	Stable	32	36.8
	With periods of exacerbation	22	25.3
	Constantly deteriorating	24	27.6
	Showing signs of improvement	9	10.3
Status of Receiving Information and Education About the Illness	Yes, I have sufficient knowledge	37	42.5
	Partly knowledgeable	42	48.3
	No, I need information	8	9.2
Most Frequently Felt Emotions During Caregiving	Constant stress and anxiety	26	29.9
	Occasional exhaustion	29	33.3
	I feel neutral	19	21.8
	I cope with it easily	13	14.9
Status of Feeling Supported During the Caregiving Process	I do not feel supported at all	20	23.0
	I feel partially supported	50	57.5
	I feel adequately supported	17	19.5

Family Stigma Stress Scale (FSSS): Chang et al. (2017) created the FSSS to gauge stigma-related stress in family caregivers of people with mental illness. It has eight items and two subscales: Perceived Coping Resources (items 5–8) measures perceived coping adequacy, scored in reverse, and Perceived Harm (items 1–4) measures the detrimental effects of stigma. A 4-point Likert scale is used to rate responses, with 1 denoting strongly disagree and 4 denoting strongly agree. Greater stigma stress is indicated by higher total scores, which range from 8 to 32. The range of subscale scores is 4–16. Because of reverse coding, lower Coping Resources scores indicate stronger coping, while higher Perceived Harm indicates greater burden.[15]

A two-factor structure with high internal consistency (α=0.91 and 0.81) and moderate test-retest reliability (r=0.62 and 0.53) was confirmed by the initial validation.

Data assessment

The Statistical Package for the Social Sciences (SPSS) 25 and Analysis of Moment Structures (AMOS) 22 programs were used to evaluate the data obtained in the study. Descriptive statistics summarize sociodemographics. Reliability was evaluated with Cronbach's α and item–total correlations. Confirmatory Factor Analysis (CFA) tested the two-factor model, with fit indices (χ^2/df, RMSEA, CFI, TLI, GFI, IFI) used to assess model adequacy. A p-value ≤0.05 was considered significant.

Psychometric assessment of the scale

Validity

Language validity

Two independent bilingual translators translated the scale into Turkish. Two native English speakers back-translated it into English following comparison and reconciliation. Five nursing experts reviewed the pre-final version after disagreements were settled. The final Turkish version was established following a pilot test with 20 caregivers to ensure clarity.[14,16,17]

Content validity

The Davis method was used to calculate the Content Validity Index (CVI). Items were rated by experts using a 4-point rating system. Adequacy was confirmed by a CVI of 0.92, and nothing was taken out..[14,18,19,20]

Construct validity

Construct validity was assessed through CFA. CFA confirmed the theoretical structure, with fit indices meeting acceptable thresholds (χ^2/df ≤5, RMSEA ≤0.08, CFI/TLI/IFI ≥0.90, GFI ≥0.85) [20,21]

Reliability

Cronbach's α, item-total correlations, test-retest, and split-half methods were used to assess reliability. A Cronbach's α of at least 0.70 was deemed acceptable. The expected item-total correlations were ≥0.30. Test–retest reliability was evaluated in a subsample of 50 caregivers selected from the main study sample. The scale was administered twice at two-week intervals, and correlation coefficients were calculated. By comparing two equal halves of the scale, the split-half method assessed internal consistency.[23,24,25]

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Ethics of the study

Permission for the Turkish adaptation of the FSSS was obtained from the original developers. Ethical approval was granted by the Non-Interventional Clinical Research Ethics Committee of Yalova University (Protocol No: 2025/69, Date: 05.03.2025). The study complied with the Declaration of Helsinki, and informed consent was obtained from all participants.

Results

Among the 87 caregivers, 65.5% were female, 72.4% married, and 48.3% high school graduates. Nearly one-third were retired, and more than half reported that their income equaled their expenses (Table 1).

Most participants provided care for individuals with Alzheimer's disease (67.8%), followed by dementia (17.2%) and Parkinson's disease (14.9%). Care recipients were mainly parents (56.3%), and nearly one-fourth had been diagnosed for more than five years. Daily caregiving varied, with 36.8% providing 1–3 hours and 32.2% providing 10 hours or more. The main challenges were behavioral problems (31.0%) and assistance with daily activities (29.9%). Responsibility was the primary reason for assuming the caregiving role (50.6%), and about one-third reported experiencing stigma. While family and social support were common (62.1%), only 29.9% received professional help. Caregiving frequently led to exhaustion (33.3%) and persistent stress or anxiety (29.9%) (Table 2).

Validity

Confirmatory Factor Analysis (CFA)

In the DFA conducted to confirm the factor structure of the scale, the fit indices were calculated as $X^2/df=2.378$, RMSEA=0.058, NFI=0.945, CFI=0.973, IFI=0.974, TLI=0.942, GFI=0.919, and RMR=0.046. These values indicate that the model fits at an acceptable level (Table 3, Figure 1). As a result, it was confirmed that the scale's structure, consisting of eight items and two factors, consistent with its original form, is also valid in Turkish culture.

Table 3. *FSSS confirmatory factor analysis results*

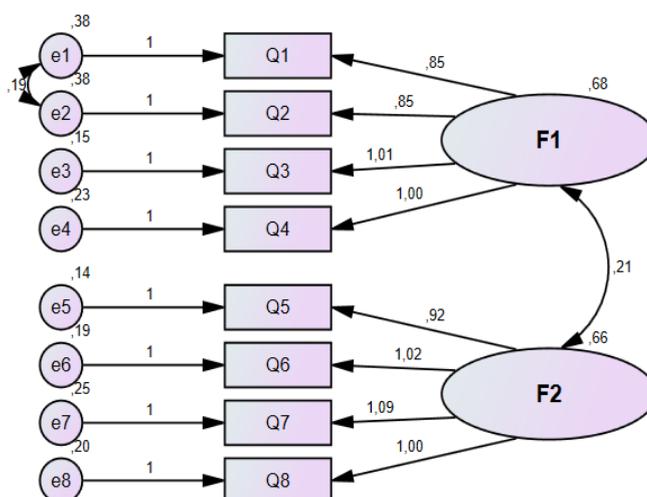| Model Fit Criteria	Estimated	Appropriate	Acceptable
X^2/df	2.378	≤3	≤5
Comparative Fit Indices			
RMSEA	0.058	≤0.05	≤0.08
NFI	0.945	≥0.95	≥0.90
CFI	0.973	≥0.97	≥0.95
IFI	0.974	≥0.95	≥0.90
TLI	0.942	≥0.95	≥0.90
Absolute Fit Indices			
GFI	0.919	≥0.90	≥0.85
Residual-based Fit Indices			
RMR	0.046	≤0.05	≤0.08

Figure 1. *PATH diagram regarding the factor structure of the scale*
Chi-square=66.584, df=28, p=0.000, RMSEA=0.058.
F1= Perceived harm
F2= Perceived coping resources

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Reliability

The reliability of the scale was assessed using different methods. Cronbach's alpha was 0,86 for the entire scale, 0.90 for the Perceived Harm subscale, and 0.93 for the Perceived Coping Resources subscale. Item–total correlation coefficients ranged from 0.53 to 0.71. Factor loadings ranged from 0.78 to 0.84 (Table 4). The test–retest correlation over two weeks was 0,92 and split-half analysis revealed a strong relationship between the two halves of the scale (p≤0.05).

Table 4. *Item-total score correlation coefficients, factor loadings alpha coefficients and explained FSSS variance*

Item	Mean (SD)	Factor Load	Corrected item total correlations	Cronbach's alpha if item deleted
1	2.21 (0.93)	0.78	0.53	0.85
2	2.33 (0.93)	0.78	0.62	0.84
3	2.37 (0.91)	0.79	0.60	0.85
4	2.41 (0.95)	0.75	0.61	0.85
5	2.44 (0.84)	0.84	0.65	0.84
6	2.51 (0.93)	0.84	0.60	0.85
7	2.56 (1.01)	0.82	0.71	0.83
8	2.60 (0.93)	0.84	0.59	0.85
Cronbach's alfa				Total: 0.86 F1: 0.90 F2: 0.93

Discussion

Currently, there is no valid and reliable scale available in Turkey for assessing the stigma stress that family caregivers experience. Therefore, this study was conducted to examine the validity and reliability of the FSSS in Turkish.

The study included 87 family members caring for individuals diagnosed with neurodegenerative diseases such as Alzheimer's, dementia, or Parkinson's. The original scale was developed in Taiwan on 300 family members caring for individuals with mental illnesses such as schizophrenia, bipolar disorder, and major depression.[15] Although the original scale was developed for caregivers of individuals with mental illness, stigma-related stress mechanisms are conceptually similar in neurodegenerative diseases, which justified its cross-diagnostic adaptation. Caregivers in Turkey and Taiwan are similarly characterized as mostly middle-aged women however cultural differences lead to variations in family roles and caregiving patterns. Despite these variations, the results confirm that the FSSS is a valid and reliable measurement tool across both cultures, with its two-factor structure aligning with the original scale and other cross-cultural psychometric evaluations.[21,26]

The effect of the stigma experience on caregivers' mental health has been addressed in the literature in various dimensions. Bhatt et al. (2022) reported that caregivers often endorsed 'stigma by association' while showing lower levels of emotional and behavioral affiliate stigma, suggesting that some may resist internalizing stigma.[4] Su and Chang (2020), in their study conducted in Taiwan, found that a high caregiving burden was associated with more severe affiliate stigma and that rates of depression and anxiety were also high in this group. It has been reported that male and young caregivers, in particular, experience more intense stigma [5]. These results indicate that the FSSS is not only a psychometrically reliable measurement tool but also has clinical value in predicting caregivers' mental health risks. Data obtained from different regions recently support these results. Evidence from Uganda and China also supports these findings, showing high levels of affiliate stigma associated with caregiver burden, depression, and limited social support.[7,8] Studies of Parkinson's disease show that the pronounced stigma associated with neurodegenerative diseases leads to social isolation and psychological distress, but also highlight the mitigating role of support groups.[9,10] Global reports, including The Lancet Commission on Dementia[11] and The Lancet Neurology[12], emphasized that dementia-related stigma contributes to social isolation, reduced quality of life, and delays in accessing care, particularly in low- and middle-income countries. This may indicate that the caregiving role strengthens social bonds, greater resilience and a reduced vulnerability to the negative effects of stigma.[4] Overall, these findings highlight that the FSSS can be used not only to identify risks but also to explore resilience and positive coping strategies among caregivers.

Limitations

This study has some limitations. Data were collected through an online survey, which may have limited participation to caregivers with internet access and higher digital literacy. The use of a convenience sample also restricts the generalizability of the findings.

Conclusion

This study examined the validity and reliability of the Turkish adaptation of the FSSS. Reliability analyses confirmed high internal consistency. The scale is therefore an important tool for assessing stigma stress in

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caregivers of individuals with Alzheimer's, dementia, or Parkinson's, as well as for predicting mental health risks, understanding resilience, and guiding community-based interventions to combat stigma.

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