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VALIDITY AND RELIABILITY OF TURKISH VERSION OF FEAR OF ALZHEIMER'S DISEASE SCALE (FADS)

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Abstract

The aim of the study is to evaluate the validity and reliability of Turkish version of the Fear of Alzheimer's Disease Scale (FADS). In the methodological study, the data of the study were collected by a questionnaire consisting of socio-demographic information, questions about dementia experience and FADS Turkish form. The sample of the study is a total of 310 adults aged 50 years and over. The validity of the scale was assessed by content validity, construct validity and predictive validity. In order to test the reliability of the scale, test-retest reliability, internal consistency coefficient, and item-total correlation coefficients were calculated. The mean of FADS scores of participants calculated as 43.48 ± 22.49 . Kendall's W coefficient was calculated as 0.92 (p<0.05). The results of the Explanatory Factor Analysis revealed that there were 3 factors explaining 68.68% of the total variance of the scale. The results of the reliability analysis showed that the test-retest reliability correlation coefficient was 0.96, the Cronbach alpha coefficient was 0.95, and the correlations of the items with the total score were above the standard value of 0.40. It was concluded that the Turkish version of FADS was a reliable and valid scale with adequate psychometric properties.

Keywords: Alzheimer's Disease, Anticipatory Dementia, Fear, Reliability, Validity.

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INTRODUCTION

Dementia, one of the diseases with the highest increase in frequency and prevalence in aging societies, is a progressive and irreversible neurodegenerative disease (Lonie et al. 2009, Du & Hu 2016). It is estimated that there were approximately 47.5 million individuals with dementia in the world as of 2015, and 9.9 million new cases of dementia develop each year (Prince et al. 2015). Alzheimer's disease is the most common type of dementia and accounts for approximately 60-80% of all dementia cases (World Health Organization [WHO] 2012). Alzheimer's disease is a brain disease that is manifested by deterioration in upper cortical functions such as memory, abstract thinking and decision making, the etiology of which is not yet fully known, and it interferes with the daily life of the person (Du & Hu 2016). According to the 2015 World Alzheimer's Report, there are 46.8 million Alzheimer's patients in the World (Prince et al. 2015). The report predicts that this figure will reach 74.7 million in 2030 and 131.5 million in 2050. It is known that there are approximately 600.000 Alzheimer's patients in Turkey (Turkish Alzheimer's Association [TAA] 2016). Turkey is expected to be one of the four countries with the highest number of Alzheimer's patients in the world by 2050 (Turkish Psychiatric Association [TPA] 2014).

With the increasing prevalence of Alzheimer's disease, concerns about developing Alzheimer's disease or dementia are also increasing (Moon et al. 2014). Despite advances in medicine, current scientific studies show that Alzheimer's disease is inevitably fatal, and there are no behavioral treatments or pharmaceuticals yet that can slow, halt, or reverse the course of the disease (Cutler 2015). However, in national and international studies, it is stated that the widespread use of stigmatizing negative metaphors about the disease in the media causes false beliefs and negative prejudices about the disease in the society (Çobaner & Yıldırım 2017). Considering the social, psychological, physical and economic burden of Alzheimer's disease, it is normal for people to be afraid of getting Alzheimer's disease (Cutler & Bragaru 2015). Data from an international study conducted in 5 different countries showed that Alzheimer's disease is the second most feared disease after cancer among individuals aged 60 and over in France, Spain, Germany and the United States (Harvard School of Public Health/Alzheimer Europe 2011). Data from a study from the UK showed that two-thirds of respondents over the age of 50 were afraid of getting Alzheimer's Disease (Huffpost Lifestyle 2011). In a study conducted by Awang et al. (2017) in Malaysia on individuals over 40 years of age, Alzheimer's was determined as the most feared disease after cancer.

The increase in prevalence, awareness and fears about Alzheimer's disease contributes to what has been termed "predictive dementia" by Cutler and Hodgson and "dementia anxiety" by Kessler et al. (Cutler 2015). Predictive dementia refers to the fear that memory problems from normal aging are a manifestation of dementia (French et al. 2012). While individuals examine their cognitive functions for possible clues of future Alzheimer's disease, cognitive errors (such as forgetting someone's name or trying to remember a word) can reveal anxiety and fear (Cutler 2015). There are some studies that show that worrying about getting Alzheimer's Disease can be detrimental to physical and psychological well-being and cognitive functioning – if it's too intense, stressful, and long-lasting (Cutler & Hodgson 2013, 2014). Recent research has shown that people who report subjective memory complaints have a higher risk of mild cognitive impairment and dementia (Cutler 2015). On the other hand, in line with the Health Belief Model, it was determined that the moderate fear of Alzheimer's disease causes health behaviors that will reduce the risk of the disease (Clark 2016), and it has been stated that it is a factor that increases the probability of participating in screening programs and thus facilitates early diagnosis.

For all these reasons, it is crucial to understand the nature of people's concerns about developing Alzheimer's disease and the factors that support these concerns. Although there is a great deal of research in the international literature to investigate the fear of Alzheimer's disease and its causes, especially among middle-aged individuals, no study has been found in written sources in Turkey. The aim of the study is to evaluate the Turkish validity and reliability of the "Alzheimer's Disease Fear Scale (FADS)", which was developed by French et al. to evaluate the fear level of Alzheimer's disease.



FADS has been used in many studies in the international literature as a valid and reliable data collection tool in determining the Alzheimer's disease fear level of individuals (Nordhus et al. 2012, Scerri & Scerri 2013, Smyth et al. 2013, Eshbaugh 2014, Kada 2015, Du & Hu 2016). It is thought that the Alzheimer's Disease Fear Scale can contribute to healthcare professionals and researchers in different ways as a standard data collection tool. First, the scale can assist healthcare professionals in their efforts to understand and reduce patients' fears by providing psychoeducation about the development, symptoms and effects of the disease and supporting their planning for future life. On the other hand, in cases where fears about the disease are considered as clues of possible Alzheimer's disease, it may be possible to slow the course of the disease and reduce its burden with early diagnosis. Second, the scale will allow researchers to examine how variables such as subjective memory, cognition, family history of Alzheimer's disease, knowledge about Alzheimer's disease, and mood may contribute to fear of developing Alzheimer's disease. Finally, it is thought that FADS could help researchers in determining whether predictive dementia can predict future Alzheimer's disease (French et al. 2012).

MATERIAL AND METHODS

This study, which was planned as a methodological research, was carried out in Ankara in April and May 2017. In order to evaluate the validity and reliability of the Fear of Alzheimer's Disease Scale by adapting it into Turkish, written permission was obtained from the corresponding author, Samantha French, via e-mail. This study was approved by xxxxxx University Institutional Review Board and Ethics Committee (Project no: KA17/114) and supported by xxxxxx University Research Fund.

Universe and sample

The population of the study consists of a total of 254.104 individuals between the ages of 50-79 living in the Çankaya district of Ankara, based on TSI 2016 data. The sample size of the study was determined as 300 people in total, taking into account the suggestion in the literature that the sample size should be 10 times the number of items in the evaluation of the psychometric properties of the scales (Field 2009:647). Individuals who were literate, non-institutional and not diagnosed with dementia were considered suitable for inclusion of participants in the research group. It was interviewed with 350 people selected by convenience sampling method. It was stated that the participation was voluntary to 340 individuals who met the inclusion criteria and were informed about the purpose of the study. The Mini Mental State Test, of which Turkish validity and reliability was performed by Gungen et al. (2002), was applied to 322 adults aged 50 and over who agreed to participate in the study, and 310 people who passed the test with a score of 25 and above were included in the sample.

Data collection tool

The data of the study were collected with a questionnaire consisting of two parts. The first part includes questions about demographic (age, gender), socio-economic (education, occupation, income) and dementia experience (family history of dementia, living with a person with dementia, caring for someone with dementia, getting dementia-related education or training). In the second part, "Fear of Alzheimer's Disease Scale" (FADS), which was developed by French et al. (2012) to determine the fear and anxiety of getting Alzheimer's disease in individuals is included. FADS is a 5-point likert scale (0=never, 1=rarely, 2=sometimes, 3=often, 4=always) consisting of 30 questions about general fear, physical symptoms, and catastrophic attitude dimensions. In the scale, there are 17 items (items 1-17) in the dimension of general fear, 8 items (items 18-25) in the dimension of physical symptoms, and 5 items (items 26-30) in the dimension. Sub-dimension scores were added to calculate the total score of the scale. The total score of the scale ranges from 0 to 120, and a high score indicates a high level of fear about Alzheimer's disease. In the study in which the Fear of Alzheimer's Disease Scale was developed, it was concluded that the scale was acceptable and reliable (French et al. 2012).

Statistical analysis

Statistical analysis was performed in IBM SPSS 25 Package program and are based on validity analysis and reliability analysis. In the scale and its sub-dimensions, firstly, descriptive statistics such as means, standard deviations, ceiling and floor effects were evaluated, and then validity and reliability analysis were applied. The ceiling effect and floor effect mean that the percentage of the best and worst possible scorers in the dimension scores, respectively, constitutes more than twenty percent of the total participants (Fitzpatrick et al. 1998).

Validity analysis

Back translation method was followed in the Turkish adaptation study of FADS (Aksayan & Gözüm 2002). First, the English version of the scale was translated into Turkish by three professional translators. The Turkish forms obtained in the second stage were translated back into English by different translators and the consistency between the two forms was examined. The Turkish forms obtained were evaluated in terms of meaning and grammar, and a single form was obtained.

The content validity of the scale was evaluated with expert opinion. The items of the scale were examined in terms of relevance for purpose by seven faculty members working in the fields of Health Management, Family Medicine, Psychiatric Nursing and Geriatric Nursing, and they were evaluated in a 4-point rating system (1=item required, 2=item useful but not sufficient 3=item useful but in need of correction, 4= item unnecessary). According to the opinions of the experts, the items requested to be corrected were reviewed and necessary corrections were made. Kendall's coefficient of concordance was calculated for the agreement between expert opinions. At the last stage, the intelligibility of the scale items was evaluated with a pilot study conducted with 30 adults aged 50 and over who were not included in the sample group. No uncertainty or hesitation was encountered.

Construct validity of the scale was evaluated by Explanatory Factor Analysis. Kaiser-Meyer-Olkin (KMO) test and Barlett tests were used to analyze the adequacy of the sample size fr factor analysis. Explanatory factor analysis was performed by Principal Components Analysis and varimax rotation methods.

For the predictive validity of the scale, the difference between the total scores of the scale according to the socio-demographic characteristics and dementia experiences of the participants was evaluated. The appropriateness of the total score of the scale to normality was analyzed with the Kolmogorov Smirnov test and it was determined that it was suitable for normal distribution (p>0.05). Independent two-sample t-test was used to compare the means of scale total and subscale scores in two-group variables, and one-way analysis of variance was used to compare the variables in more than two groups.

Reliability analysis

The reliability of the scale was evaluated with test-retest, internal consistency coefficient and item-total score correlation coefficients.

Test-Retest Reliability: 30 adults aged 50 and over who were not included in the sample group answered the FADS-T twice in a 2-month interval. Test-retest reliability was evaluated with pearson correlation coefficient and paired sample t-test.

Internal Consistency: Cronbach alpha coefficient was used for internal consistency reliability of FADS-T. It is accepted that the scale is unreliable if the reliability coefficient is less than 0.40, low if it is in between 0.40-0.59, high between 0.60-0.79, and very highly reliable when it is above 0.80.



Item-Total Score Correlation Coefficients: In item total score correlation coefficients, the correlation of the items with the total score was evaluated with the Pearson correlation coefficient. Correlation coefficients are expected to be statistically significant higher than 0.40.

RESULTS

Demographic, socio-economic and dementia experiences of 310 people participating in the study are shown in Table 1. The mean age of the participants was calculated as 59.15±7.84 years, 58.8% were male, 34.8% were high school graduates and 58.4% had incomes above the poverty line. 94% of the participants have heard of Alzheimer's disease, 18.4% had individuals diagnosed with dementia in their family (8% first degree, 10.4% second degree), 12.4% live in the same house with an individual with dementia, 13.2% of them care for an individual with dementia and 1.6% stated that they received training on dementia.

	Total (n=310)				
Age (Mean ± SD)	59.15 ± 7.84				
Gender					
Female	128 (41.2)				
Male	182 (58.2)				
Place of birth					
Village	76 (24.4)				
District	130 (42.0)				
Province	104 (33.6)				
Education					
≤ High school	218 (70.4)				
Bachelor and above	92 (29.6)				
Occupation					
Housewife	56 (18.0)				
Blue-collar worker	133 (42.8)				
White-collar worker	121 (39.2)				
Income ^a					
<4.280 Turkish Liras	129 (41.6)				
≥4.280 Turkish Liras	181 (58.4)				
Hearing about					
Alzheimer's					
Yes	291 (94.0)				
No	19 (6.0)				
Dementia in the family					
Yes	57 (18.4)				
No	253 (81.6)				
Living with a person with dementia					
Yes	38 (12.4)				
No	272 (87.6)				
Caring for the individual with dementia					
Yes	41 (13.2)				
No	269 (86.8)				
Dementia education					
Yes	5 (1.6)				
No	305 (98.4)				

Self-rated health	
Good	166 (53.6)
Poor	144 (46.4)
Chronic disease	
No	196 (63.2)
Yes	114 (36.8)

^a Poverty line as of 2017

Table 1. Descriptive characteristics of participants (n (%)).

Table 2 shows the descriptive statistics of the FADS Scale and its sub-dimensions. The total mean score of the scale is 43.48±22.49. The highest dimension score belongs to the general fear dimension (26.44). The ceiling and floor effects observed in all dimension and overall score are at an acceptable level (< 20%). Skewness is an indicator of the normal distribution of scores, and the absence of skewness means that the scale scores are in accordance with the distribution in the population. Skewness is acceptable for the scale and its sub-dimensions (<1.0).

Dimension	Min.	Max.	Mean	SD	Floor Effect	Ceiling Effect	Skewness	Internal consistency (α)
General fear	0	68	26.44	13.19	%2.4	%0.4	0.161	0.937
Physical	0	32	10.29	7.24	%6.0	%0.4	0.417	0.918
Symptoms								
Catastrophic	0	20	6.74	5.33	%13.2	%0.4	0.296	0.890
Attitude								
Total Score	0	120	43.48	22.49	%2.4	%0.4	0.332	0.955

Table 2. Descriptive statistics of the FADS-T scale and for its sub-dimensions.

Validity results

Content validity: The content validity of the scale was evaluated with expert opinions and as a result of Kendall's W analysis for the consistency between expert opinions, statistically significant (p = 0.000) Kendall's W coefficient was calculated as 0.92.

Construct validity: Explanatory Factor Analysis was performed to evaluate the construct validity of the scale. The KMO coefficient indicating the adequacy of the sample size was found to be 0.93 and the Barlett test result was found to be statistically significant ($\chi 2 = 5524.644$, p=0.000). These results show that the correlation matrix is sufficient for Principal Component Analysis. Table 3 shows the results of Principal Components Factor Analysis. As a result of factor analysis, it was determined that the scale consisted of a total of 3 factors explaining 68.68% of the total variance. The results show that the construct validity of the scale is at an acceptable level.



	EFA			
	F1	F2	F3	Dimension
1. Item	0.537			
2. Item	0.529			
3. Item	0.648			
4. Item	0.640			
5. Item	0.639			
6. Item	0.684			
7. Item	0.646			
8. Item	0.720			
9. Item	0.693			General Fear
10. Item	0.713			
11. Item	0.715			
12. Item	0.710			
13. Item	0.701			
14. Item	0.666			
15. Item	0.604			
16. Item	0.697			
17. Item	0.695			
18. Item		0.666		
19. Item	19. Item 20. Item			
20. Item				
21. Item		0.684		Physical
22. Item		0.665		Symptoms
23. Item		0.683		
24. Item		0.704		
25. Item		0.705		
26. Item			0.676	
27. Item			0.682	Catastrophic
28. Item			0.608	Attitude
29. Item			0.619	minuae
30. Item			0.569	

Table 3. Construct validity of FADS-T.

Predictive validity: For the predictive validity of the scale, the FADS-T mean scores of the participants were compared according to their socio-demographic characteristics and dementia experience, but no statistically significant difference was found in the FADS-T total and sub-dimension scores for any of the variables (p>0.05).

Reliability results

Test-Retest Reliability: The scale was administered to a group of 30 people aged 50 and over twice. The ages of the individuals in the group ranged between 50 and 76 (59.17 ± 6.91), and their FADS-T scores ranged between 16 and 91 (45.56 ± 21.53). The test-retest reliability coefficient of the scale was calculated as 0.96 (p=0.000), and it was determined that there was no statistically significant difference between the scale scores between the two times (t=-2.259 p=0.819).



Internal Consistency: The internal consistency of the scale was calculated as 0.95 with the Cronbach Alpha coefficient (Table 2). The Cronbach Alpha coefficient calculated for the sub-dimensions of the scale also shows that the internal consistency is very high in all dimensions (0.89-0.93).

Item-Total Score Correlations: The correlation of the items in the scale with the total score was evaluated with the Pearson Correlation coefficient and it was determined that it ranged between 0.44 and 0.71 (M=0.65 SD=0.05) (Table 4).

	Mean	SD	General Fear	Physical Symptoms	Catastrophic Attitude	Total
1. Item	1.62	1.00	0.561			0.443
2. Item	1.57	1.02	0.659			0.527
3. Item	1.44	1.00	0.740			0.645
4. Item	1.56	1.11	0.728			0.639
5. Item	1.49	1.13	0.692			0.635
6. Item	1.54	1.17	0.740			0.680
7. Item	1.48	1.10	0.721			0.639
8. Item	1.58	1.06	0.758			0.712
9. Item	1.50	1.11	0.735			0.687
10. Item	1.47	1.05	0.730			0.706
11. Item	1.47	1.06	0.745			0.710
12. Item	1.57	1.07	0.729			0.706
13. Item	1.64	1.19	0.734			0.699
14. Item	1.74	1.12	0.725			0.668
15. Item	1.67	1.14	0.656			0.607
16. Item	1.57	1.17	0.687			0.696
17. Item	1.53	1.11	0.659			0.691
18. Item	1.43	1.14		0.766		0.658
19. Item	1.40	1.13		0.821		0.683
20. Item	1.36	1.20		0.826		0.682
21. Item	1.18	1.11		0.825		0.680
22. Item	1.36	1.08		0.746		0.669
23. Item	1.22	1.13		0.812		0.682
24. Item	1.21	1.16		0.793		0.703
25. Item	1.14	1.10		0.783		0.706
26. Item	1.19	1.17			0.810	0.680
27. Item	1.19	1.14			0.851	0.690
28. Item	1.38	1.28			0.853	0.623
29. Item	1.24	1.26			0.825	0.631
30. Item	1.75	1.51			0.847	0.590

Table 4. Descriptive statistics for scale items and item-scale correlations (r).

DISCUSSION

This study was conducted to evaluate the validity and reliability of the Turkish version of the FADS, which was prepared to determine the level of fear about Alzheimer's disease of individuals.



The descriptive statistics of the scale showed that there was no floor or ceiling effect on the subdimensions and the total score. In the evaluation of the content validity of the scale, it was determined that there was a concordance between the expert opinions. Explanatory factor analysis results for the construct validity of the scale showed that the structure of the scale was compatible with the original scale and was acceptable at an acceptable level. For predictive validity, the FADS-T mean scores of the participants were compared according to their socio-demographic characteristics and dementia experience. The comparison results showed that there was no difference in the total and sub-dimension scores of the scale according to the independent variables used in the study. The test-retest reliability correlation coefficient, which was examined in the evaluation of the reliability of the scale, showed that the correlation coefficient was 0.96 and the mean scores calculated in two different time periods were not statistically different. The Cronbach alpha coefficient was calculated as 0.95, and it was concluded that the scale was reliable. In addition, the correlations of the items with the total score were determined above the standard value of 0.40. The psychometric results are consistent with the results found in the study in which the FADS was developed (French et al. 2012) and the studies on adaptation to Korean (Moon et al. 2014) and French (Lais 2015).

It was not possible to compare the validity and reliability results of the scale, since no validity-reliability studies of FADS or a similar scale were found in Turkish written sources to determine the fear level of Alzheimer's disease. However, as an alternative measurement tool, it may be useful to adapt the Dementia Worry Scale into Turkish and compare its psychometric results.

In the study, the scores of the participants on the Fear of Alzheimer's disease scale were found to be higher than the results of previous international studies. This result of the study should be evaluated in two ways. First of all, considering that the scale includes not only a simple fear of Alzheimer's disease, but also psychiatric symptoms, physical signs, catastrophic attitude and concerns about Alzheimer's disease, the concerns of individuals with high fear of Alzheimer's disease should not be ignored and should be considered as a signal for early diagnosis of the disease. FADS can help healthcare professionals understand whether their patients are justified in their fears. In addition, considering that excessive fear and worry is a trigger for mild cognitive impairment and early-stage Alzheimer's disease, it is very important to determine the fear of Alzheimer's disease and then plan studies and interventions to reduce it. On the other hand, it is thought that the fear of Alzheimer's disease does not arise from "information" but from "misinformation". Considering the increasing interest in the media regarding Alzheimer's disease in recent years, it should not be overlooked that there is a serious need for control mechanisms to prevent the media from presenting false information and the development of "negative stigma" through the media.

The study has some limitations. First of all, since the sample of the study was determined by convenience sampling method, adapting the results to all middle-aged and older adults in the population may lead to wrong evaluations. Second, the results of the analysis for the predictive validity of the study could not reveal the discriminating power of the scale in terms of the independent variables used. However, in the study in which the original scale was developed and in the studies in which psychometric properties were evaluated for different languages, no difference was found in the scale scores according to the socio-demographic characteristics and dementia experiences of the participants. In future studies, the evaluation of the participants' religious beliefs, the people they live with, their social support, their general anxiety levels and their knowledge about the disease, and where they obtained this information from, may reveal the factors affecting the scale's discriminating power and fear. The fact that the external validity of the scale could not be evaluated in the study can be considered as another limitation. Finally, the hoped-for advances in medical science regarding the etiology and treatment of Alzheimer's disease may require updating the scale.

CONCLUSION

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The results of the study show that the FADS-T is a reliable and valid scale with adequate psychometric properties and can be used for clinical and research purposes in the future to determine the fear and nature of Alzheimer's in adults over middle age. In addition, considering the positive effects of preventive health behaviors related to Alzheimer's disease on the risk of developing the disease and the individual and social benefits of its early diagnosis, it is believed that specific scales for Alzheimer's disease such as FADS will be useful as a tool to inform the public about the disease and to increase awareness.

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