

## Determination of Alzheimer's Disease-Related Knowledge and Stigma Levels of Adult Individuals

### Yetişkin Bireylerin Alzheimer Hastalığı ile İlgili Bilgi ve Damgalanma Düzeylerinin Belirlenmesi



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## ABSTRACT

**Aim:** In Türkiye, Alzheimer's disease (AD) and related dementia (ADRD) are among the diseases that should be addressed as a priority in terms of public health. What is known about the level of AD awareness and stigma related AD, especially among Turkish adults, is insufficient. The contribution of these two important factors to the disease burden and their impact on case finding and treatment effectiveness are unknown. In this regard, the aim of the study is to determine the knowledge and stigma levels of adults and older adults regarding AD.

**Materials and Methods:** A descriptive and analytical design was used. A total of 888 adult and older adult individuals participated in the study. Data were collected with a questionnaire, Alzheimer's Disease Knowledge Scale (ADKS) and Perceived Stigma Against AD Survey (STIGMA-AD).

**Results:** The average age of the participants is 49.75 (8.89), 85.7% are between the ages of 40-59, 64.1% are women, 60.8% are married, and 51.5% are at basic education level. The average ADKS total score of adults and older adults participating in the study is 16.97 (2.47). The average STIGMA-AD total score of adults and older adults participating in the study is 21.05 (3.69).

**Conclusion:** Serious knowledge gaps have been noted among Turkish adults and older adults in both general AD and its sub-dimensions. The level of AD-related stigma is high both in total and in all sub-dimensions. In this study, no significant relationship was found between AD knowledge and stigma.

**Keywords:** Alzheimer's Disease (AD), Dementia, Knowledge, Stigma, Adults

## ÖZ

**Amaç:** Türkiye'de Alzheimer hastalığı (AH) ve buna bağlı demans (AHBD), halk sağlığı açısından öncelikli olarak ele alınması gereken hastalıklar arasındadır. Özellikle Türk yetişkinleri arasında AH farkındalık düzeyi ve AH'ya ilişkin damgalanma konusunda bilinenler yetersizdir. Bu iki önemli faktörün hastalık yüküne katkısı, vaka bulma ve tedavi etkinliğine etkisi bilinmemektedir. Bu bağlamda çalışmanın amacı yetişkinlerin ve yaşlı yetişkinlerin AH'ye ilişkin bilgi ve damgalanma düzeylerini belirlemektir.

**Gereç ve Yöntem:** Tanımlayıcı ve analitik bir tasarım kullanıldı. Araştırmaya toplam 888 yetişkin ve yaşlı yetişkin birey katıldı. Veriler anket, Alzheimer Hastalığı Bilgi Ölçeği (AHBÖ) ve Alzheimer'a Karşı Algılanan Damgalanma Anketi (STIGMA-AH) ile toplandı.

**Bulgular:** Katılımcıların yaş ortalaması 49,75 (8,89), %85,7'si 40-59 yaş aralığında, %64,1'i kadın, %60,8'i evli ve %51,5'i temel eğitim düzeyindedir. Araştırmaya katılan yetişkin ve yaşlı yetişkinlerin ortalama AHBÖ toplam puanı 16,97 (2,47)'dir. Araştırmaya katılan yetişkin ve yaşlı yetişkinlerin ortalama STIGMA-AH toplam puanı 21,05 (3,69)'dir.

**Sonuç:** Türk yetişkinleri ve yaşlı yetişkinler arasında hem genel AH hem de alt boyutları konusunda ciddi bilgi boşlukları dikkat çekmektedir. AH ile ilgili damgalanma düzeyi hem toplamda hem de tüm alt boyutlarda yüksektir. Bu çalışmada AD bilgisi ile damgalanma arasında anlamlı bir ilişki bulunamamıştır.

**Anahtar Kelimeler:** Alzheimer Hastalığı (AH), Demans, Bilgi, Damgalanma, Yetişkinler



## INTRODUCTION

Population aging is one of the most defining demographic events of the 20th and 21st centuries. According to a report published by the United Nations, the ratio of the population aged 65 and over to the total population was 9.1% in 2019. This rate is expected to be 11.7% in 2030, 15.9% in 2050 and 22.6% in 2100 (1). Projections are that the number of people with AD could reach 16 million by 2050. These projections point to a global situation where one person every three seconds develops AD, but only 1 in 4 are diagnosed (2).

Early diagnosis of AD, which has a major socio-economic impact worldwide, is important for appropriate treatment of dementia and its psychological, emotional, familial and economic management. However, AD-related stigma is seen as a huge factor hindering the implementation of effective strategies for the disease (3). Stigma is defined as the negative attitude of society towards people who are considered to be different in terms of physical, mental and lifestyle (4). Health-related stigma is characterized by the social disqualification of individuals identified as having the disease (5). According to labeling theory (6), the individual carrying the stigma can accept and internalize what is reflected on him/her and act accordingly. The stigmatized person often reacts with a sense of shame, loss of self-esteem, and avoidance or withdrawal. Patients with memory disorders are known to judge themselves for their illness and symptoms and experience both social and internalized stigma (7). In a survey with 2500 people (dementia patients, family members and informal caregivers) from 54 countries, 24% of individuals with AD stated that they hid their diagnosis for fear of being stigmatized, and 40% stated that others avoided them due to their disease (8). Blay and Peluso (9) reported that

more than 40% of the lay public holds negative stereotypes and prejudices against individuals with dementia. Piver et al. (10) in a survey conducted with more than 500 people in France, found that average dementia stigma scores were in the “medium” range.

Studies conducted in various cultures have shown that there are differences in the acceptance and perception of dementia screening. It was determined that British elderly people had higher scores than Americans regarding perceived stigma, perceived loss of independence, and perceived pain related to dementia (11). In a study conducted in Australia, those who reported knowing a person with dementia showed more socially supportive attitudes (12). A study conducted in France found that those who had negative reactions to people with dementia were less likely to want to care for them (10).

Adequate public knowledge about AD can help identify the disorder, seek appropriate healthcare early, and reduce the stigma of the disease, while also prompting a more informed discussion about the needs of affected individuals (13, 14). Unfortunately, although information about AD has been widely disseminated on the internet, previous studies measuring society's knowledge about dementia and AD have revealed some gaps in this context (15-17). Cahill et al. (18), in a systematic review of 40 studies addressing public knowledge of AD, reported that AD literacy ranged from poor to very limited, with knowledge levels being higher among younger people, women, and better educated people, and risk factors and prevention being the most common areas of knowledge gaps. The most common misconception in general is that dementia is a normal part of aging and that it is not clear at what point normal age-related memory loss problems become severe enough to indicate dementia.

As in the rest of the world, AD and dementia are among the diseases that should be considered as a public health priority in Türkiye. In a study where news about AD and individuals with AD were examined using the qualitative content analysis method, it was revealed that the disease was often associated with old age, visualized as a progressive and dangerous disease, and patients were labeled as people who lived in their own world and were out of touch with their environment (19). In addition to the negative consequences of society's prejudices for individuals, the public health implications of stigma against AD are significant. Because it contributes to the disease burden and affects the effectiveness of case finding and treatment. Increasing literacy in Turkish society about dementia is an important step in creating dementia awareness. In this regard, the aim of the study is to determine the knowledge and stigma levels of adult and older adult individuals regarding AD.

## MATERIALS AND METHOD

The study was planned in a descriptive and analytical model. This study was conducted with adult and older adult individuals (over 40 years old), both online and face-to-face, between December 2022 and May 2023, through an online form prepared using "Google forms". Taking into account the parameters unknown prevalence = 50%, CI = 95.0%, sampling error = 5.0%, design effect = 2 and non-response rate = 5.0%, the sample size was calculated as 847 people. A total of 888 adult and older adult individuals participated in the study.

The data of the study were collected by questionnaire, Alzheimer's Disease Knowledge Scale (ADKS) and Perceived Stigma Against AD Survey (STIGMA-AD).

The questionnaire consisted of a total of 17

questions including the socio-demographic characteristics of the participants and their experiences regarding AD.

ADKS, Carpenter et al. (20) is a scale consisting of 30 true/false items, the total score of which is the number of correct answers. The test-retest correlation of ADKS in previous studies was measured as .81. The initial Cronbach's alpha of the scale was found to be low, but in another study on a sample of psychologists, Cronbach's alpha was shown to be .98 (21). ADKS, risk factors (items 2, 13, 18, 25, 26 and 27), symptoms (items 19, 22, 23), diagnosis and assessment (items 4, 10, 20 and 21), treatment and management (items 19, 22, 23), items 9, 12, 24, 29 and 30), caregiving (items 5, 6, 7, 15 and 16), course (items 3, 8, 14 and 17), and life impact (items 1, 11 and 28). It consists of seven sub-dimensions, including items 28). The scale was adapted into Turkish by Yılmaz and Çolak (22) with a total of 600 people, consisting of university students, adults aged 50 and over, and caregivers of individuals with AD. In evaluating the reliability of the scale, the test-retest reliability correlation coefficient examined was calculated as .81. It was concluded that the Turkish version of ADKS is a reliable and valid scale with sufficient psychometric properties.

STIGMA-AD is an adaptation of the "STIGMA" survey developed by Piver et al. (10) to AD by Arica Polat et al. (23). Participants are asked to act as if they have AD and evaluate how they feel. Questions are evaluated as "yes, maybe, I don't know, no" and are scored between 0-3. A score of 3 corresponds to the greatest stigma. Other answers are scored respectively. The answer "yes" is positive for questions 1, 3, 4, 5, 6, 7 and 9. For questions 2, 8 and 10, the answer "no" is negative. The total score indicates stigma. The highest score is 30; 0-7 is rated as mild, 8-11 as moderate, and 12 and above as high stigma. Perceived stigma reluctance to disclose

the illness (questions 1 and 2), emotional impact (questions 3 and 4), fear of exclusion (questions 5, 6 and 9), courtesy stigma (question 7) and fear of loss of family support (questions 8 and 10) are evaluated in terms of dimensions.

Continuous data are expressed as mean, standard deviation, minimum and maximum descriptive statistics, and categorical data are expressed as number and ratio. Categorical data were analyzed by Chi-Square or Fisher's exact tests. Distribution normality of continuous variables was calculated with the Shapiro-Wilk test. Since the variables showed normal distribution, comparisons of two groups were made with the Independent Samples T test, and comparisons of more than two groups were made with the One-Way ANOVA test. Post-hoc multiple comparison analysis was performed with significant values adjusted by Bonferroni correction. Pearson correlation analysis was used to find the relationship between continuous variables depending on the distribution. Statistical analyzes were performed using IBM SPSS v.21 software and are reported with a 95% confidence interval. Values of  $p < 0.05$  were considered significant.

## RESULTS

The average age of the participants is 49.75 (8.89), 85.7% are between the ages of 40-59, 64.1% are women, 60.8% are married, and 51.5% are at basic education level. 63.1% of the participants generally evaluated their health as "good". 7.2% have at least one physical illness and 6.5% have at least one mental illness. 80.7% have heard of AD and 19.4% have someone in their family with AD/dementia. While 48.1% of the participants evaluated the possibility of having AD as "little", 72.0% stated that they were afraid of having AD (Table I).

**Table I.** Distribution of characteristics of socio-demographic of the adults

Characteristics	n	%
<b>Gender</b>		
Female	569	64.1
Male	319	35.9
<b>Age (year) (mean)</b>	49.75(8.89)	(40-85)
<b>Age</b>		
40-59	761	85.7
60 and above	127	14.3
<b>Place of birth</b>		
District	280	31.5
Town	79	8.9
Village	218	24.5
City center	311	35.0
<b>Marital status</b>		
Married	540	60.8
Single	228	25.7
Has no spouse	120	13.5
<b>Family type</b>		
Nuclear family	635	71.5
Extended family	253	28.5
<b>Income status</b>		
Very well	55	6.2
Very bad	26	2.9
Bad	53	6.0
Neither good nor bad	574	64.6
Quite good	180	20.3
<b>Educational status</b>		
Primary/Middle School	457	51.5
High school	237	26.7
University	194	21.8
<b>General health status</b>		
Good	560	63.1
Excellent/Very good	101	11.4
Medium/ Poor	227	25.6
<b>Do you have a physical illness?</b>		
Yes	64	7.2
No	824	92.8
<b>Do you have a mental illness?</b>		
Yes	58	6.5
No	830	93.5
<b>Is there anyone in your family (elderly, sick, disabled) who needs help with their care?</b>		
Yes	210	23.6
No	678	76.4

**Table I. (continued)** Distribution of characteristics of socio-demographic of the adults

<b>Have you heard of AD?</b>		
Yes	717	80.7
No	171	19.3
<b>Is there anyone in your family with AD/dementia?</b>		
Yes	172	19.4
No	716	80.6
<b>Have you lived with someone with dementia?</b>		
Yes	163	18.4
No	725	81.6
<b>Have you cared for a person with dementia?</b>		
Yes	116	13.1
No	772	86.9
<b>How do you assess your likelihood of having AD?</b>		
Very high	192	21.6
High	128	14.4
I'm undecided	33	3.7
Little	427	48.1
Very little	108	12.2
<b>Are you fear of having AD?</b>		
Yes	639	72.0
No	249	28.0

The average ADKS total score of adult and older adult individuals participating in the study is 16.97 (2.47). When the socio-demographic characteristics of the participants were compared with the ADKS subscale and total scores; "life impact" score in the 40-59 age group; "treatment and management" score for those with single marital status; "diagnosis and assessment", "treatment and management" and "life impact" scores in those with "good" general health status; "diagnosis and assessment", "caregiving", "life impact" and total scores for those who stated that they had "heard of AD"; "caregiving" score for those who stated that they have a family member with AD/dementia and that they live with someone with dementia; "diagnosis and assessment", "caregiving", "course", "life impact" and total score for those who express

their fear of having AD are significantly higher ( $p < 0.05$ ). There was no difference between gender, presence of physical and mental illness, average age and ADKS sub-dimension and total score levels ( $p > 0.05$ ) (Table II).

The average STIGMA-AD total score of adult and older adult individuals participating in the study is 21.05 (3.69). When the socio-demographic characteristics of the participants were compared with the STIGMA-AD subscale and total scores; total score for those who are married; "reluctance to disclose the illness" score in the 40-59 age group; "emotional impact", "fear of exclusion", "courtesy stigma" and "fear of loss of family support" and their total scores for those who stated that they had heard of AD; "fear of loss of family support" score for those who stated that they have a family member with AD/dementia and that they live with someone with dementia; all subscale and total scores for those who perceive the probability of having AD as "very high"; "emotional impact", "fear of exclusion", "courtesy stigma" and total score for those who express their fear of becoming AD are significantly higher ( $p < 0.05$ ). There was no difference between gender, presence of physical and mental illness, general health status and average age, and STIGMA-AD subscale and total score levels ( $p > 0.05$ ) (Table III).

When the relationship between the ADKS subscale and total scores and the STIGMA-AD subscale and total scores of the middle and older adult individuals participating in the study is examined; there is a positive, moderate and significant difference between the subscale scores of "risk factors", "diagnosis and evaluation", "treatment and management" and "course" and the total ADKS score; there are positive, medium and high level and significant relationships between the subscale scores of "reluctance to disclose the illness", "emotional impact", "fear

of exclusion” and “courtesy stigma” and the total STIGMA-AD score ( $p < 0.05$ ). There was no significant relationship between ADKS total

score and STIGMA-AD total score ( $p > 0.05$ ) (Table IV).

**Table II.** The characteristics of socio-demographic of the adults and ADKS using bivariate analysis

Characteristics	ADKS							Total
	Risk factors	Symptoms	Diagnosis and evaluation	Treatment and management	Caregiving	Course	Life impact	
Age (year) <sup>1</sup>	0.027	-0.005	-0.045	-0.032	0.041	0.062	-0.047	0.006
<b>Age group<sup>3</sup></b>								
40-59	3.18 (1.06)	1.62 (0.70)	2.78 (0.81)	2.78 (0.80)	1.82 (0.90)	2.72 (0.87)	2.10 (0.82)***	16.99 (2.45)
60 and above	3.29 (1.09)	1.62 (0.62)	2.76 (0.75)	2.69 (0.84)	1.91 (1.04)	2.80 (0.95)	1.80 (0.82)	16.86 (2.57)
<b>Marital status<sup>2</sup></b>								
Married	3.19(1.05)	1.62(0.70)	2.81(0.77)	2.78(0.79)	1.80(0.86)	2.80(0.84)*	2.13(0.82)**	17.13(2.37)*
Single	3.21(1.10)	1.67(0.67)	2.75(0.83)	2.83(0.80)*	1.92(0.96)	2.63(0.86)	1.90(0.80)	16.91(2.52)
Has no spouse	3.21(1.10)	1.52(0.66)	2.68(0.86)	2.57(0.86)	1.79(1.10)	2.60(1.06)	1.99(0.86)	16.35(2.67)
<b>General health status<sup>2</sup></b>								
Good	3.20(1.06)	1.62(0.70)	2.86(0.75)**	2.82(0.82)**	1.75(0.92)	2.75(0.85)	2.10(0.82)*	17.08(2.44)
Excellent/Very good	3.16(1.14)	1.60(0.76)	2.60(0.93)	2.70(0.77)	2.11(0.93)***	2.56(0.84)	1.87(0.81)	16.60(2.79)
Medium/ Poor	3.23(1.04)	1.64(0.63)	2.65(0.83)	2.64(0.79)	1.91(0.90)	2.76(0.91)	2.03(0.85)	16.86(2.47)
<b>Hearing of AD<sup>3</sup></b>								
Yes	3.17(1.08)	1.61(0.70)	2.84(0.77)***	2.76(0.82)	1.77(0.92)***	2.76(0.85)	2.16 (0.80)***	17.08(2.45)*
No	3.31(1.02)	1.69(0.60)	2.52(0.89)	2.70(0.74)	2.09(0.87)	2.61 (0.95)	1.59(0.80)	16.50(2.52)
<b>Having AD/dementia in the family<sup>3</sup></b>								
Yes	3.22 (1.09)	1.61(0.71)	2.66(0.85)	2.73(0.79)	2.09(0.99)***	2.72(0.92)	1.97(0.86)	16.99(2.58)
No	3.19 (1.06)	1.62(0.68)	2.81(0.78)*	2.77(0.81)	1.77(0.90)	2.74(0.86)	2.07(0.82)	16.97(2.44)
<b>Living with someone with dementia<sup>3</sup></b>								
Yes	3.31(1.10)	1.59(0.69)	2.61(0.88)	2.84(0.76)	2.01(0.98)**	2.64(0.95)	1.91(0.95)	16.91(2.75)
No	3.18(1.06)	1.63(0.69)	2.81(0.78)**	2.75(0.82)	1.79(0.91)	2.75(0.86)	2.08(0.83)*	16.98(2.40)
<b>Caring for a person with dementia<sup>3</sup></b>								
Yes	3.39(1.09)*	1.65(0.64)	2.58(0.87)	2.87(0.73)	2.09(0.97)**	2.60(0.96)	1.82(0.83)	16.99(2.63)
No	3.17(1.06)	1.62(0.69)	2.81(0.79)**	2.75(0.82)	1.79(0.91)	2.75(0.86)	2.09(0.82)**	16.97(2.44)
<b>Probability of having AD<sup>2</sup></b>								
Very high	2.92(1.02)	1.42(0.74)	2.74(0.82)	2.41(0.74)	1.74(0.97)	2.95(1.05)	2.17(0.79)	16.36(2.45)
High	3.14(1.02)	1.71(0.68)**	2.92(0.72)**	2.87(0.77)	1.55(0.86)	2.83(0.76)	2.30(0.80)***	17.31(2.29)**
I'm undecided	3.28(1.09)	1.62(0.69)	2.81(0.78)	2.80(0.83)	1.85(0.86)	2.66(0.84)	2.05(0.83)	17.06(2.47)
Little	3.30(1.06)**	1.69(0.60)	2.56(0.90)	2.91(0.80)**	2.21(1.05)	2.68(0.88)	1.67(0.74)	17.01(2.52)
Very little	3.27(1.10)	1.60(0.66)	2.42 (0.90)	2.55(0.56)	2.36(0.78)***	2.33(0.99)***	1.49(0.71)	16.03(2.77)
<b>Fear of AD<sup>3</sup></b>								
Yes	3.23(1.06)	1.64(0.69)	2.86(0.74)***	2.78(0.79)	1.72(0.88)	2.82(0.83)***	2.15(0.83)***	17.20(2.25)**
No	3.11(1.09)	1.57(0.68)	2.56(0.91)	2.72(0.84)	2.12(0.96)***	2.50(0.96)	1.81(0.78)	16.38(2.87)
Score	3.20 (1.07)	1.62 (0.69)	2.78 (0.80)	2.76 (0.81)	1.83 (0.92)	2.73 (0.88)	2.05 (0.83)	16.97 (2.47)

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ ; <sup>1</sup> Pearson Correlation; <sup>2</sup> One-way ANOVA test; <sup>3</sup> Independent Samples T test

**Table III.** The characteristics of socio-demographic of the adults and STIGMA-AD using bivariate analysis

Characteristics	STIGMA-AD					Total
	Reluctance to report illness	Emotional impact	Fear of exclusion	Courtesy stigma	Fear of loss of family support	
Age (year) <sup>1</sup>	0.150	0.005	0.007	-0.009	0.038	0.056
<b>Age group<sup>3</sup></b>						
40-59	3.30 (0.99)	5.42 (1.15)	8.49 (1.80)	2.85 (0.76)	0.90 (1.24)	20.96 (3.70)
60 and above	3.62 (0.86)***	5.48 (1.32)	8.50 (1.92)	2.85 (0.71)	1.10 (1.29)	21.55 (3.61)
<b>Marital status<sup>2</sup></b>						
Married	3.31(0.99)	5.40(1.18)	8.60(1.88)	2.87(0.77)	0.80(1.15)	20.99(3.77)**
Single	3.30(0.99)	5.36(1.19)	8.13(1.69)	2.75(0.71)	1.15(1.29)***	20.69(3.56)
Has no spouse	3.58(0.93)**	5.64(1.14)	8.69(1.71)**	2.93(0.73)*	1.11(1.47)	21.96(3.43)

**Table III. (continued)** The characteristics of socio-demographic of the adults and STIGMA-AD using bivariate analysis

<b>Hearing of AD<sup>3</sup></b>						
Yes	3.33(0.98)	5.51(1.19)***	8.62(1.80)***	2.90(0.75)***	0.84(1.22)***	21.20(3.66)**
No	3.40(0.97)	5.08(1.08)	7.97(1.84)	2.64(0.73)	1.31(1.27)	20.40(3.79)
<b>Having AD/dementia in the family<sup>3</sup></b>						
Yes	3.47(0.98)	5.42(1.10)	8.30(1.78)	2.84(0.75)	1.11(1.30)*	21.14(3.55)
No	3.32(0.98)	5.43(1.20)	8.54(1.83)	2.85(0.75)	0.89(1.23)	21.02(3.73)
<b>Living with someone with dementia<sup>3</sup></b>						
Yes	3.34(0.76)	5.58(1.18)	8.15(1.62)	2.79(0.72)	1.12(1.20)**	20.91(3.61)
No	3.35(1.03)	5.39(1.17)	8.57(1.86)*	2.86(0.76)	0.88(1.23)	21.07(3.70)
<b>Caring for a person with dementia<sup>3</sup></b>						
Yes	3.35(0.78)	5.53(1.20)	8.01(1.68)	2.72(0.67)	1.30(1.32)	16.99(2.63)
No	3.35(1.01)	5.41(1.17)	8.57(1.83)**	2.87(0.76)	1.79(0.91)***	16.97(2.44)
<b>Probability of having AD<sup>2</sup></b>						
Very high	3.82(1.26)***	5.73(1.23)*	9.55(1.84)***	3.13(0.78)***	1.12(1.59)***	23.34(3.93)***
High	3.22(1.00)	5.43(1.16)	8.73(1.77)	2.86(0.74)	0.66(1.09)	20.91(3.77)
I'm undecided	3.26(0.94)	5.37(1.16)	8.29(1.76)	2.81(0.76)	0.90(1.16)	20.63(3.49)
Little	3.41(0.68)	5.32(1.18)	7.88(1.63)	2.73(0.69)	1.28(1.30)	20.62(3.27)
Very little	3.15(0.44)	5.18(1.13)	7.73(1.53)	2.58(0.56)	1.12(1.05)	19.76(2.77)
<b>Fear of AD<sup>3</sup></b>						
Yes	3.34(0.96)	5.49(1.15)**	8.62(1.80)**	2.89(0.75)*	0.80(1.14)***	21.13(3.55)*
No	3.37(1.03)	5.27(1.22)	8.17(1.83)	2.76(0.75)	1.28(1.44)	20.84(4.03)
<b>Score</b>	<b>3.35 (0.98)</b>	<b>5.43 (1.18)</b>	<b>8.49 (1.82)</b>	<b>2.85 (0.75)</b>	<b>0.93 (1.25)</b>	<b>21.05 (3.69)</b>

\*p < 0.05; \*\*p < 0.01; \*\*\*p < 0.001; <sup>1</sup>Pearson Correlation; <sup>2</sup>One-way ANOVA test, <sup>3</sup>Independent Samples T test

**Table IV.** The relationship between ADKS sub-dimension and total score and STIGMA-AD sub-dimension and total scores

	Risk factors	Symptoms	Diagnosis and evaluation	Treatment and management	Caregiving	Course	Life impact	Total ADKS	Reluctance to report illness	Emotional impact	Fear of exclusion	Courtesy stigma	Fear of loss of family support	Total STIGMA-AD
<b>Risk factors</b>	.190**	.162**	.173**	-.039	.108**	-.177**	.560**	-.088**	-.047	-.095**	-.113**	-.093**	-.140**	
<b>Symptoms</b>	.190**	.168**	.098**	-.081*	.072*	-.111**	.405**	-.161**	-.060	-.136**	-.099**	.001	-.149**	
<b>Diagnosis and evaluation</b>	.162**	.168**	.160**	-.306**	.405**	.122**	.564**	-.024	.129**	.147**	.128**	-.295**	.033	
<b>Treatment and management</b>	.173**	.098**	.160**	-.027	.168**	.017	.537**	-.133**	-.037	-.062	.003	-.070*	-.101**	
<b>Caregiving</b>	-.039	-.081*	-.306**	-.027	-.247**	-.272**	.046	.019	-.127**	-.133**	-.060	.243**	-.031	
<b>Course</b>	.108**	.072*	.405**	.168**	-.247**	.113**	.555**	.024	.103**	.171**	.114**	-.244**	.065	
<b>Life impact</b>	-.177**	-.111**	.122**	.017	-.272**	.113**	.212**	-.007	.109**	.153**	.116**	-.206**	.062	
<b>Total ADKS</b>	.560**	.405**	.564**	.537**	.046	.555**	.212**	-.121**	.018	.011	.023	-.224**	-.092**	
<b>Reluctance to disclose the illness</b>	-.088**	-.161**	-.024	-.133**	.019	.024	-.007	-.121**	.282**	.306**	.200**	.164**	.604**	
<b>Emotional impact</b>	-.047	-.060	.129**	-.037	-.127**	.103**	.109**	.018	.282**	.554**	.470**	-.116**	.724**	
<b>Fear of exclusion</b>	-.095**	-.136**	.147**	-.062	-.133**	.171**	.153**	.011	.306**	.554**	.708**	-.231**	.818**	
<b>Courtesy stigma</b>	-.113**	-.099**	.128**	.003	-.060	.114**	.116**	.023	.200**	.470**	.708**	-.197**	.690**	
<b>Fear of loss of family support</b>	-.093**	.001	-.295**	-.070*	.243**	-.244**	-.206**	-.224**	.164**	-.116**	-.231**	-.197**	.190**	
<b>Total STIGMA-AD</b>	-.140**	-.149**	.033	-.101**	-.031	.065	.062	-.092**	.604**	.724**	.818**	.690**	.190**	

\*. Correlation is significant at the 0.05 level (2-tailed). \*\*. Correlation is significant at the 0.01 level (2-tailed).

## DISCUSSION

This study revealed the knowledge and stigma levels related to AD among adult and older adult individuals, most of whom are married, have a basic education level, are women, and have a “good” perception of their health in general. The majority of the participants in the study have heard of AD (81%), and the rate of those who have someone in their family with AD/dementia is 19%. Approximately 13% of participants stated that they were informal caregivers for someone with AD/dementia. In Yılmaz and Çolak’s (22) study on a younger sample consisting of four different groups, AD awareness was found to be approximately 94% for the total group, while the rate of those with a family member with dementia was 15%. In another study conducted on a sample of 186 young adults from three different ethnic backgrounds (Asian, Black, White) living in the United Kingdom, 26% of the participants stated that they had a relative with AD/dementia, and 13% stated that they lived with someone with AD/dementia (24).

In this study, although the knowledge level of the participants as determined by ADKS is generally low (mean: 17), the score level of the life impact and risk factors sub-dimensions is above the medium level, and the other sub-dimensions are below the medium level. In their study conducted by Garcia-Ribas et al. (25) with 447 employees of a pharmaceutical company, they determined the average AD knowledge level as 21. In the same study, while the level of knowledge was higher in the areas of treatment and management and life impact; the level of knowledge in the areas of risk factors and caregiving is lower. In a study conducted by Jorge et al. (26) in Spain on a total of 419 people (215 caregivers and 204 people from the general population), the knowledge level of AD was 19.1 and 18.8, respectively. While the participants’ knowledge rates in the

areas of risk factors and caregiving were low, symptoms and the course of the disease were the areas that were best understood. Amado et al. (27), in a survey involving 1414 people in Brazil, found the level of knowledge about AD to be moderate (mean: 22). Kafadar et al. (24) found that the average AD knowledge score in young adults was 13.5 and that knowledge of risk factors and symptoms had a lower level of correct answers than knowledge of the course of the disease. Compared to previous study results, serious knowledge gaps in both general AD and sub-dimensions of Turkish middle and older adult individuals participating in this study are noteworthy. More importantly, participants are unaware of primary prevention regarding risk factors that may increase the tendency to develop AD and its impact on life, secondary prevention related to symptoms, evaluation and diagnosis, and tertiary prevention related to treatment and management, caregiving and the course of the disease.

In this study, married individuals have a better level of knowledge about the course of the disease, its impact on life, and total AD knowledge. Individuals with “good” general health status and awareness of AD also have a high level of knowledge in the areas of diagnosis and evaluation, treatment and management, and life impact. Those who have a family member with AD/dementia and those who live with someone with dementia are more knowledgeable in the field of caregiving. Fear of having AD has made a difference at multidimensional levels such as diagnosis and evaluation, caregiving, course, life impact, and total AD knowledge. The level of life impact knowledge is high in middle adult individuals. In this study, gender did not make a difference on AD knowledge. Kafadar et al. (24) reported that gender is associated with knowledge of the course of the



disease, proximity to people with AD/dementia is associated with symptom knowledge, living with someone aged 65 and over is associated with caregiving knowledge, interactions with people with AD are associated with risk factors, symptoms, diagnosis and evaluation, life impact, caregiving, and total AD knowledge. Garcia-Ribas et al. (25) reported in their study that the total level of knowledge about AD was high in caregivers of individuals with AD. In summary, in this study, familiarity with people with dementia, interacting, providing care, and fear of having AD have a significant impact on AD knowledge domains. This result provides an opportunity to develop new approaches to increase knowledge and awareness about AD. For example, programs can be developed that encourage ways to interact with or care for people with dementia. Kim et al. (28) demonstrated that Australian participants aged 40 to 87 years achieved a significant increase in dementia knowledge both post-intervention and at 12-week follow-up through an online education program (ED) and simulated contact contact (CT) with people with dementia and their caregivers. They suggested that the combination of ED+CT may be the best approach to educate the public.

Older adults with cognitive impairment face stigma in many cultures. In this study, although the stigma levels of the participants determined by STIGMA-AD were generally high (mean: 21), the stigma scores for reluctance to disclose the illness, fear of exclusion, and fear of loss of family support were above the medium level. Arica Polat et al. (23) showed the average stigma score for AD to be approximately 9 in 459 healthy individuals, whose average age was younger than the participants in this study. 61% of the participants were found to have a medium-high level of stigma against AD. The level of stigmatization in this study is much higher than

this previous study, both in terms of total and all sub-dimensions.

In this study, awareness of AD had a negative impact on emotional impact, fear of exclusion, courtesy stigma, fear of loss of family support, and total stigma. Those who stated that they had a family member with AD/dementia and that they lived with someone with dementia reported that they “feared the loss of family support”. Negative effects were observed on all stigma dimensions in those who perceived the possibility of having AD as “very high”, and on emotional impact, fear of exclusion, courtesy stigma and total stigma levels in those who expressed fear of having AD. While the total stigma level is high in married people, reluctance to report the disease, fear of exclusion, and courtesy stigma are high in those without a spouse (spouse deceased, separated, divorced). Arica Polat et al. (23) determined higher stigma scores that healthcare workers in all dimensions, women in the dimensions of reluctance to disclose the illness, emotional impact and loss of family support, and singles in the dimensions of emotional impact and loss of family support. In another study, the most important factor associated with perceived stigma towards AD was reported to be gender (29). In this study, unlike previous studies, stigma levels towards AD did not differ according to gender. It is thought that this result may be related to the disappearance of the traditional understanding that women are the primary caregivers of individuals with AD in our country and the fact that all family members are similarly exposed to the behavioral effects of AD. In this study, it was observed that older adults were reluctant to report the disease compared to middle adults. It is thought that this may be due to the fact that older adults are worried that reporting their illness will result in negative consequences (such as social isolation, need for care) for themselves

and their loved ones. Additionally, older adults may not have the support or resources needed to report their illness. A telephone survey of 1,000 people in the Australian community found low to moderate levels of dementia-related stigma and was higher in men and older adults (30). In the study of Piver et al. (10), stigmatization was seen at lower levels among older people. Kim et al. (28) in their study examining the effects of four different interventions on dementia-related stigma, found significant decreases in all three dimensions of stigma (cognitive, emotional and behavioral) in the ED + CT group 12 weeks after the intervention.

In this study, no significant relationship was found between AD knowledge and stigma. AD knowledge and stigma may be perceived as different constructs between Turkish adults and older adults. AD knowledge is a measure of one's understanding of the disease; stigma is a measure of a person's negative attitudes and beliefs about the disease. It is possible that the relationship between two variables is not a simple linear relationship. It means that a higher AD knowledge score does not necessarily lead to a lower stigma score. For example, it is possible that people with very high AD knowledge scores may have higher stigma scores because they are more aware of the challenges and burdens associated with the disease. The relationship between AD knowledge and stigma may vary depending on other factors such as a person's age, gender, culture, or socioeconomic status.

There are some limitations in this study. First of all, a cross-sectional study design was used in this study, so a causal relationship could not be established between the independent variables and AD knowledge score and AD-related stigma. Examining participants' level of dementia-related stigma using the ten-item STIGMA-AD scale in this study may lack sensitivity. Future studies

using a more comprehensive scale of dementia-related stigma may be needed to capture such a complex concept as stigma.

## CONCLUSION

This study showed that adults over the age of 40 in Türkiye have low levels of AD knowledge. Thus, the findings of this study supported the need to design and implement health communication interventions and policies to improve AD knowledge. Furthermore, the findings of this study revealed a currently unmet need for the development of dementia-stigma reduction strategies specifically tailored to different age groups, gender, and cultural groups. At the same time, the results of the study may help develop educational methods that address the needs of a specific population. For future research, it is recommended to examine the cause-effect relationship between the independent variables, AD knowledge score and AD-related stigma, with different research models. Additionally, a more comprehensive scale on dementia-related stigma could be used to capture a complex concept such as stigma. More research is needed to better understand the relationship between AD knowledge and stigma scores. The contribution of these two important factors to the disease burden and their impact on case finding and treatment effectiveness are also unknown.

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### Conflict of Interest

All authors declare no conflict of interest.

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## Ethical Approval

Approval was received from a state university scientific research and publication ethics committee for the implementation of the research (Decision Date: 29 December 2022, Decision No: 2022/491). Before applying, the purpose of the study was explained to the participants, their written consent was obtained, and the principle of volunteering was adhered to.

## Author Contributions

Idea: SB, PG, KK, AO, ÖÖ, ŞD, ÇE, Design: SB, PG, KK, AO, ÖÖ, ŞD, ÇE, Supervision: SB, PG, KK, AO, ÖÖ, ŞD, ÇE, Instrumentation: SB, PG, KK, AO, ÖÖ, ŞD, ÇE, Data collection and processing: SB, PG, KK, AO, ÖÖ, ŞD, ÇE, Analysis and interpretation: SB, PG, KK, AO, ÖÖ, ŞD, ÇE, Literature review: SB, PG, KK, AO, ÖÖ, ŞD, ÇE, Writing: SB, PG, KK, AO, ÖÖ, ŞD, ÇE, Critical review: SB, PG, KK, AO, ÖÖ, ŞD, ÇE.

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