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ORIGINAL ARTICLE

EVALUATION OF THE LEVEL OF KNOWLEDGE ABOUT ALZHEIMER DISEASE IN THE TEKİRDAĞ PROVINCE, TURKEY: A CROSS-SECTIONAL STUDY

ABSTRACT

Introduction: The prevalence of Alzheimer disease is increasing worldwide with increasing life expectancy. Increasing the level of community knowledge is important for early diagnosis and improving the quality of life of patients and their relatives. This study aimed to examine the level of community knowledge about Alzheimer disease and determine the areas that need to be improved with education.

Materials and Method: This descriptive and cross-sectional study was completed with 407 participants aged 18 years and older. Data were collected via Google Surveys using snowball sampling. "Alzheimer's Disease Knowledge Scale" and "Socio-demographic form" were used to collect data.

Results: Women, younger population, health personnel, and those with higher education have more knowledge. On the other hand, there is a lack of knowledge about symptoms and caregiving. Most of the respondents were unaware of the risk factors that may increase susceptibility to the development of Alzheimer disease. While the level of knowledge about Alzheimer disease was higher in individuals who received education earlier, it was observed that living in the same house with an Alzheimer patient did not affect the level of knowledge.

Conclusion: There is a need to increase society's knowledge about the symptoms, risk factors, and caregiving related to Alzheimer disease. Regular training programs to raise public awareness should be planned face-to-face or online by the authorities of the subject, especially researchers, and should be included in health policies.

Keywords: Alzheimer Disease; Awareness; Knowledge.

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INTRODUCTION

Since the beginning of the twentieth century, developments in medicine and public health have led to an increase in life expectancy and an increase in the elderly population (1). According to the estimates of the World Health Organization, one out of every six people in the world will be 60 years of age or older by 2030, and this number is expected to double by 2050 (2). According to the data of the Turkish Statistical Institute, while the population aged 65 years and over constituted 12.9% of the population in 2023, this number is expected to increase to 25.6% in 2080 (3). Alzheimer's Disease (AD), the incidence of which increases with age, affects 10% of individuals over the age of 65 and approximately 50% of individuals over the age of 85 (4). AD affects more than 6.5 million adults aged 65 years and older in the United States and accounts for approximately one-third of all deaths among the elderly (5). According to the data of the Turkish Ministry of Health in 2018, there are approximately 500 thousand diagnosed Alzheimer's patients in Turkey, and according to the 2019 Health Statistics Yearbook, 6% of the health problems experienced by individuals aged 65 years and over in the last 12 months are caused by AD (6).

Memory disorders that occur in the early stages of the disease are generally considered a normal aging process by the relatives of the patients due to the absence of behavioral problems and significant effects on social life (7). Associating forgetfulness with aging may cause the diagnosis process to be delayed for up to four years, even if the symptoms are advanced (8). The addition of impairment in non-memory cognitive functions and behavioral problems, as well as the effects on daily living activities usually causes the patient's relatives to realize that there is a problem that requires applying to a health institution (4,9,10). As the disease progresses, the need for caregiver support increases. In countries where nursing homes are limited, this situation increases the caregiver burden of individuals within the family and causes a loss of

labor force and social problems. Informing people about the disease will lead to earlier diagnosis and early initiation of supportive treatments. In addition to medical treatment, early initiation of rehabilitation and social support services for the patient's relatives will reduce the caregiver burden by supporting the preservation of the individual's independence (4,7).

Since AD poses a medical, social, and economic burden, the WHO determined in 2011 that early diagnosis should be the primary goal for Alzheimer's patients to receive effective support, treatment, and care (11). Different countries have developed different cultures of science communication and citizen participation. The most developed countries have well-organised public participation and science communication processes (12). Since the development of a country and its people depends to a large extent on the maturity of scientific and technological development, it is essential to reflect on how this development takes place, particularly with regard to the involvement of citizens in research projects and the dissemination of knowledge to society. Researchers, research units and universities have a responsibility to make information accessible, user-friendly and usable. Its other mission is to synthesise evidence to support informed health decision-making and to provide the best information and products to end users (health professionals, citizens and policy-makers).

The motivation for this research was to identify gaps to increase people's level of knowledge about AD and to create projects to disseminate information in this direction. Therefore, in this study, we aimed to examine the community's level of knowledge about Alzheimer's disease and to determine the areas that need to be improved with education.

MATERIALS AND METHOD

Design of Research

The study was planned as a descriptive and cross-sectional type. The convenience sampling method



was used in the study, and data were collected from December 2023 to March 2024 with an electronic questionnaire form.

Population and sample of the research

In determining the sample size, the data of the Turkish Statistical Institute for the year 2022 were used. The population of Tekirdağ is 1,142,451 people. These individuals constitute the finite universe of the study, and individuals over the age of 18 who agree to participate in the study constitute the study sample. The sample number was determined as 385 people with a regular distribution of 95% confidence by calculations made with the Raosoft Sample Size Calculator program (<http://www.raosoft.com/samplesize.html>). The data collection form was prepared using the Google forms application and a link was created for this form. Each item was marked as 'necessary/required' to ensure that there was no missing data. The link created was delivered to 407 people by snowball sampling method and data were collected.

Inclusion criteria

Individuals who volunteered to participate in the study, were over 18 years of age, could read and write, and could use the Internet were included in the study.

Data Collection Tools

The self-designed socio-demographic questionnaire form and the Alzheimer's Disease Knowledge Scale (ADKS) were used as measurement tools in the study. At the beginning of the questionnaire sent to the participants, the purpose of the study and the information that participation in the study was voluntary were included. Participants' names were not included in the questionnaire. The response time of the questionnaire is 5-10 minutes.

Socio-demographic form: The form, which was created in order to determine the descriptive characteristics of the participants, includes eleven questions.

Alzheimer's Disease Knowledge Scale (ADKS): The 30-item, seven-subscale scale developed by Brian Carpenter in 2009 assesses AD knowledge. Scores range from 0 to 30, with one point awarded for each correct answer. Higher scores indicate better knowledge. The Turkish adaptation by Yılmaz and Çolak showed test-retest reliability of 0.81 and a Kuder-Richardson 20 coefficient of 0.74 (13).

Statistical Analysis

Jamovi 2.3.28 statistical program was used to evaluate the data obtained from the study. Descriptive statistical techniques (mean, standard deviation, median, frequency, ratio, minimum, maximum) were used to analyse the study data. The normality test was performed with the Shapiro-Wilk Test. Since the data did not show normal distribution, the Mann-Whitney U test was used to compare two groups, and the Kruskal-Wallis test was used to compare more than two groups. Dwass-Steel-Critchlow-Fligner (DSCF) post-hoc analysis was used for significant differences between groups in the Kruskal-Wallis test. $p < 0.05$ was accepted as significant.

Ethical approval

Ethical approval has been obtained from the Ethics Committee of the Faculty of Medicine (approval number: 2023.206.11.20 dated November 28, 2023).

RESULTS

Participants socio-demographic characteristics

64.6% of the participants were female. The mean age was 28.6 ± 13.0 years (min:18-max:65), and the mean duration of education was 12.1 ± 3.33 years (min:4-max:2). It was observed that more than 80% of the participants had not received any education about AD or had not known any Alzheimer's patient. Half of the participants stated that they heard about AD from their neighborhood (family, friends, etc.). The data related to the socio-demographic characteristics of the individuals included in the study are presented in Table 1.

Table 1. Participants Socio-demographic characteristics

Variable	Category	n	%
Gender	Female	263	64.6
	Male	144	35.4
Age	≤ 25 years	258	62.9
	26-50 years	47	11.5
	≥ 51 years	104	25.6
Education status	5 years	47	11.5
	6-12 years	104	25.6
	≥13 years	256	62.9
Marital status	Married	120	29.5
	Single	287	70.5
Employment status	Yes	150	36.9
	No	257	63.1
Income-level	Income = expenditure	213	52.3
	Income < expenditure	138	33.9
	income > expenditure	56	13.8
Status of being a health care worker	Yes	65	16.0
	No	342	84.0
Alzheimer's disease recognition	Yes	136	33.4
	No	271	66.6
Living in the same house with an Alzheimer's patient	Yes	54	13.3
	No	353	86.7
Receiving education on Alzheimer's disease	Yes	66	16.2
	No	341	83.3
How they first heard about Alzheimer's disease	From the environment (family, friends, etc.)	204	50.1
	Book- journal-school	62	15.2
	Internet-television	141	34.7

Table 2. ADKS and sub-dimension scores and correct answer percentages (n=407)

Sub-dimension of the questions	Point range	Mean±SD	Min-Max (Median)	Correct answers%
Life impact (1,11,28)	0-3	2.14±0.79	0-3 (2)	70.7
Risk factors (2,13,18,25,26,27)	0-6	2.94±1.23	0-6 (3)	48.1
Symptoms (19,22,23,30)	0-4	2.19±0.89	0-4 (2)	54.8
Treatment and management (9,12,24,29)	0-4	2.48±0.79	0-4 (3)	62.1
Caregiving (5,6,7,15,16)	0-5	1.77 ±0.89	0-5 (2)	35.4
Assessment and diagnosis (4,10,20,21)	0-4	2.83±0.87	0-4(3)	70.8
Course (2,8,14,17)	0-4	2.79±0.85	0-4(3)	69.9
ADKS (Total)	0-30	17.10±2.53	9-24(17)	58.8



AKDS sub-dimension and question analysis

The mean ADKS score was found to be 17.1 ± 2.53 . The sub-dimension with the lowest knowledge level was caregiving (35.4%). The highest levels of knowledge were found in the sub-dimensions of the life impact (70.7%) and assessment and diagnosis (70.8%). ADKS sub-dimension and total scores of the participants are presented in Table 2.

It was observed that the three items with the highest rate of incorrect answers were “Carers should take over as soon as people with AD start to have difficulty caring for themselves,” “Once people have developed AD, they are no longer able to make informed decisions about caring for themselves,” and “Mental exercise can prevent a person from developing AD has been

Table 3. Participants’ correct answer percentages according to the scale items (n = 407)

		% of correct answers
1	People with AD are especially susceptible to depression.	76.4
2	Mental exercise can prevent a person from developing AD has been scientifically proven.	17.2
3	The average life expectancy after AD symptoms is 6 to 12 years.	56.3
4	If a person with AD becomes agitated, a medical examination may reveal other health problems that are causing the agitation.	82.8
5	People with AD do best with simple, step-by-step instructions.	46.4
6	Carers should take over as soon as people with AD start to have difficulty caring for themselves.	4.4
7	If a person with AD becomes alert and agitated at night, a good strategy is to try to make sure they get plenty of exercise during the day.	84.5
8	In rare cases, people have recovered from AD.	46.4
9	Psychotherapy for depression and anxiety can benefit people whose AD is not yet severe.	86.5
10	If you start having problems remembering and thinking confusedly, AD is likely.	43.0
11	Most people with AD live in a nursing home.	63.4
12	AD symptoms can be worsened by poor diet.	75.4
13	AD can affect people in their 30s.	56.5
14	A person with AD is more likely to fall as the disease gets worse.	91.4
15	When people with AD repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.	25.3
16	Once people have developed AD, they are no longer able to make informed decisions about caring for themselves.	16.2
17	Eventually, a person with AD will be in need of 24-hour care.	85.3
18	A risk factor for AD may be high blood cholesterol.	52.8
19	Hand or arm tremor is a common symptom in people with AD.	42.0
20	AD symptoms can be mistaken for symptoms of severe depression.	69.8
21	AD is one type of dementia.	87.7
22	Problems with money or bills are common early symptoms of AD.	59.2
23	One of the symptoms that can occur in AD is the belief that other people are trying to steal their things.	63.6
24	When a person has AD, the use of reminder notes is a crutch that can contribute to their decline.	21.9
25	Prescription drugs prevent AD.	41.5
26	Hypertension may increase the risk of AD.	47.2
27	Genes can only partly explain why AD develops.	78.4
28	It is safe for people with AD to drive as long as they’re accompanied.	74.2
29	AD cannot be cured.	64.4
30	Most people with AD have a better memory of recent events than of things in the past.	54.3

scientifically proven." The three items that most of the participants answered correctly were "A person with AD is more likely to fall as the disease gets worse," "AD is one type of dementia," and "Psychotherapy for depression and anxiety can benefit people whose AD is not yet severe." Table 3 shows the number of correct answers according to the items of the ADKS scale.

Analysis of socio-demographic characteristics related to ADKS

Females had higher ADKS total scores than males ($p<0.05$). Among the age groups, the ADKS total score of the group aged 25 years and younger was found to be higher than the other groups ($p<0.05$).

It was determined that the AD knowledge level of the participants was affected by the level of education. In the post-hoc analysis, it was found that the knowledge of life impact sub-dimension was significantly higher in those with 13 years of education and above than in those with five years of education ($p=0.006$). The total scale score, risk factors and symptom knowledge dimensions were found to be higher in those who were healthcare professionals and had received education about Alzheimer's disease compared to those who were not healthcare professionals and had not received education about Alzheimer's disease ($p<0.05$). The mean scores of the care sub-dimension of the scale were higher in those with poor economic status. Those who lived in the same house with an AD patient had higher 'symptom' subscale scores but lower 'treatment management' subscale scores than those who did not ($p<0.05$). Alzheimer's knowledge levels of the participants according to their socio-demographic characteristics are presented in Table 4.

DISCUSSION

In this study, the level of knowledge in a group of individuals between the ages of 18-65 was analyzed

by using the online survey method. Results revealed that the level of knowledge was higher in women, the younger, those with higher education levels, and health care staff. In today's world where internet usage and online health platforms have become widespread, although access to information is easier, information pollution makes it difficult to access accurate information. The data we obtained supports the need for more accurate dissemination of correct information through organized educational activities. It is important that regular training programs on the early diagnosis and treatment of AD, which poses the risk of an economic burden in the future, should be implemented face-to-face or online by the authorities of the subject, especially researchers, and should be included in health policies to raise public awareness (14,15). Ma et al. in their study evaluating the effectiveness of offline and online training with community health service center staff with a mean age of 35 years reported that no difference was found in terms of information between the types of training (14). In this study, the level of knowledge was higher in the younger age group. Considering the studies that emphasize regional and cultural differences in community information activities (15,16,17,18,19,20), starting education programs at a younger age, perhaps in the compulsory education processes of countries, can be an important investment to ensure accurate and reliable knowledge about health among society members.

According to previous studies, being a healthcare staff is a positive factor in terms of knowledge level. In the studies conducted for healthcare staff, the mean score of ADKS varies between 10 and 26 [Malaysian study 18.47 and 19.05 (21), Australia evaluated 23.6 (22), Brazilian 23.46 (20), Norwegian 24.10 (23), Saudi Arabia 10.77 and 26,7 (16,17)]. Healthcare staff constituted 16% of our study group, and most were not medical professionals or physicians. Although the mean ADKS score was



Table 4. Alzheimer's knowledge level according to socio-demographic characteristics

	Variables	Life impact	p	Risk factors	p	Symptoms	p	Treatment and management	p	Caregiving	p	Assessment and diagnosis	p	Disease course	p	ADKS	p
Gender	Female	2.18	0.379	3.00	0.187	2.16	0.308	2.48	0.669	1.78	0.476	2.92	0.009	2.86	0.060	17.42	0.006
	Male	2.07		2.83		2.25		2.49		1.74		2.68		2.68		16.72	
Age	≤ 25 years	2.17	0.303	3.03	0.166	2.23	0.253	2.50	0.940	1.80	0.578	2.88	0.038	2.78	0.683	17.38	0.023
	26-50 years	2.12		2.78		2.08		2.47		1.72		2.78		2.85		16.78	
	≥ 51 years	1.97		2.79		2.27		2.42		1.70		2.70		2.73		16.58	
Education status	5 years	1.87	0.002	3.09	0.096	2.19	0.238	2.47	0.388	1.64	0.390	2.72	0.311	2.77	0.754	16.74	0.003
	6-12 years	2.01		2.73		2.09		2.40		1.74		2.76		2.82		16.55	
	≥ 13 years	2.24		2.99		2.23		2.52		1.80		2.88		2.79		17.46	
Married Single	Married	2.08	0.431	2.82	0.257	2.17	0.675	2.52	0.327	1.15	0.611	2.80	0.620	2.82	0.798	17.03	0.253
	Single	2.16		2.99		2.20		2.47		1.78		2.85		2.78		17.22	
Employment status	Yes	2.09	0.595	2.88	0.497	2.11	0.076	2.49	0.893	1.75	0.650	2.76	0.162	2.79	1.000	16.87	0.066
	No	2.17		2.97		2.24		2.47		1.78		2.88		2.80		17.30	
Income-level	Income = expenditure	2.11	0.501	2.86	0.197	2.13	0.081	2.66	0.103	1.73	0.004	2.91	0.187	2.83	0.580	17.04	0.315
	Income < expenditure	2.15		3.09		2.20		2.52		1.93		2.72		2.79		17.43	
	income > expenditure	2.23		2.82		2.66		2.41		1.52		2.82		2.66		17.14	
Status of being a health care worker	Yes	2.32	0.039	3.29	0.011	2.38	0.049	2.42	0.184	1.85	0.325	2.98	0.083	2.75	0.754	18.00	0.001
	No	2.11		2.87		2.15		2.49		1.75		2.80		2.80		16.98	
Alzheimer's disease recognition	Yes	2.20	0.258	2.99	0.506	2.31	0.061	2.49	0.938	1.63	0.064	2.79	0.322	2.88	0.118	17.29	0.452
	No	2.11		2.91		2.13		2.48		1.84		2.85		2.75		17.07	
Living in the same house with an Alzheimer's patient	Yes	2.15	0.940	2.96	0.854	2.46	0.041	2.39	0.345	1.48	0.010	2.72	0.181	2.93	0.111	17.09	0.848
	No	2.14		2.93		2.15		2.50		1.81		2.88		2.77		17.15	
Receiving education on Alzheimer's disease	Yes	2.23	0.474	3.23	0.028	2.45	0.003	2.62	0.187	1.79	0.651	3.06	0.024	2.80	0.880	18.17	0.001
	No	2.12		2.88		2.14		2.45		1.77		2.79		2.79		16.95	

higher in the healthcare personnel group (18.0 vs. 17.0), it was lower compared to most of the publications in the literature. It has been reported that medical professionals and physicians have a higher level of knowledge (24,25). Considering that this group was not included in our study sample, it can be said that the low mean values are due to the data of the auxiliary health personnel. In accordance with the literature, it was observed that the level of knowledge about the impact of the disease on life, risk factors, and symptoms was higher in health workers. All these results emphasize that health professionals have a more accurate understanding of AD than the general population, confirming the expectations.

There are fewer studies in the literature assessing the level of knowledge of society members other than health professionals. Our results revealed that respondents had a good understanding of some items in all categories. The category 'assessment and diagnosis' received the highest mean percentage of correct responses (70.8%), followed by 'life impact' (70.7%), 'course' (69.9%), 'treatment and management' (62.1%), and 'symptoms' (54.8%). However, there was a lack of knowledge about the 'risk factors' (48.1%) and 'caregiving' (35.4%). Although the level of knowledge of our sample about risk factors was found to be higher than the studies examining the level of knowledge of the population in the UK, Brazil, and Saudi Arabia, it was observed to be lower than two studies conducted in different regions of the UK and Saudi Arabia (16,17,19,20). A considerable proportion of participants believed that using reminder notes could contribute to a decline in Alzheimer's patients and were not aware that mental exercise was important for brain health. Also, few participants were aware that HT and hyperlipidemia may be risk factors, supporting previous studies (16,19,20). The level of knowledge about caregiving was found to be significantly lower than other studies in the

literature. In particular, 95% of the respondents incorrectly answered the question "*Carers should take over as soon as people with AD start to have difficulty caring for themselves.*" The evaluation of the two items with the lowest level of knowledge reveals the insufficient level of knowledge about mental exercise and rehabilitation in our society. Educational programs emphasizing the importance of mental exercise along with environmental factors and healthy living requirements in the prevention of neurodegenerative diseases of the brain such as AD will increase the level of knowledge among people on this subject. In support of previous research, knowledge of AD differed between age groups and educational levels (17,18,20). While the knowledge levels of those who had a diagnosis of AD among their relatives did not differ, it was found that individuals living with AD had more knowledge about the symptoms. However, it was noteworthy that individuals living with AD had a lack of knowledge about caregiving. AD is a disease with a high caregiver burden and therefore creates serious financial and moral problems within the family (16,18,20). Informing and supporting family members about the disease and caregiving is important in reducing the caregiver burden. In addition to cognitive rehabilitation of the patient, family training can increase the quality of life of individuals by reducing the caregiver burden. It was observed that the participants who stated that they had received education before had a higher level of knowledge, especially about symptoms and risk factors.

The study has several limitations. Firstly, this study used a cross-sectional design, so it was not possible to establish a causal relationship between the independent variables and the AD knowledge score. Since this study was conducted to determine the Alzheimer's knowledge of individuals living in a region with a scale whose validity and reliability study has been conducted in our country, it does not include inter-regional differences. Using such



a convenience sample might limit the capability to generalize findings. The study, whose data were collected through Google Surveys, was limited by the fact that individuals with digital literacy and high educational status participated in the study. Future research should be carried out in a larger sample, and regional differences in the level of AD knowledge should be explained by considering socio-demographic data. The study included participants between 18 and 65 years old, and data were collected with an electronic questionnaire form which could have a bias for older adults.

CONCLUSION

The level of knowledge was higher in women, the young population, healthcare staff, and those with higher education levels. However, there are gaps in knowledge about symptoms and caregiving. Most crucially, a considerable proportion of those surveyed were unaware of risk factors that may increase one's predisposition to developing AD. In line with the findings obtained; healthcare professionals' informing the community to change cultural thought patterns (forgetfulness is the result of the aging process etc.) is important for early diagnosis. A delayed diagnosis is expected to increase the burden of family care. To increase people's level of knowledge about AD, we recommend that correct information should be conveyed by healthcare professionals through the Internet, social media, support groups, and awareness campaigns.

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