

REVIEW AND PRELIMINARY RESULTS

Senior Moments Are Never-ending Times When You Are Old (Are They?): First Step of Turquoise Project

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ABSTRACT

Introduction: The number of dementia patients in Turkey is increasing, as well as all over the world. However, we do not know how much society knows about dementia. The aim of this study is to evaluate people's concept of dementia, their awareness of dementia research and treatment, whether dementia and forgetfulness are considered normal in old age, and whether having dementia is associated with a lack of mental abilities.

Methods: A Dementia Awareness Questionnaire was created in the form of a self-report questionnaire, consisting of 20 questions and using a five-point Likert-type answering method in order to question participants' information about dementia. In addition, we asked for demographic information such as age, gender, occupation, education level of the participants, as well as whether they have had relatives diagnosed with a neurodegenerative disease. The surveys were administered online.

Results: A total of 1551 participants from 53 cities were included in the study. Approximately half of the participants did not know the definition of dementia, 20.9% thought that dementia and Alzheimer's disease were the same; 50.4% considered forgetfulness, and 55.2% considered

dementia as a natural consequence of aging. While 34.5% of the participants thought that dementia patients could be dangerous, 10.3% thought they could not continue living as a part of society. While 38.5% of healthcare professionals do not know the definition of dementia, 18.5% of them say that dementia and Alzheimer's disease are the same, 58.5% think that dementia patients are not fit to make their own decisions, 40.6% believe that dementia patients have criminal liability, 15.8% of healthcare professionals thought that dementia is only seen in elderly people; 21.4% thought that dementia, and 49.2% thought that forgetfulness was a result of normal aging.

Conclusion: Our study confirms that dementia is still an unknown concept in society and among healthcare professionals. It is widely believed that forgetfulness and dementia are part of normal aging, and there is no cure for dementia. This study, which we have done in order to understand the level of dementia awareness in Turkish society, reveals the necessity for research on dementia and studies on how to increase dementia awareness.

Keywords: Dementia, Alzheimer's Disease, aging, knowledge

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INTRODUCTION

Dementia can be defined as deficits in more than one cognitive domain due to damage to the central nervous system, at a severity level that causes impairment in the activities of daily living. Although the word dementia is widely used in everyday life in western languages, its Turkish equivalent, "bunama" –originating from the root *bun-* or *mun-*, which means "disease, distress, stupidity" in old Turkish– is commonly known in society.

The history of dementia actually goes back to antiquity. In ancient Greek and Greco-Roman texts, old age was inevitably associated with mental deterioration. The view was also put forward by Plato and Aristotle, the most important names of ancient philosophy. On the other hand, Cicero is one of the first names to say that aging does not always cause

Highlights

- The knowledge about dementia is insufficient both in wider society and among healthcare professionals.
- Dementia and forgetfulness are seen as a part of normal aging.
- Society has a negative prejudice toward aging.
- Dementia research should regularly be shared with healthcare professionals and society in general.

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mental changes. The view that mental deterioration might be a disease was put forward by Hippocrates in Ancient Greece and by Galenus in Rome (1).

In 1025, Avicenna collected mental disorders under the title of “Nesyan” in the great encyclopedia of medicine, *Al-Qanun fi't-Tibb* (Canon Medicinæ), and made the first known classification in history by dividing them into three subgroups: 1) *Fisad-al-Zekr*, 2) *Fisad-al-Fekr*, and 3) *Fisad-al-Takhayol*. It can be said that the first of these classifications correspond to Alzheimer’s disease (AD) with memory impairment, the second to fronto-temporal dementia with personality change, and the third to dementia with Lewy bodies with hallucinations and sleep disorders (2).

In the Middle Ages, the dominance of religious thought affected the definition of dementia as it did everything else. According to Roger Bacon, “senility is a consequence of the original sin” (3).

This point of view started to change with modernity and the development of experimental techniques. By 1907, Alois Alzheimer published the case of Auguste D, and consequently the disease became known as “Alzheimer’s disease,” named after him. However, due to the atypical features of this first case, AD was classified as one of the rare diseases together with Pick’s disease under the category of “pre-senile dementias” until the mid-1970s (1). This point of view could only be overcome by Robert Katzman’s statement in 1976 that “senile dementia is AD” (4,5). This statement of Katzman was also a turning point for AD research. The number of studies on AD increased exponentially in the following years. It was understood that dementia develops at a stage where neurodegenerative diseases cross a certain threshold in the pathogenetic processes. This has led researchers to identify diseases at an early stage and thus to develop early treatment interventions.

This highly simplified history shows that although mental disorders go back to ancient ages, it also indicates that it was not sufficiently recognized until recently. So much so that the 1967 edition of the famous *American Textbook of Neurology* did not have a title for Alzheimer’s disease. A special volume for dementia was published in the *Handbook of Clinical Neurology* as late as 2008 (6).

The most important step in diagnosing a disease is still people seeking medical help due to a complaint. First of all, a person needs to realize that the mental deterioration is not “normal.” Considering how difficult it was to accept diseases that cause mental disorders even in the medical community, it is essential to understand society’s level of knowledge and awareness about dementia.

According to Alzheimer’s Disease International, there are more than 55 million people with dementia globally, and it is predicted that this number may increase to 78 million in 2030 and 152 million in 2050. Someone develops dementia every three seconds, and it is stated that the annual cost of dementia is 1 trillion dollars in the United States, and this number is expected to double in 2030 (7). It is estimated that approximately 75% of people with dementia are undiagnosed globally, and this rate can reach up to 90% in some low and middle-income countries. It is thought that the lack of diagnosis of the disease is due to low awareness and stigmatization (8).

The 2019 World Alzheimer’s Report findings on the stigma and attitudes about dementia are quite striking. In the survey, which included 70,000 participants from 155 countries, two-thirds of all participants and 62% of healthcare professionals stated that they think dementia is a result of normal aging. While 95% of the participants felt that they could have dementia at any time in their lives, a quarter of them stated that they thought there was nothing that could be done to prevent dementia (7).

In a population study, including 859 participants aged 70 and over, aiming to evaluate the attitude towards dementia symptoms in Turkey,

showed that although 66% of the participants thought that dementia is normal in old age, only 6%–25% of the participants thought that dementia symptoms were normal in advanced age when questioned individually. This means that dementia is perceived as a concept separate from its symptoms (9).

This study, which we planned as the first step of the multi-centered Turquoise Project, aims to understand society’s view of the concept of dementia and the processes related to dementia in our country. In this context, it looks to see the effects of age, education, being a healthcare professional, being a relative of a patient with a neurodegenerative disease on people’s views regarding dementia.

METHODS

The Turquoise Outreach Project is a multi-centered project carried out in partnership with Dokuz Eylül University, Istanbul University and Koç University and supported by American Alzheimer’s Association and Global Brain Health Institute (GBHI) in affiliation with the University of California San Francisco (UCSF). The main purpose of our project is to build a bridge between community and dementia research. This study is planned as the first step of the Turquoise Project. The study was conducted in accordance with the Declaration of Helsinki with the approval of the ethics committee of Dokuz Eylül University dated 06.10.2021 and decision number 2021/27-01.

The Dementia Awareness Questionnaire

The Dementia Awareness Questionnaire (Appendix-1) was prepared by experts working in the field of dementia. The aim of the questionnaire is to investigate the awareness of dementia and dementia-related concepts and common misinformation about dementia-related topics in Turkish society. First, the problem was defined, and questions were determined in accordance with the purpose of this questionnaire. Secondly, seven different researchers who are experts in the field of dementia examined the draft questionnaire, and before it was finalized, it was administered to a total of 35 participants, including healthcare professionals and patient relatives, within the scope of the preliminary study. Later, the participants were asked open-ended questions about their opinions about dementia. Some examples of answers given to these open-ended questions are shown in Figure 1. The experts evaluated this feedback, and the questionnaire was finalized accordingly.

Participants

The sample of the study consists of individuals between the ages of 18–87 living in Turkey. The simple random sampling method was used. The participants included in the study were those who gave consent. The demographic characteristics of the participants are presented in Table 1.

Data Collection

The Dementia Awareness Questionnaires were conducted online. Data were collected from 53 cities in Turkey. 122 participants were excluded because they were either living outside of Turkey or their demographic information was missing. 1551 participants in total answered the demographic questions and Dementia Awareness Questionnaire in full and were included in the analysis.

The Dementia Awareness Questionnaire developed by the researchers was used as a data collection tool. The questionnaire is a self-report survey, which consists of 20 questions excluding demographic data. Demographic information includes information about the participant’s age, gender, occupation, education level, and whether there are cases of dementia among their relatives. Participants were asked to answer the questions using a five-point Likert-type evaluation method (1=Strongly Disagree, 2=Disagree, 3=I Don’t Know, 4=Agree, 5=Strongly Agree).

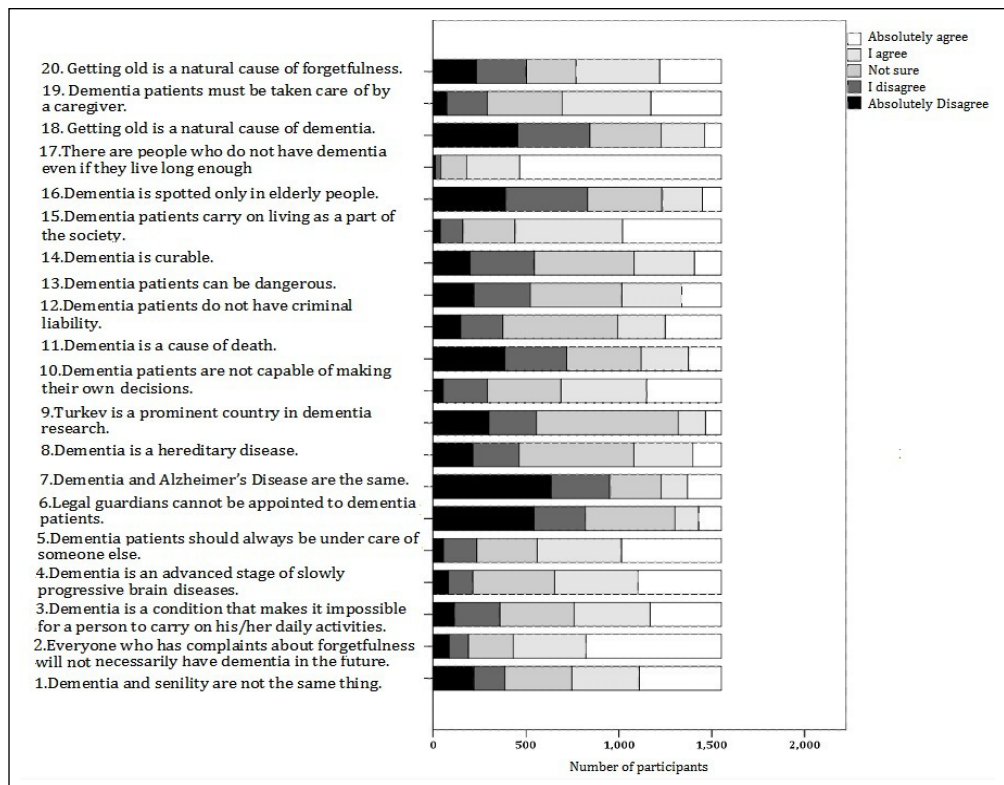


Figure 1. Examples from the comments of the participants in the preliminary study.

Table 1. Demographic characteristics of participants (n=1551)

Age (year) ^a	45.84 (13.78)
Age (Group) ^b	
18-32	304 (19.9)
33-59	955 (61.6)
60 +	292 (18.8)
Education ^b	
Literate	7 (0.5)
Elementary School	16 (1.5)
Secondary School	28 (1.8)
High School	200 (12.9)
University	846 (54.5)
Master's Degree	269 (17.3)
PhD	185 (11.9)
Gender ^b	
Female	983 (63.4)
Male	563 (36.3)
Other	5 (0.3)
Occupation ^b	
Healthcare professionals	544 (35.1)
Other	1007 (64.9)
Relatives diagnosed with neurodegenerative disease ^b	
Yes	807 (52.0)
No	744 (48.0)

a: Data are presented as mean (standard deviation).

b: The data indicate the number of participants and the (percentage).

Statistical Analysis

The data obtained was analyzed using the SPSS 24.0 package program. Descriptive statistical methods (arithmetic mean, number, percentage) were used in analysis. The differences between the groups formed according to demographic variables were examined with the Mann-Whitney U test and the Kruskal-Wallis test.

RESULTS

The distributions of all responses collected in this study are summarized in Figure 2.

Health Employees

In our study, the Mann-Whitney U test was used to determine whether there was a difference between the responses given by health employees and people working in other fields. It was found that the median values for items 1, 6, 7, 8, 14, 15, and 18 of health workers were lower in the test results (all, p<0.025). On the other hand, it was identified that the median values for items 2, 11, and 17 were higher for health workers (all, p<0.031). There was no difference between being a health worker and participants from other occupational fields for the other survey items. The items with a median difference between the answers given by those who are healthcare workers or not are summarized in Table 2.

Education Level

The education level of participants was examined under two groups, divided as low education (LE) - high school and below level, and upper

Caregiver	<p>"...she/he had a slight forgetfulness, we thought it was old age, but now she/he can't recognize us..."</p> <p>"...she/he has been forgetful for a long time, but we did not bring her/him because we thought there was no cure for this disease...."</p> <p>"...is it really hereditary? Am I going to be demented as well?..."</p>
Healthcare Professional	<p>"...I feel desperate facing a dementia patient, there is no cure..."</p> <p>"...although not everyone has dementia in old age, but forgetfulness is inevitable..."</p> <p>"...I myself am afraid of getting dementia as well..."</p>
Others	<p>"...What is dementia? I've never heard of it..."</p> <p>"...all old people forget anyway..."</p> <p>"...I am terrified of getting dementia in the future. ..."</p>

Figure 2. Distribution of overall questionnaire responses.

Table 2. The comparison of healthcare professionals and the professionals in other fields

	Occupation	Absolutely disagree	I disagree	Not sure	I agree	Absolutely agree		
	HP (n=544) Other (n=1007)	n (%)	n (%)	n (%)	n (%)	n (%)	U	p
Dementia and senility are not the same thing.*	HP	122 (22.4)	74 (13.6)	75 (13.8)	125 (23.0)	148 (27.2)	243412.5	<0.001
	Other	98 (9.7)	93 (9.2)	285 (28.3)	238 (23.6)	293 (29.1)		
Everyone who experiences forgetfulness will not necessarily have dementia in the future.*	HP	35 (6.4)	23 (4.2)	51 (9.4)	123 (22.6)	312 (57.4)	320040.5	<0.001
	Other	52 (5.2)	80 (7.9)	190 (18.9)	269 (26.7)	416 (41.3)		
Legal guardians cannot be appointed to dementia patients.*	HP	247 (45.4)	112 (20.6)	111 (20.4)	35 (6.4)	39 (7.2)	219089	<0.001
	Other	297 (29.5)	163 (16.2)	371 (36.8)	93 (9.2)	83 (8.2)		
Dementia and Alzheimer's Disease are the same.*	HP	303 (55.7)	96 (17.6)	44 (8.1)	42 (7.7)	59 (10.8)	213157.5	<0.001
	Other	333 (33.1)	218 (21.6)	234 (23.2)	100 (9.9)	122 (12.1)		
Dementia is a hereditary disease.*	HP	97 (17.8)	100 (18.4)	175 (32.2)	125 (23.0)	47 (8.6)	255634.5	0.024
	Other	118 (11.7)	148 (14.7)	442 (43.9)	194 (19.3)	105 (10.4)		
Dementia is a cause of death.*	HP	133 (24.4)	122 (22.4)	92 (16.9)	118 (21.7)	79 (14.5)	292383.5	0.024
	Other	253 (25.1)	211 (21.0)	309 (30.7)	136 (13.5)	98 (9.7)		
Dementia is curable.*	HP	80 (14.7)	159 (29.2)	152 (27.9)	108 (19.9)	45 (8.3)	243702	<0.001
	Other	119 (11.8)	188 (18.7)	383 (38.0)	217 (21.5)	100 (9.9)		
Dementia is spotted only in elderly people.*	HP	199 (36.6)	171 (31.4)	88 (16.2)	58 (10.7)	28 (5.1)	205538.5	<0.001
	Other	190 (18.9)	271 (26.9)	312 (31.0)	161 (16.0)	73 (7.2)		
There are people who do not have dementia even if they live long enough.*	HP	3 (0.6)	5 (0.9)	19 (3.5)	90 (16.5)	427 (78.5)	313989.5	<0.001
	Other	11 (1.1)	22 (2.2)	120 (11.9)	196 (19.5)	658 (65.3)		
Getting old is a natural cause of dementia.*	HP	185 (34.0)	130 (33.9)	113 (20.8)	89 (16.4)	27 (5.0)	256162	0.030
	Other	270 (26.8)	259 (25.7)	272 (27.0)	145 (14.4)	61 (6.1)		

HP: Healthcare professionals.

* Statistically significant differences across groups $p < 0.05$.

education (UE) – university and higher level. The medians of the two groups were compared with Mann-Whitney U test for each of the survey items. We found that while the LE group had significantly higher median values for items 6, 7, 9, 14, 16, and 18, we saw that the UE group had significantly

higher median values only for items 2 and 17 (all, $p < 0.004$). The percentage values of the answers given to the items, which show a significant difference according to the level of education, are reported in Table 3.

Table 3. Comparisons between groups by education

	Education	Absolutely disagree	I disagree	Not sure	I agree	Absolutely agree		
	LE (n=1300) HE (n=251)	n (%)	n (%)	n (%)	n (%)	n (%)	U	p
Everyone who experiences forgetfulness will not necessarily have dementia in the future.	HE	69 (5.3)	84 (6.5)	181 (13.9)	321 (24.7)	645 (49.6)	1038368.5	<0.001
	LE	18 (7.2)	19 (7.6)	60 (23.9)	71 (28.3)	83 (33.1)		
Legal guardians cannot be appointed to dementia patients.	HE	487 (37.5)	231 (17.8)	385 (29.6)	107 (8.2)	90 (6.9)	133145.5	<0.001
	LE	57 (22.7)	44 (17.5)	97 (38.6)	21 (8.4)	32 (12.7)		
Dementia and Alzheimer's Disease are the same.	HE	573 (44.1)	266 (20.5)	208 (16.0)	110 (8.5)	143 (11.0)	126405.5	<0.001
	LE	63 (25.1)	48 (19.1)	70 (27.9)	32 (12.7)	38 (15.1)		
Turkey is a prominent country in dementia research.	HE	269 (20.7)	223 (17.2)	626 (48.2)	124 (9.5)	58 (4.5)	138256.5	<0.001
	LE	31 (12.4)	34 (13.5)	136 (54.2)	23 (9.2)	27 (10.8)		
Dementia is curable.	HE	177 (13.6)	301 (23.2)	448 (34.5)	268 (20.6)	106 (8.2)	136161	<0.001
	LE	22 (8.8)	46 (18.3)	87 (34.7)	57 (22.7)	39 (15.5)		
Dementia is spotted only in elderly people.	HE	340 (26.2)	377 (29.0)	324 (24.9)	182 (14.0)	77 (5.9)	144653.5	0.003
	LE	49 (19.5)	65 (25.9)	76 (30.3)	37 (14.7)	24 (9.6)		
There are people who do not have dementia even if they live long enough.	HE	11 (0.9)	19 (1.5)	102 (7.8)	230 (17.7)	938 (72.2)	187133.5	<0.001
	LE	3 (1.2)	8 (3.2)	37 (14.7)	56 (22.3)	147 (58.6)		
Getting old is a natural cause of dementia.	HE	411 (31.6)	333 (25.6)	301 (23.2)	187 (14.4)	68 (5.2)	130950.5	<0.001
	LE	44 (17.5)	56 (22.3)	84 (33.5)	47 (18.7)	20 (8.0)		

The table includes the distribution of items which was found group differences at the results of the Mann-Whitney U Test.

The data are presented as the number of participants (percentages).

The U and p values were elicited with Mann-Whitney U Test.

HE: higher education, LE: lower education.

Table 4. Comparisons between groups whether have a relative with a neurodegenerative diagnosis

	A relative with diagnosis	Absolutely disagree	I disagree	Not sure	I agree	Absolutely agree	U	p
Dementia patients should always be under care of someone else.	Yes	28 (3.5)	88 (10.9)	142 (17.6)	251 (31.1)	298 (36.9)	324500	0.004
	No	29 (3.9)	91 (12.2)	183 (24.6)	202 (27.2)	239 (32.1)		
Legal guardians cannot be appointed to dementia patients.	Yes	320 (39.7)	147 (18.2)	225 (27.9)	61 (7.6)	54 (6.7)	263821	<0.001
	No	224 (30.1)	128 (17.2)	257 (34.5)	67 (9.0)	68 (9.1)		
Dementia patients do not have criminal liability.	Yes	70 (8.7)	123 (15.2)	301 (37.3)	140 (17.3)	173 (21.4)	317176.5	0.045
	No	78 (10.5)	105 (14.1)	317 (42.6)	115 (15.5)	129 (17.3)		
Dementia is curable.	Yes	124 (15.4)	199 (24.7)	258 (32.0)	155 (19.2)	71 (8.8)	268440	<0.001
	No	75 (10.1)	148 (19.9)	277 (37.2)	170 (22.8)	74 (9.9)		
There are people who do not have dementia even if they live long enough.	Yes	10 (1.2)	11 (1.4)	58 (7.2)	142 (17.6)	586 (72.6)	318004	0.012
	No	4 (0.5)	16 (2.2)	81 (10.9)	144 (19.4)	499 (67.1)		
Dementia patients must be taken care of by a caregiver.	Yes	34 (4.2)	104 (12.9)	194 (24.0)	246 (30.5)	229 (28.4)	331678	<0.001
	No	41 (5.5)	113 (15.2)	208 (28.0)	232 (31.2)	150 (20.2)		

The table includes the distribution of items which was found group differences at the results of the Mann-Whitney U Test. The data are presented as the number of participants (percentages). The U and p values were elicited with Mann-Whitney U Test. HE: higher education, LE: lower education.

Having a Relative with a Diagnosis of Neurodegenerative Disease

The median of survey responses from people who have a relative with a diagnosis of neurodegenerative disease and people who do not were compared with the Mann-Whitney U test. In the analysis results, it was observed that the medians of the responses given to items 5, 12, 17, and 19 by those with a diagnosed relative were found to be significantly higher, while the medians of the responses given to items 6 and 14 by those who did not have a diagnosed relative were found to be significantly higher (all, p<0.046). The percentage distributions of the items with responses in which there is a significant difference are presented in Table 4.

Age Groups

The age variable was divided into 3 levels according to the mean and standard deviation values. Participants between the ages of 18 and 32

were categorized as young adults, 33 and 59 as adults, 60 and over as mature individuals. The responses of these groups to the survey items were tested with the Kruskal-Wallis. There were significant differences between age groups in items 3, 5, 6, 8, 10, 11, 12, 15, 16, 17, 18, 19, 20 (all, p<0.043). These differences were further analyzed, and the significant pairwise group comparisons are listed in Table 5.

DISCUSSION

Our aim for this study was to evaluate the concept of dementia in our country, the awareness of dementia research and treatment, whether dementia and forgetfulness are considered normal in old age, and whether having dementia is associated with lack of mental abilities among a population that includes healthcare professionals. The most striking findings among the study results show that concepts related to dementia are generally not known correctly within society and/or that their

Table 5. Comparisons between groups by age

Items	18-32 and 33-59 age	33-59 and 60+ age	18-32 and 60+ age
Dementia is a condition that makes it impossible for a person to carry on his/her daily activities.	18-32<33-59 p<0.001		18-32<60+ p<0.001
Dementia patients should always be under care of someone else.	18-32<33-59 p<0.001		18-32<60+ p<0.001
Legal guardians cannot be appointed to dementia patients.			18-32>60+ p=0.011
Dementia is a hereditary disease.			18-32>60+ p=0.001
Dementia patients are not capable of making their own decisions.		33-59<60+ p<0.001	18-32<60+ p=0.001
Dementia is a cause of death.		33-59>60 p=0.022	
Dementia patients do not have criminal liability.		33-59<60+ p=0.001	18-32<60+ p<0.001
Dementia patients carry on living as a part of the society.	18-32>33-59 p=0.018		18-32>60+ p=0.001
Dementia is spotted only in elderly people.			18-32<60+ p<0.037
There are people who do not have dementia even if they live long enough.	18-32<33-59 p=0.010	33-59<60+ p<0.001	18-32<60+ p=0.002
Getting old is a natural cause of dementia.	18-32<33-59 p=0.015		
Dementia patients must be taken care of by a caregiver.	18-32<33-59 p=0.005	33-59<60+ p=0.001	18-32<60+ p=0.001
Getting old is a natural cause of forgetfulness.	18-32>33-59 p=0.001	33-59<60+ p<0.001	

The data present the pairwise comparisons of responses that there were group differences at the Kruskal-Wallis Test. Greater-than and less-than signs are used for mean rank values.

definitions are confused with each other. Only 25% of the participants think that dementia and senility are synonymous. However, 20.9% of the participants believe that dementia and Alzheimer's disease are the same. To a large extent it has been understood that the concepts of dementia and Alzheimer's disease are different from each other, possibly due to the terminology being commonly mentioned and information being relayed through the media. However, it has been observed that a group of 38.8% is still confused about these concepts. In order to attract society's attention, non-governmental organizations and associations related to dementia tend to prefer using Alzheimer's disease in their names (Alzheimer Association, Alzheimer's Voice Application). However, this approach is thought to possibly be feeding into the misinformation among society.

The fact that 50.4% of the participants see forgetfulness and 55.2% see dementia as a natural result of aging indicates that the awareness of healthy aging is not fully understood in society. In a similar study conducted in Turkey, 66% of 859 participants over the age of 70 stated that dementia is a result of normal aging (9). While age-related physical changes are almost always taken into account, cognitive changes and performance changes in activities of daily living are thought to have a higher threshold (10). Accepting dementia and forgetfulness as normal with age is an important factor that prevents the chance of early diagnosis (11). On the other hand, 88.4% of the participants think that living longer does not definitely cause dementia, 72.2% believe that everyone with a complaint of forgetfulness may not have dementia in the future, and 53.6% of them believe that dementia is not specific to elderly people. According to the 2019 World Alzheimer's Report, 95% of 70,000 participants from 155 countries support the idea that dementia can occur at any stage of life, not only in the elderly (7). These findings indicate that, despite the fact that the concept of healthy aging is not understood, the concepts of forgetfulness and dementia can be distinguished from each other.

Another conceptual confusion noticed in our study is related to the definition of dementia. It was observed that nearly half of the population did not have a correct information in the responses given to the following statements: *Dementia is a condition that makes it impossible for a person to carry on his/her daily activities*, and *Dementia is an advanced stage of slowly progressive brain diseases*, which are the two essential components of the clinical diagnosis of dementia. This uncertainty about the definition is thought to support the stigmatization of dementia (8). Another issue that is not fully understood is the familial/hereditary aspect of dementia. The impression we got during our pilot study was that the lack of understanding of this issue among people who have family members with dementia increases the fear of dementia (Figure 1). However, it is noteworthy that the vast majority do not have knowledge about dementia treatment and legal processes related to dementia.

It has been observed that the concepts of dementia and its subtypes (such as the proposition that *Dementia and Alzheimer's Disease are the same*) are not fully known and cannot be differentiated in the general sample group, and this is more prominent in individuals with high school or lower education. The items *Everyone who has complaints about forgetfulness will not necessarily have dementia in the future* and *Getting old is a natural cause of forgetfulness* are answered differently according to education level, suggesting that individuals with high school and below education may have low awareness of the concept of healthy aging as well as dementia awareness. Notably, awareness of legal processes is higher at university and higher education levels, yet dementia awareness and stigmatization do not change depending on education level. The fact that the awareness of the 18–32 age group is lower than the other age groups indicates that young groups need to be further educated on dementia for a healthy aging culture to be established in the future (12).

While 34.5% of the participants think that dementia patients can be dangerous, 10.3% do not believe they can continue to live as a part of

society. In addition to this stigmatization for the diagnosis of dementia, dementia is considered to be the single cause of death in 27.8% of cases. In similar studies, it has been stated that the main reason for stigmatization is lack of knowledge regarding the concept of dementia (13), which also leads to delays in diagnosis (14).

According to our study, it is quite remarkable that the knowledge about dementia is insufficient among healthcare workers. 38.5% of health professionals gave the answers disagree/strongly disagree/don't know to the proposition that *Dementia is an advanced stage of slowly progressing brain diseases*. 18.5% of healthcare professionals stated that dementia and Alzheimer's disease are the same, 58.5% that dementia patients are not competent to make their own decisions, and 40.6% that dementia patients do not have criminal liability. These prejudices can lead to the conclusion that a person diagnosed with dementia is not able-minded, regardless of the stage of the disease or the person's judgement/abstraction skills.

The percentage of healthcare professionals who believe that dementia patients may be dangerous is reported as 11.9% for high-income countries, 21.5% for high-middle-income countries, and 37.8% for low/low-middle-income countries (7). Our study found the rate of health professionals who think that dementia patients could be dangerous to be 37.7%, which is equal to the rate reported for low-middle-income countries.

While 43.9% of healthcare professionals thought that dementia treatment is not possible, 27.9% answered "I don't know". 15.8% believe that dementia is only seen in elderly people; 21.4% believe that dementia, and 49.2% believe that forgetfulness is a result of normal aging. In the 2019 World Alzheimer Report, the rate of healthcare professionals who believe that dementia is a result of normal aging was reported as 62% (7). Although this rate was significantly low in our study, it still shows that there is a substantial lack of knowledge among healthcare professionals. The belief that forgetfulness and dementia are part of normal aging and that there is no cure for dementia causes delays in the diagnosis of patients (11).

When the effect of education level on dementia awareness is examined, it is seen that individuals with university and higher education levels are less likely to agree with the proposition, "*Turkey is a prominent country in dementia research*", but there is a lack of information in the general society. It is essential to make dementia research a state policy, encourage it more, and further educate the community about the research currently done in this field, in order to raise the awareness of dementia in all segments of society.

Another variable our study examines is the effect of having a relative with a diagnosis of neurodegenerative disease on participants' responses to the questionnaire. The results show that people with a diagnosed relative are more aware of the burden of care and legal processes. The lack of difference in other items suggests even the relatives of patients do not sufficiently understand that the concepts related to dementia and dementia subtypes and that healthcare professionals are inadequate in informing the relatives of patients on these subjects. These findings remind us of the fact that researchers have a duty to disseminate research results and inform the public, in addition to conducting scientific studies. Therefore, cooperation with the media is mandatory (15).

It is undeniable that the vast majority of older people complain of cognitive impairment. This fact underlies the belief that forgetfulness is a part of normal aging. The "normal" ranges of cognitive tests are arranged according to age, for this very reason. However, a person being in the normal range for their age group does not mean that they have not worsened compared to their own normal. On the other hand, people who maintain their cognitive capacity at advanced ages have led to the emergence of the concept of superager. Although genetic background

plays an important role in super-aging (e.g., not carrying the APOE E gene risk allele $\epsilon 4$), it is also important that these people lead active mental and physical lives (16,17). Two other important concepts that have become more popular in recent years are resistance and resilience (18). These features describe a person's resistance to the deterioration of the brain structure and their ability to maintain cognitive capacity despite age and neuropathological background. Modifiable factors such as higher education, an active physical and mental life, and a healthy diet seem to contribute to a person's resistance and resilience. As these concepts become more commonly known, it becomes possible for old age to no longer be equated with forgetfulness.

The limitations of our study are that healthcare professionals were not categorized according to their fields (such as nurses, healthcare personnel, and physicians according to their specialties), and although whether participants have a relative with dementia is questioned, people who directly cared for a dementia patient were not questioned separately.

For future research, adding questions specific to patients themselves and people who directly care for them, applying a more structured scale for evaluating knowledge, attitude and stigma towards dementia, and conducting research with a wider population would allow us a clearer understanding of dementia awareness in Turkey.

The majority of the participants in our study have an education level of high school and above. Since the survey was conducted online, only participants who had internet access and were able to fill out the online form were included, which may be a possible reason for the high level of education. The fact that the level of knowledge about dementia is insufficient, even in a population with high levels of education, makes the findings even more striking.

The 2019 World Alzheimer's Report indicates that this situation is not unique to our country. It is necessary for work to be done in order to increase knowledge and awareness about the concepts of dementia and normal aging. In 2017, The World Health Organization published a global action plan for dementia. In this plan, 7 areas of action were defined as, 'dementia as a public health priority', 'dementia awareness, and dementia-friendly society', 'reducing the risk of dementia', 'dementia diagnosis, treatment, care, and support', 'supporting caregivers', 'dementia information systems', and 'dementia research'. The aim is to carry out at least one public awareness campaign in all countries, and plan at least one dementia-friendly initiative in at least half of the countries by 2025, in order to promote a dementia-inclusive society (19). Our work is an initial step for this issue, which is currently an urgent worldwide agenda. At this time, our knowledge of the pathophysiology of illnesses causing dementia is constantly expanding, and candidate treatments for AD –which is the most common of these– is on the agenda; thus, such works are essential for early diagnosis of the disease, as well as protecting the rights of patients and allowing them to participate in society.

The main purpose of the Turquoise Project, which consists of multiple stages, is to build a bridge that brings dementia research to society; and this study enables us to determine the level of dementia awareness in Turkish society, as a first step for creating a national strategic plan for dementia research and raising dementia awareness.

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