

Stigma Against Alzheimer's Disease In Turkish Population

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Abstract

Introduction: Cognitive, behavioral, and psychiatric disorders associated with dementia cause stigma against Alzheimer's disease (AD) in both patients, caregivers, and healthy individuals in public. To the best of our knowledge, since stigma against AD is not investigated in the Turkish public, we wanted to evaluate the stigma of healthy Turkish people according to their demographic characteristics in our study. **Materials and Methods:** 439 healthy participants without any history of neurological and/or systemic disease were included in this cross-sectional observational study. Demographic characteristics and knowledge about the AD of the participants were recorded. A ten-question survey was applied to the participants to assess the stigmatization against AD. Factors associated with the stigma score were evaluated in regression analysis. **Results:** 253 men and 186 women were included in this study (mean age: 35.7 ± 9.8 years). Most of them had knowledge about AD (94.3%). Only 18.5% had a family history of AD. Sixty-five percent had married. 95 of 439 persons (21.6%) worked in health fields. 60.6% of healthy participants had a moderate-high stigma against AD. The mean stigma score was 8.95 ± 4.79 . Total stigma scores were higher in women and single persons ($p = 0.001 / p < 0.001$). Healthcare workers expressed the highest levels of stigma ($p < 0.001$). Age, knowledge, and family history of AD did not influence stigma. Shame, loss of self-esteem, and fear of exclusion were expressed the most. **Conclusion:** To the best of our knowledge, this is the first study that evaluated perceived stigma against AD in the Turkish healthy population. The higher incidence of stigma among women and single persons can be explained by cultural reasons. Stigma in health professionals may lead to delay in early diagnosis and management of AD. Further studies of perceived stigma are necessary to improve intervention strategies.

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Keywords: Alzheimers Disease, Stigma, healthcare workers, healthy population

What's Known

AD is considered a less fortunate disorder than those with treatable diseases that result in stigmatization by some societies.

Understanding the perception of stigma in healthy individuals and educating society with accessible and effective methods helps increase disease-related awareness and improve disease management.

What's New

The present study is the first study to investigate the frequency of perceived stigma against AD in the healthy Turkish population.

It has been shown that 60.6% of healthy participants have a moderate-high stigma against AD with higher stigma levels in women, singles, and healthcare workers.

Introduction

Alzheimer's disease (AD) is a progressive neurodegenerative disease that presented with episodic memory impairment and gradually decreases other cognitive functions.(1) The global prevalence of the disease, which increases twice every 5.5 years, is expected to be 114.5 million in 2050.(2,3) Early recognition of this disease, which has a great socio-economic impact worldwide, is significant in increasing appropriate treatment of dementia and managing it in psychological, emotional, familial, economical terms. However, the perceived stigma against AD is seen as a huge factor in preventing effective strategies for the disease.(4)

Stigma is defined as the negative attitude of the social public towards people who are thought to be different in terms of physical, mental, and lifestyle. People who carry this label are less desired.(5) Patients with memory impairment are known to judge themselves due to their illness and symptoms and experience both social and internalized stigmatization.(6) In addition, family members and caregivers have stigmatization also.(7) Moreover, some people believe that those diagnosed with AD are less fortunate than those with treatable diseases.(5) Understanding the perception of stigma in healthy individuals and educating the society with accessible and effective methods helps to increase disease-related awareness and improve disease management.(8-9)

There is no study evaluating the perceived stigma against AD in healthy people in Turkey to the best of our knowledge. Therefore, this study aims to investigate the perceived stigma level against AD in healthy people. Its second aim is to reveal the demographic characteristics and related factors of people with high stigmatization.

Materials And Methods

Study population

439 healthy participants (253 men, 186 women) living in Turkey's capital Ankara were included in This cross-sectional observational study. Participants in the study had no known neurological and/or systemic disease. Participants' age, gender, marital status, educational status, and occupations were recorded. Participants were asked about knowledge and family history of AD

Survey

A ten-question survey (Table 1) was applied to the participants to assess the perceived stigma against AD. This questionnaire is the adaptation of the "STIG-MA" survey developed by Piver et al. in 2012, with the author's permission (10). Participants were asked to pretend that they had Alzheimer's disease and rate what they felt. The questions were answered as "yes, maybe, I don't know, no" and scored between 0-3. The score 3 corresponded to the greatest stigma, either YES if the question was positive (questions 1, 3, 4, 5, 6, 7, and 9) or NO if the question was negative (questions 2, 8 and 10). Other answers scored respectively. The total score indicated the stigma severity. The highest score was 30. 0-7 was graded as mild, 8-11 as a moderate, and 12 and above the high stigma.

The questions were also grouped to explore several dimensions of 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)

The study's Ethics committee approval for the research and permissions for data sharing for scientific purposes was obtained (23.12.2020 / 96537014). The Helsinki Declaration 2008 principles conducted the study.

Statistical Methods

Descriptive statistics were expressed as mean, standard deviation (SD), median, minimum, and maximum for continuous data; and as count and proportion for categorical data. Categorical data were analysed with the Chi-Square or Fisher's exact tests. The distribution normality of the continuous variables was calculated with the Shapiro-Wilk test. We analysed the two groups with Independent Samples T test for the normally distributed variables and with the Mann-Whitney U Test for the non-normally distributed variables. We compared the more than two groups with One-way ANOVA for the normally distributed variables and with the Kruskal-Wallis test for the non-normally distributed variables; post-hoc multiple comparison analysis was performed with significant values that have been adjusted by the Bonferroni correction. Pearson's or Spearman's correlation analysis was used to find the relationship between continuous variables, depending on the distribution.

Statistical analyses were performed using the IBM SPSS v.24 for Windows software and was reported with 95% confidence intervals. Values of $p < 0.05$ were considered significant

Results

439 healthy participants (186 females (42.4%), 253 males (57.6%), mean age 35.7 years \pm 9.8) without neurological and/or systemic diseases were included in this study. 94.3% ($n = 414$) of the participants stated that they had knowledge about AD. But only 18.5% ($n = 81$) had a family history of AD. 95 (%21,6) of the participants were healthcare workers. Also, 152(%34,6) participants were singles.

According to the STIG-MA survey, the mean stigma score of the participants against AD was 8.95 ± 4.79 . 60.6% of healthy participants have a moderate-high stigma against AD..Mean scores of the dimensions of perceived stigma are summarized in Table 2.

Participants were divided into three groups according to their scores from this questionnaire: mild stigma ($n = 173$, 39.4%), medium stigma ($n = 133$, 30.3%), and severe stigma ($n = 133$, 30.3%). 31.8% of the participants in the mild stigma group, 50.4% of those in the medium stigma group, and 48.1% of those in the severe stigma group were women ($p = 0.001$). The mean stigma score was higher in singles ($p < 0.001$). Medium-severe stigma was detected in 72 (75.8%) of 95 healthcare workers participating in the study, and the stigma in healthcare workers was found to be statistically significant compared to non-healthcare workers ($p < 0.001$). The three groups were similar in terms of age, knowledge about AD, family history of AD, and occupations (Table 3).

Correlation analysis was applied to investigate the relationship between dimensions of perceived stigma against AD and age, gender, AD awareness, marital status and occupation. The stigma scores of healthcare workers in all dimensions were higher than those without, and this result was statistically significant (respectively; $p = 0.006$, $p = 0.034$, $p < 0.001$, $p = 0.021$, $p = 0.009$). It was observed that women got higher

scores in the dimensions of "reluctance to declare the illness", "emotional impact" and "loss of family support" ($p = 0.018$, $p < 0.001$, $p < 0.001$, respectively.). In singles, stigma scores were higher in the dimensions of "emotional impact" and "loss of family support" ($p = 0.006$, $p < 0.001$). Other factors did not have a significant effect on the dimensions of the perceived stigma.

Discussion

Our study has shown that 60.6% of healthy participants have a moderate-high stigma against AD. However, stigma levels were higher in women, singles, and healthcare workers.

Older people with cognitive impairment encounter stigmatization in many cultures. Stigmatization causes a delay of 1.5-1.8 years in the diagnosis of cognitive impairment (11). It has been reported that older people are stigmatized due to their age, and additional cognitive impairment increases the risk of stigma three times (12). Cognitive, behavioral, and psychiatric disorders associated with dementia cause some issues such as denial, embarrassment, and irritability associated with AD in both patients, caregivers, and healthy individuals in the community. In Western societies, dementia is seen as a loss of youth, functionality, and independence. This, in turn, is associated with reduced tolerance and increased risk of stigma for dementia patients (13). In Eastern countries such as Japan, China, and India, dementia is perceived not as a disease but as a part of aging. Therefore, in these countries, unlike in Western societies, the fear of having AD and the frequency of stigma associated with it are less common (14-16). While some African-Americans see dementia as the inevitable consequence of aging, others define it as a form of mental illness because of their spiritual and religious beliefs. Therefore, these populations experience less stigma, caregiver burden, and caring problems against AD(17,18). In Arabic countries, because of prohibitions on disclosing personal and family issues to foreigners, Alzheimer's patients' access to hospitals has decreased and resulted in criticism and ridicule (19). On the other hand, solid religious beliefs increase compassion and the willingness to help patients with Alzheimer's disease and reduce the aggression towards patients (13). In a study conducted with a population of AD and caregivers, approximately two-thirds of the participants stated that they were not understood by others and were exposed to negative associations in society (20). In our study, the perceived stigma against AD was high in more than half of the healthy Turkish participants. While this rate is similar to some studies reported in Western societies, it is higher than the stigma in Eastern cultures. This difference may be due to the cultural factors and demographic characteristics of the participants.

Some factors affect people's perception of stigma, such as gender, age, education level, cultural beliefs, knowledge about Alzheimer's disease, or being an AD caregiver. The most important factor associated with the perceived stigma against AD is gender (21). In a study from Australia, stigmatization against AD was found to be higher in men. However, in elderly societies with a higher male population and gender discrimination, women have three times more risk (22,23). In our study, the stigmatization against AD was found to be higher in women than in men. This result was thought to be related to the fact that women are more interested in the care of AD patients in our country, and therefore women are more exposed to the behavioral effects of the disease.

Studies have shown that the perception of stigma in young people is higher than in the elderly (22,24). Different from previous studies, although most of our participants were young, age did not have any effect on stigmatization in our study.

The socioeconomic factors and education level affect stigmatization (25). In highly educated and developed countries, cognitive impairments are known as an unavoidable part of normal aging. This increases fear and anxiety in individuals, feelings of hopelessness, and stigmatization (26). In the less developed countries, people accept patients with AD more easily and stigmatize them less (25). In some studies, it has been shown that education level does not affect stigma (21,27). Similarly, no relationship was found between marital status and stigmatization (28). In our study, the stigma level was not affected by the education level and the occupation. However, in contrast to the literature, it was observed that single participants got higher scores in the "Fear of loss of family support " and "Emotional impact" dimensions. The high stigmatization in these dimensions is thought to be due to people not having any idea about their future partners and their

behavior.

Although the vast majority of the participants (94.3%) included in our study have knowledge about AD, they had a high stigma against the disease. This result is different from other studies reporting the relationship between having less knowledge about the disease and a high risk of stigma. People who have more information about AD have less stigma (29). In a study conducted in 155 countries with more than 70.000 participants, it was found that two-thirds of the participants accepted AD as a part of the aging process, not as a neurodegenerative disease. This indicates the lack of knowledge about AD that may result in stigma (31).

There was no difference in stigma between those who had a family member with dementia and those who did not. (21,24,31). Only about one-fifth of our participants had a family history of AD, which was not associated with stigma level, consistent with previous studies.

It has been demonstrated that approximately 62% of healthcare workers know dementia as a part of normal aging in a large study. (32). Education of healthcare professionals about AD and increasing their awareness about the disease is necessary for early diagnosis of AD and developing effective strategies to manage the disease. Thus, national dementia outcomes could be improved (33). A few studies have shown that the perception of stigma against AD is high among healthcare professionals (10,32). Our study also revealed a high stigma against AD in most healthcare workers.

Our study is the first investigating the perceived stigma prevalence against AD in the healthy Turkish population to the best of our knowledge. However, the study has some limitations. Participants are generally young people, so stigmatization in older individuals is not clear. Besides, since AD caregivers were not included in this study, the stigmatization of them couldn't be evaluated.

Conclusion

In conclusion, perceived stigma against AD is frequent in healthy Turkish individuals and is higher in women, singles, and healthcare workers. The prevalence of stigma may vary between different cultures. Stigma not only delays the diagnosis of AD, but also prevents patients from accessing medical and surgical interventions, making decisions about their own care and legal processes, and also expressing opinions on AD treatment and support. It is important to provide national strategies for eliminating the perception of stigma. There is a need for randomized, controlled, large-scale studies investigating the frequency of stigma and related factors in the general population.

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Table Ten questions about perceived stigma in the STIG-MA survey

If you were suffering from Alzheimer’s disease

1. Would you rather people did not know about your disease? 2. Would you tell the person you are closest to? 3. Would you

Table Global stigma score and five dimensions of perceived stigma

Global Stigma score (m±sd)	8.95
Reluctance to disclose the illness (m±sd)	0.93
Emotional impact (m±sd) Fear of exclusion (m±sd) Courtesy stigma (m±sd) Fear of loss of family support (m±sd)	3.00

m: mean sd: Standard deviation

Table 3 Stigma levels of the participants according to their demographic characteristics.

	Mild Stigma (n=173)	Moderate Stigma (n= 133)	High Stigma (n=133)	p value
Age (year), (m±Sd)	36.8 (±10.3)	35.3 (±10.3)	34.7 (±8.6)	0.242
Gender, female n, (%)	55 (31.8)	67 (50.4)	64 (48.1)	0.001*
Knowing about AD n, (%)	14 (8.1) 35 (20.2) 40 (23.1) 156	5 (3.8) 27 (20.3) 52 (39.1) 115	6 (4.5) 19 (14.3) 60 (45.1) 126	0.062 0.903 0.000* 0.071
Having family member with AD n, (%) Marital status, single n, (%) Occupation, worker n, (%) Heathcare worker n, (%)	(90.2) 23 (13.3)	(86.5) 28 (21.1)	(94.7) 44 (33.1)	0.000*

n: number m: mean sd: standart deviation