

Perceived Stigma Against Alzheimer's Disease in the Turkish Population

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Abstract

Objective: Cognitive, behavioral, and psychiatric disorders that are associated with dementia cause stigma against Alzheimer's disease (AD) in patients and caregivers as well as in healthy individuals in public. To the best of our knowledge, stigma against AD is not investigated in the Turkish population; therefore, this study aimed to evaluate the stigma of healthy Turkish people according to their demographic characteristics.

Materials and Methods: This cross-sectional observational study included a total of 439 healthy participants without any history of neurological and/or systemic disease. Demographic characteristics and AD-related knowledge of participants were recorded. A 10-item questionnaire survey was applied to the participants to assess the stigmatization against AD. Factors associated with the stigma score were evaluated in regression analysis.

Results: This study included 253 males and 186 females (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, and 65% were married. Of 439 persons, 95 (21.6%) worked in healthcare fields. Of the healthy participants, 60.6% had a moderate-high stigma against AD. The mean stigma score was 8.95±4.79. The total stigma scores were higher in females and singles ($p=0.001$ and $p<0.001$, respectively). Healthcare workers expressed the highest levels of stigma ($p<0.001$). Age, knowledge, and family history of AD did not influence the stigma. Shame, loss of self-esteem, and fear of exclusion were most expressed stigmas.

Conclusion: To the best of our knowledge, this is the first study that evaluated perceived stigma against AD in the healthy Turkish population. The higher incidence of stigma among females and singles can be explained by cultural reasons. Stigma in health professionals may lead to delay in the early diagnosis and management of AD.

Keywords: Alzheimer's disease, stigma, healthcare workers, healthy population

Introduction

Alzheimer's disease (AD) is a progressive neurodegenerative disease that presents 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 tremendous socio-economic impact worldwide, is important for increasing appropriate treatment of dementia and managing its psychological, emotional, familial, economic 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 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 AD patients are less fortunate than those with treatable diseases (8). Understanding

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the perception of stigma in healthy individuals and educating society with accessible and effective methods helps to increase disease-related awareness and improve disease management (9).

To the best of our knowledge, there is no study evaluating the perceived stigma against AD in healthy people in Turkey. 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

Four hundred thirty-nine 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 cognitive and/or systemic disorders. Participants' age, gender, marital status, educational status, and occupation 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. (10) in 2012, with the author's permission. Participants were asked to pretend that they had AD and rate what they would feel. 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 were scored respectively. The total score indicated the stigma severity. The highest score was 30. Zero-seven was graded as mild, 8-11 as 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 were conducted the study.

Statistics

Descriptive statistics were expressed as mean, standard deviation, 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

Four hundred thirty-nine 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 have 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%), moderate 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 moderate stigma group, and 48.1% of those in the severe stigma group were women. Moderate and severe stigma scores were significantly higher in women than in men ($p = 0.001$). The mean stigma score was higher in singles

Table 1. Ten questions about perceived stigma in the stigma 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 lose self-esteem because of the disease?
4. Would this disease cause you shame or embarrassment?
5. Would your neighbors, your colleagues have less respect for you?
6. Do you think others would avoid you because of the disease?
7. Would your neighbors, your colleagues have less esteem for your family?
8. Do you think your wife/husband would stay with you and support you?
9. Do you think people you know at work or friends would ask you to stay away, even if you were taking medication for the disease?
10. Would your family give you their support right from the start?

Table 2. Global stigma score and five dimensions of perceived stigma

Global stigma score (M ± SD)	8.95 (±4.79)
Reluctance to disclose the illness (M ± SD)	0.93 (±1.44)
Emotional impact (M ± SD)	3.00 (±2.18)
Fear of exclusion (M ± SD)	3.67 (±2.49)
Courtesy stigma (M ± SD)	0.72 (±1.01)
Fear of loss of family support (M ± SD)	0.60 (±1.01)
M: Mean, SD: Standart deviation	

(p<0.001). Moderate-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). Healthcare workers had higher stigma scores than non-healthcare workers. The three groups were similar in terms of age, knowledge about AD, family history of AD, and occupation (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. 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 stigmatization threefold (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, unlike in Western societies, the fear of having AD and the frequency of stigma associated with it are less common in these countries (14-16). While some African-Americans think of dementia as the inevitable consequence of aging, others define it as a 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, resulting in criticism and ridicule (19).

On the other hand, solid religious beliefs increase compassion and the willingness to help patients with AD and reduce 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 AD, 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, women have three times more risk in elderly societies with a higher male population and gender

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
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*
Knowledge about AD***, n, (%)	14 (8.1)	5 (3.8)	6 (4.5)	0.062
Family history with AD***, n, (%)	35 (20.2)	27 (20.3)	19 (14.3)	0.903
Marital status***, single n, (%)	40 (23.1)	52 (39.1)	60 (45.1)	0.000*
Occupation***, worker n, (%)	156 (90.2)	115 (86.5)	126 (94.7)	0.071
Healthcare worker***, n, (%)	23 (13.3)	28 (21.1)	44 (33.1)	0.000*

N: Number, M: Mean, SD: Standart deviation, AD: Alzheimer's disease, *p-value <0.05 **independent samples Kruskal-Wallis test, ***chi-square test

discrimination (22,23). In our study, perceived stigma 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 socio-economic factors and education level affect stigmatization (25). In high educated and income 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 low income 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 an increased 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 (30).

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, 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 it. 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.

To the best of our knowledge, our study is the first to investigate the perceived stigma prevalence against AD in the healthy Turkish population. 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, their stigmatization could not be evaluated.

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. Similar evaluations have been made before, especially in high- and low-income societies. Still, such an evaluation has never been made before in a middle income country such as Turkey. Therefore, our study is valuable because it shows the levels of stigma against AD in Turkish society, especially according to occupational groups, and such an evaluation has not been made before. Nevertheless, there is a need for large-scale studies investigating the frequency of stigma and related factors in the general population.

Information

This study was previously published on the preprint (Authorea) server. Doi:10.22541/au.161973544.40611837/v1

Ethics

Ethics Committee Approval: 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 were conducted the study.

Informed Consent: All volunteers participating in the survey were informed about the study and agreed to participate. Since there was no patient group, an extra voluntary consent form was not obtained.

Peer-review: Externally peer-reviewed

Authorship Contributions

Surgical and Medical Practices: M.T., Concept: N.K., B.S.A.P., Design: N.K., B.S.A.P., Data Collection or Processing: M.T., N.T.B., B.S.A.P., Analysis or Interpretation: M.T., N.K., N.T.B., B.S.A.P., Literature Search: M.T., N.T.B., B.S.A.P., Writing: M.T., B.S.A.P.

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