

Research Report

Attitudes of Family Members and Caregivers Regarding Alzheimer's Disease Pre-Symptomatic Screening

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Abstract.

Background: In recent years, studies have examined the acceptability and attitudes that influence the intention to early screen for Alzheimer's disease (AD) in the general population, older people, carers, and asymptomatic individuals who report a family history of AD. However, it remains unclear what specific factors promote or reduce the acceptability of pre-symptomatic screening.

Objective: The aim of this study is to explore the attitudes of family and non-family members as well as caregivers and non-caregivers toward the pre-symptomatic screening of AD.

Methods: A total of 213 participants completed the Perceptions regarding pRE-symptomatic Alzheimer's Disease Screening (PRE-ADS) Questionnaire. Group comparisons using t-test and one-way ANOVA were used to examine differences in attitudes toward pre-symptomatic screening regarding age, family history, knowing someone with AD, influence of depression, and feelings of anxiety. The subscale "Acceptability of Screening" was developed to investigate the willingness to undergo pre-symptomatic screening.

Results: Participants with a family history showed greater acceptance of pre-symptomatic screening while both caregivers and non-caregivers had similar attitudes. People with a family history as well as those with personal connections to dementia indicate a greater need for knowledge. The findings suggest that younger adults appear to perceive less harm from testing, whereas those who experience higher levels of anxiety and depression seem to perceive more testing harms.

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Conclusions: Comparing the attitudes of people with and without a family history as well as caregivers and non-caregivers toward pre-symptomatic screening of AD is critical to understand the differences between these groups and develop comprehensive screening programs.

Keywords: Acceptance, Alzheimer's disease, attitudes, caregivers, family history, screening

INTRODUCTION

Alzheimer's disease (AD) is one of the most prevalent forms of dementia. AD is a progressive, neurodegenerative disorder that affects memory, cognitive functions, and behavior [1]. As life expectancy rises and people live longer, the number of people affected by AD (PwAD) has also grown, making it a significant global public health concern [2]. While the overall prevalence of dementia is increasing, the age-specific incidence (the number of new cases occurring in a given age group) is decreasing. This decline in incidence is attributed to preventive measures [3]. At the same time, there is currently no cure for AD. Therefore, ongoing research is focused on gaining a better understanding of the underlying mechanisms of the disease and identifying potential ways to delay or slow its progression [4].

Screening methods, including a combination of diagnostic tools and medical history to make an accurate diagnosis, have important clinical implications for the prevention and treatment of AD [1]. Pre-symptomatic screening, which identifies healthy "at-risk individuals" years before the onset of clinical symptoms, is also becoming increasingly important [5]. However, there is a concern that this screening may label these individuals as "patients-in-waiting" [6]. Early detection of individuals before symptoms of AD may become necessary, as these individuals would benefit the most from potential disease-modifying treatments and preventive measures [4]. Methods to assess disease risk and help in early detection, diagnosis, and monitoring of the disease include AD biomarkers, such as non-invasive neuroimaging markers (e.g., ^{18}F -fluorodeoxyglucose (FDG-PET), ^{11}C -Pittsburgh Compound B (PiB), or retinal imaging) and body fluids, blood plasma (cerebrospinal fluid such as $\text{A}\beta_{1-42}$, $\text{A}\beta_{1-40}$, tau and phospho-tau, blood, saliva, tears, or urine) [4, 7]. Most of these methods are becoming more available and accessible in clinical practice [8].

As the prevalence of AD increases rapidly, more people have experience as caregivers and family members of a person with dementia and thus become more concerned about early screening [9]. Family

caregivers play a critical role in supporting and caring for individuals with AD, as the majority of these people are largely dependent on the care of family members and informal caregivers [10]. Therefore, AD not only affects the person with dementia but also has a significant impact on the family members and informal carers providing care and support [11]. They witness first-hand the impact of the syndrome on various aspects of their loved one's life, including cognitive abilities, daily functioning, behavior, mood, and social interactions [1], and this experience increases the perception of a more considerable risk for AD and the motivation for pre-symptomatic screening [1, 12].

Many studies in the literature have focused on the factors that may influence the attitudes toward screening for dementia or AD in different groups such as the general population or older people [13–18]. Moreover, previous studies have examined the attitudes and perceptions of caregivers and family members regarding the motivations and barriers to screening for AD [10, 19–21]. However, little is known about the attitudes of these groups toward pre-symptomatic screening for AD.

Given that cognition (beliefs and assumptions), emotions (feelings and affect), and behavior (actions) are the three components that comprise an "attitude" [22], it stands to reason that knowledge of dementia from having a family member with AD and the associated emotional experience will also impact the acceptability and motivation for a pre-symptomatic screening. Acceptability is often used to describe how acceptable, agreeable, and suitable a given health intervention is found to be by individuals or groups [23]. Motivations are the reasons or driving forces behind pre-symptomatic screening, resulting from a particular class of stimuli [23]; on the other hand, barriers are the impediments, difficulties, or perceived "costs" that prevent pre-symptomatic screening from being accepted or put into practice [23].

On the one hand, receiving a pre-symptomatic screening result or a screening result for AD of the relative and participating in counseling and support programs may provide a sense of relief and a feel-

ing of control to some carers and family members. This can be achieved by increasing knowledge about dementia and screening methods and reducing risk perceptions [20, 24]. Access to knowledge facilitates appropriate interventions, support services, and community resources helps family members decide whether or not to participate in advanced pharmaceutical treatments to prevent disease and develop plans for the future [16, 25, 26]. Thus, the need to gain valuable information about dementia, risk reduction measures, and new treatments are critical predictors of positive intentions for pre-symptomatic screening for AD [16, 21, 27].

On the other hand, some family members and caregivers may have concerns and fears about receiving a result of pre-symptomatic screening for AD and perceive negative societal attitudes toward it [10, 25, 26]. They may worry about the potential loss of “normal” life or experience anxiety, grief, depressed feelings, and emotional distress, which may influence their preference not to know the results [28]. In addition, caregivers’ attitudes toward pre-symptomatic screening and early detection can vary based on their unique experiences and perspectives [10]. Therefore, the perceived benefits and harms that influence the family members’ decisions to undergo pre-symptomatic AD screening need to be further explored to better understand their needs.

Comparing the attitudes of individuals with and without family members with AD as well as caregivers and non-caregivers toward pre-symptomatic screening for AD can provide valuable insights into understanding the differences between these groups. This information can help us identify and address barriers, raise awareness, and provide appropriate support for individuals and families affected by AD [12, 16]. Such comparisons may facilitate the development of well-informed pre-symptomatic detection programs, including genomic counseling that mitigates the potential negative effect of participation in a pre-symptomatic screening process and announcement of results, which is mainly offered without any support and guidelines [12, 29]. Ideally, dementia risk communication strategies should maximize the desired impact of risk information on individuals’ understanding of their health, risk status, and risk perceptions and minimize potential harms [29]. Consequently, health professionals should provide education, training, and counseling that addresses the emotional needs and concerns of families and carers [14, 16]. The success of such strategies depends on the attitude of family members

and caregivers and the perceived benefits and harms of pre-symptomatic screening.

The main aim of the current study is to compare the attitudes and to measure the acceptability and perceived harms and benefits of pre-symptomatic AD screening among individuals with and without the experience of AD caregiving and those with and without a family history of AD. For this comparison, the study has used a newly validated tool, the “Perceptions regarding pre-symptomatic Alzheimer’s Disease Screening” (PRE-ADS) Questionnaire [30] (see Supplementary Material). More specifically, the study aims to investigate the differences between these groups regarding the acceptance of pre-symptomatic screening for AD, the need for knowledge, and concerns about getting AD, as well as finding potential differences in age groups, self-perceived health status, mood, anxiety levels, and personal relations to PwAD. Due to the personal experience of family members and caregivers caring for someone with AD and witnessing the impact of the disease firsthand, we hypothesized that the individual with this experience may have more positive attitudes toward pre-symptomatic screening and greater acceptance for AD than those without such experience.

MATERIALS AND METHODS

Study design

This is a quantitative cross-sectional study to assess the attitudes, barriers, and motivations toward pre-symptomatic screening for AD among persons with and without a family member with AD and people with and without caregiving experience. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Checklist was used for research reporting (Supplementary Material).

Study procedure

The study was conducted in North Greece between October 2021 and June 2022. Caregivers and family members of people with dementia completed the online survey through an active link via Google Forms. We used the online distribution of the questionnaire due to the restrictive measures of the COVID-19 pandemic and in order to collect data at a faster rate compared to the traditional methods. All participants were informed of the purpose of the study

and consented to participate. The approximate time to complete the procedure was 15-20 min.

Settings and participants

In order to have better access to the target groups of this study, the questionnaire was randomly emailed to approximately 300 members of the Panhellenic Federation of Alzheimer's Disease and Related Disorders (PFADR) and the Greek Association of Alzheimer's Disease and Related Disorders (GAADR day centers) where two of the authors (M.M. and M.T.) are researchers. The organization uses the members' mailing list for communication purposes, in which all members have agreed to be contacted for research purposes. The main eligibility criteria for the inclusion of participants were to be 18 years of age or older and to have Greek as their mother tongue.

Questionnaire

The "Perceptions regarding pRE-symptomatic Alzheimer's Disease Screening" (PRE-ADS) Questionnaire [30] was used in the study. The specific questionnaire assesses the attitudes, barriers, and motivations to pre-symptomatic AD screening. Specifically, it contains 25 items, and each item is scored on a 5-point Likert scale with a range of responses: strongly agree, agree, do not know, disagree, and strongly disagree (1 = strongly disagree to 5 = strongly agree). It consists of four factors: "Perceived harms of testing", which includes 10 items (9, 10, 11, 12, 15, 16, 18, 19, 20, 21) and refers to the negative effects on family and emotions and the feeling of stigma, "Acceptance of testing", which includes 5 items (1, 2, 3, 4, 5) and refers to the preference to be informed about the higher risk and the willingness to be tested for AD, "Perceived benefits of testing", which includes 6 items (13, 17, 22, 23, 24, 25) and refers to the time for future planning for an individual's health and more time for discussion as a whole in order to deal with care and financial issues, and finally the "Need for knowledge", which includes 4 items (6, 7, 8, 14) and refers to the desire to receive more information about testing and preventive measures. Ten of the 25 items were reverse-scored (9, 10, 11, 12, 15, 16, 18, 19, 20, 21), with higher scores indicating greater agreement with the acceptability of pre-symptomatic screening for AD and the perceived benefits of screening, greater need for knowledge about AD risk, and less perceived harm. The internal consistency of all

25 final items of the questionnaire is good (Cronbach's $\alpha = .82$). The total score of the PRE-ADS scale measures the positive attitude about pre-symptomatic screening of AD; the higher the score, the more positive the participants' attitude.

Ethical considerations

The GAADR's Scientific and Ethics Committee approved the study protocol (Meeting Number: 65/06-02-2021), which was developed in accordance with the ethical standards specified in the Declaration of Helsinki. To ensure compliance with the Greek Law of Data Protection and the General Data Protection Regulation (EU) 2016/679 of the European Parliament, the collected data was kept anonymous and confidential. Participation in the study was voluntary, and all participants were informed about the objectives of the study and gave their informed consent before participating in the survey.

Statistical analysis

SPSS V 27.0 (IBMC Corp, Armonk, NY, USA) was used for statistical analysis. Descriptive statistics were utilized to examine the profiles of caregivers and non-caregivers as well as family and non-family members in relation to their perceived acceptability, benefits, and harms of pre-symptomatic AD screening. A two-sample Kolmogorov-Smirnov test was applied to test the normal distribution of the data. As the data were not normally distributed, non-parametric tests were performed. We utilized these non-parametric tests to compare responses between different groups, such as caregivers versus non-caregivers, individuals with or without a family history of AD, and those who know someone with AD. Independent samples t-tests were used to compare means between different age groups for variables as the totals (sum) of the questions. The subscale "Acceptability of Screening" was developed as a short instrument for clinical use investigating the willingness to undergo pre-symptomatic AD screening. This dichotomous variable was created, corresponding to factor 2 of PRE-ADS, in which the score on the acceptance of screening questions (questions 1-5) was dichotomized so that scores between 1.0 and 3.0 were transformed to 0, indicating "no acceptance". In contrast, we transformed scores between 3.1 and 5.0 to 1, indicating "acceptance". In addition, cross-tab analyses were performed to examine the distribution and percentages of responses within different groups

based on variables such as “Acceptance of Screening”, “caregivers and non-caregivers”, and “with and without a family history”. Moreover, chi-squared tests we used to assess associations and independence between categorical variables. These tests examined the relationships between the variables “Acceptance of Screening” and “having a family history”. One-way ANOVA was used to compare the 4 factors of the PRE-ADS with the duration of caregiving, age at diagnosis of relative/friend, health status, mood, and anxiety.

RESULTS

A total of 213 participants, including caregivers ($n=96$) and non-caregivers ($n=117$), and participants with a family history of AD ($n=134$) and without a family history of AD ($n=79$) participated in the study. In the overall sample, more females participated, and more individuals aged between 20 and 60 in all different groups. Caregivers and participants without a family history exhibited a varied educational distribution. In contrast, non-caregivers and participants with a family history had a higher percentage of individuals with 16+ years of education (Table 1).

The mean score for perceived harm of testing was 22.49 ($SD=6.68$, $SE=0.46$), with a 95% confidence interval ranging from 21.59 to 23.40. The mean score for acceptance of testing was 19.48 ($SD=4.16$,

$SE=0.28$), and the 95% confidence interval ranged from 18.92 to 20.05. For perceived benefits of testing, the mean score was 22.95 ($SD=3.30$, $SE=0.22$), with a 95% confidence interval spanning from 22.50 to 23.40. The mean score for need for knowledge was 18.14 ($SD=1.95$, $SE=0.13$), and the 95% confidence interval extended from 17.87 to 18.40. The mean score for the sum of questions was 83.08 ($SD=9.31$, $SE=0.64$), and the 95% confidence interval covered a range from 81.81 to 84.34.

Total scores

The Mann-Whitney U test revealed that there was no statistically significant difference in total score between the non-caregivers ($Mdn=102.84$, $Mean\ Rank=102.84$) and the caregivers ($Mdn=109.86$, $Mean\ Rank=109.86$) groups ($U=5143.500$, $Z=-0.831$, $p=0.406$, two-tailed). Participants with a family history ($Mdn=112.66$, $Mean\ Rank=112.66$) had significantly higher ranks than those without ($Mdn=94.65$, $Mean\ Rank=94.65$) ($U=7382.50$, $Z=-2.070$, $p=0.038$, two-tailed). Therefore, we conducted further analysis on the groups and the four factors of the PRE-ADS questionnaire.

Acceptance of testing

“Acceptance of Testing” was significantly higher in the Mann Whitney U test among participants with

Table 1
Participant characteristics and beliefs of the total sample and subgroups, n (%)

Characteristics	Caregivers ($n=96$)	Non-caregivers ($n=117$)	With family history ($n=134$)	Without family history ($n=79$)	Total Sample ($n=213$)
Age (y)					
20-60	82 (85.4)	95 (81.2)	113 (84.3)	63 (79.7)	176 (82.6)
60+	14 (14.6)	22 (18.8)	21 (15.7)	16 (20.3)	37 (17.4)
	[Mean = 61 y]	[Mean = 45 y]	[Mean = 56 y]	[Mean = 46 y]	[Mean = 43 y]
Education (y)					
6-12	30 (31.2)	16 (13.7)	13 (25.4)	12 (15.2)	46 (26.1)
12-16	31 (32.3)	44 (37.6)	45 (33.6)	30 (38)	75 (35.2)
16+	35 (36.5)	57 (48.7)	55 (41.1)	37 (46.8)	92 (43.2)
Female	81 (84.4)	98 (83.8)	109 (81.3)	70 (88.6)	179 (84)
Married	57 (59.4)	58 (49.6)	77 (57.5)	38 (48.1)	115 (54)
Family history of AD	83 (86.5)	51 (43.6)	-	-	134 (62.9)
I feel happy most of the times	50 (52.1)	59 (50.4)	68 (50.7)	41 (51.9)	109 (51.2)
I feel depressed most of the times	5 (5.2)	6 (5.1)	8 (6)	3 (3.8)	11 (5.2)
Sometimes I feel stressed	66 (68.8)	70 (59.8)	82 (61.2)	54 (68.4)	136 (63.8)
Belief of having a higher risk to develop AD	24 (25)	10 (8.5)	32 (23.9)	2 (2.5)	34 (16)
Have more memory problems than people in my age	21 (21.9)	23 (27.4)	33 (24.6)	20 (25.3)	53 (24.9)
Don't believe treatment for AD is currently available	42 (43.8)	54 (46.2)	63 (47)	33 (41.8)	96 (45.1)

Table 2
Participants with or without a family history of AD and the 4 Factors

4 Factors	With history of AD	Without history of AD	Sig.
	Mean Rank	Mean Rank	
Perceived harms	102.19	112.50	0.236
Acceptance of testing	118.63	87.27	0.000
Perceived benefits of testing	110.70	100.72	0.251
Need for knowledge	113.22	96.44	0.048

a family history of AD (Mdn_No History = 87.27, Mdn_With History = 118.63; $U = 3734.50$, $z = -3.612$, $p < 0.001$) (Table 2). Post-hoc analysis using the Tukey HSD method indicated that the group referring “Good” ($M = 20.5$, $SD = 3.6$) health status had a lower mean “Acceptance of Testing” compared to the group “Very good” ($M = 18.6$, $SD = 4.2$), with a mean difference of -1.89 ($SE = 0.66$, $p = 0.048$) (Supplementary Table 1).

Need for knowledge

The Mann Whitney U test revealed a significant difference in the “Need for Knowledge” between participants with and without a family history of AD showing a higher mean score of participants with AD family history (Mdn_No History = 96.44, Mdn_With History = 113.22; $U = 4459.00$, $z = -1.981$, $p = 0.048$) (Table 2). Furthermore, a two-sample t-test indicated that the group “Knowing a person with dementia” had a significantly higher mean score on the “Need for Knowledge” factor compared to the group “Not knowing any person with dementia” ($t(211) = -3.30$, $p = 0.001$).

Perceived harm of testing

We conducted a Mann-Whitney U test to compare the responses of younger adults (<60) and older adults (≥ 60) for each variable. There was a statistically significant difference between these two age groups (Mann-Whitney $U = 2310.000$, Wilcoxon $W = 17886.000$, $Z = -2.338$, $p = 0.019$). Participants under the age of 60 years old (Mean Rank = 101.63) reported significantly lower levels of perceived harm (Sum of Ranks = 17886.00) compared to those 60 years and older (Mean Rank = 128.00, Sum of Ranks = 4480.00).

The group “Depressed most of the times” ($M = 15.3$, $SD = 4.3$) showed higher perceived harm of testing than the “Happy” ($M = 24.2$, $SD = 6.32$) and “Sometimes Depressing Feelings” ($M = 21.2$, $SD = 6.5$) groups, with mean differences of 8.93

Table 3
Acceptance of testing

		Acceptance of Testing	
		Accept number (%)	Do not accept number (%)
Age	Under 60	143 (80.8%)	34 (19.2%)
	Over 61	33 (91.7%)	3 (8.3%)
Caregiver	No	95 (81.2%)	22 (18.8%)
	Yes	81 (84.4%)	15 (15.6%)
Family history	No	58 (73.4%)	21 (26.6%)
	Yes	118 (88.1%)	16 (11.9%)

($SE = 2.10$, $p = 0.000$) and 5.95 ($SE = 2.11$, $p = 0.016$) respectively. The ANOVA results are presented in Supplementary Table 2.

The results of the one-way ANOVA indicated that the group “Always anxious” ($M = 16.5$, $SD = 5.18$) had the highest score in the factor “Perceived harm of testing”. The group “Never anxious” ($M = 30.7$, $SD = 8.86$) had a lower score on this factor compared to the group “Sometimes anxious” ($M = 23.3$, $SD = 5.81$), with a mean difference of 7.37 ($SE = 2.27$, $p = 0.008$), and “Anxious most of the times” ($M = 20.42$, $SD = 7.0$), with a mean difference of 10.32 ($SE = 2.36$, $p = 0.000$). The results of the ANOVA are presented in Supplementary Table 3.

The mini scale “Acceptance of Screening”

A frequency analysis was conducted to examine the younger adults (<60) and older adults (≥ 60) in the acceptance of screening by using the dichotomous variable. Within the age group under 60 years old, 80.8% reported accepting screening, while 19.2% indicated that they do not accept screening. Of the older adults, 91.7% reported accepting screening, and 8.3% expressed not accepting it. The overall totals show that 176 participants (82.6%) in the entire sample accepted screening, and 37 participants (17.4%) did not accept it (Table 3).

Furthermore, we performed frequency analysis to examine the acceptance of screening among the caregiver/non-caregiver groups. Of the non-caregivers, 18.8% indicated that they do not accept

Table 4
Concerns about getting AD and family history of AD

	Without a family history of AD (N= 79) N (%)	With a family history of AD (N= 134) N (%)	Total (N= 213) N (%)
I believe that I am at a higher risk of getting AD	2 (2.5%)	32 (23.9%)	34 (16%)
I will develop AD	11 (13.9%)	27 (20.1%)	38 (17.8%)
I have more memory problems than others in my age	20 (25.3%)	33 (24.6%)	53 (24.8%)
I don't concern if I will get AD	46 (58.2%)	42 (31.3%)	88 (41.3%)

screening, while 81.2% reported accepting screening. Among caregivers, 15.6% expressed not accepting screening, and 84.4% reported accepting it (Table 3).

A frequency analysis was conducted to examine the participants with and without a family history on the acceptability of screening. Among individuals with no family history, 26.6% indicated that they do not accept screening, while 73.4% reported accepting screening. Among those with a family history, 11.9% expressed not accepting screening, and 88.1% reported accepting it (Table 3).

The association between the existence of family history and concerns about getting AD

Individuals with a family history of AD ($N=32$, 23.9%) are more likely to express concerns about developing AD themselves, than those without a family history ($N=2$, 2.5%). Additionally, it is noteworthy that a substantial proportion of respondents ($N=42$, 31.3%) with a family history are not concerned about developing AD at all, suggesting variations in perceptions and concerns related to AD within this population. The results are described in Table 4.

Finally, a chi-square test was conducted to examine the association between having a family history and concerns about developing AD and revealed a significant relationship ($\chi^2=23.975$, $df=3$, $p<0.001$). The likelihood ratio ($\chi^2=27.912$, $df=3$, $p<0.001$) and linear-by-linear association ($\chi^2=23.246$, $df=1$, $p<0.001$) both indicated statistically significant associations between having a family history and the concerns about getting AD.

DISCUSSION

The aim of this study was to assess the attitudes and differences in perspectives toward pre-symptomatic screening of AD between those with and without family history as well as caregivers and non-caregivers of PwAD in Greece. To this end, 213 participants com-

pleted the “Perceptions regarding pre-symptomatic Alzheimer’s Disease Screening” (PRE-ADS) Questionnaire.

Overall, the results suggest that individuals with a family history of AD are more open to pre-symptomatic AD screening, although they perceive similar levels of harms and benefits as individuals without an affected family member. The findings suggest that people with a family history as well as those who know someone with dementia demonstrate a stronger desire for knowledge regarding pre-symptomatic screening for AD. In addition, both caregivers and non-caregivers had similar beliefs regarding the perceived harms and benefits of pre-symptomatic screening of AD, acceptance of screening, and the need for knowledge. Other variables such as feelings of depression and mood status seem to influence the perceived harms of pre-symptomatic screening, and, more precisely, those who feel more anxious and depressed appear to interpret testing harms as being greater. Moreover, the younger age group appears to perceive less harm from testing than older individuals. In contrast, no significant differences between age groups were discovered in acceptance of testing, whereas 82.6% of the overall sample showed that they accept pre-symptomatic testing. Finally, the results highlighted that there is a significant relationship between having a family history and being concerned about developing AD.

According to our results, a percentage-based inspection of the 5-item subscale “Acceptability of Screening” showed that most participants of the sample expressed a willingness to accept pre-symptomatic AD screening. This trend of Greek participants could be due to a variety of cultural, societal, or healthcare-related factors specific to Greece. The Greek healthcare system and its emphasis on early detection and preventive measures could lead to higher awareness and willingness to engage in such screenings [31, 32]. Greece enacted the National Dementia Strategy in 2014 to design policies and improve care for people with dementia and their car-

ers, thus new educational programs and campaigns related to dementia and screening have been organized to educate families of people with dementia, informal caregivers, and family members as well as health-care professionals. These initiatives have also played a role in increasing the acceptance of pre-symptomatic screening observed among our results and developing a more positive attitude [33, 34].

In addition, Greek cultural attitudes and beliefs toward health, aging, and family dynamics could also play a significant role in the increased acceptance of pre-symptomatic screening. As Greek culture strongly emphasizes caring for elderly family members, there might be a higher openness to screening for potential health issues [35–37]. This can also explain the results revealed from this study concerning family members. According to these findings, individuals with an affected family member are more open to pre-symptomatic AD screening compared to individuals without a family member. This tendency may be linked to the Greek family-oriented cultural attitudes, where it is common for adult children to care for their elders until the end of their lives, even in the presence of illness, such as AD [38]. These familial experiences and the heightened awareness of the disease can influence their perception of acceptance of genetic testing for AD [28]. Our results align with other studies that indicate that the majority of participants who refer to family history express their willingness to undergo pre-symptomatic testing [10, 39–42].

Also, individuals with a family history of AD, have a possible genetic predisposition to AD or an increased risk for the disease [28, 42, 43]. Knowing that AD runs in their family, they may be more motivated to seek pre-symptomatic screening to assess their own risk, relieve uncertainty, be prepared for the disease, and plan for the future [21, 42]. In line with our results, the study of Bassett et al. (2004) revealed that 72% of individuals with a family history of AD would choose to have a genetic test if it was offered to them [44]. Furthermore, in the REVEAL II cross-sectional study, participants with more than one PwAD in the family had significantly higher risk perceptions compared to those with only one relative with AD [45]. According to these findings, a strong belief in genetics as an AD risk factor may be a substantial predictor of higher perceived risk among people with family histories and may also increase the likelihood that they will consent to pre-symptomatic screening. Additionally, having a family history only sometimes translates into a higher desire to pro-

ceed with pre-symptomatic screening. Alanazy et al. (2019) discovered that people with a positive family history were less likely to get screened [26].

According to the results of this study, the significant difference in the need for knowledge about AD pre-symptomatic screening and potential outcomes between participants with or without a family history of AD suggests that individuals with a familial link to AD are more driven to acquire information about the pre-symptomatic screening [12]. Family members perceive a greater urgency to learn about screening for AD due to concerns about their susceptibility, their need to learn more about measures to delay a potential high risk of AD as well as stay updated on new treatments or developments in the AD field [25, 43]. Thus, this need for knowledge stems from a desire to make well-informed decisions regarding pre-symptomatic screening, risk-reduction measures, and potential interventions.

The finding that individuals who reported “Knowing a person with dementia” had a significantly higher mean score on the factor “Need for knowledge” compared to those who reported “Not knowing any person with dementia” aligns with expectations and seems to link with the above results of increased need for knowledge of family members. The results indicate that the influence of prior experience with dementia seems to be significant in a person’s willingness to ask for more information and advice. People become more aware and understanding of a disease when they witness the challenges and impact it has on individuals and their families, and when they have a personal experience with it [21, 41]. This increased knowledge can lead to a greater awareness of the importance of staying informed about pre-symptomatic screening, potential risk reduction measures, new treatments for AD as well as feeling in control [21, 25].

The results regarding caregivers indicate no differences between caregivers and non-caregivers on the four factors of the questionnaire. These findings agree with the research conducted by Alpinar-Sencan et al. (2020) in which they compared family caregivers’ perspectives on biomarkers with general public attitudes toward genetic testing of dementia prediction [10]. However, in many other studies, participants who have served as caregivers for a PwAD expressed a higher interest in undergoing genetic testing and a greater acceptance of the available methods [43, 46]. This positive attitude can be explained as caregivers have first-hand experience and knowledge of the challenges and implications of AD due to their caregiving responsibilities and thus a higher concern for AD risk.

In contrast, it is crucial to highlight that although Boustani et al. (2011) focus on dementia screening and non-pre-symptomatic screening, they observed that caregivers had a significantly lower acceptance of screening than non-caregivers [20].

The results indicate that individuals who reported feeling “Depressed most of the time” had a higher perceived harms of pre-symptomatic AD screening compared to those who reported feeling “Happy” or experiencing “Sometimes Depressing Feelings”. This finding suggests that individuals with higher levels of depression may have a different perspective on the potential harms associated with screening. Individuals experiencing depression already face significant challenges in their lives, making the potential harms associated with pre-symptomatic screening seem relatively more significant in comparison [47]. They focus more on the existing emotional burdens and feel that participating in a pre-symptomatic screening or a disclosure process of an increased risk will lead to an increase in specific screening-related depression feelings [48].

The outcomes also reveal that people who were “Always anxious” had the highest perceived harms of pre-symptomatic AD screening, while those who reported being “Never anxious” had the lowest perceived harms. This suggests that anxiety levels can influence individuals’ perception of harms associated with screening [49]. Those who are “Always anxious” might be accustomed to living with a higher level of perceived risk and uncertainty, leading them to perceive the potential harms of screening as relatively more significant [48, 50]. In contrast, individuals who reported being “Never anxious” might have a higher tolerance for uncertainty and may perceive even minimal risks as significant harms.

In addition, the groups aged “20–60” and “60 plus” years old indicate that the younger group has lower levels of perceived harms of pre-symptomatic screening. Older people face more barriers in accepting the screening process such as their fear of stigmatization or loss of independence, or the negative impact on their emotional health [51]. According to Roberts et al. (2004), participants who were aged below 60 years have a higher interest in genetic testing than older people, and this reflects the fact that planning for future issues is most prominent in middle age [40]. Also, Akinleye et al. (2011) researched knowledge, attitudes, and motivations regarding genetic susceptibility testing for AD and suggested that younger age is associated with higher concern about developing AD [52]. Other studies that dive into dementia screen-

ing concluded that age and perceived problems with memory are associated with positive attitudes toward dementia screening [43, 53, 54]. However, these studies focus on dementia screening attitudes and not pre-symptomatic screening, and thus a positive attitude of older people is expected as they need to know more about their health status due to their cognitive symptoms. In the current study, the main target group that was sent the questionnaire was young (83% between the age of 20–60), as it is focused on pre-symptomatic screening. According to the findings, these people tend to perceive themselves as having no cognitive symptoms or other concerns about getting AD. In consequence, they were more likely to state that they felt fewer harms from pre-symptomatic AD screening.

The results of this study revealed a significant relationship between the existence of a family history and concerns about developing AD. One possible explanation for these results could be that people who are aware that AD runs in their family perceive themselves as having a genetic predisposition to AD or an increased risk for the disease [42, 43]. Our findings extend similar research in this area and further illustrate that some people may pursue pre-symptomatic screening not only for practical decision-making and satisfying their curiosity, but also to address fears and anxiety about getting AD [40, 52]. Although our results focus on pre-symptomatic screening, they are consistent with the findings of Wikler et al. (2013) on attitudes toward early diagnostic testing for AD, in which participants who worried about developing AD expressed higher interest in undergoing genetic testing and most of them were first-degree relatives [43].

According to the findings of this study, 41.3% of the overall sample did not concern themselves with getting AD. This aligns with the highest acceptance of pre-symptomatic screening of the entire sample and also can be explained by the younger age of most participants. In addition, a significant percentage (25%) of caregivers and people with a family history (23.9%) were more inclined to believe in having a higher risk of developing AD compared to non-caregivers and those without a family history. These results suggest that first-hand AD experience increases the perception of a more considerable risk for AD [1, 12]. Waterink (2023) highlighted that most participants believed their personal risk for AD was higher than the general population risk, and that was explained by the large proportion of participants with first-degree relatives in this study [42].

In conclusion, the findings suggest differences between people with and without a family history in their acceptance of pre-symptomatic screening for AD, need for knowledge, and concerns about getting AD. Various factors such as age, self-perceived health status, mood, anxiety levels, and personal connections to AD, can influence individuals' acceptance of pre-symptomatic screening, perception of harm, and need for knowledge. This study highlights the different needs of people who have firsthand experience with AD, particularly those with a family history of the disease. By gaining insights from these groups, researchers and healthcare professionals can better comprehend the risks and benefits of pre-symptomatic screening of dementia or AD. This understanding can lead to improvements in the early identification process, which is crucial for timely and appropriate intervention [20].

Limitations and future research

The present study has several limitations. First, it is important to highlight that a reproductive decision for proceeding with pre-symptomatic screening is still very complex and personal. The main reason for deciding to proceed with this screening is the availability of treatment. With the new clinical studies, treatment seems to be a more realistic scenario within the next few years. However, this will be mainly for families where the disease is running, but individuals do not have symptoms. This fact increases the importance of pre-symptomatic screening for AD, and according to our results, it is very significant to improve the support for families with devastating genetic conditions like AD, which is currently the most that clinical geneticists and genetic counselors can do.

Second, it is important to note that although a convenience sample was utilized, most of the participants were recruited from an Alzheimer's Association. This suggests that they possessed some level of knowledge regarding AD and screening. As a result, the generalizability of these findings may be limited. Also, it is crucial to highlight that our study focuses on pre-symptomatic screening attitudes of AD and thus the questionnaire was sent mainly to young people. A future study needs to be applied to the general population and include more age groups. Another important further research could be a large-scale study across multiple countries or regions that provides a more comprehensive understanding of the cultural, socio-economic, and healthcare factors influencing family

members' and caregivers' motivation to undergo pre-symptomatic AD screening.

Another limitation relates to the content of the questions of the PRE-ADS scale. In the "Acceptance of Testing" factor there are not enough questions about pre-symptomatic screening. More questions on genetics and biomarkers need to be added to improve the goals of these scales in a future study.

Furthermore, it would be valuable to investigate the specific factors that motivate people with an affected family member with AD to undergo pre-symptomatic AD screening. By conducting qualitative interviews or surveys, researchers can gain useful insights into family members' perspectives, concerns, and motivations related to screening. Understanding the underlying reasons behind their decision-making process can help healthcare professionals and policymakers develop tailored interventions and support systems to promote screening uptake among family members.

Conducting longitudinal studies that follow our target groups over an extended period could provide valuable insights into how their motivations and attitudes toward pre-symptomatic AD screening evolve over time. Longitudinal designs would allow researchers to examine the impact of different caregiving stages, disease progression, and experiences on family members' and caregivers' screening decisions. This knowledge can shape the development of targeted interventions and support services tailored to the changing needs of family members and caregivers throughout the journey of the disease.

AUTHOR CONTRIBUTIONS

Marina Makri (Conceptualization; Data curation; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing); Magda Tsolaki (Supervision); Akyllina Despoti (Formal analysis; Methodology; Writing – original draft; Writing – review & editing); Birgit Teichmann (Methodology; Writing – review & editing); Mara Gkioka (Methodology; Writing – review & editing); Despoina Moraitou (Writing – review & editing); Liana Fidani (Supervision); Thomas Tegos (Supervision).

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CONFLICT OF INTEREST

The authors have no conflict of interest to report.

DATA AVAILABILITY

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <https://dx.doi.org/10.3233/ADR-230145>.

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