Older adult perception of preclinical Alzheimer's disease screening and treatment

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Abstract

Introduction: Preclinical Alzheimer's disease (AD) accounts for more than 80% of patients on the AD continuum.

Objective: The objective of this study is to query patient concerns towards their risk of developing preclinical Alzheimer's disease and assess patient beliefs and preferences towards screening and taking potential preventive therapies.

Methods: An electronic survey assessed older adult perceptions towards their risk of developing preclinical AD, screening, and preventive therapies.

Results: One-hundred eight patients aged 55 to 80 years completed the survey during routine care at a family medicine clinic. Overall, 89% of participants would undergo blood screening for preclinical AD, despite 75% not believing they are at higher risk than peers. When asked about treatment, 83% showed interest in medication treatments, with 71% interested in intravenous (IV) formulations and 61% in subcutaneous formulations. These data show a slight preference for IV formulations. There were no significant differences between demographic groups and willingness to test or treat preclinical AD.

Conclusion: These findings highlight the need for patient-centered approaches to preclinical AD screening and treatment.

Keywords: Alzheimer's disease, attitude, prevention, treatment, route of administration

Introduction

Alzheimer's disease is the most common type of dementia in the world. One in nine U.S. adults over the age of 65 years is living with Alzheimer's Disease (AD).[1] AD is the fifth leading cause of death of individuals over 65 years in the U.S., an increase of 140% since 2000.[1] The disease involves the destruction of neuronal communication that is characterized by biomarkers that include an accumulation of tau proteins and amyloid plaques in the brain. The exact cause of AD is unknown, but genetics, environmental factors, and lifestyle factors likely influence disease development and progression.[1] AD can be split up into three stages: preclinical AD, mild cognitive impairment (MCI), and symptomatic AD. In preclinical AD, biomarkers like tau and amyloid plaques are present, but symptoms are not yet experienced.[1] Approved drug therapies for AD have targeted clearing amyloid plaques, but a broader range of treatment targets are currently undergoing clinical trials.[2]

Preclinical AD is a significant area of research focus, as it encompasses more than 80% of all individuals on the AD continuum.[3]

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Although disease-modifying treatments have so far only been approved for clinical AD, patients with preclinical AD may become a focus of future expansion and development of these treatments. These patients may derive substantial benefits from early diagnosis and treatment, given that current pharmaceutical therapies for AD primarily aim to slow symptom progression.

Exploring perceptions of the disease and evaluating how individuals respond to hypothetical treatments lays the foundation for guiding patients through advancements in diagnosis, treatment, and care. Existing studies indicate a strong willingness among individuals to undergo biomarker testing for AD, highlighting the need for enhanced education to support patient understanding of risks and planning future care needs.[4,5]

Understanding personal AD risk remains complex and is frequently cited as a challenge for individuals to conceptualize.[5,6] Genetic risk, as an example, is complicated as genes associated with AD are more commonly susceptibility markers rather than deterministic.[7] Concern over developing AD is often linked to personal familiarity with AD patients and age.[8-10] Recent studies indicate the reliability of blood biomarkers is comparable to cerebrospinal fluid testing.[11] The lower cost and invasiveness may expand the feasibility of biomarker testing. Care for individuals on the AD continuum places substantial demands on healthcare resources, caregivers, and the psychological well-being of the patients themselves. Greater understanding of patient perspectives on testing and treatment is crucial for guiding patient-centered care practices.

Objectives

The objectives of this study are to query patients about their concerns towards the risk of developing preclinical Alzheimer's disease and assess patient beliefs and preferences towards screening and taking newly developed preventive therapies.

Methods

This cross-sectional survey study was conducted in the Midwest United States (U.S.) at a family medicine clinic. This study was approved as human subjects research (IRB:MO2023-02). The survey was conducted with written informed consent of subjects.

Recruitment and survey administration

The study included participants 55 to 80 years of age, with able vision and hearing. Participants were excluded if they had known MCI, AD, dementia, or other neurodegenerative diseases, had an unstable illness, or lived in a care facility. Eligible participants were identified within the patient database of a family medical clinic in the Midwest U.S. Patients willing to participate completed the survey via interview by a pharmacist or student pharmacist following a family medicine appointment. An informational graphic was developed to facilitate discussion and provide patients a baseline understanding of the progression from preclinical AD to mild cognitive impairment, to symptomatic AD (Appendix A). This was reviewed with subjects prior to survey completion. Surveys were collected between February 2023 and January 2024.

Measures

The survey (Appendix B) included 18 questions to assess patient attitudes towards screening and preventive treatments for preclinical AD. Questions assessed perceived risk, willingness to undergo biomarker blood testing, and interest in potential treatments. Demographic data such as age, living situation, and personal connections to individuals diagnosed with AD were also collected to assess for factors that may influence patient responses. A 5-point Likert scale was used to quantify patient interest in different treatment modalities, taking into consideration factors like route of administration and anticipated efficacy.

Analysis

Surveys were entered into Microsoft Excel, cleaned, and imported into SPSS v29. Descriptive statistics were calculated and compared by Chi-squared test to evaluate associations in willingness to undergo screening and preferences for treatments.

Results

Of 138 participants screened at the clinic, 108 met inclusion criteria and 30 were excluded (Table 1). Demographics for participants is detailed in Table 1.

Table 1. Patient Eligibility and Characteristics

Patient Eligibility and Characteristics	**Number of Patients =138 N (%)**
Patients not eligible	30
Known MCI or dementia	4 (13.3)
Neurodegenerative disease	8 (26.7)
Unstable illness	1 (3.3)
Current or previous medications to treat MCI or dementia	0 (0)
Did not want to participate/Did not have enough time	17 (56.7)
Patients eligible	108
Gender	
Male	39 (36.1)
Female	69 (63.8)
Age (years)	
55-60	21 (19.4)
61-65	24 (22.0)
66-70	18 (16.7)
71-75	23 (21.3)
76-80	22 (20.4)
Level of Education	
Did not complete high school	8 (7.4)
High school	50 (46.3)
College Degree (Associates, Bachelors)	40 (37.0)
Graduate Degree	10 (9.3)
Race/Ethnicity	
White	89 (82.4)
Black or African American	15 (13.9)
Other	4 (3.7)
Housing Status	
Living Alone	32 (29.6)
Living with a spouse or partner	68 (63.0)
Living in an assisted facility	1 (0.9)
Other	7 (6.5)

Abbreviations: MCI, mild cognitive impairment

Participants evaluated their perceived risk of developing AD. Respondents tended to evaluate their own risk as equal to or lower than their peers (75%). The overall willingness to receive blood testing for AD biomarkers was high (88%). When presented with a hypothetical preclinical AD diagnosis, 39% rated themselves as having a 0% 20% chance of developing symptoms within the next four years. Table 2 summarizes participants' perceived risk of developing AD and willingness to receive a blood test for AD.

Table 2. Perceived Risks of Developing Alzheimer's Disease (n=108)

Item	N (%)
Do you have a relative or friend who has developed Alzheimer's Disease?	
Yes	59 (54.6)
No	49 (45.4)
Do you believe you are at a higher risk of Alzheimer's Disease than others of your same age?	
Yes	27 (25.0)
No	81 (75.0)
Assume a blood test is available which can identify if you have "preclinical Alzheimer's Disease." Would you be willing to obtain this blood test now?	
Yes	95 (88.0)
No	12 (12.0)
How concerned are you about personally developing Alzheimer's Disease in the future?	
Not at all concerned	21 (19.4)
A little concerned	38 (35.2)
Somewhat concerned	31 (28.7)
Very concerned	18 (16.7)
Assume you have been diagnosed with preclinical Alzheimer's Disease from this new blood test. What do you think the risk is that you would develop symptomatic Alzheimer's Disease (where symptoms of Alzheimer's Disease would interfere with your everyday activities, such as cooking, dressing, bathing, or forgetting appointments) within the next four years?	
0-20%	42 (38.9)
21-40%	17 (15.7)
41-60%	31 (28.7)
61-80%	12 (11.1)
81-100%	3 (2.8)

A combined 83% reported some level of willingness to undergo treatment for preclinical AD (Table 3). These responses varied with respect to the route of administration, with 71% of patients expressing interest in the intravenous (IV) formulation, and 61% reporting they would be interested in subcutaneous formulations (Table 3).

Of those responding, 91% considered a 50% reduction in AD risk to be effective (Table 3). Conversely, only 67% perceived a 25% risk reduction as significant. Additionally, 56% of patients reported some level of concern regarding a 5% - 10% chance of experiencing temporary brain swelling or microbleeding (Table 3). Although not statistically significant, willingness to test for AD was higher among those identifying as white, having graduated college and those without a friend or family member with AD (Table 4). Individuals willing to take a hypothetical IV treatment for AD were more likely to be males, identifying as non-white and those with a friend or family member with AD (Table 4).

Table 4. Willingness to Test and Treat by Demographic Characteristic

	Number and Percent of respondents willing to obtain blood test N (%)	Number and Percent of respondents willing to take IV medication N (%)
Age (based on median)		
<68 years old	44 (83)	39 (74)
>68 years old	44 (92)	34 (71)
Gender (n)		
Male	28 (88)	27 (84)
Female	60 (90)	46 (69)
Race (n)		
White	73 (89)	57 (70)
Other	15 (79)	16 (84)
Education (n)		
High school or did not complete high school	47 (87)	40 (74)
College or graduate school	41 (91)	33 (73)
Friend or close family member with AD (n)		
Yes	49 (88)	43 (77)
No	39 (91)	29 (67)
Concerned about personally developing ALZ (%)		
Yes	71 (89)	57 (71)
No	17 (85)	15 (75)
Believe that they have a higher risk than peers (%)		
Yes	26 (96)	22 (82)
No	62 (85)	50 (69)

Discussion

This study addresses patient concerns regarding their risk of developing preclinical AD and evaluates preferences for screening and preventive therapies. Results align with previous findings demonstrating an interest in AD biomarker testing and suggest trends for further study.

Perceived Risk and Concern for developing AD

In the present study, 25% of respondents judged themselves as having a higher AD risk than their peers, which is higher than some previous work.[4] Previous studies have demonstrated people are most likely to recognize an increased personal risk when they have a close family member with AD[6,8] and perception of risk has been shown to vary across demographics and cultural groups.[12] Personal perception of memory problems has been shown to correlate

with perceived risk, though these perceptions can be incorrect and may contribute to reluctance to discuss memory problems with providers.[4,6,13] Although no statistically significant demographic trends were observed in the present survey, future work with larger samples and testable theoretical propositions may help delineate variation of opinion among the population.

Interest in biomarker testing

Willingness to receive AD biomarker testing was 88% in the present study, a result higher than most previous surveys. Others have reported interest between 60% to 80% of adults.[4,5] Discussing the risks and benefits of testing can increase interest.[5] Interest in testing tends to be higher among women and with a college level of education and those under the age of 60.[13] One finding from the present study that may differ from other surveys was the relatively high interest in being tested for AD by the oldest age categories, particularly those 76 years of age and older. However, it can be difficult to compare directly between surveys when age categorization varies between surveys. There are conflicting results regarding testing among those who are or have been caregivers for people with AD.[14] Pharmacists can have a role in providing patients with support and information about potential biomarker testing.

Risk after a positive test

As previously mentioned, AD risk can be difficult for patients to understand. One study by Magin, et. al. showed the majority of patients given AD risk information believed their actual risk was more than 5% different than the risk level provided for them.[4] In the present study, when presented with a hypothetical positive test for preclinical AD, 39% of individuals felt they would have less than 20% chance of going on to develop clinical AD. Despite a tendency to minimize one's own risk, positive test results have been correlated with the intention of planned behavior change.[15] Proactive adoption of lifestyle changes has been found to be low prior to diagnosis.[12] The present survey suggests patients receiving positive preclinical AD results may need assistance in interpreting the results which can be critical to adopting positive lifestyle changes and for care planning. Pharmacists may be able to contribute to aspects of this discussion as a member of the patient's care team.

Perception of an effective treatment

The lack of effective treatment for AD is commonly cited as a reason for not being tested.[16] The present survey suggests most people (83%) are interested in potential treatments if diagnosed as having preclinical AD and interest was high for both IV and subcutaneous administration and effectiveness. The present survey indicates even a 25% reduction of AD risk is considered effective by most respondents (67%). In light of these results, treatments with only modest improvements in outcomes may be appealing to patients at risk of developing AD.

Preference for administration

Trends in preference for route of administration are not well-established in general. There is some evidence that younger patients are more open to IV medication compared to older patients which is also reflected in the present survey.[17] Choice of route of administration is multifaceted, but patients appear to be willing to accept increasingly invasive routes if they are less frequent.[10] One important generalization that has been made regarding IV versus subcutaneous administration is that patients are more likely to feel comfortable maintaining the route of administration with which they are most familiar.[18] This may well simply be a preference for routine over change. Nevertheless, it suggests entrenchment within an established route of administration while initiating a preferred route of administration may be more readily done initially compared to switching routes after treatment has started. The present survey suggests a greater percentage of individuals may prefer IV administration over a subcutaneous route, although it is unknown if this is because IV routes are considered more effective or potent or if patients are hesitant to take on this responsibility for themselves or rely on a caretaker to provide the injection which may be challenging with MCI.

Implications for Clinical Pharmacists

Clinical pharmacists are well-positioned to counsel patients on AD testing and preventive treatments. By using patient-centered approaches, pharmacists specializing in geriatrics can be prepared to effectively communicate the risks, benefits, and limitations of AD biomarker testing, helping patients to make informed decisions. Pharmacists also can contribute through education on lifestyle modifications and adherence to preventive medications, incorporating patient preferences and concerns. Pharmacists also can use their expertise in medication management to address potential side effects and optimize treatment for patients with AD.

Limitations

The survey results are subject to bias and limitations. Patients can have difficulty discussing memory problems and often do not have a deep knowledge of AD risk, therefore, delivering the survey orally may have introduced social desirability bias. The present survey was limited to a single site which may affect generalizability. Also affecting generalizability are response bias, sample size, and selection bias. Patients in the study were asked about hypothetical treatments and responses may be different when and if actual treatments for preclinical AD are developed.

Future Research

AD research is progressing with new diagnostic and treatment options. Understanding patient preferences is essential, including differences related to medication administration. Addressing these concerns will be important for patients and medical professionals to use the new diagnostic and treatment choices effectively. For example, tools to communicate AD risk, interpret biomarker results, and validate treatment

effectiveness are important for optimizing value from new treatments. There also appears a need to better understand why patients may prefer to receive IV treatments in the clinic versus self-administer subcutaneous injections at home. Further research into demographic trends in AD opinion may be helpful in developing targeted interventions.

Conclusions

Among older patients of this Midwest U.S. clinic, respondents expressed a strong interest in receiving blood testing and taking preventive medications, regardless of their perceived risk for developing preclinical Alzheimer's disease. Individuals had a stronger interest in IV administration of treatments in comparison to subcutaneous administration. It was also notable that respondent demographics were not associated with willingness to test or treat preclinical Alzheimer's disease.

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Table 3. Interest in Treatment (n=108)

Questions	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
If diagnosed with pre-clinical symptoms of Alzheimer's disease, I would be interested in taking this medication.	1%	1%	16%	34%	49%
I would be interested in taking this medication even if it involved an **IV (intravenous)** dose every 4 weeks for a total of 9 doses.	2%	7%	19%	37%	34%
I would be interested in taking this medication even if it involved **self-administered SC (subcutaneous or under the skin) injections** once weekly for one year.	6%	13%	21%	32%	29%
If this medication **lowered my risk of developing Alzheimer's disease over the next 5-10 years by 50%**, I would consider the medicine effective.	0%	2%	7%	58%	33%
If this medication **lowered my risk of developing Alzheimer's disease over the next 5-10 years by 25%,** I would consider the medicine effective.	0%	7%	26%	51%	16%
If the risk of me having any temporary symptoms … was **5-10%**, I would be concerned about my safety	1%	15%	29%	39%	17%