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## Geriatricians' Perspectives on the Multiple Dimensions of Utility of Genetic Testing for Alzheimer's Disease: A Qualitative Study

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### Abstract

**Background and Objectives:** Research advancements in Alzheimer's disease (AD) raise opportunities for genetic testing to improve diagnostic and risk assessment. Despite emerging developments, it is unclear how geriatricians perceive the potential clinical and personal utility of genetic testing for their patients. Geriatricians' perspectives are essential to understanding potential ethical, policy, and clinical challenges given their central role in treating older adults.

**Research Design and Methods:** We conducted semi-structured interviews with California geriatricians within different practice settings to collect and characterize their perspectives on genetic testing for AD. We used an adapted grounded theory approach to analyze recorded and transcribed interviews.

**Results:** We identified geriatricians' (n=10) perspectives on the clinical and personal utility of testing, alongside their views on clinical care approaches for older adults. Geriatricians perceived minimal clinical utility of genetic testing for AD, though that may change with the availability of disease-modifying therapies. Yet, they recognized the potential personal utility of testing (e.g., assisting with future financial planning). Finally, geriatricians expressed concerns regarding patients' anxiety from learning about genetic status, particularly through DTC testing.

**Discussion and Implications:** Our data highlight that the decision to order genetic testing requires clinical and ethical considerations, including balancing limited clinical utility with the potential personal utility. Although DTC testing is available, geriatricians perceive that they have an important role in managing the decision to test and interpreting the results. Further research

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is needed to inform policy and ethical guidelines to support geriatricians' critical role to counsel patients considering clinical and DTC genetic testing.

### Keywords

Alzheimer's disease; direct-to-consumer testing; APOE; genetic testing

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### Introduction

Alzheimer's disease and related dementias (ADRD) as a field has experienced dramatic shifts over the last two decades. Alzheimer's disease (AD), specifically, has experienced a shift in definition from a clinical syndrome defined by symptoms to a biological syndrome. [1] Associated with the shift in definitions, researchers have expanded knowledge regarding the potential role of genetic risk factors and identified biomarkers as indicators of the disease process, although the exact pathophysiology of the disease remains unclear.[2] Most recently the Food and Drug Administration (FDA) approved aducanumab, the first disease-modifying therapy for AD, triggering new discussions about the role of genetic testing and biomarkers for clinical care.[3] In the light of these shifts, clinicians are faced with difficult conversations with patients and families regarding predictive and risk assessment testing for AD. Thus far the literature has primarily focused on sub-specialists defined as "dementia experts" when considering ethical, policy, and clinical decision-making.[4] The focus on dementia experts is logical given their critical role in offering emerging technologies as experts in AD. Yet, this overlooks the imperative role of geriatricians, who are most likely to be the ones identifying early symptoms of AD and involved in counseling patients regarding decisions to pursue risk assessment or diagnostic testing[5].

Despite geriatricians' central role in diagnosing and treating AD, there is a gap in the literature describing their perspectives on the potential clinical and ethical challenges that emerge alongside genetic testing. While genetic testing for AD has historically been limited in clinical settings and done mostly by specialists[6], it is likely that shifts in the field will increase patient and family interest in testing. First, the FDA approval of aducanumab has generated a new potential use for genetic testing, specifically for *APOE* status, to gauge the risk of a common side effect of the medication, amyloid-related imaging abnormalities (ARIA).[3] Second, the availability of direct-to-consumer (DTC) testing makes testing for *APOE* directly available to the public, increasing the potential that patients and families will bring test results to their clinicians for guidance to interpret the results.[7,8] And while there are previous studies on the use of DTC testing, the primary focus has been on the consumers' perspectives and their use of the information.[7] There is a gap in the literature understanding clinicians' perspectives on the use of this information for clinical or personal utility.

We conducted a qualitative study of geriatricians in California who practice in diverse clinical settings to understand their perspectives on genetic testing for AD, with a specific focus on testing for *APOE*. Here, we describe geriatricians' experiences and perspectives on the clinical and personal utility of genetic testing for AD.

## Methods

We conducted a qualitative study of California-based geriatricians using semi-structured interviews to collect their experiences and views of genetic testing for AD within their practice area. Semi-structured interviews are ideally suited for this study to allow for open-ended questions without preconceived responses.[9] This structure allowed interviewees to provide unique insight based on their specific experiences. The University of California San Francisco Institutional Review Board approved this study.

## Sample

We recruited California-based geriatricians through a combination of network contacts known to the research team, a listserv of geriatricians, and internet searches. Additionally, we used a snowball approach to identify potential interviewees. We ceased recruitment at the point of data saturation (the point at which no new information was elucidated from data collection).[10]

## Interview Guide Development & Interview Administration

We developed the interview guide using standardized and rigorous methods. We reviewed the existing literature to develop interview questions that responded to the aims of the study. We identified primary domains and then integrated follow-up probes. A group of subject matter and methods experts reviewed the guide for question comprehension and consistency with study goals. The study team revised the guide before piloting it with 3 initial interviews. The study team then met to review the quality of interviews. Upon consensus that the interview guide met its intended purpose, three members of the study team (JA, GL, AT) completed the remaining interviews. All interviews were recorded and transcribed for analysis using a professional service. We removed identifying information and a study team member (MD) conducted a quality review of transcripts for accuracy.

## Analysis

Transcripts were analyzed using an iterative adapted grounded theory approach to identify themes based on geriatricians' perspectives on genetic testing for AD.[11] First, 3 investigators (JA, GL, AT) read 3 interviews to inductively identify themes emerging from the data, and a codebook was developed through consensus. The codes were then applied to 3 additional interview transcripts for validation. Upon agreement about the final codebook, codes were applied to all 10 transcripts using qualitative analysis software (Dedoose, Los Angeles, CA). Codes were given definitions to assure consistency across coders. Each interview was coded by two coders; disagreements among coders were resolved during regular consensus meetings. The team then analyzed data according to specific codes to elucidate themes and phenomena relevant to the study purpose.

## Results

Invitations for interviews were sent to 65 geriatricians, not including those invited through listserv distributions, at 11 institutions in California. Fourteen geriatricians responded to the invitations, and we completed 10 interviews. We reached data saturation at

approximately six interviews; this was determined through regular consensus meetings to review preliminary insights. We continued to ten interviews to confirm saturation and met to review additional insights on new interviews, with particular attention to any potential new themes that emerged. After determining that the additional interviews did not generate new themes, we ceased recruitment. Table 1 reports on the demographics of the sample from the 9 geriatricians who completed the demographics survey. The geriatricians who completed interviews came from varied practice settings including a safety-net hospital (1), a community hospital (1), a private practice setting (1), and academic medical centers (AMC) (6). Seven of 9 geriatricians reported their gender as female, and the most common range of experience was five to ten years in practice.

Eight of the 10 geriatricians who completed interviews reported that they had experience with genetic testing, including genetic testing for non-ADRD conditions. Of those, two reported experiences with ordering genetic tests for AD and six reported experiences with DTC testing (but not necessarily related to AD), including patients who brought the results to a clinical visit. Clinical utility of AD genetic testing, and personal utility (for patient/family) were the most prominent themes we identified in the data. We defined clinical utility as the use of genetic testing for clinical decisions (e.g., risk prediction or treatment). Comparatively, consistent with the literature[12], we defined personal utility as the use of genetic testing and results for personal or family reasons (Table 2). A third overarching theme was identified regarding the use of genetic testing and its role within the rubric of the overall care of older adults.

### Clinical Utility

Geriatricians reported that they perceived genetic testing for AD to offer limited clinical utility. They emphasized that genetic testing, particularly for late-onset AD, would not be helpful for risk prediction or alter the clinical management of symptomatic older adult patients. While this perspective was emphasized in the context of AD, geriatricians referenced similarities and differences with other conditions.

“Knowing that you have high cholesterol doesn’t tell you will have a heart attack, in the same way that knowing you have a [*APOE*] e4 allele will not tell you that you will get Alzheimer’s disease. And if you don’t have one, you can’t be falsely reassured that you will not get Alzheimer’s disease”

(Geriatrician 8, AMC)

Despite the emphasis on the lack of clinical utility under current circumstances, geriatricians reported two scenarios where genetic testing for AD could have clinical relevance: (1) in the context of early-onset AD, and (2) if disease-modifying therapy were available. Importantly, while our interviews presumed a focus on *APOE* genotyping, clinicians referenced other genetic markers in the context of early-onset AD.

“In the situation of early-onset AD where the risk of an autosomal dominant mutation is higher...that would have implications for their kids...it wouldn’t make a difference for their diagnosis, but for their kids, it might make those children who are still young, [in their] twenties, choose a different life path.”

(Geriatrician 8, AMC)

In the potential scenario where disease-modifying therapies were available, geriatricians perceived that there would be a shift in the clinical utility and frequency of ordering genetic testing. While we conducted these interviews prior to the FDA approval of aducanumab, the potential for a future disease-modifying therapy was raised by 7 of the 10 participants. The availability of therapy was perceived to increase the importance of genetic testing by improving diagnostic certainty and assisting with targeting therapies to patients that would most likely benefit from treatment and be least likely to experience adverse harms of treatment.

“I think the presence of disease-modifying therapies will change a lot. Right now, there’s ...not a lot of motivation to be very clear about who’s in what track. But if we had to have specific people in a specific diagnostic category to know that we were giving them the right therapy, I think that would...change a lot.”

(Geriatrician 7, safety-net hospital)

Another geriatrician referenced the potential approval of aducanumab as increasing the importance of genetic testing in the clinical management of patients with AD:

“If you know your carriers, it’s conceivable that for aducanumab...that if they show in their data a differential effect for  $\epsilon 4$  carriers or not or somebody does a prevention study that shows  $\epsilon 4$  carriers who take anti-amyloid drugs have a delayed onset of AD...then maybe you would get genetic testing instead of a very expensive PET scan.”

(Geriatrician 8, AMC)

Finally, some geriatricians also reported some wariness about the potential widespread use of genetic testing, particularly beyond specialty clinics. Concerns raised included the current lack of knowledge about the appropriate use of testing, as one geriatrician expressed.

“There’s just so little knowledge about how to apply these things. As much as I wish it weren’t so, I just feel like...certain areas of geriatrics...it’s like symptom, med, symptom, med...And so what that will turn into is *APOE*, if it’s really heavily promoted as the right test, then plug in your disease-modifying therapy plan. It scares me a little bit.”

(Geriatrician 7, safety-net hospital).

### Personal Utility

Geriatricians reported that, in their experience, patients and families often requested *APOE* testing for reasons we coded as “personal utility.” Examples of personal utility included use of testing results for financial, legal, and family planning, as well as to provide general health information that may be useful to other family members.

“I did get the impression that the family was particularly concerned for [the patient’s] well-being, but also for their own. So, it was like, ‘Will information that we get impact my future?’”

(Geriatrician 7, safety-net hospital) “

“I notice...that the family plays a big role in wanting to find out more about what the patient has been undergoing and...to find out how it will impact them going forward.”

(Geriatrician 9, AMC)

Geriatricians also cited a perception that family planning, including financial and legal planning for the patient, may have motivated patients and families to pursue or ask for genetic testing. While they reported on their experience with patients, in some cases this area of discussion generated personal reflection on their own family.

“I had a young patient with early-onset AD and their son...really wanted to be tested. If he was a carrier of an autosomal dominant mutation, he was not going to have kids...if he wasn't, then he could go forward with his life.”

(Geriatrician 8, AMC)

“My dad wanted specifically to know...if there is or there isn't the gene...to actually decide what your directions would be like in life and how to plan your estate.”

(Geriatrician 3, private practice)

Geriatricians also perceived personal risk assessment and personal interest in health, as well as curiosity, to be drivers of genetic testing. This perception was highlighted in the context of DTC testing.

“A lot of the people I deal with ... take on a lot of personal interest in their own health. And so having that information tends to be a part of the culture of being able to be empowered, to take charge.”

(Geriatrician 3, private practice setting)

This perception of patient and family interests in obtaining genetic testing included the potential broader testing available through DTC, where learning health information might be semi-incident. For example, individuals who use DTC testing to learn more about their ancestry and then decide to learn health-related information offered as part of the panel.

“I think for a lot of people it's curiosity about ... where their ancestors have migrated from. And sometimes additional health data is ancillary...”

(Geriatrician 4, AMC)

Geriatricians reported mixed views regarding personal utility as a motivation for ordering genetic testing. While some were supportive of ordering testing to address family concerns, others reported that they guided patients and families to consider whether the information would be helpful. These two perspectives can be compared in the quotes below.

“Really, it's about what they want. If after we talk through things and there's a level of concern, certainly if there's a family history ... I would be supportive if they were interested.”

(Geriatrician 2, AMC)

“Sometimes children have brought it [genetic testing] up to me ... and then a long conversation ensues about, what are you going to do with that information?”

(Geriatrician 8, AMC)

### Clinical and Personal Utility of Direct-to-Consumer Testing

Geriatricians reported that DTC testing results for *APOE* status generally did not provide clinically relevant information. Some described the tension between the commercial aspect of DTC testing and the potential value to customers (patients).

“I think that sometimes the marketing exceeds the clinical basis for those statements.”

(Geriatrician 2, AMC).

This sentiment was taken further by geriatricians who were concerned about the potential harms associated with DTC testing.

“...The potential of just being...depressed about the results and worried about ‘when am I going to develop Alzheimer’s,’ all that extra stress is putting them at higher risk of developing a neurocognitive disorder.”

(Geriatrician 6, AMC)

Yet, some geriatricians differentiated the lack of clinical utility from the potential personal utility of DTC for patients and their families. Some examples raised included assessing personal risk for AD, future planning, and general curiosity. Geriatricians identified the potential that DTC could be used for planning while protecting individual privacy and preventing medical insurers from accessing the results.

“If you knew you had two *e4*s and you’re 55 years old, if it was me, I would use that information and I would buy long-term care insurance, because the chance that I’m going to need it is really high. But I would prefer to get that information from 23andMe and have it not be in ... my medical record where somebody someday ... could discriminate against me and not sell me insurance.”

(Geriatrician 8, AMC)

### Reflection of Broader Clinical Approach & Concerns Regarding Testing

Geriatricians’ attitudes toward genetic testing for AD were consistent with their general philosophy of testing in an older population, including an assessment of how test results may affect clinical management.

“Well, I think it gets down to that question of every test...if you’re going to order a test, ask yourself what you’re going to do with the results. And if the answer is nothing...then don’t order the test.”

(Geriatrician 6, AMC)

Additionally, geriatricians reported concerns regarding potential harms associated with genetic testing for AD. As a result of this perspective, geriatricians viewed counseling patients as one of their most important roles when considering genetic testing.



“All the genetic testing can cause anxiety, but there’s definitely some differences in the gene that tells if you can taste cilantro, versus the one that can potentially increase your risk of Alzheimer’s dementia. The implications there are a little bit more there.”

(Geriatrician 5, AMC)

“Some people are going to get it if they want to, and all we can do is educate and help them think through how it might be different, how they might use that information.”

(Geriatrician 8, AMC)

## Discussion & Conclusion

The clinical care of older adults, particularly those with cognitive impairment related to ADRD, is rapidly evolving. In this study, we found that geriatricians had varied experiences with genetic testing for AD, and they viewed the decision to test not only from a perspective of clinical utility, but also considered whether there may be personal utility of genetic testing for patients and families. There was acknowledgement that while testing offered minimal utility for clinical management of AD in most cases and may cause harm, it also may provide information that patients and families may find valuable for future planning. Additionally, the emergence of disease-modifying therapies for AD and the availability of DTC testing underscored the important role of geriatricians in counseling patients about such testing.

Utility, both clinical and personal, informs the potential benefits of any medical or research procedure when determining whether it is ethically justified. Determining the benefits of a program or procedure is generally an initial criterion of most ethical frameworks.[13] In the context of genetic testing within the geriatric care setting, establishing potential benefits relies on the question of “how will this information be used?” This allows for the weighing of the potential utility as a benefit to be weighed against the potential risks of harm. Our study found that geriatricians’ view of genetic testing for AD is consistent with the view that, in the absence of early-onset symptoms or available disease-modifying therapy, testing does not affect the patient’s care.[14] However, as has been discussed in the literature previously, information from genetic testing may be of personal utility to patients even in the absence of clinical utility.[14-16] In our study, geriatricians discussed how genetic testing for AD may assist patients and their families in terms of informing personal, legal, or financial plans, and that they could understand why patients would pursue testing, particularly DTC testing. While they were also concerned about the harms from knowing genetic information about AD risk without disease-modifying treatments being available, geriatricians’ view that personal utility was an important consideration and part of counseling patients may mean that clinicians could be more willing to support genetic testing for their patients to offer personal utility – a perception emerging in the literature.[17]

The availability of DTC testing for AD risk became available in 2017 following the FDA approval of the 23andMe Personal Genome Service Genetic Health Risk test, which includes an option to learn *APOE* status.[18] Interest in DTC testing has soared; for example, one

study showed that 43% of patients expressed interest in DTC testing.[19] In our study, geriatricians' reported a lack of clinical utility for DTC testing for AD were, consistent with their views on clinical genetic testing, while also recognizing the potential of personal utility of testing, and raised concerns about potential risks.[7,8,19,20] However, an additional challenge to DTC testing was counseling patients who bring test results to the clinic for help interpreting the results, and worried about the distress that unanticipated results may cause. This finding matches prior literature that suggests that patients are curious about their genetic background but worried about the distress that DTC testing for AD may cause,[20] uncertain about how to interpret results and with whom to share information,[21] and the accuracy of DTC testing results.[22] Potential integration of *APOE* testing into clinical care thus must also consider the role and impact of DTC tests, particularly as disease-modifying drugs like aducanumab become more available, which may drive greater interest in testing.

While the data we present here were collected using rigorous qualitative methods, there are some limitations to this study. First, our sample is limited to geriatricians practicing within a single state. We made the decision to recruit within a single state to eliminate variations based on state law, including scope of practice considerations, for this preliminary study. We diversified our recruitment by inviting geriatricians from multiple regions within the state and from different practice settings (AMCs, private practices, and safety-net settings). Additionally, our sample size of 10 is not sufficient to produce generalizable results. This was not the aim of this study, as we sought to get in-depth perspectives of geriatricians based on their individual experiences. We ceased data collection only after the team felt confidently that new themes would be generated by continuing to conduct interviews. Future studies will aim to address issues of generalizability through broadening our eligibility criteria (e.g., beyond California) and changing data collection methods (e.g., surveys). Still, the data from this study provide insight on geriatricians' experiences and views, which have not been previously described. Another limitation was the timing of the interviews, which were conducted prior to the FDA approval of aducanumab. This limits our ability to report on the impact of that decision. While the geriatricians we spoke to considered, unprompted, the impact of a disease-modifying therapy on genetic testing practices, this is an area that warrants further exploration. Finally, this study does not reflect patient or family perspectives. Patients and families are a critical stakeholder group, and it is imperative than any change of practice standards should reflect their values and considerations.

This study provides additional data to consider when evaluating the benefits and risks of genetic testing for AD within geriatric clinical practice. Geriatricians' role as the primary care providers for older adults makes them a critical stakeholder when considering the use of genetic testing for AD. The geriatricians we spoke with reported views on the current clinical utility of genetic testing for AD that are consistent with prior research and policies. Yet, their reflections on emerging and evolving trends in AD signal a need for further exploring the multiple dimensions and factors influencing utility – including the relative importance of personal utility. Additionally, future research to inform the implementation of genetic testing for AD into geriatrics practice centers, such as the factors that influence decisions to offer or order testing, as well how to best prepare geriatricians for an increased interest in genetic testing for AD, will be important to advance the field. Finally, as the population ages and AD becomes a disease defined by biomarkers, geriatricians will play

an increasingly important role in the diagnosis and management of AD, and thus their perspectives are critical to understanding the implementation and use of genetic testing for AD in clinical care.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Demographics of interviewed geriatricians (n=9). One participant did not complete the demographic survey, their demographic data is not reported.

**Table 1.**

N=9	Men	Women
<b>AGE</b>		
30-39	2	3
40-49	0	4
<b>ETHNICITY</b>		
Hispanic or Latinx	0	0
Not Hispanic or Latinx	2	7
<b>Race</b>		
Caucasian	1	3
Asian	1	3
More Than One Race		1
<b>TYPE OF INSTITUTION</b>		
Community	0	1
Academic	2	4
Private	0	1
Safety-Net	0	1
Years in Practice	0	
0-5	0	2
5-10	2	1
10-20	0	4
<b>PERCENTAGE OF CLINICAL TIME</b>		
0-20	0	1
21-40	0	2
41-60	0	1
61-80	1	0
81-100	1	3

**Table 2.**

**Key Themes for Utility of Genetic Testing for Alzheimer’s Disease**

SETTING	TOPIC	KEY THEMES
<b>Clinical Setting</b>	Clinical Utility	• Not generally useful for risk assessment beyond clinical and family history or with current treatments
		• May be useful in the context of treatment with disease-modifying therapy
		• May be useful in context of early onset Alzheimer’s disease
	Personal utility	• May be useful in younger patients for family planning
		• Impact on financial/legal/estate planning
		• Implications for family members’ risk
<b>Direct-to-Consumer Testing</b>	Clinical Utility	• Use for individuals’ own risk assessment
		• Curiosity about ancestry
		• Perception of lack of clinical utility to DTC genetic tests
<b>General Approach to Genetic Testing for Geriatric Patients</b>	Personal Utility	• Marketing exceeds utility of tests
		• Results can cause additional stress due to uncertainty about the relevance of the results
		• Can provide information about ancestry
	Testing in Context of Clinical Care of Older Adult	• Many people are curious
		• Could be personally useful for future planning
		• Could be useful to do genetic testing outside of medical system for privacy reasons
Geriatric Patients	Reflections about their own personal experiences with genetic testing influences their opinions	• Assessment of utility of genetic testing in the context of patient’s overall health and goals, and potential to change management
		• Concern about balance of harms and benefits of tests, particularly causing greater anxiety
		• Geriatricians’ reflections about their own personal experiences with genetic testing influences their opinions