

Featured Article

# Perceptions of precision medicine among diverse dementia caregivers and professional providers

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## Abstract

**Introduction:** Underrepresented groups experience health disparities and a history of exploitation by researchers and the health-care system that may contribute to distrust of new treatments and technologies. This study aims to understand how diverse family caregivers and health-care professionals view the benefits and risks of precision medicine as well as cultural dimensions to consider when developing and implementing precision medicine interventions in dementia care.

**Methods:** Eight focus group sessions and one individual interview were conducted over a 6-month period. Fifty-four focus group participants included African-American, American Indian, rural Caucasian, Latino, and West African caregivers and health professionals. The majority of participants were female (73%) and were of Hispanic/Latino ethnicity (68%). About a third of participants identified their race as white. Participants were presented with four hypothetical scenarios related to precision medicine diagnostic and treatment approaches in dementia care: (1) genetic testing for dementia risk, (2) health-care informatics to determine individualized medication dosages based on health and family history, (3) a smartphone application providing dementia caregiving tips, and (4) remote activity monitoring technology in the home. Focus groups' responses were coded using thematic analysis.

**Results:** Participants indicated skepticism regarding the use of precision medicine in their communities. Concerns included cost of precision medicine and insurance coverage; lack of alignment with cultural norms; fraught relationships between communities, health professionals, and researchers; data ownership and privacy; and the trade-off between knowing risk and treatment benefit.

**Discussion:** Establishing relationships with underserved communities is crucial to advancing precision medicine in dementia care. Appropriate engagement with diverse racial, ethnic, and geographic communities may require significant investment but is necessary to deliver precision medicine effectively.

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## Keywords:

Precision health; Technology; Utility; Acceptability; Diverse; Underserved; Feasibility; Communication; Health literacy

The authors certify that this work is novel or confirmatory of recent novel clinical research.

Clinical care/health policy impact: This study offers novel insights to practitioners and researchers into underserved communities' perceptions of precision medicine approaches to diagnose, prevent, or treat Alzheimer's disease and related dementias.

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## 1. Background

Precision medicine [1] (PM) refers to a strategy to prevent and treat disease that is individualized to each person based on their genetics, lifestyle, and environment [1]. The core elements of PM include risk stratification, early identification of pathophysiological processes, and “alignment of mechanism of (intervention) action with the individual’s molecular driver of disease” [2] [p. 500]. Although no cure exists, genetic, lifestyle, environment, and their complex interactions have been shown to contribute to Alzheimer’s disease (AD) risk. Due in part to the complex risk profile of AD, PM approaches have not yet evolved into effective preventive or treatment options for AD as they have in some other chronic diseases [1,3]. However, there is some hope that adoption of PM as a framework for treatment and prevention may advance what is known about AD and how to slow or halt its progression.

PM strategies have altered how AD is diagnosed or soon will. The validation of various biomarkers of AD has led to a dramatic shift in how the disease is identified and measured over time [4]. For example, biomarkers of amyloid  $\beta$  and tau proteins accurately identify the presence of pathological changes that serve as precursors to the cognitive, behavioral, and functional symptoms that served as the traditional basis of AD diagnosis. Challenges, including cost, accessibility, and invasiveness of these techniques, have led to calls to develop more effective screening techniques [5].

Researchers have also begun to explore whether the application of PM methodologies and interventions could improve AD risk reduction when compared to more standardized/universal population health strategies. Targeting or stratifying risk reduction and management strategies by APOE  $\epsilon$ 4 carrier status is one such strategy [6]. Genome-wide association analyses have identified a number of additional genetic loci, and as genetic insights advance they could be used to individualize diagnosis and prognosis [7]. Initial examinations of PM in AD have also focused on developing therapies to treat the likely multiple causes of the disease, including personalized risk management approaches [8–12]. With advances in computing power, data collection frequency, and technology integration revolutionizing health care [13], researchers have also examined technologies with the potential to individualize care regimens and improve dementia care outcomes [14,15].

A key consideration of PM in the context of Alzheimer’s disease and related dementias (ADRDs) is how clinical information is communicated to individuals and families. Such communication should allow individuals and families to feel informed and confident and to facilitate necessary next steps to ensure improved health [16,17]. Effective communication of innovative treatment approaches is particularly critical among diverse populations such as African-American, Latino, and aging rural communities [18]. Such populations experience health disparities and a

history of exploitation [19–21] that may contribute to distrust of new technologies or treatments. Further, as the U.S. population becomes increasingly older and more diverse, it is important to understand how historically underserved communities perceive PM. To more fully explore these issues, we conducted focus groups with diverse family caregivers and health-care professionals to better understand their views on the potential benefits, risks, and important cultural considerations when developing and implementing novel PM interventions for ADRD.

## 2. Methods

### 2.1. Design and procedure

A series of focus groups were conducted to ascertain how family members, professionals, and other individuals involved in providing care to people with dementia perceived PM approaches for the diagnosis and treatment of ADRD. An initial focus group guide was developed in collaboration with a group of interdisciplinary faculty to explore research initiatives related to PM and health. The focus group guide (see [Supplementary Material](#)) included a series of general open-ended questions that asked about participants’ experiences related to ADRD care, perceived challenges, gaps in care, and overall perceptions of PM in the context of ADRD care. The focus group guide concluded with the presentation of four hypothetical scenarios related to precision health diagnostic and treatment approaches in ADRD. This analysis focused on responses to four scenarios: (1) genetic testing for dementia risk, (2) health-care informatics to determine individualized medication dosages based on health and family history, (3) a smartphone application providing dementia caregiving tips, and (4) remote activity monitoring technology in the home. These questions were designed to elicit responses regarding perceptions of the appropriateness of various PM approaches in ADRD. Sociodemographic information was also collected from participants. This study received an exemption from the University of Minnesota Institutional Review Board (#1702E06621).

The first author as well as dementia care professionals who shared the cultural/ethnic background of focus group participants conducted focus group sessions. The locales of the focus groups varied but were conducted in a location that was familiar and convenient for participants (e.g., local community center). Focus group sessions were primarily conducted in English, although one focus group interview was conducted in Spanish and translated for subsequent qualitative analysis. Focus group sessions were audio taped and transcribed verbatim by a professional transcription service; each session lasted for approximately 90 minutes. The first author accommodated the availability of a participant interested in contributing their perspective and conducted one individual interview.

The first author has long-standing relationships with a number of organizations that serve diverse older adults. These organizations along with a number of cultural consultants in dementia care from the Minnesota Board on Aging agreed to assist with recruiting older persons living with AD/DR and their families for the focus groups. After this outreach, eight focus groups and one semi-structured interview were conducted over a 6-month period. Focus groups were chosen to represent key underrepresented groups in Minnesota: rural Caucasians (n = 1), African-Americans (n = 1), American Indians (n = 1), Latinx (n = 2), West Africans (i.e., Nigerians, Ghanaians, and Liberians; n = 1), and members of several different cultural groups together (i.e., the Minnesota Board on Aging dementia care cultural consultants described previously, n = 2). Most focus groups ranged in size from 3 to 8, although one group included 20 participants. This group was larger than the rest in order to align the focus group meeting with the ongoing programming at a local community cultural center.

## 2.2. Analysis

The qualitative analysis was conducted according to Braun and Clarke's six steps of thematic analysis and focused on identifying positive and negative reactions to each technology [22]. The analysis was guided by two research questions: (1) in what ways do participants find these technologies and ideas attractive or useful? and (2) in what ways do participants find these technologies and ideas concerning or problematic? H.M. and L.L.M. first read all transcripts, noting initial ideas and emerging patterns. Next, they convened to discuss patterns and generate an initial coding framework. H.M. and L.L.M. re-read all transcripts and convened to compare interpretations and revise the coding framework. Next, H.M. and L.L.M. coded all material, meeting weekly to discuss points of divergence and to further revise the coding framework. After finalizing the coding structure, they re-coded all material, collating codes into potential themes. Reliability was calculated for all transcripts (K = 0.81). Consensus was established, and all disagreements were resolved through discussion. Next, themes were reviewed in the context of the data set and research questions, and themes were defined and named. Audit trails and weekly debriefing between all three authors enhanced transparency and credibility [23].

## 3. Results

### 3.1. Participant characteristics

Participant characteristics are provided in Table 1. The majority of participants were female (73%) and of Hispanic/Latino ethnicity (68%). About a third of participants identified their race as white.

Table 1  
Participant demographics

Variable	N (%)
Age in years (mean, SD)	50.48 (16.71)
Female	35 (72.9)
Hispanic/Latino	32 (68.1)
Race	
American Indian	4 (8)
Asian	1 (2)
Black/African-American	9 (18)
White	17 (34)
Some other race	16 (32)
Two or more races	3 (6)
Marital status	
Married or living with partner	26 (54.2)
Widowed	2 (4.2)
Divorced	7 (14.6)
Separated	1 (2.1)
Never married	12 (25)
Education	
Did not complete junior high/middle school	3 (6.7)
Did not complete high school	2 (4.4)
High school degree	11 (24.4)
Some college courses	3 (6.7)
Associate's degree	3 (6.7)
Bachelor's degree	7 (15.6)
Some graduate courses	3 (6.7)
Graduate degree	11 (24.4)
Other	2 (4.4)
Provided care to person with memory loss in professional capacity	23 (50)
Work status	
Full-time	20 (41.7)
Part-time	8 (16.7)
Keeping house full-time	4 (8.3)
Retired	9 (18.8)
Unemployed	1 (2.1)
Other	6 (12.5)
Provide care to family or friend with memory loss	39 (81.3)
Length of time caregiving in months (mean, SD)	63.8 (50.4)

Abbreviation: SD, standard deviation.

### 3.2. Discussion themes

#### 3.2.1. Barriers to access

Barriers to access were a concern that participants noted for all four of the PM technologies examined in the present study and especially RAM technology. PM was perceived as potentially very expensive, and participants were uncertain about whether insurance providers would consider PM interventions eligible for coverage. Cost and insurance coverage were concerns particularly in regard to genetic testing and informatics. One participant explained, saying:

If it's any kind of patient with memory problems, when [the doctor] mentions [doing a] memory assessment—if they don't have insurance, I don't see a gain to [going to] the doctor. [The doctor does not file] any tests, because as soon as they mention ["tests"], what does that mean? How much will be the costs? Do I need to have those?

In addition to financial barriers, participants noted technological barriers, including lack of access, and low comfort or familiarity with technology. Two Latino participants discussed such barriers related to accessing RAM:

...To be realistic,—most of our community is low income. They don't have— ...our families don't have [that] accessible—I am thinking of that.

Maybe Internet. Some of them they don't have Internet.

### 3.2.2. Cultural competence

Many participants raised concerns about the potential inconsistency of PM with cultural norms and values. For example, one Latino participant discussed how RAM might conflict with cultural values around family caregiving:

I believe that, also, the role of the family, of the family nucleus, of the background that you have. For example, we as Latinos, I would not dare leave my parents if I know they have a need. So, I think that culture has to do a lot, where you come from and the way you are willing to do things. For me, that would take a primary role, of what I feel is my duty before I go with something else, when there is no other option.

The goals that RAM is designed for may not be relevant in a cultural context where family caregiving is an expected and valued role for children of aging parents. Such comments convey a sense that RAM and other PM technologies are fundamentally misaligned with some minority groups' cultural values and expectations.

Participants also indicated a need for adapting PM to particular cultural contexts. Some saw potential in technologies such as the smartphone app for specifically targeting members of a cultural group with tailored, culturally relevant information in users' native language. The scenario presented in the interview guide did not suggest providing culturally or linguistically tailored tips and guidance, but participants felt this adaptation would make the technology much more useful.

### 3.2.3. Exploitation

Exploitation was a major concern of PM for many participants, particularly in response to the informatics and genetic testing scenarios. Participants expressed the concern that their communities would be used as "guinea pigs:" that participating in the informatics test would confer no benefits to them or their community, but would instead be used to benefit white and more resourced communities and researchers. One Latino participant elaborated saying:

...See how much money they're going to make out of it. And we who are suffering with Alzheimer's, heart disease, everybody here has it, we're lab rats. And they're using our information or your information to benefit someone other than those who really need it. I'm extremely skeptical with anything that has to do with the government, pharmaceutical companies... And we're the lab rats.

For several participants, the genetic testing and informatics scenarios raised concerns of historical and current exploitation by researchers. Several cited historical examples of researchers benefiting at the expense of minority communities. One participant explained her skepticism of PM by giving the example of Henrietta Lacks whose cells (HeLa cells) were taken without her consent and resulted in many scientific breakthroughs and a multimillion dollar industry (<http://www.lacksfamily.net/henrietta.php>).

A very good example is the [HeLa cells]. What happened to the family? Twenty five tons of [cells] have been created from the sample that they [took], and the family have absolutely nothing. [Now it] is a multi million industry. And these cells were taken without consent even. So it's exactly the same we are facing here right now [with genetic testing].

Others expressed distrust of research establishments, saying that researchers are involved in their communities so long as their grant is dependent on it. After the grant, the researchers are gone, leaving the community with little benefit.

Participants also frequently expressed concerns about conflicts of interest among the companies providing the PM technology and entities providing the medication that may be indicated by test results. Such conflicts of interest could lead to exploitation if unnecessary treatments are prescribed because of genetic testing or informatics-based prescribing. One participant explained,

My only question is, is the informatics company working together with the pharmaceutical company[?] [If] they are not the actual people producing the medication, so all this data that they're collecting, it's all good and dandy, if they're working independently... If I am the wife, I would hesitate until I know exactly how this will come to benefit my husband.

### 3.2.4. Privacy

Concerns about privacy arose frequently in response to the genetic testing and medical informatics scenarios. Participants felt uncertain about who would have access to any personal health data collected and used for genetic testing and informatics-based prescribing. Many expressed discomfort at the idea that their data may not be stored securely and thus accessible to unknown third parties. Some raised the possibility that such data and test results might be shared with insurance companies and could result in changing rates or eligibility. One participant expressed,

The problem here is who is going to be the gatekeeper of this information... You don't know actually how many companies are involved here. You don't know who is dealing with your data. You don't know what these people are doing with your data.

### 3.2.5. Risks of knowing

The prospect of genetic testing for dementia raised concerns about potential unintended negative consequences of

finding out one's level of risk. Participants anticipated that receiving test results that indicate high risk of developing dementia could cause feelings of hopelessness and depression, potentially leading to desperate and harmful actions. One African-American participant offered a personal example,

[W]hat do you do with the knowledge? Does it make you more planful? Does it have you manage it better? One of the people I grew up with, her husband got a diagnosis of Alzheimer's, and he was physically fit, socially active, strong family provider, and he went to the park, sat on the bench and shot himself—committed suicide.

Apart from the concerns for the safety and well-being of the test recipient, participants were also concerned that children and grandchildren who are genetically related to the test recipient would experience distress as well, as such test results would indicate that they have heightened risk as well.

### 3.2.6. Utility

Many participants questioned the utility of PM, suggesting that the particular approaches described would not make a meaningful difference in decisions or actions around dementia care. The majority of the references to utility were in relation to genetic testing. Participants felt that knowing one's genetic risk of developing dementia was not particularly useful given that there are currently no viable treatments for stopping or reversing the progression of dementia. For these participants knowing was not worth the potential distress of receiving a negative test result:

Even if then you do the test and you still have no cure, there's an ethical dilemma. Do I care to know about my death? You know? You're not [able to] cure me, and I'm going to live with this information that I can't get rid of, then what's the point?

Others felt that genetic testing did not offer any benefit, especially in comparison to existing methods such as behavioral assessment or evaluation of family history. For instance, one participant expressed,

This is just ridiculous, because the genetic profile is just the risk of getting Alzheimer's. And if you did already the ten warning signs from the Alzheimer's Association and you said you might have Alzheimer's, why don't you do the following testing instead of a genetic test.

Concerns about utility were also raised for informatics, RAM, and the smartphone app, with participants questioning whether these technologies provided a useful benefit over and above existing approaches.

### 3.2.7. Additional support needed

Participants frequently provided recommendations for additional support that would make PM more useful or appropriate. They felt such technologies should be seen as a tool to enhance, but not replace, the care provided through human interactions with health-care professionals, social service workers, and family caregivers.

In particular, participants felt that additional support was needed for users of genetic testing. Perhaps because of the fears and concerns around genetic testing discussed previously, participants felt that families who received the testing should receive counseling, as well as specific guidance on how to interpret test results and take appropriate action. Participants emphasized that such support should engage directly with the family, not just with the test recipient. One focus group of West African participants discussed these considerations, saying:

I would say [genetic testing is] a good thing, too, but the approach is what I don't like. It's too direct. This can set someone off. Alzheimer's is not something you're going to cure. It means he's going to get worse. To have a test that they can use to determine if he's at risk is good, to me, but I would not approach it in this way, not just one visit. A social worker has to come in; they have to have a genetic counselor come in.

And the wife.

She is going to be supporting him.

Right, and the kids.

He's going to be deteriorating. He's not going to tell her. He'll maybe brush it off, so she needs a support system

Participants also emphasized the need for maintaining a "human touch" when using RAM and not using it as a replacement for in-person contact with caregivers and health-care professionals.

## 4. Discussion

Although PM is perceived by some scientists to have the potential to prevent dementia, help families prepare for a diagnosis, and reduce caregiver stress, there is skepticism and concern for the use of PM in these communities. Sporadic cost and insurance coverage; lack of alignment of PM with cultural norms and values; historically and currently fraught relationships between communities, health professionals, and researchers; unclear privacy and data ownership; and the potential trade-off of knowing risk versus treatment benefit were among the most notable concerns of our diverse sample of participants.

### 4.1. Key scientific and clinical issues

As the findings of this study emphasize, engagement with communities, particularly historically underserved ones, is needed when developing, communicating, and implementing PM innovations. In many ways, PM was perceived as not meeting the needs of underserved groups. For example, some participants felt RAM technology was misaligned with cultural norms and values around the family's role in

caregiving. Others pointed out that a smartphone app providing caregiving tips that were not culturally tailored missed an important opportunity to maximize the relevance and utility of PM for underserved groups. For many, concerns about privacy and exploitation outweighed the potential benefits of genetic testing or medical informatics. These findings suggest that many forms of PM are not integrated with the needs and concerns of underserved communities, limiting the potential for PM to improve health and quality of life for persons with dementia and their family caregivers. Although engagement in diverse communities is likely to require time and expense to do so successfully, it is critical in allowing PM researchers and clinicians to understand what is most important to community members and address those needs when providing PM information. Community-based participatory research (CBPR) paradigms are one important strategy for ensuring interventions address the needs of underserved communities [24], and these paradigms have recently begun to be applied to PM development [25,26]. In community-based participatory research, members of the community are included as partners throughout the entire research process, including identifying problems, setting goals, and designing and evaluating solutions. Such methods represent a promising approach to addressing mistrust and perceived lack of relevance of PM among diverse groups. It is also crucial that providers accurately communicate the potential benefits and drawbacks of using PM and ensure users of such technology have realistic expectations about its effects.

The present study had some notable limitations. Although this study is among the first to describe perceptions of PM among diverse caregivers and health-care professionals, the interview was not designed to probe directly for the specific reasons underlying such perceptions. Future research should explore how cultural factors such as family dynamics, religious and spiritual beliefs, histories of exploitation, and cultural conceptions of aging and dementia may explain the perceptions of PM that we observed. Another potential limitation is that the interpreter assisting the focus group conducted in Spanish had not been trained specifically in health-care interpreting.

## 5. Conclusion

As with other areas of ADRD care, the importance of establishing relationships with underserved communities is crucial to advancing PM in ADRD diagnosis, prevention, and treatment. If PM innovations in ADRD are as promising as some suggest, the costs of inadequately engaging with underserved communities could be immense. Proactive and culturally/linguistically appropriate engagement with diverse racial, ethnic, and geographic communities may require significant investment of resources and personnel but is necessary to ensure

the benefits of PM are accessible to all persons with ADRD and their caregivers.

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Author Contributions: J.E.G. conceived of the study and its design, engaged in data collection, and prepared this manuscript. H.M. and L.M. conducted the final qualitative data analysis and drafted the methods, results, and other sections of the article. The sponsor had no role in the paper beyond its generous financial support.

## Supplementary Data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.trci.2019.07.005>.

## RESEARCH IN CONTEXT

1. **Systematic review:** The authors reviewed the literature using PubMed to identify research on precision medicine treatments for dementia. Although there is substantial literature available on perceptions of research practices among underrepresented groups, we were unable to find any research pertaining specifically to such groups' perceptions of precision medicine approaches to dementia and dementia caregiving.
2. **Interpretation:** Our results align with general findings on perceptions of underrepresented groups toward research (e.g., concerns about exploitation), as well as some concerns that are relevant specifically to precision medicine treatments (e.g., concerns about data ownership and insurance coverage).
3. **Future directions:** Important areas for future research include developing effective methods for ensuring fully informed and voluntary consent among diverse research participants and for communicating genomics and other precision medicine information.

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