

Decision-Making Around Alzheimer’ Research Participation Among Hispanic/Latino Older Adults

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Background

- Hispanic/Latino adults are at high risk of cognitive impairment yet remain underrepresented in Alzheimer’s disease (AD) research.
- Improving clinical trials representation is a major focus of research. Prior work has largely conceptualized research participation as a function of barriers and facilitators.

Objective This study examines how community-dwelling Hispanic/Latino older adults evaluate and navigate decisions about Alzheimer’s disease research participation.

Methods

- Qualitative study using semi-structured interviews of community-dwelling Hispanic adults ages 50 and over.
- Bilingual (English/Spanish) interviews conducted by trained interviewers through the Chicano Federation.
- Thematic analysis of participants' decision-making regarding research participation in the APT Webstudy.
- APT Webstudy is a remote longitudinal registry of cognitively unimpaired adults that includes quarterly and bi-annual cognitive assessments and serves as a pathway to future Alzheimer's disease research studies.

Results

Theme 1: Willingness is Conditional

Informational Transparency

“ Yes, but first with information.” -P15

Perceived Applicability

“ only if it’s related to cancer...I’m worried more about this.” -P14

Domain-specific Willingness

“ I would participate (the Webstudy), because it doesn't involve any medication.” -P14

Theme 2: Personal Outreach Enables Participation

- Most participants did not know where to have access to research.
- Effective community recruitment involves with personalized, bi-directional conversations that foster understanding and trust.

“ If someone approached me and explained the study... yes, I would participate.” -P09

Theme 3: Participation is Driven by Personal Relevance

Understanding myself

“ To get to know myself a little better too” -P12

Family experiences with Alzheimer’s disease often intensified this interest

“ my dad got Alzheimer’s at a very young age. now at 61 I want to see how my brain is functioning.” -P01

Compensation was rarely the primary reason for participation.

“ That (money) doesn’t matter!” -P02

Theme 4: Structural Barriers to Participation

Limited Knowledge of Enrollment

“ Honestly...I really don’t know how to navigate.” -P24

Digital literacy

“ Using the computer is what worries me...I don’t have a computer.” -P09

Physical & Age-Related Barriers

“ Due to my age, I don’t have strength to do that anymore.” -P28

Conclusion These findings highlight that research participation, among Hispanic/Latino older adults, is a dynamic decision-making process in which initial conditions that includes trusted outreach and informational transparency, shape subsequent evaluations of personal relevance and practical feasibility, rather than reflecting a simple balance of barriers and facilitators.