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Bridging lived experience and research: lessons from Mexican families affected by autosomal dominant Alzheimer's disease

Sofía C. Arboleya-García
Universidad de Guadalajara
Angélica Zuno-Reyes
Universidad de Guadalajara
Mellissa Withers
University of Southern California
Isis E. Medina Roman
Universidad de Guadalajara
Frida Rosales-Leycegui
Universidad de Guadalajara
Isaac Enrique Berumen-Ocegueda
Universidad de Guadalajara
Ana Karen Preciado Barón
Universidad de Guadalajara
Aranzazú González Bravo
Universidad de Guadalajara
Lilibeth Barrera
University of Southern California
Claudia Alvarado
University of Southern California
Lina M. D'Orazio
University of Southern California
John M. Ringman
University of Southern California
Esmeralda Matute
maria.matute@academicos.udg.mx

Universidad de Guadalajara

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Abstract

Sustained participation of families affected by autosomal dominant Alzheimer's disease (ADAD) is essential for longitudinal research, yet informational, caregiving, and psychosocial barriers challenge this endeavor. We examined the experiences of Mexican families carrying the *PSEN1*A431E or *APP*V717I variants after three Community Networking (CN) meetings held in Jalisco in 2024. Of 91 attendees, 73 returned an anonymous questionnaire with four open-ended questions about their needs related to ADAD and their expectations for future meetings. We analyzed the responses using thematic analysis. Four themes emerged: Research Group Efforts, Health Information, Caregiving, and Psychosocial Support. Participants described the ADAD information as accessible and expressed a desire for further contact with researchers and other families. Family needs differed across sites: Caregiving predominated at Site 1, while Caregiving and Health Information were equally frequent at Sites 2 and 3. These findings suggest that community-based engagement supports trust, knowledge, social connection, and continued participation in ADAD research.

Introduction

Participant involvement in research, recruitment, and protocol adherence are major challenges to progress in Alzheimer's disease (AD) studies, including biomarker research and clinical trials[1]. Challenges in sustaining participation in clinical research can overlap and differ across cultures and regions. For individuals, these include the burden of living with AD (e.g., reduced physical energy or language difficulties), transportation issues, time demands, and other daily-life priorities[1]. Limited access to clinical research, insufficient information about research projects or their benefits, and underrepresented populations at high demographic risk of AD (e.g., Hispanics and African descent people) also play a role. Other reported barriers include perceiving the research as religiously inappropriate, concerns about treatment effectiveness, fear of physical injury, and mistrust of researchers[2,3].

Trust among potential research participants, their families, and the research group can foster participants' willingness to engage in research[4]. However, trust is not inherent; people must actively establish and negotiate it through social interaction, and organizations must support its implementation[5]. Building trust in clinical research requires sustained interaction between the two main parties: researchers and participants[6]. Researchers are individuals involved in the systematic design, conduct, analysis, and reporting of scientific studies[7]. In contrast, a research participant is a living individual who voluntarily provides data, experiences, or biospecimens to help answer the study's research questions[8].

This is especially significant when working with families who have lived with a condition for generations. Researchers have identified pathogenic variants that cause ADAD in the amyloid precursor protein (*APP*), presenilin 1 (*PSEN1*), and presenilin 2 (*PSEN2*) genes. Most follow an autosomal dominant inheritance pattern, show complete penetrance, and account for approximately 1–5% of all AD cases worldwide[9]. Because of this inheritance pattern, one parent carrying one copy of the variant gives each offspring a 50% chance of inheriting it and developing the disease[10]; as a result, family histories often show affected individuals across generations. Cognitive and functional decline usually starts before age 60, and its progressive nature compromises the individual´s independence[11], increasing the need for caregiver support as the patient navigates through the disease stages.

For nearly 10 years, our group has worked with families in Jalisco, Mexico, who carry the ADAD *APP*V717I and *PSEN1*A431E variants[12]. Most *APP*V717I families we work with live in a single rural community, while families carrying the *PSEN1*A431E variant live in several locations, including both urban and rural areas[13–15].

In Latin American countries, including Mexico, the family is commonly understood in its extended form, which includes parents, children, grandparents, and other relatives[16]. Within this structure, family members most often assume caregiving responsibilities without prior training[17]. In Mexican families at risk of ADAD, the caregiver role may be assumed by parents (caring for an affected child), children (who may even be minors caring for a parent), siblings (caring for a brother or sister), or grandchildren[18]. Caregiver tasks vary by dementia stage and range from supervision and assistance with activities of daily living to decisions about long-term care and treatment[19–21], including authorizing participation in research protocols. For families affected by ADAD, opportunities to interact directly with other families who have had similar experiences, as well as with researchers and clinicians, may also reduce feelings of isolation while promoting a greater sense of community and hope[16,18,22].

Community engagement has emerged as an important strategy for strengthening partnerships between researchers and participants while creating opportunities to disseminate scientific information and foster dialogue, reciprocal learning, and shared decision-making[1,23]. These approaches (e.g., participatory workshops, family support meetings, and community advisory panels) strengthen trust, improve communication, enhance understanding of research, and encourage continued participation in longitudinal studies[23,24], involving ADAD families in clinical studies years or decades before symptom onset[15].

Although community engagement initiatives are increasingly recognized as valuable components of dementia research[1], relatively little is known about how families affected by ADAD across generations perceive these activities, which aspects they find most meaningful, and how they can provide feedback to evaluate research programs effectively. Understanding participants' perspectives is essential for developing engagement strategies that address affected families' evolving needs and strengthen trust between researchers and communities[5].

In this context, research involving families with ADAD poses significant practical and ethical challenges, including the need to understand AD's causes, complex study designs (e.g., clinical procedures), and genetic risk considerations. These factors, among others, can make it difficult to obtain fully informed consent in such complex research contexts[25].

The present study aimed to recognize participants' experiences and perceptions of the research group work (e.g., research procedures, health information provided, and other efforts to strengthen the community) following three Community Networking (CN) meetings among Mexican families affected by ADAD. Using thematic analysis of anonymous written responses, we identified and classified the messages participants took from the meetings, clarified remaining informational needs, explored recommendations for future community engagement activities, and better understood the ongoing needs of families living with ADAD.

Methods

Participants

We invited all participants from our database of Mexican families affected by or at risk for ADAD associated with *PSEN1*A431E and *APP*V717I variants to the periodic CN meetings. We held three CN meetings in Jalisco in December 2024, each representing a distinct family group at risk for a specific variant, and they took place within communities with diverse geographic and socioeconomic contexts, including rural and urban settings, distinct predominant economic activities, and varying access to healthcare (Table 1). Site 1 corresponds to the institution where the research team is based, and its meeting brought together attendees from nine municipalities. In contrast, Sites 2 and 3 each correspond to a single municipality, and our team traveled to each community to hold the CN meeting.

Table 1
Sociodemographic and community characteristics of the study sites

Characteristic	**Site 1** **(n = 33)**	**Site 2** **(n = 36)**	**Site 3** **(n = 22)**
Population setting	Urban	Rural	Urban
Familial ADAD-associated variant	*PSEN1*$_{A431E}$	*APP*V_{717I}	*PSEN1*$_{A431E}$
Main economic activities	Retail trade in groceries, service provision, and manufacturing[26,27].	Grocery retail, food and beverage preparation, garment manufacturing, agriculture, and livestock farming[27,28].	Grocery wholesale, food industry, and wholesale of agricultural and forestry raw materials, and dairy farming[29].
First CN meeting with the family group	2017	2015	2024

Rural = fewer than 2,500 inhabitants; urban = 2,500 inhabitants or more[30]; ADAD = autosomal dominant Alzheimer's disease; CN = community networking.

A total of 91 participants attended one of the three meetings, including family members living with symptomatic ADAD, presymptomatic carriers, non-carriers, spouses, and other family members involved in caregiving or family support.

Data Collection

Since 2015, our research group has held meetings with families from Jalisco about ADAD associated with the *PSEN1*A431E and *APP*V717I variants. We initially developed these meetings to provide participating families with research updates and information about ADAD. In 2024, however, we adopted a more participatory structure to enable bidirectional communication between families and the research group.

At each meeting, we presented updates on our advances in ADAD research in Jalisco, along with brief updates on ongoing AD studies worldwide. We encouraged participants to ask questions throughout the sessions and to share concerns and needs related to ADAD. To promote interaction among participants, the meetings also included participatory activities, including guided small-group discussions,

followed by a collective plenary session. The meetings concluded with an informal social gathering that facilitated further interaction among members of the same family, across families, and between families and researchers.

At the end of the meeting, we invited family members to complete a questionnaire with four open-ended questions to explore participants' experiences, perceptions, and needs. The questionnaire was administered in Spanish. The questions asked were: (Q1) What message do you take away with you from this meeting? [¿Qué mensaje te llevas?], (Q2) What was unclear about the research presentation [¿Qué cosas no quedaron claras con la presentación de resultados?], (Q3) What recommendations would you make for future meetings [¿Qué recomendaciones harías para la próxima reunión?], and (Q4) What needs do you and your family have regarding Alzheimer's disease [¿Qué necesidades tienen tú y tu familia con relación al Alzheimer?].

Each participant received a questionnaire and was informed that responses would remain anonymous. Participants completed the forms by hand, folded them, and placed them in a designated collection box. We then scanned the completed questionnaires, organized them by site, and entered them into a database for qualitative analysis. The complete set of original responses is provided in Supplementary Table 1.

Qualitative Analysis

We analyzed responses using thematic analysis[31]. Three members of the research group (S.C.A.G., I.E.M.R., and A.Z.R.) independently reviewed all written responses to become familiar with the data. During the initial analysis, the researchers identified frequently occurring words, expressions, and concepts in participants' responses. These recurring elements then guided the development of preliminary descriptive categories that captured the data's main ideas.

We compared the independently generated descriptive categories, discussed and resolved discrepancies through iterative review and consensus. We then consolidated conceptually similar categories into four themes: Research Group Efforts, Health Information, Caregiving, and Psychosocial Support. We classified responses as substantive if they aligned with a thematic category. We used two additional, non-thematic categories to classify responses that did not align with these themes. We categorized responses indicating that participants had no needs to report as "No Needs Reported," and unanswered questions as "Non-Response." Because responses could include multiple themes, category frequencies and percentages are not mutually exclusive (Table 2).

Table 2
Thematic categories emerged across the questionnaire

Category	Description	Questions where the category emerged
Research Group Efforts	Perceptions of the meetings, research updates, recommendations for future meetings, and interaction with the research group	Q1–Q4
Health Information	Information needs regarding ADAD, genetics, prevention, treatment, scientific advances, and education	Q1–Q4
Caregiving	Practical caregiving strategies, support services, home care, institutional resources, and material needs	Q1, Q3, Q4
Psychosocial Support	Hope, emotional support, peer interaction, support groups, psychological services, and community building	Q1–Q4
Q1 = What message do you take away with you from this meeting? Q2 = What was unclear about the research presentation? Q3 = What recommendations would you make for future meetings? Q4 = What needs do you and your family have regarding Alzheimer's disease?		

Because participants could express more than one idea in a single written response, individual responses could be assigned to receive multiple categories and therefore contribute to more than one category. Consequently, category frequencies represent theme occurrence rather than mutually exclusive participant responses, and percentages do not necessarily sum to 100%.

For each site and question, we calculated category frequencies to describe the relative prominence of participants' concerns, experiences, recommendations, and needs. We used these site-specific frequencies to identify recurring themes across groups and selected representative quotations to illustrate the categories while preserving participant anonymity. Bilingual members of the research group translated participants' responses from Spanish to English, using DeepL[32] as a supplementary tool. They reviewed all translations to ensure accuracy and fidelity to the original responses.

Ethical Considerations

We conducted all procedures as part of ongoing community engagement activities. Participation was voluntary and anonymous, and we did not collect identifying information. All procedures followed ethical standards for research involving human participants. Given the sensitive nature of working with individuals at genetic risk of ADAD, we ensured confidentiality and handled data with strict privacy considerations.

We recruited adult participants through the ongoing research project Phenotype and Genotype of Autosomal Dominant Alzheimer's Disease in Jalisco, Mexico, which has been conducted since 2021 at the Laboratorio de Neuropsicología y Neurolingüística, Instituto de Neurociencias, Universidad de Guadalajara. The Ethics Committee of the Instituto de Neurociencias approved the research project (approval no. ET082020-301). Participants provided written informed consent to participate in this research project. However, because this questionnaire was anonymous and we collected no identifying information, we could not determine which participants took part in the activity or link their responses to individual records in the research project.

Results

A total of 91 participants attended the three community meetings: 33 at Site 1, which was associated with families carrying the *PSEN1*A431E variant (60.6% were women); 36 participants attended Site 2 related to the *APP*V717I variant (61.1% were women); and 22 participants attended Site 3 related to the *PSEN1*A431E variant (50.0% were women). Overall, 58.2% of participants were women and 41.8% were men. Participation in the meetings and responses to the anonymous evaluation questionnaire were voluntary, and we applied no exclusion criteria beyond attendance. Because participation was anonymous, we did not collect additional sociodemographic data such as age or educational attainment; however, all questionnaire participants were adults.

Response Frequencies by Site

Of the overall 91 participants who attended one of the three meetings, 73 returned the anonymous questionnaire. At Site 1 (n = 33), 28 participants returned the questionnaires (84.8% of attendees); at Site 2 (n = 36), we collected 24 questionnaires (66.7%); and at Site 3 (n = 22), 21 participants returned the questionnaire (95.5%).

Response frequency varied across items because participants could choose whether to respond to each question. Seventy participants provided substantive responses to Q1, fifty-six to Q2, fifty-nine to Q3, and fifty-four to Q4. Frequencies of Non-Response and No Needs Reported varied across questions, as shown in Table 3.

Table 3

Frequency of response categories by question

Question		Attendees	Returned forms	Substantive responses	Thematic Categories				Non-Thematic Categories	
					Research Group Efforts	Health Information	Caregiving	Psychosocial Support	No Needs Reported	Non-Response
		n	n	F (%)	F (%)	F (%)	F (%)	F (%)	F (%)	F (%)
Q1	Site 1	33	28	27 (96.4)	3 (11.1)	18 (66.7)	2 (7.4)	4 (14.8)	0 (0.0)	1 (3.6)
	Site 2	36	24	24 (100.0)	10 (41.7)	6 (25.0)	2 (8.3)	6 (25.0)	0 (0.0)	0 (0.0)
	Site 3	22	21	19 (90.5)	3 (15.8)	7 (36.8)	3 (15.8)	6 (31.6)	0 (0.0)	2 (9.5)
	Total	91	73	70 (95.9)	16 (22.9)	31 (44.3)	7 (10.0)	16 (22.9)	0 (0.0)	3 (4.1)
Q2	Site 1	33	28	23 (82.1)	13 (56.5)	8 (34.8)	0 (0.0)	2 (8.7)	0 (0.0)	5 (17.9)
	Site 2	36	24	21 (87.5)	15 (71.4)	6 (28.6)	0 (0.0)	0 (0.0)	0 (0.0)	3 (12.5)
	Site 3	22	21	12 (57.1)	6 (50.0)	5 (41.7)	0 (0.0)	2 (16.7)	0 (0.0)	9 (42.9)
	Total	91	73	56 (76.7)	34 (60.7)	19 (33.9)	0 (0.0)	4 (7.1)	0 (0.0)	17 (23.3)
Q3	Site 1	33	28	25 (89.3)	18 (72.0)	7 (28.0)	1 (4.0)	2 (8.0)	0 (0.0)	3 (10.7)
	Site 2	36	24	21 (87.5)	15 (71.4)	5 (23.8)	0 (0.0)	2 (9.5)	0 (0.0)	3 (12.5)
	Site 3	22	21	13 (61.9)	7 (53.8)	5 (38.5)	1 (7.7)	0 (0.0)	0 (0.0)	8 (38.1)
	Total	91	73	59 (80.8)	40 (67.8)	17 (28.8)	2 (3.4)	4 (6.8)	0 (0.0)	14 (19.2)
Q4	Site 1	33	28	24 (85.7)	5 (20.8)	9 (37.5)	11 (45.8)	4 (16.7)	0 (0.0)	4 (14.3)
	Site 2	36	24	16 (66.7)	3 (18.8)	5 (31.2)	5 (31.2)	3 (18.8)	1 (6.2)	8 (33.3)
	Site 3	22	21	14 (66.7)	1 (7.1)	6 (42.9)	6 (42.9)	2 (14.3)	1 (7.1)	7 (33.3)
	Total	91	73	54 (74.0)	9 (16.7)	20 (37.0)	22 (40.7)	9 (16.7)	2 (3.7)	19 (26.0)

Q1 = What message do you take away with you from this meeting? Q2 = What was unclear about the research presentation? Q3 = What recommendations would you make for future meetings? Q4 = What needs do you and your family have regarding Alzheimer's disease? F = frequency. Response percentages (%) are calculated relative to the number of questionnaires returned at that site (28, 24, and 21 for Sites 1–3, respectively; 73 overall); category and No Needs Reported percentages are calculated relative to the number of substantive responses; Non-Response % is calculated relative to the number of questionnaires returned.

Category Frequencies by Site

Table 3 presents the category frequencies by site and question; below, we report the most frequent category for each question at each site.

Site 1. Health Information was the most frequent category in Q1 (18/27, 66.7%), and Research Group Efforts was the most frequent in Q2 (13/23, 56.5%) and Q3 (18/25, 72.0%). In Q4, Caregiving was the most frequent category (11/24, 45.8%), followed by Health Information (9/24, 37.5%).

Site 2. Research Group Efforts was the most frequent category in Q1 (10/24, 41.7%), Q2 (15/21, 71.4%), and Q3 (15/21, 71.4%). In Q4, Health Information and Caregiving were equally frequent (5/16, 31.3% each).

Site 3. Health Information was the most frequent category in Q1 (7/19, 36.8%), followed by Psychosocial Support (6/19, 31.6%), and Research Group Efforts was the most frequent in Q2 (6/12, 50.0%) and Q3 (7/13, 53.8%). The most frequent categories in Q1–Q3 matched those of Site 1. In Q4, Health Information and Caregiving were equally frequent (6/14, 42.9% each).

Representative Quotes by Question

What messages will you take away from this meeting? (Q1). The most prominent, consistent theme across all sites was Health Information (44.3%; Table 3), reflecting the importance of staying informed about ADAD. For some, this meant learning new information about the disease or receiving updates. As one participant from Site 2 said, "It is very important to learn about Alzheimer's disease, including symptoms, care, nutrition, etc., so that we can actively contribute to the well-being of any family member." Participants described the meeting as a valuable reminder to keep learning about ADAD and stay up to date with scientific developments. As one participant from Site 1 explained, "It is extremely important to have the necessary knowledge about this disease so that we can manage possible situations when they arise."

Learning about ongoing research also motivated participants to maintain connections with physicians and investigators and to continue supporting research efforts. As one participant from Site 2 stated, "We need to continue working together with all the doctors and move forward with the research." Others expressed a desire to remain engaged with future family meetings, noting that continued participation would help them gain a deeper understanding of the disease over time. As one participant stated, "I will continue participating to gain more knowledge about the disease in the future."

A second theme, reflected in the Psychosocial Support category (23% of responses; categories: Coexistence and Support groups, n = 8 each; Table 3), was solidarity and support. Participants valued the opportunity to connect with others facing similar challenges and emphasized the importance of community. For some, the meeting reinforced the idea that families affected by ADAD are not alone in their experiences. A participant from Site 1 wrote, "There are so many people living with this disease and seeing the courage and effort we put into managing this mutation."

A third, cross-cutting theme in the project evaluation's written comments was hope. More than half of the participants described the meeting as providing a positive, optimistic message (a subset of responses in the Health Information and Psychosocial Support category). For many, this stemmed from learning about ongoing scientific efforts to better understand and treat ADAD, as well as encouragement from the dedication of researchers and healthcare professionals. These factors raised expectations that a cure is possible. One person from Site 1 explained: "I see a great deal of interest in supporting us and helping us learn about the disease." Another realized that "Efforts are underway to help people with Alzheimer's, with the hope and goal of improving the lives of those who have the disease."

Several participants emphasized that the meetings reinforced the message that families affected by ADAD are not forgotten and that their experiences and needs matter. The research group's time to share information with family members made families feel the team truly cared. One participant from Site 3 said they felt supported because, "I see a lot of interest in supporting us and learning about the disease." For many participants, the meeting also reminded them to appreciate the present and make the most of each day despite the disease's uncertainties. For example, one participant said the meeting reminded them of "The importance of living and enjoying every moment, and the importance of building community."

What was unclear about the research presentation? (Q2). Participants generally found the meeting information clear, though some identified specific areas where they wanted more information. At Site 1, a participant reported that "Everything was clear, an excellent presentation." At Site 2, a participant similarly stated, "Everything was clear; it was explained very well." However, we identified some specific areas where they wanted more information. Among the responses requesting additional information, participants asked about the disease, its symptoms, and treatment. At Site 1, one participant replied, "That there is no cure yet and why it can develop at a young age." At Site 2, another participant replied, "How do the first symptoms of the disease present themselves?" At Site 3, a participant specifically asked, "How much does the treatment cost?" These responses show that, despite generally positive evaluations of the meeting, participants still had important and specific questions about disease progression and treatment.

What recommendations would you make for future meetings? (Q3). Consistent with Research Group Efforts being the most frequently cited category (68%; Table 3), the most frequent recommendations concerned requests for more participatory activities (category: Participatory activities, 18%; Table 3) and continued satisfaction with the meeting format (Satisfaction with the Meeting, 17%). In addition, many participants desired more interactions among families and between families and the research group. They responded well to the more participatory nature of the meetings and requested more time for testimonials and sharing experiences, which they saw as valuable parts of the workshop. They felt that they could benefit by learning from other families' experiences. For example, one person from Site 2 requested: "Exchange ideas and continue learning from others." They also suggested that, if possible, people in the early stages of the disease speak for

themselves. For example, one person from Site 1 said, “Try to give people with the disease an opportunity to speak when they can do so.” They also requested that more affected families be invited to the meetings and that the meeting size be increased.

Additional responses from other sites similarly emphasized participation and continued engagement. At Site 3, for example, one participant suggested, “Let’s get more people together.”

Health Information was the second most frequently cited category (29%), reflecting inquiries about new advances in AD research and treatment, how to delay symptom onset, the symptoms and etiology of ADAD, and treatment options. Participants also sought more information on caring for loved ones at home. One participant from Site 1 said, “more information about the medical care necessary for the patient at home.”

Moreover, what needs do you and your family have regarding Alzheimer’s disease? (Q4). Participants described needs related to Caregiving, Health Information about ADAD, and Psychosocial Support. At Site 2, caregiving responses emphasized the need for practical information and preparation, including “Continue to keep us informed and help us prepare to continue caring for our loved ones” and “How can we care for my sick family member?” At Site 3, participants similarly requested practical guidance, including “To know how to care for them.” One participant from Site 3 also identified the need for specific caregiving resources, stating, “Special beds, air mattresses.”

Health Information was also recurrent in Q4. At Site 1, participants requested “Information about any medication or vitamin that might help” and “Just the knowledge to be able to cope with the disease.” At Site 2, one participant requested, “More information about some kind of treatment or medication.” At Site 3, participants similarly asked for more information, including “To learn more about the disease.”

Psychosocial support also appeared in responses from Sites 2 and 3. At Site 2, one participant requested, “Psychological support for caregivers and close family members of those in the most advanced stages of the disease.” At Site 3, another participant emphasized family support, stating, “Mutual support among families.” These responses illustrate that participants' needs extended beyond information and caregiving skills to include emotional and interpersonal support for families living with ADAD.

Discussion

The written responses to the research project evaluation questionnaires from direct and in-law family members of people with ADAD provided valuable insight into their perspectives and needs. They can guide how we shape the content, format, and focus of our future engagement activities with these families. Participants reported high satisfaction with the CN meetings, noting that they increased their understanding of the disease, received caregiving counseling, felt reassured about ongoing research efforts, and felt hopeful.

Overall, category frequencies showed a recurring emphasis on Health Information and Research Group Efforts in the responses about the meeting (Q1–Q3). At the same time, Caregiving became particularly prominent when participants described their families’ needs (Q4), although the balance differed by site.

Regarding response frequency by site, participants at Site 1 emphasized the importance of accurate, understandable information from trusted sources. Participants most often reported taking home health-related information from the meeting (66.7% of Q1 responses; Table 3). This lack of health information about ADAD is reflected in reports on families affected by the disease[15,18]. For Q4, participants placed the strongest requests in the Caregiving category (45.8%; Table 3), consistent with the burden of assisting relatives through progressive motor, cognitive, and functional decline[33], and, at this site, related to ADAD due to *PSEN1*A431E.

At Site 2, our only *APP*V717I group and the one we have worked with the longest, we observed a different trend: for Q2 and Q3, Research Group Efforts was the most frequent category at all three Sites, but it was more prominent at Site 2 than at the other two Sites when participants described the messages they took home (Q1; 41.7% vs. 11.1% and 15.8%) and what was unclear in the presentation (Q2; 71.4% vs. 56.5% and 50.0%; Table 3). This suggests that participants there placed greater weight on the research group's presentation and activities. Years of contact with our group may have given these participants a basis in past CN meetings for evaluating our current activities and format. Their family needs were evenly distributed between Caregiving and Health Information (31.3% each).

At Site 3, where the 2024 meeting was our first, participants' take-home messages (Q1) were most evenly distributed across the four categories. Yet family needs converged with Site 1 in prioritizing Caregiving (42.9%, equal to Health Information; Table 3), suggesting that motor and functional care demands weigh heavily on daily life for both *PSEN1*A431E family groups, in whom symptom onset is anticipated around age 42.5 ± 3.9 years[34], characterized by a greater prevalence of early motor symptoms and spastic paraparesis compared with individuals carrying *APP* mutations[10,35,36].

Regarding response frequency per question, Health Information was the most frequent category for Q1 (44.3%; Table 3). Participants said they needed to stay informed and keep pace with scientific developments and ongoing clinical research. Such information may be especially

meaningful in ADAD and other causes of early-onset AD, where families report living with the uncertainty of elevated genetic risk and may follow research developments closely in hopes of future prevention or treatment options[9]. As several participants said, staying informed about the latest advancements inspired them to continue participating in research studies.

Many participants also identified, as a key takeaway from Q1, the importance of connecting with other families with similar experiences, highlighting peer support's role in reducing feelings of isolation. Caregiving for AD can be an isolating experience, particularly for families affected by rare inherited forms of dementia who continuously interact with other relatives living with similar circumstances[37,38]. Creating spaces where caregivers can share experiences, exchange practical advice, and build supportive relationships may improve emotional well-being and strengthen community[39]. This may be especially valuable for Latino families, particularly if they migrated to other countries. Studies show that immigrants face unique experiences and needs, including language barriers, limited access to culturally appropriate resources, stigma surrounding dementia, and concerns about genetic risk across multiple generations[16,40]. Furthermore, the strong emphasis on family interconnectedness in many Latino communities means the impact of ADAD often extends beyond the individual caregiver to affect entire family networks[16]. Workshops that foster social connection and culturally responsive engagement may therefore play an important role in addressing these needs and in building trust and community among affected families[41].

Finally, in response to Q1, participants frequently identified CN meetings as a source of hope. They attributed this hope to learning about ongoing scientific progress and to observing the commitment of other families globally, as well as researchers and clinicians in the field. Hope supports family resilience during periods of chronic stress and uncertainty[38]. Direct engagement with research groups and exposure to emerging discoveries may further enhance this sense of hope and build trust among researchers, healthcare providers, and affected communities[5]. These factors are likely to influence affected families' future participation in AD research.

For Q2, participants generally found the presentation clear, though some specific questions remained. Participants' most common questions included why the disease can appear at a young age, how the first symptoms present, why there is no cure, and treatment costs. Educational programs that translate complex scientific information into accessible language may help reduce this uncertainty, promote acceptance and coping, and strengthen caregivers' confidence in navigating care decisions[21].

In Q3, Research Group Efforts was the most frequent category (67.8%; Table 3). Participants’ recommendations emphasized more participatory activities, including more time for testimonials and experience-sharing, greater interaction among families and between families and the research group, and opportunities to learn from other families. They also asked that people in the early stages of the disease be allowed to speak for themselves and that we invite more affected families to the meetings. The request for more participatory activities aligns with community-engagement approaches that emphasize bidirectional communication, reciprocal learning, and opportunities for participants to contribute to research-related activities[1,23]. It also suggests that participants valued direct interaction with the research group more than receiving information solely through formal presentations. This result also points to the importance of sustained engagement between the research group and participant communities: families who contribute to research often want not only to advance scientific knowledge for future generations, but also to understand how findings may ultimately benefit their own communities[2,3]. This aligns with evidence that trust in the research team predicts willingness to participate in AD research[24]. Health Information was the second most frequent category (28.8%) in Q3 responses, with requests for information on research advances, ways to delay symptom onset, treatment options, and home care for loved ones. Accessible updates on research progress and opportunities for meaningful dialogue may strengthen trust, promote continued participation, and keep research responsive to affected families’ priorities[5].

In Q4, when participants described their families’ needs, they cited Caregiving, Health Information, and Psychosocial Support. Their requests ranged from practical guidance and equipment to treatment information and emotional support. Caregivers are essential throughout ADAD, often serving as advocates, care coordinators, decision-makers, and providers of daily support[19]. The demands associated with caregiving have been linked to elevated rates of stress, depression, anxiety, social isolation, financial strain, and physical health problems[16,41,42]. These findings also underscore the importance of recognizing caregivers' physical and emotional needs, including opportunities for self-care and respite, which family contexts that strongly emphasize caregiving responsibilities may not readily identify or prioritize. In this sense, research has widely recognized the importance of the psychological toll of the caregiving burden for people with dementia[18]. In ADAD, disease onset often occurs during prime working and family-rearing years, creating unique disruptions to employment, finances, parenting responsibilities, and long-term life planning[18,43]. Caregivers are often "co-survivors" of this hereditary condition, managing not only caregiving responsibilities but also their own concerns about genetic risk. This, in turn, underscores the need to expand access to genetic testing and counseling[15,44,45], a health service that remains scarce in Latin America, though initiatives are underway to implement safe, standardized protocols[46]. Such initiatives must address the ambivalence many at-risk family members feel toward pre-symptomatic screening, which surveys in other populations show can coexist with strong interest in research participation[47]. Our study therefore identifies a clear need for additional

psychosocial support, including caregiver psychological support, genetic counseling, and mutual support among families, to help family members navigate these challenges.

These study findings have important implications for both clinical practice and research. Caregiver support and informational counseling should be an essential component of comprehensive AD care, not a supplementary service[19,48]. Educational workshops, support groups, community engagement activities, and opportunities for direct interaction with healthcare providers and researchers may help address caregivers' informational and emotional needs[16,39,41]. For families affected by early-onset and inherited forms of AD, interventions should be tailored to acknowledge their unique concerns. Digital and online interventions may further extend the reach of such support, particularly for caregivers with limited access to in-person services[49]. Together, these site-level responses suggest that although the broad categories of needs were shared across the three communities, each family group's genetic variant, community setting, history with our research group, and daily caregiving context may have shaped the relative weight of these needs, underscoring the value of tailoring future community engagement activities to each site's specific circumstances.

Several limitations warrant consideration. Participants who attended the CN meetings may have been more engaged, motivated, or connected to research activities than family members who did not actively participate in the clinical protocols, which could affect the nature and quality of their responses. Across the three sites, the response frequencies showed that participants engaged most consistently with Q1 (95.9%) and least consistently with Q4 (74%). Non-Response was also lowest for Q1 (4.1%) and highest for Q4 (26.0%; Table 3). Our data cannot show whether this pattern reflects fatigue as participants moved through the questionnaire, a particular interest in sharing the messages they took home, or a different meaning of a blank response, since for Q2 an empty response may signal that nothing was unclear, or for Q4 a subjective absence of needs related to ADAD. Q4 may also have been harder to respond to because it asked participants to put their families' needs into words.

Engagement also varied by site, which may reflect our research group's history and trajectory of contact with each Site: we have met with Site 2 since 2015 and with Site 1 since 2017, whereas Site 3 attended its first meeting in 2024. In addition, because responses to this questionnaire were anonymous, we did not collect sociodemographic data or participants' roles within the family (e.g., caregiver, at-risk relative, or spouse). As a result, we could not examine whether needs and perceptions differed by these characteristics. Because participants could express multiple ideas within a single response, category frequencies reflect how often themes were mentioned rather than the proportion of participants endorsing them. Finally, the Sites differed in the ADAD genetic variant, community setting, and duration of contact with our group, so we cannot disentangle the influence of these factors, and our cross-site comparisons remain descriptive.

In conclusion, this study shows that families affected by ADAD valued educational and community-based engagement activities. Beyond increasing knowledge, such programs foster hope, strengthen social connections, and build trust in healthcare and research systems, potentially facilitating sustained participation in AD research protocols. As the prevalence of AD continues to increase globally, greater investment in the dissemination of clear informational resources and caregiver support initiatives, particularly those tailored to the unique challenges of early-onset and inherited forms of dementia, will be essential to improving the well-being of both caregivers and people with ADAD.

Declarations

Data availability

The data supporting this study's findings are available from the corresponding author upon justified request, subject to ethical and privacy restrictions due to the population's sensitive nature.

Code availability

This study did not involve developing custom code or software.

Competing Interests

The authors declare no competing interests.

Author Contribution

S.C.A.G., A.Z.R., and I.E.M.R. conceived and designed the study, developed the study materials, conducted the qualitative analysis, interpreted the findings, and drafted the initial manuscript. S.C.A.G. and A.Z.R. supervised the entire process to reach the final version.M.W. provided

scientific guidance, interpreted the findings, organized and presented the results, developed the discussion and conclusions, and provided important intellectual input and critical feedback on the manuscript.F.R.L., I.E.B.O., A.K.P.B., A.G.B., L.B., C.A., L.M.D. critically revised the manuscript and provided important intellectual input.J.M.R. provided scientific guidance, edited, and critically reviewed the manuscript.E.M. conceived and directed the study, provided scientific guidance, interpreted the findings, critically reviewed the manuscript, and had final responsibility for the decision to submit the manuscript for publication.All authors reviewed and approved the final version of the manuscript.

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