Patient and Caregiver Experiences of Novel Anti-Amyloid Therapies for Alzheimer's disease in Rhode Island

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Introduction

Dementia is a syndrome characterized by progressive cognitive decline, ultimately interfering with an individual's behavior, cognition, and ability to perform activities of daily living.[1-2] While a number of diseases and injuries can cause dementia, Alzheimer's disease (AD) is the most common and extensively studied cause. Its pathological features include neuronal atrophy, synaptic loss, abnormal accumulation of amyloid-β protein plaques, and tau protein tangles. Together, these neuropathological changes can lead to memory loss and a range of cognitive deficits that impair independent functioning.[3]

As of 2024, there are approximately 7.2 million Americans aged 65 and older living with Alzheimer's dementia, and without any major therapeutic developments, this number is projected to rise to 13 million by 2050.[4] As the population continues to age, the societal and economic burden of Alzheimer's disease and related dementias (ADRDs) has become increasingly evident not only in rising healthcare costs, but also in the emotional, financial, and physical demands that unpaid caregivers face.[5]

In response to the public health crisis posed by AD and the absence of a cure, researchers have increasingly focused on developing disease-modifying therapies (DMTs) aimed at slowing disease progression. Among these treatments, anti-amyloid therapies (AATs) have emerged as promising therapeutic agents. These novel infusion therapies act by targeting and reducing β-amyloid plaques, one of the key pathological features of AD.[6,7] In order to be eligible for AATs, patients must be diagnosed with either Mild Cognitive Impairment (MCI) due to AD or mild AD dementia, and have PET scan confirmation of β-amyloid plaques.[8] Following clinical trial evidence demonstrating significant plaque reduction, the FDA granted approval to three AATs: Aducanumab (Aduhelm) in June 2021, Lecanemab (Leqembi) in July 2023, and

Donanemab (Kisunla) in July 2024.[9–11] However, it remains unclear whether this reduction translates to significant improvements in cognition or daily functioning.[12]

While AATs represent an important advancement in AD treatment, their use presents a number of clinical, financial, and logistical challenges for both patients and caregivers. One of the most serious clinical risks associated with these treatments is amyloid-related imaging abnormalities (ARIA). ARIA is characterized by brain swelling or microscopic bleeds, and requires routine MRI monitoring throughout treatment. Although some ARIA are asymptomatic, others can present with headache, confusion, dizziness, nausea, seizures, and, in rare cases, death.[13-14] Patients may be at increased risk for ARIA based on their apolipoprotein E (APOE) ε4 allele carrier status. The APOE gene is a confirmed risk factor for AD with three major alleles: ε2, ε3, and ε4. Individuals with two copies of the ε4 allele have a significantly increased risk of developing AD and experiencing ARIA compared to other genotypes.[14–16]

The cost of treatment also plays a major role in shaping the treatment experience, as the annual cost of these therapies ranges from $26,000 to $56,000. In April 2022, the Centers for Medicare and Medicaid Services (CMS) issued a National Coverage Determination (NCD), approving coverage of FDA approved AATs under Coverage with Evidence Development (CED). Under this CED, Medicare Part B covers AATs for beneficiaries with a confirmed diagnosis of MCI due to AD or mild AD dementia, confirmed amyloid plaque pathology, and enrollment in a CMS-approved registry or study.[17] However, Medicare beneficiaries remain responsible for a 20% copayment, leading to significant out-of-pocket costs for many patients.[18,19]

Because AATs are novel treatments with limited research exploring how patients and caregivers experience them in practice, studies on infusion-based treatments for other chronic

conditions, including multiple sclerosis, kidney failure, and cancer, provide insight into the logistical and social challenges participants may face. For example, caregivers of individuals undergoing chemotherapy often report burnout due to emotional exhaustion, financial stress, and a lack of support, resulting in significant disruptions in their daily lives.[20] Similarly, patients undergoing chemotherapy report difficulty navigating treatment-related logistical burdens including scheduling and attending appointments, managing medication, and navigating the health care system.[21] Studies involving patients receiving hemodialysis treatment show similar results, highlighting the isolating and time consuming nature of caregiving which can strain relationships and reduce opportunities for social engagement.[22] The treatment schedules for AATs, including monthly infusions for Aducanumab and Donanemab, and biweekly infusions for Lecanemab, may present similar challenges that are further compounded by transportation barriers, parking costs, and conflicts with work schedules. Given this insight, the demands of treatment can contribute to caregiver burden and negatively impact patients' health and adherence to treatment.[6]

Rhode Island is an important setting for examining how patients and caregivers experience AATs, as access to these therapies is largely shaped by the state's health equity landscape. Approximately 13% of Rhode Island adults aged 65 and older are living with ADRD, with the highest prevalence of cases in Central Falls, Pawtucket, and Providence.[23] These same cities also experience the highest rates of poverty and largest proportions of residents without a high school diploma.[24,25] While the need for treatment may be the greatest in these communities, socioeconomic disparities can significantly hinder access to AATs. Barriers such as transportation, difficulty navigating insurance, and the logistical demands of ongoing clinical

treatment and monitoring may disproportionately affect these populations and shape their treatment experiences.

While AATs are clinically promising in AD treatment, clinical risks, financial burden, and logistical demands make them complex to navigate. Although studies have explored their clinical outcomes, there is a critical gap in understanding how patients and caregivers experience this treatment in practice. Therefore, this study aims to explore the experiences of patients and caregivers in Rhode Island receiving AATs.

Methods

Study Sample

This analysis is a part of a larger ongoing study that seeks to further understand decision-making for AATs, with a goal of developing a decision-aid for participants considering treatment. This thesis focuses on the overall experiences of people who agreed to treatment, but the larger study will include people who declined treatment as well.

Participants for this study were recruited in collaboration with Butler Hospital's Memory and Aging Program (MAP), a part of the Care New England Health System. MAP is a specialty research program that focuses on the detection and treatment of AD through clinical care, training, and research. Following FDA approval of AATs, MAP began offering these treatments at its clinic. Potential participants were identified through the MAP clinical database in coordination with Dr. Athene Lee, a neuropsychologist at MAP, and the clinic manager. MAP nurses first obtained permission to contact from patients or caregivers before sharing contact information with the Brown University research team. Eligible participants in this study included patients diagnosed with MCI due to AD or mild AD dementia who were currently receiving, had recently completed, or had recently discontinued anti-amyloid therapy, as well as their caregivers.

All participants were required to be able to provide informed consent and complete an interview. Capacity to consent was assessed by a member of the Brown University research team during eligibility screening and before the start of the interview. Capacity was evaluated using a modified tool from a previous study to assess the patient's ability to make a reasoned and consistent choice to participate in the study. The assessment evaluated participants' ability to understand the purpose and procedures of the study, acknowledge its risks and benefits,

comprehend the confidentiality and the voluntary nature of participation, identify appropriate study contacts, and communicate a reasoned and consistent choice about participation. For patients with a dementia diagnosis who lacked the ability to consent, consent was completed together with their legally authorized representative (LAR). Participants received a $100 Amazon gift card for their participation in this research study. This study was approved by the Butler Hospital Institutional Review Board (IRB) in July of 2025.

Data Collection and Analysis

Data was collected through semi-structured qualitative interviews conducted by trained members of the research team. Four separate interview guides were developed for patients and caregivers: 1) patient currently receiving treatment, 2) caregiver of patient currently receiving treatment, 3) patient who discontinued/completed treatment, and 4) caregiver of patient who discontinued/completed treatment. Interviews explored participants' experiences with AATs, including perceived risks and benefits, financial and logistical barriers, communication with healthcare providers, and reflections on the overall treatment process. The interview guides were initially developed based on a literature review, and were further modified following feedback from a qualitative methods expert, members of the Brown University research team, and Dr. Lee. After the guides were piloted with several participants, additional changes were made.

All interviews were audio-recorded using an encrypted password-protected audio recorder and uploaded to the Care New England server. Transcription was completed by members of the research team on a Care New England issued laptop, and all personally identifying information was redacted during transcription. De-identified transcripts were then analyzed using Braun & Clarke's six phase approach to thematic analysis to identify, analyze, and interpret meaningful themes and patterns across our interviews.[26] Deductive codes were

derived from the study's selected areas of interest and previous literature on infusion-based treatments, while inductive codes emerged from participant responses.

Members of the research team first reviewed transcripts independently to become familiar with the data, noting initial codes and developing a coding framework. Transcripts were then coded in Microsoft Excel. Differences in coding were discussed to clarify code definitions, refine the coding framework, and determine whether additional codes were needed. In order to enhance rigor across our analysis, interviews were coded by multiple members of the research team.

Codes with similar meanings were grouped into broader themes that captured patterns across patient and caregiver narratives. After these themes were reviewed for consistency and relevance across the dataset, they were further refined, defined, and named to reflect their meaning.

Results

Sample Characteristics

This study analyzes interviews from 10 participants, including five patients and five caregivers. The study sample included four patient-caregiver dyads, one patient whose caregiver declined participation, and one caregiver whose patient declined participation. All participants identified as White. Among patients, there were four women and one man, with a mean age of 71.4 years. Four of the five patients held at least a college degree and three of them were retired. There were three patients diagnosed with MCI due to AD and two patients diagnosed with mild AD dementia. Among caregivers, there were four men and one woman, with a mean age of 66.4 years. All caregivers held an associate's degree or higher, and four were retired. As far as treatment status, two dyads were actively receiving treatment, one dyad was on maintenance, one dyad had discontinued treatment, one patient was actively receiving treatment, and one caregiver's patient had discontinued treatment. Interviews were conducted either in person or by telephone, and ranged from 16 to 76 minutes in length.

Throughout the interviews, participants described the various aspects of how they experience AATs in practice and three main themes emerged: (1) Motivations for Pursuing Treatment, (2) Importance of Trust, Transparency, and Safety Monitoring During Treatment, and (3) Impact of Treatment on Daily Routines. Table 1 includes additional quotes to support each theme.

Theme 1: *Motivations for Pursuing Treatment*

Participants described understanding that AATs were not curative and were unlikely to dramatically improve cognition, yet they still described powerful motivations for pursuing treatment. Participants candidly spoke about how the reality of their cognitive decline, prognosis, and limited treatment options shaped their decision-making. When asked about the decision to pursue treatment, one patient explained, "*Some of the reasons are kind of morbid, but I mean the bottom line is I'm dying. So, I figured let's put it to use*" (Patient 3). She later continued, adding, *"What do I have to lose? And, you know [sighs] it's not really a sacrifice in any way, so it's pretty easy to make this decision [laughs]"* (Patient 3). A caregiver described a similar perspective as he reflected on how his wife weighed the risks of treatment. He recalled,

> *[Patient] said, 'Well, I'm going to die anyway, I mean I don't know what the risk is. I mean the risk is that my life is shorter than it will be, but I don't want it to be the full duration given what I know will happen in the end' (Caregiver 6).*

Patients were aware of the risks and limitations of treatment; however, they still found it valuable given their progressive decline and limited alternatives. Rather than minimizing the potential risks involved, patients weighed them against the inevitability of their decline and the belief that there was little to lose in trying treatment.

Other patients described treatment as an opportunity to take action against progressive decline rather than remaining passive. One patient framed the choice to pursue treatment as a decision between, *"not getting anything and knowing that your cognition is going to be destroyed, essentially, versus going to a place where, you know, you have some hope…there's no downside"* (Patient 4). For these patients, the value of treatment extended beyond its potential effectiveness, but also offered an opportunity to do something in response to their diagnosis.

While some patients were motivated by a nothing-to-lose mentality and desire to take action, caregivers described treatment as a source of hope, particularly in its potential to delay decline and preserve their loved one's current functioning for as long as possible. For some caregivers, previous experiences observing decline in family members and friends with AD shaped how they viewed the urgency and emotional significance of treatment. One caregiver explained,

> *We're aware that there's no cure, there's no reversing, all we can do is slow the progress. If [patient] were to stay just this way in the Mild Cognitive Impairment stage, you know, we could live with that. It's watching the way her sister and brother deteriorated, watching how my mother deteriorated, the way my neighbor and other people did, I hate to see that* (Caregiver 14).

Later, when asked about the most influential factors in their decision to pursue treatment, he reiterated this motivation more directly, explaining that, "*slowing the progress of the disease, even if it's just a few more months, it's worth it"* (Caregiver 14). Another caregiver shared a similar experience:

> *My father ended up with dementia in his late 70s early 80s, and we saw him over 5 years going through the whole process of decline, of not knowing who anyone was and being bedridden. So, seeing that, we had a good example of what the future was and so that was instrumental in pursuing this drug* (Caregiver 6).

Caregivers' motivations were shaped not only by hope that treatment would slow disease progression, but also by vivid memories of decline and a deep understanding of what a future of further deterioration could look like. Given their firsthand experiences witnessing decline, treatment served as more than a clinical intervention; it offered a chance to slow disease progression they had already witnessed in others. As one caregiver framed it when asked about the benefits of treatment, "*if nothing else, it certainly provides some hope"* (Caregiver 10).

Although patients and caregivers described distinct motivations for pursuing treatment, both perspectives suggest that the value of treatment extended beyond its expected clinical

benefits and was shaped by the unique realities of progressive decline for both patients and caregivers.

Theme 2: *Importance of Trust, Transparency, and Safety Monitoring During Treatment*

Participants described trust in the clinical team as an integral part of feeling safe and supported throughout treatment despite its risks. This trust developed progressively through honest communication in the decision-making process, routine monitoring throughout treatment, and clinical guidance when participants faced difficult treatment decisions.

The clinical team established a foundation of trust through honest, personalized conversations about treatment risks, potential side effects, and realistic expectations for treatment benefits. Rather than deterring participants from pursuing treatment, this transparency appeared to give them the confidence to move forward with a clear understanding of what treatment could entail. Participants recalled clinicians being direct about the demands of treatment and the potential for serious side effects. One patient explained, "*They did not give me any false, magical outcomes. They explained the toughness of it all, and that it's a serious thing you know?"* (Patient 7). A caregiver shared a similar perspective as he recalled being given a clear explanation of potential risks from the start:

> *Very clearly, we knew exactly what we were getting into. [Nurse practitioner] let us know that there were potential side effects: headaches, nausea, dizziness, brain swelling, brain bleeds and potential devastating effects of some of those more serious side effects. So, I mean she gave us a very clear picture* (Caregiver 14).

For some participants, this trust was built upon through personalized conversations about how treatment risks applied to their specific genetic background, particularly for those at increased risk for treatment-related complications due to their APOE ε4 homozygote status. One caregiver recalled how the clinical team explained the patient's heightened risk and how it might affect the effectiveness of treatment, explaining,

> *[Nurse practitioner] laid out all the facts and figures. They said you know a potential 27% improvement. And then she said, 'But you're not going to see 27% improvement because you've got the two markers and there hasn't been independent testing on that. If you were making me tell you, I might say…I don't know 17%...20% improvement'* (Caregiver 2).

These individualized discussions about how the patient's genetic risk could impact both treatment safety and effectiveness appeared to help participants make a more informed decision about treatment.

Participants also described the importance of frequent monitoring as a source of safety and comfort throughout treatment. For some participants, the MRI monitoring built into treatment helped reassure them that any potential treatment-related complications would be promptly identified and addressed. One patient reflected on how these priorities were translated into practice, explaining,

> *They told me the truth, that I could come and I would be carefully monitored and that was absolutely true, and I felt well taken care of…so they do a good job assuring you that they'll be there, and you'll be safe and you'll have resources right there* (Patient 9).

Throughout treatment, monitoring served as not only a clinical safety measure, but also as a way to reinforce participants' trust in the clinical team by showing them that risks were being taken seriously and closely monitored.

The importance of this ongoing clinical support became especially clear when one dyad faced the decision of whether to continue treatment without the same level of care. The caregiver detailed their decision not to continue treatment after the drug was no longer offered at the original site. Although another location could administer the drug, he explained that continuing treatment without *"medical backup, no one [he] could turn to,"* felt too risky (Caregiver 6). This perspective suggests that participants' sense of safety depended not only on monitoring, but also on continuous access to a knowledgeable and responsive clinical team in case of complications.

Trust in the clinical team also shaped decisions when treatment-related complications occurred. In one interview, a caregiver recalled asking the clinical team for their recommendation after they detected brain bleeds during a routine MRI. Although they could have continued treatment, the dyad ultimately decided to follow the team's recommendation to stop, explaining that *"[the clinical team's] recommendation pretty much was to not continue. So, again, we could have, we could have, but we didn't"* (Caregiver 8). This experience suggests that participants valued the clinical team's judgment not only throughout treatment, but also to determine when discontinuing treatment was the safest course of action.

Theme 3: *Impact of Treatment on Daily Routines*

Participants described AD itself as deeply disruptive to their everyday lives, explaining that the demands of progressive decline often altered their daily routines, future plans, and sense of normalcy. However, for some participants, this disruption was attributed less to treatment itself than to the diagnosis and its implications for their shared future. When asked how the decision to pursue treatment affected their future plans, one caregiver clarified,

> *Well, I wouldn't say this treatment, but the diagnosis. I was retiring at 60 and the idea was: 'Alright I'll keep going and if the career works out really well and we have plenty of money, then I'll retire at 60 and we can travel.' And that didn't happen* (Caregiver 2).

Rather than becoming another disruption amid the unpredictability of the disease, participants actively found ways to incorporate treatment into daily life by adapting routines and creating new forms of structure that helped establish a new normal.

For several participants, treatment became a predictable part of their routines through regularly scheduled infusion visits. As one patient explained, *"I'm retired from work and I'm a pretty laid back person, so that didn't cause any problem at all. It didn't get in the way of my life because I don't have one"* (Patient 7). In some cases, the clinical team helped reinforce the

routine and structure surrounding treatment by proactively scheduling treatments on the same day and time of the week. As one caregiver explained,

> *One of the nurses down there comes up and says, 'Hey, I took the liberty of booking you another six Tuesdays at 11:00. Does that continue to work?' and it's perfect. That way, it's just on [patient's] calendar forever. She's got to the point where the calendar is everything* (Caregiver 2).

At a time where dependable routines became especially important, this scheduling structure helped make treatment a predictable part of everyday life.

Participants also described adapting their schedules around infusions in ways that allowed them to continue prioritizing activities that remained important in their daily lives. In some cases, this meant reorganizing infusions around valued commitments rather than completely giving them up. One caregiver explained that the main scheduling challenge they faced involved scheduling around the patient's university classes:

> *The only thing that we have to juggle is her classes at [University], she cherished those. In fact, I have to reschedule next month's infusion because she's taking a class at the time she's scheduled for the next infusion* (Caregiver 14).

While participants prioritized treatment, they also remained intentional about ensuring that it did not displace the activities and routines that were important to their sense of identity and normalcy.

For some dyads, adapting to treatment also meant finding creative ways to make infusion visits feel more positive despite the reality of the situation they were facing. One caregiver described intentionally turning trips for treatment into an enjoyable experience for him and his wife by staying at nice hotels and trying new restaurants, explaining that they tried to make it "*like a little mini vacation before coming up to [Hospital] and facing the reality of the situation"* (Caregiver 6). Participants were not only creating structure and routine around treatment, but

also shaping those routines in ways that helped them cope with the emotional weight of living with and managing the disease.

One patient explained incorporating treatment into her daily life by maintaining independence. She explained that she preferred attending appointments alone because, "*I'm like a big girl, I can do this. Until I can't. If I can't then I'll get somebody to bring me…I just kind of wanted to do it myself"* (Patient 9). For this participant, treatment offered a way to preserve her agency and independence for as long as possible, even while navigating progressive decline.

Rather than simply restructuring daily life around treatment, participants actively incorporated it into a new normal in ways that allowed them to create structure, support emotional coping, and maintain independence amid a progressive illness.

Table 1: *Additional quotes to support themes*

Thematic Findings	Quotes
Theme 1: Motivations for Pursuing Treatment	
Participants valued treatment for its potential to preserve everyday functioning, independence, and social engagement.	*"Just prolonging the ability to function, to take your own shower and brush your own teeth and get dressed in matching clothes, not putting in two different earrings and doing crazy stuff. And she's doing well that way, she can drive to the store, drive locally, she meets with a couple of her girlfriends on a monthly basis and goes out for lunch and just enjoys her friends."* - Caregiver 14
Patients were willing to accept treatment risks when weighed against the anticipated trajectory of their decline without treatment.	*"[Patient] said, 'I'd rather pass early than go through this whole process. If that's the risk of this drug, the ARIA risk, I'm willing to take that risk.'"* - Caregiver 6
Theme 2: Importance of Trust, Transparency, and Safety Monitoring During Treatment	
Participants' willingness to continue treatment depended on knowing they had access to a knowledgeable clinical team and reliable safety monitoring.	*"To continue the drug after [Hospital] stopped, they identified an infusion center kind of in our area, a couple of hours away. At that center they indicated that they would be willing to get [patient] that drug if Biogen would have continued providing that drug, but we wouldn't have had any support at all and they made that pretty clear. So up until then, like one time she had tingling and double vision, I could call [Hospital], I could send an email, I'd get a response back, but it was very clear that [Hospital 2] said you're going to have no support from anyone and no one down here knew anything about the drug. So we made the decision that we weren't going to continue it. We just thought it would have been too big of a risk to continue on our own, with no medical backup, no one I could turn to, to read an MRI or whatever."* - Caregiver 10
Participants valued upfront communication and attentive monitoring throughout treatment.	*"Well, first of all, what they did was they made sure that they explained what was going to happen. So, okay, you go through some testing, they would take some blood, they would check your heart, that kind of stuff. But then, when it was time, or sitting in the chair getting your infusion, you know, they would pop around, make sure that everything was going okay. It's, you know, it's about an hour, an hour and a half at least, maybe*

	two. And, you know, once you were done, you were tired. They told us that in advance." - Patient 4
Theme 3: Impact of Treatment on Daily Routines	
For some participants, treatment was not disruptive to their daily life.	*"I just got into the flow of it. I don't mind going to [Hospital]...I guess I could say I look forward to it, but that might sound silly, but it doesn't bother me in any way."* - Patient 7
Some dyads found ways to incorporate treatment into routines that made it feel manageable and more enjoyable.	"*Certainly this is not an impact on [their responsibilities]. This is just once every two weeks, it's no big deal. We come in here, we usually go to…it's kind of [patient's] favorite thing to do and I don't mind either. We come in here, we do that, and then we run to Trader Joe's and buy a bunch of stuff at Trader Joe's and go home."* - Caregiver 2

Discussion

This study explored the experiences of patients in Rhode Island receiving AATs for AD and their caregivers. Although AATs present clinical risks, logistical demands, and financial burden, patients found treatment meaningful for what it offered in the broader context of living with a progressive disease. Findings from this study suggest that understanding how patients and caregivers experience AATs requires looking beyond the clinical outcomes of treatment to fully capture the emotional and practical realities of what treatment represents in practice.

Although both patients and caregivers were often aligned in their decision to pursue treatment, their motivations reflect the differing realities and stakes each member of the dyad faced in managing the disease. Patients often approached treatment as an opportunity to take action against progressive decline and maintain a sense of agency while living with a disease characterized by loss. This finding aligns with literature suggesting that independence and the ability to perform activities of daily living are some of the most important treatment outcomes to patients with AD.[27] Caregivers, however, emphasized slowing disease progression, preserving the patient's functioning, and extending the amount of meaningful time left together, motivations shaped not only by the emotional weight of witnessing the patient's deterioration, but also by a clear understanding of what progressive decline could mean for their everyday life and future caregiving responsibilities. Despite these differences, both perspectives suggest that treatment was valued not only as an opportunity to potentially slow decline, but also for what it represented in the context of living with a progressive disease. Recognizing the different ways in which caregivers and patients approach treatment may help clinicians create tailored support for participants considering and actively receiving treatment. Patients may benefit from conversations that allow them to remain actively involved in their care, encouraging autonomy

and independence. Caregivers, on the other hand, may benefit from honest, specific information on what slowing disease progression looks like in practice, particularly in relation to the patient's independent functioning and time-saved.[28]

These findings also provide insight into why participants were willing to pursue treatment despite its risks and limitations. While participants understood that AATs had significant clinical risks and were unlikely to produce dramatic changes in cognition, they were not discouraged from pursuing treatment. Instead, the reality of living with a progressive illness appeared to reshape how participants viewed and evaluated the risks involved. As participants accepted that decline was inevitable and there were limited alternatives, the "nothing to lose" mindset that emerged across several patient narratives may reflect acceptance of a reality in which every option, including inaction, involved some form of loss. Within this context, treatment appeared to be approached not with unrealistic expectations or dismissal of risks, but as a response to the reality of progressive decline. Current guidelines for clinician-patient communication regarding AAT risk emphasize clear communication of risks and benefits, but may not fully consider how patients' perception of their prognosis reshapes the way risk is weighed in practice.[29] This suggests that risk communication for patients considering AATs requires not only a standard acknowledgement of risks involved, but consideration of the emotional and practical context in which these treatments are being offered.

Participants' willingness to move forward with treatment despite its risks also depended on the trust they developed with the clinical team. Transparent communication about risks, personalized discussions about the role of APOE status in treatment, and consistent MRI monitoring contributed to patients feeling safe and supported throughout treatment. This is consistent with literature suggesting that patient trust relies not on reassurance alone, but also on

transparent communication that keeps patients and their support systems well informed and actively engaged in their care.[30] Trust may play a particularly important role in how AATs are experienced in practice, especially given the novelty of these treatments, the seriousness of the potential side effects involved, and the vulnerability of patients and caregivers facing progressive decline with limited treatment alternatives. As AATs become available in more healthcare settings, these findings suggest that access to a knowledgeable and responsive clinical team may be as important to participants as the treatment itself.

These findings also help contextualize the treatment burden associated with AATs. On paper, AATs appear burdensome, consisting of biweekly or monthly infusions, frequent MRI monitoring, and follow up appointments after treatment has been completed. However, rather than describing treatment as disruptive, participants described actively incorporating treatment into their lives in ways that created structure, supported emotional coping, and allowed them to maintain a sense of normalcy and independence. In contrast to prior studies examining treatment burden among patients undergoing infusion therapies for cancer, kidney failure, and MS, participants' experiences with AATs were shaped by different expectations, responsibilities, and life circumstances. In this study, participants often approached treatment with an understanding that treatment was unlikely to dramatically alter their disease trajectory. Additionally, because many participants were retired, the anticipated logistical demands associated with treatment may have been experienced differently than treatment for other conditions where work and additional caregiving responsibilities can directly shape burden. These findings are consistent with qualitative work suggesting that people living with AD often adopt coping strategies following their diagnosis that allow them to maintain their sense of identity, quality of life, and continuity.[31] For some participants, AATs became a part of how they adapted to their diagnosis, rather than

being an additional burden. This distinction has important implications for how future studies examine the burden of AATs. While current burden measures typically focus on logistical demands, they may not fully capture how participants integrate treatment as a source of meaning and purpose in daily life.

Strengths and Limitations

This study has several limitations that should be considered when interpreting the findings. The sample included all White participants, and the majority had some degree of a college education. Additionally, all participants were recruited from a specialty clinic that is known to serve a well-resourced population. These factors limit the transferability of our results to broader populations, particularly those who may face structural, financial, and logistical barriers to accessing AATs. This is particularly relevant given the health equity landscape in Rhode Island, where communities that experience the greatest burden of AD are historically socioeconomically disadvantaged. Additionally, because recruitment was conducted from a single specialty clinic, participants' experiences may have been shaped by specialized communication, monitoring, and clinical support. These findings may not translate in clinical settings with limited resources and less specialized care. Future studies should focus on recruiting a more diverse sample and capturing the perspectives of patients and caregivers who declined treatment, as their experiences may provide additional context on important decision-making factors that this study did not capture.

Despite these limitations, this study also has several strengths. While existing studies have focused on the clinical outcomes of treatment, this is one of the first qualitative studies to capture the emotional, logistical, and practical aspects of treatment. By including the perspectives of both patients and caregivers, this study offers a more complete picture of how treatment is experienced within the dyad and provides insight into the unique support that each member may need. Additionally, including patients who experienced ARIA and discontinued treatment provides insight into the role treatment-related complications play in shaping patients' and caregivers' experiences of AATs. Finally, because AATs are still relatively new, these

findings can inform how healthcare organizations support patients and caregivers as treatment becomes more widely available.

Conclusion and Implications

This project contributes to broader efforts that aim to understand how patients and caregivers experience AATs in practice, especially as they are being introduced into clinical settings for a population experiencing progressive decline and limited treatment alternatives. Overall, the findings suggest that the value of treatment extended beyond its expected clinical benefit and was shaped by how participants perceived risk, built trust with their clinical team, and adapted treatment to cope with the realities of living with a progressive disease. These findings have implications for how clinicians, healthcare organizations, and researchers should approach conversations and care practices surrounding AATs. Clinicians should acknowledge that patients and caregivers bring different experiences and emotional stakes to treatment decisions and therefore might need tailored support. Healthcare organizations should consider not only the delivery of treatment itself, but the environment and actions that make participants feel safe and supported throughout decision-making and treatment. Finally, future research should focus on recruiting more diverse populations, as understanding the experiences of those facing structural barriers to treatment and those who declined treatment may help develop a more complete understanding of how AATs are experienced across different populations and settings.

Appendix

Interview Guide for Patients Receiving Treatment

Introduction: We are interviewing people who are receiving treatment with anti-amyloid therapies to learn about their experiences and help other patients and care partners face similar decisions in the future.

(Sub questions are potential probes)

1) **When and where did you first learn about anti-amyloid therapies?**
    - Who first discussed them with you?
    - What types of tests did you have to check if you were eligible for anti-amyloids?
    - Were any alternatives to anti-amyloid therapies discussed with you?
    - Were the potential benefits and harms explained to you during the decision process? How did they affect your decision?
    - What do you understand to be the potential benefits of amyloid therapies? The potential harms?

2) **In addition to the clinician who referred you for treatment, did you speak to any other healthcare providers, like primary care or neurologists, when making this decision?**
   Remember, anything we discuss is confidential and will not be shared with your healthcare providers
    - Which healthcare providers did you talk to? (prompt: primary care, neurologist, geriatrician, neuropsychologist, psychiatrist)
    - Did you feel that your questions and concerns were addressed adequately? If not, what areas do you feel were left unaddressed?
    - How did your conversations with doctors or specialists influence your decision?

3) **How did you approach the decision to receive treatment with amyloid therapies?**
    - Was anyone else, such as a spouse or child, involved in the decision-making?
    - Outside of talking to health care providers, did you look for information on anti-amyloid therapies (e.g., online)? Where did you look for information? Was it helpful? How did this information play into your decision to receive treatment?
    - Do you feel that you had enough information available about anti-amyloid therapies to help you make this decision?
    - What factors were most influential in your decision-making?

4) **Were there any delays in starting treatment?**
    - Did you face any financial barriers (e.g., insurance)?
    - Were there any logistical hurdles (travel, appointments) during this process?
    - Were there any delays or difficulties in getting referrals or second opinions as part of starting these treatments?

5) **How do these treatments fit into your daily routine?**
    - How long have you been receiving treatment?
    - How often do you attend doctors' appointments related to anti-amyloid therapies? Have you had any challenges with scheduling appointments?
    - How has receiving anti-amyloid therapies affected your finances?
    - Have you been able to continue your usual routine and hobbies while receiving treatment?
    - What were you hoping to get out of treatment? Have your experiences differed from your expectations?

6) **Have you noticed any changes to your symptoms since starting treatment?**
    - Have you noticed changes to your memory?
    - Have you experienced any side effects? If yes, can you tell me more about this?

7) **What would you tell a friend or family member about anti-amyloid therapies? Would you recommend they take them?**
    - We are interested in hearing how you think about these treatments and their role in your experience.
    - How do you think patients and care partners can be better supported when making decisions about treatments for Alzheimer's disease?
    - What did this decision come down to?

Is there anything else you would like to tell us about anti-amyloid therapies or treatments for [MCI/Alzheimer's disease] more generally that we have not asked about?

Interview Guide for Patients To A Person Who Completed or Discontinued Treatment

Introduction: We are interviewing patients with MCI or Alzheimer's disease who received treatment with anti-amyloid therapies to learn about their experiences and help other patients and care partners face similar decisions in the future.

(Sub questions are potential probes)

1) **When and where did you first learn about anti-amyloid therapies?**
    - Who first discussed them with you?
    - What types of tests did you have to check if you were eligible for anti-amyloids?
    - Were any alternatives to anti-amyloid therapies discussed?
    - Were the potential benefits and harms explained to you during the decision process? How did they affect your opinion? How did they affect your decision?
    - What do you understand to be the potential benefits of amyloid therapies? The potential harm?

1) **In addition to the clinician who referred you for treatment, did you speak to any other healthcare providers, like primary care or neurologists, when making this decision?**
    - Which healthcare providers did you talk to? (prompt: primary care, neurologist, geriatrician, neuropsychologist, psychiatrist)
    - Did you feel that your questions and concerns were addressed adequately?
    - How did your conversations with doctors or specialists influence your decision?

2) **How did you a approach the decision to receive treatment with amyloid therapies?**
    - Was anyone else, such as a child or other family members, involved in the decision-making? How did you come to the decision? Were there any disagreements at any point and how were they resolved?
    - Outside of talking to health care providers, did you look for information on anti-amyloid therapies (e.g., online)? Where did you look for information? Was it helpful?
    - Do you feel that you had enough information available about anti-amyloid therapies to help you make this decision?
    - What factors were most influential in your decision-making?

3) **Were there any delays in starting treatment?**
    - Were there any financial barriers (e.g., insurance)?
    - Were there any logistical hurdles (travel, appointments) during this process?
    - Were there any delays or difficulties in getting referrals or second opinions as part of starting these treatments?

4) **How do these treatments fit into your daily routine?**

- How often do you attend doctors' appointments related to anti-amyloid therapies? Do you attend appointments with your care partner? Have there been any challenges with scheduling appointments?
- Have you been able to continue your usual routine, responsibilities, and hobbies while you have been receiving treatment?
- If you are working, how have you managed treatment around your work schedule?
- What were you hoping you would get out of treatment? Have your experiences differed from your expectations?

5) **Have you noticed any changes to your symptoms since starting treatment?**
   - Have you noticed changes to your memory?
   - Have you experienced any side effects? If yes, can you tell me more about this?

6) **I understand that you ended treatment. Did you complete the course of therapy or stop early?**
   - What factors precipitated this decision?
   - Has ending treatment changed your daily routines? If so, how?
   - Now that treatments have finished, has your opinion about these therapies changed? If so, how?
   - Have you noticed changes to your symptoms since you stopped treatment?

7) **What would you tell a friend or family member about anti-amyloid therapies? Would you recommend they take them?**
   We are interested in your reasoning and what you think the value of these treatments is.
   - What did this decision come down to?
   - How do you think patients and care partners can be better supported when making decisions about treatments for Alzheimer's disease?

Is there anything else you would like to tell us about anti-amyloid therapies or treatments for [MCI/Alzheimer's disease] more generally that we have not asked about?

Interview Guide for Care Partners To A Person Receiving Treatment

Introduction: We are interviewing care partners to people with MCI or Alzheimer's disease who received treatment with anti-amyloid therapies to learn about their experiences and help other patients and care partners face similar decisions in the future.

(Sub questions are potential probes)

1) **When and where did you first learn about anti-amyloid therapies?**
    - Who first discussed them with the person you are caring for? Who first discussed them with you?
    - What types of tests did the person you are caring for have to check if they were eligible for anti-amyloids?
    - Were any alternatives to anti-amyloid therapies discussed?
    - Were the potential benefits and harms explained to you during the decision process? How did they affect your opinion? How did they affect the person you're caring for's decision?
    - What do you understand to be the potential benefits of amyloid therapies? The potential harms?

1) **In addition to the clinician who referred you for treatment, did you speak to any other healthcare providers, like primary care or neurologists, when making this decision?**
    - Which healthcare providers did you and the person you care for talk to? (prompt: primary care, neurologist, geriatrician, neuropsychologist, psychiatrist)
    - Did you feel that your questions and concerns were addressed adequately?
    - How did your conversations with doctors or specialists influence your decision?

2) **How did you and the person you care for approach the decision to receive treatment with amyloid therapies?**
    - Was anyone else, such as a child or other family members, involved in the decision-making? How did you come to the decision? Were there any disagreements at any point and how were they resolved?
    - Outside of talking to health care providers, did you look for information on anti-amyloid therapies (e.g., online)? Where did you look for information? Was it helpful?
    - Do you feel that you had enough information available about anti-amyloid therapies to help you make this decision?
    - What factors were most influential in your decision-making?

3) **Were there any delays in starting treatment?**
    - Were there any financial barriers (e.g., insurance)?
    - Were there any logistical hurdles (travel, appointments) during this process?
    - Were there any delays or difficulties in getting referrals or second opinions as part of starting these treatments?

4) **How do these treatments fit into yours and the person you care for's daily routine?**

- How often does the person you care for attend doctors' appointments related to anti-amyloid therapies? Do you attend appointments with them? Have there been any challenges with scheduling appointments?
- Have you been able to continue your usual routine, responsibilities, and hobbies while the person you care for has been receiving treatment?
- If you are working, how have you managed the person you care for's treatment around your work schedule?
- What were you hoping the person you care for would get out of treatment? Have your experiences differed from your expectations?

5) **Have you noticed any changes to the person you care for's symptoms since starting treatment?**
    - Have you noticed changes to their memory?
    - Have they experienced any side effects? If yes, can you tell me more about this?

6) **What would you tell a friend or family member about anti-amyloid therapies? Would you recommend they take them?**
    We are interested in your reasoning and what you think the value of these treatments is.
    - What did this decision come down to?
    - How do you think patients and care partners can be better supported when making decisions about treatments for Alzheimer's disease?

Is there anything else you would like to tell us about anti-amyloid therapies or treatments for [MCI/Alzheimer's disease] more generally that we have not asked about?

Interview Guide for Care Partners To A Person Who Completed or Discontinued Treatment

Introduction: We are interviewing care partners to people with MCI or Alzheimer's disease who received treatment with anti-amyloid therapies to learn about their experiences and help other patients and care partners face similar decisions in the future.

(Sub questions are potential probes)

8) **When and where did you first learn about anti-amyloid therapies?**
    - Who first discussed them with the person you are caring for? Who first discussed them with you?
    - What types of tests did the person you are caring for have to check if they were eligible for anti-amyloids?
    - Were any alternatives to anti-amyloid therapies discussed?
    - Were the potential benefits and harms explained to you during the decision process? How did they affect your opinion? How did they affect the person you're caring for's decision?
    - What do you understand to be the potential benefits of amyloid therapies? The potential harm?

2) **In addition to the clinician who referred you for treatment, did you speak to any other healthcare providers, like primary care or neurologists, when making this decision?**
    - Which healthcare providers did you and the person you care for talk to? (prompt: primary care, neurologist, geriatrician, neuropsychologist, psychiatrist)
    - Did you feel that your questions and concerns were addressed adequately?
    - How did your conversations with doctors or specialists influence your decision?

9) **How did you and the person you care for approach the decision to receive treatment with amyloid therapies?**
    - Was anyone else, such as a child or other family members, involved in the decision-making? How did you come to the decision? Were there any disagreements at any point and how were they resolved?
    - Outside of talking to health care providers, did you look for information on anti-amyloid therapies (e.g., online)? Where did you look for information? Was it helpful?
    - Do you feel that you had enough information available about anti-amyloid therapies to help you make this decision?
    - What factors were most influential in your decision-making?

10) **Were there any delays in starting treatment?**
    - Were there any financial barriers (e.g., insurance)?
    - Were there any logistical hurdles (travel, appointments) during this process?
    - Were there any delays or difficulties in getting referrals or second opinions as part of starting these treatments?

11) **How do these treatments fit into yours and the person you care for's daily routine?**

- How often does the person you care for attend doctors' appointments related to anti-amyloid therapies? Do you attend appointments with them? Have there been any challenges with scheduling appointments?
- Have you been able to continue your usual routine, responsibilities, and hobbies while the person you care for has been receiving treatment?
- If you are working, how have you managed the person you care for's treatment around your work schedule?
- What were you hoping the person you care for would get out of treatment? Have your experiences differed from your expectations?

12) **Have you noticed any changes to the person you care for's symptoms since starting treatment?**
    - Have you noticed changes to their memory?
    - Have they experienced any side effects? If yes, can you tell me more about this?

13) **I understand the person you care for ended treatment. Did they complete the course of therapy or did they stop early?**
    - What factors precipitated this decision?
    - Has ending treatment changed your daily routines? If so. how?
    - Now that treatments have finished, has your opinion about these therapies changed? If so, how?
    - Have you noticed changes to the person you care for's symptoms since they stopped treatment?

14) **What would you tell a friend or family member about anti-amyloid therapies? Would you recommend they take them?**
    We are interested in your reasoning and what you think the value of these treatments is.
    - What did this decision come down to?
    - How do you think patients and care partners can be better supported when making decisions about treatments for Alzheimer's disease?

Is there anything else you would like to tell us about anti-amyloid therapies or treatments for [MCI/Alzheimer's disease] more generally that we have not asked about?

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