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Original article

Simulated shared and supported decision making for amyloid immunotherapy in Alzheimer's disease: A bicentric study

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Abbreviations: AD, Alzheimer's disease; ADCS-ADL-MCI, Alzheimer's Disease Cooperative Study–Activities of Daily Living for mild cognitive impairment; ARIAs, amyloid-related imaging abnormalities; ARIA-E, amyloid-related imaging abnormalities with cerebral oedema/effusion; ARIA-H, amyloid-related imaging abnormalities with microhaemorrhage/superficial siderosis; CDR-SB, Clinical Dementia Rating-Sum of Boxes; EMA, European Medicine Agency; MRRC, Memory Resources and Research Centre; PET, positron emission tomography; SDM, shared decision making; MacCAT-T, MacArthur competence assessment tool for treatment.

https://doi.org/10.1016/j.neurol.2026.01.267

Please cite this article in press as: Burry E, et al. Simulated shared and supported decision making for amyloid immunotherapy in Alzheimer's disease: A bicentric study. Revue neurologique (2026), https://doi.org/10.1016/j.neurol.2026.01.267

INFO ARTICLE

Article history:
Received 29 December 2025
Received in revised form
27 January 2026
Accepted 28 January 2026
Available online xxx

Keywords:
Alzheimer's disease
Anti-amyloid therapy
Supported decision-making
Shared decision-making
Informed consent

ABSTRACT

Lecanemab, the first anti-amyloid therapy approved by the European Medicines Agency, has demonstrated a statistically and clinically significant but moderate slowing of decline in early Alzheimer's disease (AD). In contrast, its long-term impact on the disease course is not formally established. Any benefit, therefore, needs to be carefully weighed against its adverse effects and practical constraints, which must be discussed with patients and caregivers within a shared decision-making process (SMD). However, applying SDM in this context is challenging due to treatment complexity, cognitive impairment and the involvement of care partners. Supported decision-making, which aims to assist individuals with decisional limitations in participating in important choices, has been promoted as a relevant approach. In this bicentric study conducted in France, we evaluated a simulated supported decision-making process in 25 patients with early AD who were eligible for lecanemab and faced the decision to choose anti-amyloid immunotherapy. We created a written decision aid using a consensus-based method to provide clear, accurate, and scientifically validated information to patients and care partners. After a one-week reflection period, both patients and care partners demonstrated a good overall understanding of the information provided, though care partners showed higher levels of comprehension and retention. The treatment was considered acceptable by most patients and their care partners. While patients ultimately remain the decision-makers, these findings highlight the central role of care partners in strengthening supported decision-making, notably through frameworks such as the French "trusted person" model.

1. Introduction

Already approved and in use in the United States since 2023 [1], lecanemab became the first anti-amyloid therapy to be approved by the European Medicines Agency (EMA) for the treatment of early symptomatic Alzheimer's disease (AD) in 2024 [2]. Lecanemab is a passive immunotherapy that uses a humanised monoclonal antibody targeting Aβ aggregates [3]. It exhibits high clearance properties, removing amyloid plaques and normalising amyloid positron emission tomography (PET) scans in 68% of patients after 18 months [4,5]. In the phase III CLARITY-AD trial, lecanemab met its primary and secondary endpoints on cognition and function at 18 months [4]. Cognitive and functional decline was slowed by 27% on the Clinical Dementia Rating-Sum of Boxes (CDR-SB) scale, and functional decline was slowed by ∼37% on the Alzheimer's Disease Cooperative Study–Activities of Daily Living for Mild Cognitive Impairment (ADCS-ADL-MCI) scale. At 18 months, modelling of the benefits may correspond to a gain of five to six months relative to the natural course of the disease [6]. The exploratory quality-of-life and caregiver burden scales showed ∼50% less decline in the lecanemab group [7].

Although the observed clinical effect at this stage of AD exceeds that of prior disease-directed approaches, its magnitude remains modest. By promoting amyloid plaque clearance rather than enhancing neurotransmission, lecanemab has a plausible disease-modifying mechanism [8] and could, in theory, alter the long-term trajectory of the disease [9]. However, the hypothesis of a cumulative benefit over time — i.e., progressively diverging slopes between active treatment and placebo over several years—remains only partially supported and warrants confirmation in longer-term studies [10,11].

Concomitantly, lecanemab increases the risk of amyloid-related imaging abnormalities (ARIAs), encompassing vasogenic oedema (ARIA-E) and haemorrhagic manifestations (ARIA-H) that are typically linked to cerebral amyloid angiopathy, a frequent comorbidity in AD [12]. ARIAs usually occur in the first four months following treatment initiation. Most are asymptomatic and resolve spontaneously. Symptomatic ARIAs, occurring in 2.8% of treated patients, typically manifest with headache, confusion, nausea, blurred vision, gait disturbance or dizziness and tend to be transient. Clinically severe ARIAs, manifesting with persisting delirium, stroke-like symptoms and/or seizures, occur in ∼1%, resulting in death in some cases [13]. To mitigate the risk of clinically severe ARIA, the EMA marketing authorisation has incorporated risk-minimisation measures, including exclusion of *APOE4* homozygous individuals (given the association of *APOE4* with cerebral amyloid angiopathy and increased ARIA risk), exclusion of patients receiving anticoagulant therapy and close surveillance with sequential magnetic resonance imaging (MRI) scans during the first months of treatment. The French Federation of Memory Clinics even go further by recommending an additional safety MRI for patients carrying one *ApoE4* allele before the 27th infusion. Prescribed in this carefully selected and monitored population targeted by the EMA authorization, the therapeutic index appears more favourable, with a numerically similar or slightly greater slowing of clinical decline (about 33% vs 27% less CDR-SB progression than placebo in the restricted vs overall trial population) but lower incidences of ARIA-E (8.9% vs 12.6%), ARIA-H (12.9% vs 16.9%) and serious ARIA-E (0.5% vs 0.8%). Furthermore, as effectiveness was demonstrated for early

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symptomatic AD patients, EMA recommends to discontinue treatment once patients progress to moderate AD or if the clinical course suggests that lecanemab has not demonstrated effectiveness [2]. However, residual safety concerns and uncertainties about the long-term consequences of ARIA and associated brain volume changes persist [14].

Additionally, lecanemab treatment is burdensome. Patients must consent to bimonthly hospital visits for intravenous infusions and repeated MRI scans, whose stressful nature should not be disregarded in vulnerable and aged individuals [15]. Anti-amyloid immunotherapies are a relatively intensive and demanding treatment that requires patient compliance.

Shared decision-making (SDM) is now considered the norm [16,17]. It differs from traditional medical decision-making in that it is more interactive and recognises that each participant shares some responsibility for the decision. Yet applying SDM to lecanemab treatment is challenging, given its complexity and the uncertainties it entails. Physicians should possess a thorough understanding of the therapy and be able to communicate relevant information to patients effectively. In turn, patients should be able to comprehend and contextualise this information within the framework of their own lives to provide informed consent. In that regard, the factual ability of individuals with AD to truly consent, by understanding the uncertainties, risks, and constraints, should not be overestimated [18]. Indeed, at the mild cognitive impairment and mild dementia stages that define early amnestic AD, there is already a significant impairment of episodic memory that can have substantial repercussions in the ability to retain (more than understand per se) complex information. Although less prominent, impairment of executive functions and working memory is usually present, which may interfere with reasoning [19]. In such instances, the related concept of supported decision-making, a process in which persons with decisional limitations receive assistance or guidance from written support and a care partner to participate as fully as possible in essential decisions [20,21], has been promoted. The inclusion of the care partner in this collaborative process with the medical team can be seen as an aid to decision-making, helping finalise the medical approach based on the patient's preferences [22]. In the context of lecanemab treatment for early AD, shared decision-making faces three challenges: conveying the benefit–risk balance and burdensome nature of the therapy while accounting for the patient's early cognitive impairment, and clarifying the partner's role.

In this context, the objectives of this bicentric survey were threefold:

- to elaborate a supported decision-making protocol for lecanemab treatment;
- to test understanding and retention of treatment issues in the dyad of the patient and their care partner;
- to gain insights into the acceptability of the treatment from the perspective of patients and their care partners.

The study was conducted in the weeks leading up to the French Health Authority's decision on lecanemab listing and discontinued after it was denied.

2. Patients and methods

2.1. Development of a decision-making tool

We have developed an information booklet, intended as a decision-making tool, using a methodology inspired by the Delphi method (a method for reaching consensus among experts). [23]. The first step was to define the minimum, yet simplified and accurate information a lecanemab booklet should provide to enable an informed decision. To determine this, we brought together a group of experts from Lille and Dijon Memory Resources and Research Centres (MRRC, i.e. expert memory clinics involved in teaching and research in France) with direct (involved in anti-amyloid clinical trials) or indirect (theoretical knowledge) experience with immunotherapies. After a consensus was reached, the elements considered relevant and essential were as follows:

- basic elements on AD neuropathology and the amyloid cascade, as well as the mode of action of amyloid immunotherapies;
- the established short-term clinical benefits and uncertainties of the long-term benefits of lecanemab treatment;
- the treatment constraints and adverse effects;
- keys for reaching an informed decision.

This enabled us to develop an initial document, which we submitted to a two-step review. The booklet was first reviewed by the French Federation of Memory Clinics working group on anti-amyloid immunotherapies [24]. This step enabled adjustments to the essential information to be conveyed. The second review was carried out by an expert carer from Lille University Hospital and a group of seven non-expert individuals aged 65 or older, with no medical knowledge, to ensure the text was understandable. The same consensus method enabled adjustments to the wording. A 28-page A5 booklet was finally designed and validated collectively (Supplemental data 1).

2.2. Patient selection

Recruitment was conducted at the MRRC of the Dijon and Lille University Hospitals between June and September 2025. The inclusion criteria were defined based on the appropriate lecanemab use recommendations published by the French Federation of Memory Centres [24]. Eligibility criteria were as follows: *i*) age between 50 and 90 years; *ii*) diagnosis of mild cognitive impairment or mild major cognitive impairment associated with Alzheimer's disease, with relative preservation of autonomy assessed by an IADL-4 score $\geq$ 2 [25]; *iii*) common Alzheimer's disease phenotype, i.e. amnestic syndrome, primary progressive logopenic aphasia or posterior cortical atrophy syndrome [26,27]; *iv*) positive AD biomarkers, assessed either by cerebrospinal fluid analysis or amyloid positron electron tomography; *v*) Mini-Mental State Examination (MMSE) score $\geq$ 22 [28]; *vi*) body mass index between 17 and 35; and *vii*) availability of a care partner. The exclusion criteria followed French recommendations and EMA marketing authorisation [2,24]. The only exception was *APOE* genotyping, which was not available in some patients. When

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available, homozygous *APOE4* patients were excluded; participants without *APOE* information were selected solely based on the other criteria. We also collected data on the level of education [29] and the socio-professional category [30,31]. Participants with both a high level of education and a high professional category were classified as high, those with both low levels were classified as low, and mixed or intermediate profiles were classified as intermediate. Sociocultural data on care partners were not available.

We recruited consecutive patients attending Dijon or Lille MRRC from June to September 2025, in the interval between the EU marketing authorisation of lecanemab on 15 April 2025, and the French *Haute Autorité de Santé*'s decision of 4 September 2025 to refuse early market access ('*accès précoce*'). Because this procedure provides derogatory access to medicines before formal reimbursement, the concrete possibility that lecanemab might soon become available in France justified conducting the survey during this period. The survey was discontinued immediately after the negative early-market access decision to avoid creating expectations that could no longer be met in patients and care partners.

2.3. Survey protocol

The study consisted of a 30-min semi-structured, face-to-face interview conducted by a trained neurologist at the MRRC with the patient and their care partner, covering the main points of the written information booklet. Throughout the interview, patients were encouraged to ask questions and to restate the information in their own words. The booklet was eventually given to the patient and their care partner at the end of the consultation. They were asked to read it carefully over the following days and discuss it with the relatives or carers whom the patient wished to involve.

A follow-up telephone interview was conducted approximately one week later. During this consultation, an eight-item questionnaire was administered to the care partner alone, followed by the patient. The questionnaire was designed to assess their understanding of the information provided and their opinion on the acceptability of lecanemab treatment after a one-week reflection period. Understanding and retention of the information were assessed using seven questions covering lecanemab's benefits, route and frequency of administration and adverse effects. Five questions were closed-ended multiple-choice. The two addressing the adverse effects were open-ended short-answer questions (Table 1).

Responses to open-ended questions were evaluated as follows: for the question concerning the description of the main adverse effects, a response was considered correct if it referred to ARIA, cerebral haemorrhage, cerebral oedema or stroke. For the question on serious adverse effects, the response was considered correct if the patient or care partner mentioned at least three adverse effects from the following list: epileptic seizure, headache, vomiting, confusion, visual disturbances, walking difficulties, dizziness, speech difficulties, cerebral haemorrhage and death.

Lecanemab's acceptability was measured using a five-point Likert scale ('strongly disagree' to 'strongly agree'), with icons and colours visually facilitating the response. The patient responded to the statement 'I would like to receive this treatment' while the care partner responded to the statement 'I would recommend this treatment to my friend or family member'. A positive opinion (acceptability) was defined as a response of the 'agree' or 'strongly agree' type. We also asked patients and care partners about the reasons behind their position on the acceptability of treatment.

Table 1 – Treatment understanding questionnaire.

1. Based on current knowledge, it is estimated that anti-amyloid immunotherapy can:
   a. Cure Alzheimer's disease
   b. Stop Alzheimer's disease, preventing it from worsening
   c. Slow down Alzheimer's disease
   d. Unknown
2. Based on current knowledge, how much time can be gained on the disease with anti-amyloid immunotherapy?
   a. 3 months
   b. 6 months
   c. 1 year
   d. 2 years
   e. An indefinite amount of time: the disease is halted
   f. Unknown
3. How is anti-amyloid immunotherapy administered?
   a. Oral route (tablet)
   b. Subcutaneous injection, like a vaccine
   c. Intravenous infusion
   d. Unknown
4. How often are anti-amyloid immunotherapies administered?
   a. Every week
   b. Every 2 weeks
   c. Every month
   d. Every quarter
   e. Unknown
5. Can you describe the main side effects of anti-amyloid immunotherapies?
6. About serious side effects, the ones that can lead to hospitalisation at the very least, how can they manifest themselves? What can be the consequences?
7. In your opinion, are these serious side effects:
   a. Very common, affecting more than 1 in 10 people
   b. Common, affecting 1 to 10 people in 100
   c. Uncommon, affecting 1 to 10 people in 1,000
   d. Rare, affecting 1 to 10 people in 10,000
   e. Very rare, affecting less than 1 person in 10,000

2.4. Statistical methods and compliance with standards of research

Statistical analyses were performed using chi-squared tests for all categorical variables. Results are presented as frequencies with percentages. Statistical significance was set at $p < 0.05$.

The study was approved by the data protection officer of CHU Lille and declared under the number DEC25-353. The project meets the European Commission's definition of anonymity. Data protection procedures were not applicable in this context.

3. Results

3.1. Study population

Of the 31 patients approached, 25 agreed to participate in the study (12 men and 13 women). Their average age was

70.6 ± 7.9 years. By design, all had early clinically and biologically defined AD (24 amnestic typical AD, 1 posterior cortical atrophy) and no exclusion criteria for lecanemab. The mean MMSE score was 25.7 ± 2.0, and the median IADL-4 score [25] was 4. Fifteen participants were treated with acetylcholinesterase inhibitors. *APOE* status was available for six patients, four of whom were heterozygous for the *APOE4* allele.

The patient population studied had a generally favourable socio-cultural profile, with 36% of patients belonging to the high socio-cultural level, 32% to the intermediate socio-cultural level, 28% to the low socio-cultural level and 4% not specified.

3.2. *Evaluation of the understanding and retention of information on lecanemab treatment*

In the care partner group, results showed a good overall understanding, with ≥17/25 (68%) correct answers to the multiple-choice questions and 18/25 (72%) and 20/25 (80%) correct answers to the two open-ended questions on adverse effects (Table 2). In contrast, performance in the patient group was generally lower. While over 20/25 (80%) of patients answered correctly the questions related to overall efficacy and route of administration, 10 to 14/25 (40 to 56%) answered correctly the questions concerning the time gained in disease progression, frequency of administration, and frequency of clinically serious adverse effects. Regarding the latter, two patients overestimated the frequency; 10 estimated it correctly; three underestimated it; and 10 stated they did not know. The lowest performance on the multiple-choice questions was recorded for the item on ''time gained'' in disease progression, with only 12/25 patients (48%) answering correctly, compared with 22/25 (88%) in the care partner group ($p = 0.006$). Half of the patients answered correctly, while the other half overestimated the time gained (7/25), thought that lecanemab would stop the disease (2/25) or did not know how to answer (4/25).

Performances were generally poor on the open-ended questions in the patient group, with only 11/25 (44%) and 9/25 (36%) satisfactory descriptions of adverse effects and serious adverse effects, compared with 18/25 (72%) and 20/25 (80%) in the care partner group ($p = 0.086$ and 0.004, respectively).

3.3. *Treatment acceptability*

After a week of reflection, patients had a favourable opinion of lecanemab treatment in 21/25 (84%) of cases. Care partners had a favourable opinion in only 16/25 (64%) of cases, although no statistically significant difference was observed between the two groups ($\chi^2 = 1.66$; $p = 0.2$) (Fig. 1). Among the patient–care partner pairs, five dyads (20%) disagreed consistently: patients favoured lecanemab treatment, whereas their care partners showed reluctance or hesitation.

Acceptability remained high among the 14 patients who cited death as a potential adverse effect, since 13 out of 14 (93%) still favoured the treatment. Among the 11 patients who could describe the main adverse effects, 10 (91%) still wanted to receive lecanemab. Similarly, among the nine patients who correctly identified the serious adverse effects, eight (89%) expressed a favourable opinion.

The main arguments expressed by the patients and their care partners in favour of lecanemab were its proven efficacy and the enhanced medical supervision it entails. The innovative nature of the treatment was seen as a source of hope and a way to advance knowledge, considering the lack of therapeutic alternatives. Few participants mentioned the availability of the treatment in other countries, and their willingness to 'try anything' in the face of the disease's natural course of deterioration. Arguments against lecanemab included treatment constraints, concern about modest clinical benefit, and the fear of serious adverse effects. Some care partners considered the patient to be currently ''stable'' or ''well'', which limited the perceived value of the treatment. Others mentioned the recent nature of this therapy, the uncertainty about its long-term benefits, and the emotional burden associated with regular hospital visits, which were experienced as a recurring reminder of the disease.

4. Discussion

The principal findings of this survey were threefold. First, we designed and implemented a supported decision-making protocol comprising a written decision aid and the involvement of a care partner. This protocol included a personalised educational booklet, co-developed by experts, laypeople, and caregivers. Its effectiveness was demonstrated by knowledge

Table 2 – Results of the information comprehension assessment questionnaire.

Multiple-choice questions	Patients (% correct answers)	Care partners (% correct answers)	P-value
Overall efficacy of lecanemab	88% (22/25)	100% (25/25)	0.234
Time gained on illness	48% (12/25)	88% (22/25)	0.006[a]
Route of administration	80% (20/25)	96% (24/25)	0.192
Frequency of administration	56% (14/25)	76% (19/25)	0.232
Frequency of the clinically serious adverse effects	40% (10/25)	68% (17/25)	0.089
Open-ended questions	**Patients (% correct answers)**	**Care partners (% correct answers)**	**P-value**
Description of the main adverse effects	44% (11/25)	72% (18/25)	0.086
Description of the clinically serious adverse effects	36% (09/25)	80% (20/25)	0.004[a]

[a] $P < 0.05$.

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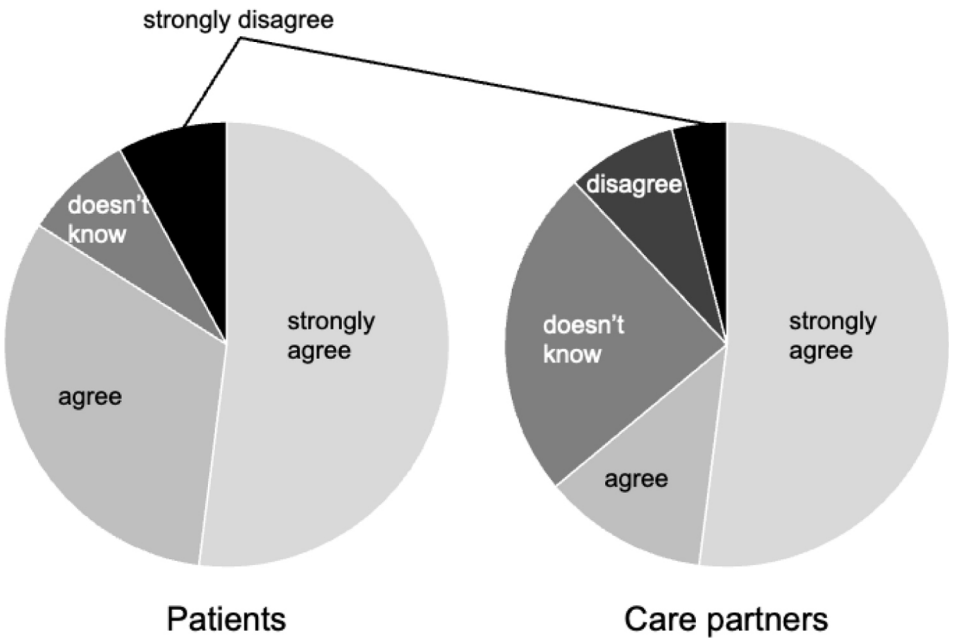

Fig. 1 – Treatment acceptability.

retention and comprehension among both patients and care partners. Second, care partners achieved better outcomes than patients, highlighting their added value in supported decision-making. Third, the majority of patients and care partners expressed a favourable opinion of the treatment after receiving information regarding its uncertainties, risks, and practical constraints.

4.1. *The challenge of informing*

SDM in the context of anti-amyloid immunotherapies is widely advocated, and recommendations for its implementation have already been published [24,32–37]. However, putting it into practice poses several questions. Two seminal studies by Parks *et al*. have directly explored the challenges faced by clinicians and patients [38,39]. The first focused on clinicians, highlighting significant variability in how they presented the treatment's risks and benefits [39]. Differences in training, perceptions of therapeutic uncertainty, and previous experience led to discussions that were sometimes overly optimistic, generating unrealistic expectations, or, conversely, excessively pessimistic. The abundant use of medical jargon and the overestimation of patients' skills also limited understanding. Our semi-structured interview and information booklet offer a possible solution by providing a degree of homogeneity in the information presented, grounded in professional consensus.

Key strategies for improving communication and SDM in anti-amyloid immunotherapy include using simple language, visual aids, and focusing on essential decision factors, such as accurate risk information. Furthermore, checking understanding through rephrasing and allowing adequate time across multiple meetings promotes more direct and balanced discussions, helping patients to make informed choices [34,39]. In line with the latter recommendations, our booklet provides simplified information without compromising the scientific data, and we offered time to reflect and assimilate the information. Its clarity and comprehensibility have been confirmed by care partners' excellent understanding and retention of the information. Patients also demonstrated a significant level of understanding, though it was more variable. Furthermore, in Parks' survey, although physicians freely provided information about treatments, they rarely explored patients' personal goals and values [39]. Hence, the interview and booklet we propose include several key questions for the patient to discuss with care partners, such as ''*What is my current quality of life and does AD threaten it?*'', ''*What would be my definition of a beneficial treatment?*'' and ''*What is an acceptable risk of side effects?*''. Together, this structured interview and the accompanying booklet provide a decision-making framework that places patients' values at the centre of the discussion.

Nevertheless, despite the use of a simplified, evidence-based patient information process, differences remained between care partners' and patients' answers. These discrepancies may be partly explained by cognitive impairment, which can limit patients' ability to remember or rephrase information coherently. They could also be partly explained by patients' perceptions of their illness influencing their assessment of the risks and benefits associated with treatment.

4.2. *The challenge of choosing in early AD*

Early AD is a stage at which cognitive impairment has little or no repercussions on functional abilities [24]. Yet several studies [19,40,41] suggest that it can alter the four components of clinical competence, as defined by Roth and taken up by Applebaum, that are essential to making a choice: unders-

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tanding, appreciation, reasoning, the expression of choice [42–44] and its maintenance over time [45]. In our survey, immediate understanding did not appear to be altered, as patients were regularly encouraged to restate the information in their own words throughout the structured interview. Instead, despite a protocol designed to convey essential information and reinforce learning clearly, we suspect that impairments in episodic memory posed a greater threat to the capacity to maintain consent. Indeed, limited retention of key treatment information, such as adverse effects, was observed in the delayed questionnaire. Patients performed better on multiple-choice questions than on open-ended questions, consistent with the observation that recall and recognition from cues may be partially effective in early-stage AD [46]. There remains, therefore, uncertainty regarding patients' actual reasoning regarding the information provided. To address this issue, several studies have explored the use of decision-making capacity assessment tools, such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) [47–49]. Although frequently cited in the literature, the MacCAT-T is difficult to implement in routine clinical practice: it is time-consuming, was not specifically designed for this clinical context, and lacks clearly established interpretative thresholds [50]. Moreover, as highlighted by Karnoboge *et al.*, even when a patient is considered unable to provide informed consent according to the MacCAT-T, they should nonetheless be involved in the decision-making process [51].

Consequently, while our findings regarding patients' abilities underscore the fragility of their decision-making capacities, we believe that the appropriate response is not to assess decisional incapacity per se, but rather to focus on strengthening supported decision-making processes.

A previous qualitative study by Park *et al.* examined how patients evaluate the potential benefits and costs of an anti-amyloid immunotherapy. Patients tended to magnify the gains over time, ''feeling like themselves, doing enjoyable activities,'' and being independent. Risks were often downplayed or put into the perspective of an inevitably progressive disease, and very few patients mentioned death as a possible outcome [38]. Our results consistently showed an overestimation of time saved. In our study, treatment desirability was high among patients, even though the risks of adverse events were understood. These results may reflect the strong desire to benefit from an effective treatment. The fear of the disease and the desire to remain active and independent could lead to considering the expected benefits of treatment to outweigh the risks [38].

The results of our study support the idea that clear, simplified information is not sufficient to overcome the difficulties encountered in the decision-making process. On the other hand, care partners who have a good understanding and retention of the information provided seem to be a valuable resource for strengthening the decision-making process.

4.3. *Strengthen the role of the care partner*

Supported decision-making involves mobilising various levers to assist and help people whose cognitive abilities or mental health are impaired. Among these levers, the presence of a person responsible for accompanying the patient to medical appointments, providing practical and emotional support, helping them to remember information and express their preferences appears particularly relevant. It plays a structuring role in implementing the SDM [52,53]. Under French law, a trusted person (''*personne de confiance*'') is a third party designated by the patient to assist the patient in making medical decisions. Their role as principal care partners is primarily identified in contexts where patients are unable to express their wishes. Still, the law also stipulates a privileged position for accompanying patients at all stages of care [54]. A triadic relationship among the physician, the patient, and the third party involved emerges throughout the decision-making process. The inclusion of these third parties in the SDM process facilitates two-way communication between patient and clinician. It allows therapeutic decisions to be better tailored to the patient's preferences. In the context of anti-amyloid immunotherapies, supported decision-making models should therefore closely integrate clinicians, patients, and trusted persons.

However, as stated in Parks *et al.* [38], the role of care partners can vary considerably and may sometimes conflict with the patient's wishes [37]. Some care partners are very supportive, while others express reservations about the patient's decision. Indeed, although not significantly, treatment desirability was higher among patients (21/25, 84%) than among care partners (16/25, 64%). Accordingly, the five instances of disagreement we observed always went in the same direction: the patient favoured lecanemab, and the care partner was reluctant. It is essential to emphasise that the role of the trusted person is not to influence the patient according to their own beliefs or preferences. Rather, their function is to support the patient in clarifying the patient's values and preferences and to help compensate for cognitive impairment [54]. Consequently, concordance between the patient's and the trusted person's views is not an expected outcome of the SDM process; indeed, divergence may even reflect the independence of the opinions expressed. Nevertheless, concerns may arise regarding the potential influence of the trusted person on the patient, particularly during the process of reformulating information through the lens of their own beliefs. This observation underscores the need to strengthen the information provided to trusted persons about their roles in the decision-making process. Supported decision-making explicitly encourages patients to define the boundaries of this role at the outset of the process [21].

4.4. *Limitations*

Our study has several limitations. First and foremost, the sample size was low due to the French Health Authority's decision to deny early market access to lecanemab. This decision resulted in the survey being stopped early, as continuing was neither ethical nor practical, given that treatment access in the coming months was no longer feasible. There were limitations as well in the conception of the structured interview and booklet. During its elaboration and writing, the document was reviewed by older individuals and care partners, but not by patients themselves. While the document was generally understandable to a general

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audience, the difference in understanding between patients and care partners suggested that the information may not be clear enough for patients with early AD. Further reviews by patients and patient associations should be sought to assess which information is necessary for informed decision-making. A framing effect may be present, as benefits were presented before adverse events. Clearer information on the conditions for treatment discontinuation, particularly in the event of progression to the moderate stage, should be included in the booklet. This would help patients prepare for this possibility, as recommended by the Federation of Memory Clinics [24]. Next, it would have been relevant to test patients' understanding at the end of the interview and again one week later. However, as in a real SDM process, we wished to give the patient time for reflection. At the end of the process, it would have been relevant to assess patients, care partners and physicians' perception of the patient's decision-making autonomy, asking to what extent they felt ready to make a choice. Finally, although we recruited consecutive patients with early AD, we can assume that patients followed in our two memory clinics are more open to research and more inclined to trust medicine and science, which could limit the generalisability of the results.

4.5. *Perspectives*

The prospects for this work lie in improving supported decision-making for patients eligible for anti-amyloid immunotherapy and in exploring the role of care partners. While the booklet we elaborated can serve as a basis for enhancing the supported decision-making process, the optimal methods for implementing it remain to be defined. By making our protocol, booklet and data available, we hope to inspire future studies to address unanswered questions. *What is the optimal timing for reflection between the doctor providing the information and the decision being made? What is the number of interviews needed to ensure adequate understanding and an informed decision, while balancing limited health professional resources and avoiding delays in access to treatment? How should disagreements between patient and care partner be managed? What would be the correct attitude to deal with patients showing unrealistic expectations?* In any case, this work reinforces the importance of the care partner in supported decision-making. We believe that promoting the involvement of care partners is essential to strengthening supported decision-making, drawing on models such as the French ''trusted person'' framework.

Disclosure of interest

The authors declare that they have no competing interest.

Independent of this work, NV received research support from Fondation Bettencourt-Schueller, Fondation Servier, Union Nationale pour les Intérêts de la Médecine (UNIM), Fondation Claude Pompidou, Fondation Alzheimer, Banque Publique d'Investissement, Lion's Club Alzheimer and Fondation pour la Recherche sur l'Alzheimer; travel grant from the Movement Disorders Society, Merz-Pharma, UCB Pharma, and GE Healthcare SAS; is an unpaid local principal investigator or sub-investigator in NCT05531526 (AR1001, AriBio), NCT06079190 (AL101, GSK), NCT04241068 and NCT05310071 (aducanumab, Biogen), NCT05399888 (BIIB080, Biogen), NCT03352557 (gosuranemab, Biogen), NCT04592341 (gantenerumab, Roche), NCT03887455 (lecanemab, Eisai), NCT03828747 and NCT03289143 (semorinemab, Roche), NCT07169578 and NCT07170150 (trontinemab, Roche), NCT04619420 (JNJ-63733657, Janssen–Johnson & Johnson), NCT06544616 (JNJ-64042056, Janssen–Johnson & Johnson), NCT04374136 (AL001, Alector), NCT04592874 (AL002, Alector), NCT04867616 (bepranemab, UCB Pharma), NCT04777396 and NCT04777409 (semaglutide, Novo Nordisk), NCT05469360 (NIO752, Novartis), NCT06647498 (remternetug, Washington University School of Medicine); is the unpaid French national coordinator in NCT05564169 (VHB937, Novartis); has given unpaid lectures in symposia organized by Eisai, Novartis and the Servier Foundation; has been an unpaid expert for Janssen–Johnson & Johnson, Eli-Lilly, Novartis.

MAM participated as unpaid investigators in clinical trials funded by Lilly, Novartis, Janssen, Alector, BMS, GSK and Roche.

ARS participated as unpaid investigators in clinical trials funded by Lilly, Novartis, Janssen, Alector, BMS, GSK and Roche. She reports having received honoraria for one symposium by Eisai.

During the past three years, VP was a local unpaid investigator or sub-investigator for clinical trials granted by Novo Nordisk, Janssen, Alector, BMS and Roche. He received research grants from Agence Nationale de la Recherche, Fondation PSP-France and Fondation Recherche Alzheimer.

DW is an unpaid investigator in clinical trials and studies funded by, Novartis, Roche, Alzheon, BMS, Lilly.

TL declares that he provided expertise and participated in symposia for Eisai, Lilly, and Novo Nordisk, without personal remuneration. He participated as an investigator in clinical trials funded by Lilly, Novartis, Janssen, Alector, BMS and Roche, without receiving personal remuneration. He received research grants from the Ministère de la Santé (PHRC), Région Hauts de France, Fondation pour la Recherche sur le Cerveau, Fondation Recherche Alzheimer.

GF is an unpaid investigator in clinical trials and studies funded by Roche.

TT reports receiving salary support from the Fonds de Recherche du Québec (FRQ-S). He reports research funding from public sources, including the National Research Council of Canada and the federal EnvisAGE program, as well as philanthropic funding from the Fondation de l'Institut de Gériatrie de Montréal. He reports having received honoraria for occasional participation in conferences and advisory boards organized in Canada by Eisai and Eli-Lilly. All relationships are outside the submitted work.

Acknowledgements

The authors wish to thank the laypeople and caregivers who read and commented on the first versions of the booklet for their valuable comments.

Please cite this article in press as: Burry E, et al. Simulated shared and supported decision making for amyloid immunotherapy in Alzheimer's disease: A bicentric study. Revue neurologique (2026), https://doi.org/10.1016/j.neurol.2026.01.267

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.neurol.2026.01.267.

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