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#### **RESEARCH ARTICLE**



# Personal value of Alzheimer's disease biomarker testing and result disclosure from the patient and care partner perspective

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#### Abstract

**INTRODUCTION:** We described patients' and care partners' experiences with Alzheimer's disease (AD) cerebrospinal fluid (CSF) biomarker testing and result disclosure in routine care.

**METHODS:** IMPACT-AD BC is an observational study of clinic patients who underwent AD CSF biomarker testing as part of their routine medical care (n = 142). In the personal utility arm of the study, semi-structured phone interviews were conducted with a subset of patients (n = 34), and separately with their care partners (n = 31). Post-disclosure interviews were conducted ~1 month and ~6 months after biomarker result disclosure and investigated the patients' decision-making process around testing, impact of receiving results, wellness and lifestyle changes, and future planning.

**RESULTS:** A majority of patients (90%) rated their decision to undergo testing as "easy." Post-disclosure, the majority (82%) reported overall positive feelings from having greater certainty and the ability to plan ahead, and results spurred them to adopt/continue healthy behaviors such as exercise (84%) and cognitive activities (54%). Care partners expressed relief from having more diagnostic certainty, increased

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appreciation of future caregiving responsibilities, and a desire to connect with support resources.

**DISCUSSION:** Perspectives of persons with lived experience in dementia provide new insight into the value of biomarker testing and should be included as part of evidence-guided considerations for pre-test counseling and result disclosure. Moreover, study findings identify an interval when patients and care partners are highly receptive to positive lifestyle and medical interventions.

#### KEYWORDS

Alzheimer disease, biomarkers, caregivers, cerebrospinal fluid, counseling, decision making, dementia, diagnosis, disclosure, emotions, life style, patients

#### 1 | BACKGROUND

As biomarker testing for Alzheimer's disease (AD) is increasingly used in medical care, particularly with regulatory approval of disease modifying therapies (DMTs),<sup>1,2</sup> a greater understanding of its impacts on patients and caregivers is needed. In the context of biomarker-assisted AD diagnosis, while individuals and their family members have demonstrated high interest in learning their biomarker results and risk of disease progression,<sup>3</sup> the literature on patient and caregiver experiences with biomarker testing as part of routine medical care is limited.

AD cerebrospinal fluid (CSF) biomarker testing is recommended for use in select clinical scenarios where AD is a diagnostic consideration.<sup>4</sup> The core biomarkers in CSF include amyloid- $\beta$  and tau proteoforms,<sup>5</sup> which combined have high diagnostic accuracy for detection of AD pathology.<sup>6–8</sup> Many countries have implemented CSF biomarker testing as part of routine practice in specialized care to aid diagnosis and evaluate risk for disease progression.<sup>9</sup> Furthermore, biomarker evidence of AD pathology, either by positron emission tomography (PET) or CSF, will be required for treatment with AD DMTs and may affect drug coverage decisions.<sup>1,2,10</sup> Unfortunately, little is known about how AD biomarker testing as part of routine medical care alters patient management, and even sparser information is available on patients' and caregivers' perspectives of the testing process and value, if any, of testing on their lives. The bulk of the information on patients' and caregivers' perspectives originates from disclosure of amyloid PET results to cognitively unimpaired individuals, and from disclosures occurring within research settings like clinical trials where the timing and approach for disclosure are highly controlled.<sup>11-16</sup> The extent to which the results of these studies apply in clinical settings and are transferable to AD CSF biomarker testing is not known.

To bridge this gap in knowledge, we developed the "Investigating the Impact of Alzheimer's Disease Diagnostics in British Columbia" (IMPACT-AD BC) study. Study pillars involved examining the impact of AD CSF biomarker testing on medical decision-making (medical utility), health system costs (economic utility), and personal decision-making (personal utility). Here, we report findings from the personal utility pillar where patients and their family or friends described their experiences with the testing process – from consideration of undergoing testing, to the procedure itself, to post-result disclosure – and the impact on their decision-making and planning.

#### 2 | METHODS

#### 2.1 Study design

The IMPACT-AD BC study was approved by the University of British Columbia and Providence Health Care Research Ethics Board (H17-01339). The study was designed as an observational, longitudinal, cohort study assessing the impact of AD CSF biomarker testing on clinical management,<sup>17</sup> health system utilization, and patients and their care partners, with outcomes preregistered with ClinicalTrials.gov (NCT05002699). Medical utility and health system economics were examined in the study's main cohort (n = 142 patient participants) and are described elsewhere.<sup>17</sup> Personal utility was assessed in a subcohort of the study's participants (n = 34) and their care partners (n = 31), and is reported on herein.

Patients for whom physicians deemed biomarker testing to be medically appropriate<sup>4</sup> and had consented to testing as part of their medical care, were approached for informed consent to participate (Figure 1 and Supplementary material 1). For the medical utility pillar, detailed clinical management plans were collected via physician questionnaires pre- and post-biomarker disclosure.<sup>17</sup> For the personal utility pillar, patients were invited to participate in phone interviews and identified a "care partner" to participate in separate interviews. The care partner was most commonly a family member.

As an observational study, the decision to disclose biomarker findings to the patient and/or care partner was at the discretion of the patient's physician and no script was provided to guide disclosure. Following usual practice, the dementia specialist considered the patient's psychological safety prior to disclosure, and when disclosed, biomarker findings were communicated along with the overall diagnosis and any other relevant considerations. Patients could take home a copy of the interpretive report appended with a lay explanation of the biomarkers measured and their relevance to AD pathology.<sup>18</sup>

#### **RESEARCH IN CONTEXT**

- Systematic review: Our current understanding of patient and caregiver perspectives with Alzheimer's disease (AD) biomarker testing originates from disclosure of amyloid imaging results in controlled research settings. We found limited information on the experiences of patients and caregivers with AD cerebrospinal fluid (CSF) biomarker testing and disclosure in clinical practice, and impacts on decision-making and planning.
- Interpretation: This observational study of patients who underwent AD biomarker testing as part of usual medical care, and their care partner, revealed diagnostic clarity was the major driver for testing, and both groups used the biomarker results to their benefit in making wellness and lifestyle changes, and in preparing for the future.
- 3. Future directions: Patient and care partner perspectives should be incorporated into pre- and post-test counseling, and they highlight opportunities to translate positive components of their experiences in specialized practice to inform biomarker utilization in other/broader contexts.

#### 2.2 | Interviews

Patients and care partners were interviewed independently to capture their distinct perspectives. The semi-structured interviews examined the patients' decision to undergo testing, understanding of the biomarker results, wellness and lifestyle decision-making, long-term planning, use of support resources, and effect of testing and result disclosure on the patient and family and friends (Supplementary material 2). Care partner interviews captured their perspective of the patients' behavior on the same topic areas and the care partners' experience with the testing process.

Interviews were conducted by two researchers (K.J.P., D.Y.) between August 2020 and February 2022. All patients and care partners completed an "initial" post-disclosure interview ~1 month post-disclosure, and a subset completed a "follow-up" interview ~6 months postdisclosure (Figure 1 and Supplementary material 1). While 92% of participants in the IMPACT-AD BC study (130/142) consented to participate in the interviews (Table S1), sample size was determined based on data saturation, that is, when new participant responses were determined not to have changed relative to the pattern of preceding interviews,<sup>19,20</sup> decided by consensus of the interviewers.

#### 2.3 Data analysis

Thematic content analysis was performed using MAXQDA software [v.20.4.1, Germany]. Coded interview responses (see Supplementary material 1) were searched for themes relevant to the research ques-

tion and topic areas, and for relationships between themes. Content analysis was applied for responses to close-ended questions, with frequencies reported as percentages of relevant responses to reflect experiences and behaviors linked to biomarker result disclosure. For each question, the total number of relevant responses is provided noting that participants were not required to answer questions and any non-relevant responses were excluded (see Supplementary material 1 for details). Initial and follow-up interviews were analyzed independently and compared, with only notable changes reported herein.

#### 3 | RESULTS

#### 3.1 | Participants

Post-disclosure interviews were conducted with 34 patients (median [IQR] age, 63 [57–68] years; 59% female), and 31 care partners (58% female) (Table 1). Of the interviewed patients, 86% were White, 12% Asian, and 2.9% Indigenous individuals; 82% had partially or fully completed post-secondary education (Table 1, Table S2). The majority of the interviewed patients had mild cognitive impairment (MCI, 74%) at enrollment, and a biomarker profile on the AD continuum (71%). Age, sex, race, and biomarker profile of the interviewed subgroup were similar to the overall study cohort; however, there was a greater proportion of patients in the MCI stage (74% vs. 55%, Table 1) as we sought patients predominantly able to communicate their experiences without the assistance of their care partner.

#### 3.2 Decision to undergo biomarker testing

Most patients (19 of 21 [90%]) rated their decision to undergo testing as "easy" (scores 1–4 on a Likert scale from 1 ["very easy"] to 10 ["very difficult"]), with the remainder (2 [10%]) noting the decision-making was neither easy nor difficult ("neutral") (Figure 2A). All care partner respondents (19 of 19 [100%]) rated the patients' decision-making "easy" on the same scale.

Among patients who shared a reason for their ease of decisionmaking, the majority (10 of 16 [63%]) attributed this to their desire for a diagnosis (Figure 2B), described by one patient as wanting "the best kind of test possible to confirm the diagnosis." For a few patients (2 [13%]), clear communication with their doctor regarding the procedure and trust in their doctors' advice eased their decision to undergo testing.

#### 3.3 Post-disclosure wellness and lifestyle changes

When patients were asked how they felt after learning their biomarker results, the majority (23 of 28 [82%]) responded that their overall feelings were positive (Figure 2C). Few described negative feelings (2 of 28 [7%]), with the primary reason being their concern about future





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**FIGURE 1** Flow diagram of the personal utility and medical utility arms of the IMPACT-AD BC study in relation to the routine medical care. AD, Alzheimer's disease; CSF, cerebrospinal fluid.



**FIGURE 2** Most patients found the decision to undergo AD CSF biomarker testing an easy one to make and a majority reported positive feelings after learning their biomarker test results. (A) Patients' rating for the ease/difficulty of making the decision to undergo testing and (B) primary reasons for "easy" decision-making. (C) Patients' feelings post-result disclosure, (D) care partners' perspective of the patients' feelings post-result disclosure, (E) primary reasons for patients' reporting overall positive feelings, and (F) primary reasons for patients' reporting mixed or overall negative feelings. Values represent the percentage of relevant patient or care partner responses. AD, Alzheimer's disease; CSF, cerebrospinal fluid.

**TABLE 1** Demographic characteristics of patients and care partners in IMPACT-AD BC.

Patient characteristics	Main cohort $(n = 142)$	Patients interviewed $(n = 34)$
Age, median (IQR) – years	64 (59–69)	63 (56–68)
Sex, no. (%)		
Male	74 (52)	14 (41)
Female	68 (48)	20 (59)
Race <sup>a</sup> , no. (%)		
White	117 (80)	30 (86)
East Asian	12 (8.2)	2 (5.7)
Southeast Asian	7 (4.8)	1 (2.9)
South Asian	5 (3.4)	1 (2.9)
Indigenous (First Nations, Inuk/Inuit, Métis)	3 (2.0)	1 (2.9)
Middle Eastern	2 (1.4)	O (O)
Black or African American	1 (0.7)	O (O)
Highest level of education <sup>b</sup> , no. (%)		
Education that ended before high school	5 (3.5)	O (O)
High school graduation or less	42 (30)	6 (18)
Some post-secondary education	24 (17)	11 (32)
Post-secondary degree/diploma	71 (50)	17 (50)
Cognitive impairment at baseline, no. (%)		
Subjective cognitive impairment	8 (5.6)	2 (5.9)
Mild cognitive impairment	78 (55)	25 (74)
Dementia	56 (39)	7 (20)
Biomarker profile, no. (%)		
AD continuum	85 (60) <sup>c</sup>	24 (71)
Not on AD continuum	57 (40) <sup>d</sup>	10 (29)
Health region, no. (%)		
Vancouver Coastal Health	122 (86)	31 (91)
Island Health	19 (13)	2 (5.9)
Northern Health	1 (0.7)	1 (2.9)
		Care partners
Care partner characteristics		interviewed (n = 31)
Gender, no. (%)		
Male		13 (42)
Female		18 (58)
Relationship to patient, no. (%)		
Spouse		27 (87)
Adult child		2 (6.5)
Friend		2 (6.5)

Abbreviation: AD, Alzheimer's disease.

<sup>a</sup>The IMPACT-AD BC cohort included five individuals identified as Indigenous-White (n = 2), East Asian-White (n = 2), and East Asian-Southeast Asian (n = 1); of these persons one individual identified Indigenous-White was included in the interviewed group. Race was not used in the selection of interviewed subjects; study personnel arranging interviews did not have access to this data at the time of the interviews.

<sup>b</sup>Post-secondary education includes trade/apprenticeship/community college, Bachelor's programs, postgraduate programs, and professional degrees. <sup>c</sup>A total of 77 of these participants consented to be contacted for phone interviews.

<sup>d</sup>A total of 53 of these participants consented to be contacted for phone interviews.

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cognitive decline (Figure 2F), such as being "worried about my memory being, you know, lost."

Over half of the patients who expanded on reasons for feeling positively post-disclosure (12 of 22 [55%]) reported this was a result of the new certainty related to their diagnosis (Figure 2E). One patient described this as "knowing that it wasn't all in my head, that there is something going on, gave me relief." About a quarter of the patients (5 [23%]) attributed the positivity to having more information to guide planning, shared by one patient as "now I can plan for my future and get everything in place, because I am a planner."

Most care partners (20 of 31 [65%]) also observed that the patients' overall feelings post-disclosure were positive (Figure 2D), largely from having answers to questions about their cognitive health concerns (8 of 18 [44%]). As one care partner relayed, the biomarker results allowed the patient to "understand more clearly why she is having some of the issues she is having" and "make meaning of some of the struggles that she has been having for [...] the last 5 years." A minority of care partners noted that the patient had overall negative feelings (5 of 31 [16%]), explained by one care partner as "I think how [the patient] was understanding it, he thought maybe it would show something different and then when it ... confirmed the diagnosis then that was upsetting to him."

Following the disclosure, most patients (16 of 19 [84%]) reported an increase in the amount they exercised or encouragement they felt to continue their current routine (Figure 3A,C). Among patients who had the possibility to make dietary changes, over half reported making healthier choices or being motivated to continue an already healthy diet (13 of 22 [59%]) and adding or continuing cognitively stimulating activities (13 of 24 [54%]) such as crossword puzzles and sudokus.

Care partner responses regarding patients' post-disclosure wellness and lifestyle changes followed a similar pattern to patients' self-reported behavior (77% concordance, Figure 3A). As one care partner noted, the patient is "very keen to do whatever she can to delay the impact of this disease" and another shared that the patient is "trying to keep his brain going more."

#### 3.4 | Post-disclosure planning

Many patients (15 of 26 [58%]) reported making changes to their finances (Figure 3B,C), including changes to their will, bank accounts, and tax and property management. While most patients had not thought about planning for future home care assistance (27 [79%]) or moving to a long-term care home (32 [94%]), a subset of these patients (6 [22%] and 5 [16%], respectively) reasoned this was not something they needed yet.

Care partner responses regarding patients' future planning were stable over time, whereas patient responses were modestly more dynamic. From initial to follow-up interviews, the proportion of patients thinking about moving into long-term care increased (1 of 15 [7%] to 3 of 15 [20%]) and the proportion planning finances decreased (7 of 13 [54%] to 4 of 12 [33%]).

## 3.5 | Effect of biomarker testing on patients, family, and friends

The dominant theme in both patient and care partner responses was that the biomarker results were valued because they provided more clarity on the cause of the patients' cognitive symptoms (Figure 4). Many patients expressed acceptance of their diagnosis with an intention to focus on the present, while some shared their concern about family and friends' potential reaction to their test results. Many care partners identified that the biomarker results made them more aware of their future managing and caregiving responsibilities (Figure 4). Some also expressed a desire to connect with resources to help navigate the caregiver role, stated by one care partner as "I would like to see something so I can read up on it a little bit just so I know that when it is time, I will have some resources that I can contact." From the group of care partners that indicated biomarker testing increased their awareness of future caregiving responsibilities, the majority were female (8 of 10 [80%], Figure 3D).

Many care partners (10 of 24 [42%]) noted family and friends engaging in more supportive interactions with the patient post-disclosure, making "more of an effort to communicate" and "get together." A few family members (3 of 24 [13%]) noted concern about their own brain health after learning the patients' biomarker results, including one son who "changed his diet" because "he's afraid that he might get [AD] too."

#### 4 DISCUSSION

This work is the first-of-its-kind to describe the impact of AD CSF biomarker testing from the perspectives of the individuals undergoing testing, and their care partners, in a clinical care setting. For patients actively searching for answers about their cognitive health concerns, disclosure of AD biomarker results provided them with the desired diagnostic clarity, with majority reporting overall positive postdisclosure emotions. Knowledge of the biomarker information spurred patients to make positive lifestyle changes and both patients and care partners used the information to plan for their future and their family's future. Care partners also valued the biomarker results in recognizing and planning for their future caregiving responsibilities. While protocols and recommendations for the analytical aspects of AD biomarker testing are available,<sup>9,21</sup> there are varied practices and a lack of guidelines with regards to pre-test counseling and result disclosure to patients and their families.<sup>22-24</sup> Our study has identified factors important to patients and care partners in the clinical application of biomarker testing.

Patients' motivations to undergo testing, largely the desire to understand the cause of their cognitive symptoms and plan for the future, were similar to those underlying the interest of cognitively healthy individuals in learning their amyloid PET or apolipoprotein E status,<sup>25</sup> or risk of AD dementia based on a research brain magnetic resonance imaging (MRI) scan.<sup>26</sup> Trust in medical professionals and knowledge of the lumbar puncture (LP) procedure were also important, with



FIGURE 3 Positive lifestyle changes were made by many patients post-result disclosure, and both patients and care partners utilized the biomarker results for future planning. (A) Patients' self-reported wellness and lifestyle behavior changes and the care partners' perspective of the patients' behavior changes and (B) patients' self-reported planning decisions and the care partners' perspective of the patients' decision-making. (C) Patients' self-reported wellness and lifestyle changes and support-seeking and planning decisions stratified by patient sex. (D) Major themes regarding the personal utility of biomarker results from the care partner perspective, with stratification by care partner gender. Values represent the percentage of relevant patient or care partner responses for each behavior change, planning decision, or theme.

patients and care partners expressing a desire to have materials to take home as they considered the decision to undergo testing (LP and biomarker testing guides developed by the study team in collaboration with patients, care partners, and varied health care professionals can be found on the study website<sup>18</sup>). An understanding of the testing procedure along with result disclosure in the context of the overall diagnosis likely explains why patients directly linked overall positive feelings post-disclosure to a reduction in anxiety around the cause of their cognitive symptoms. Our findings highlight important considerations for physicians recommending AD biomarker testing, as patients with a strong desire to learn about the cause of their cognitive symptoms generally received biomarker information positively, especially when equipped with knowledge of the testing procedure and possible test outcomes.

Of the handful of patients reporting negative post-disclosure feelings, many clarified that initial feelings of shock were quickly replaced with relief of the anxiety from not having an explanation for their cognitive decline. This is in line with another study's finding that disclosure of positive amyloid PET results to memory clinic patients with subjective cognitive decline was not associated with clinically significant psychological risk,<sup>27</sup> but in contrast to a randomized control trial noting emotional distress among cognitively impaired patients receiving positive amyloid PET results.<sup>12</sup> We attribute these differences to the different perspectives of persons seeking testing as part of their medical journey (i.e., individuals grappling with their cognitive health concerns and actively seeking clarity about their diagnosis) versus those seeking to participate in dementia research. Disclosure in clinical care allows for an active discussion between physicians, patients, and family members,

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**DIAGNOSTIC CLARITY** 

DIAGNOSIS

progresses

responsibilities

PLANNING

Both patients and care partners

patients' cognitive symptoms

reported gaining more clarity about

whether AD was responsible for the

PERCEPTIONS OF LIVING WITH THE

Many patients expressed acceptance of

their test results and diagnosis with an

intention to focus on the present, with

some care partners feeling concerned

about future challenges as the disease

IMPACT OF DIAGNOSIS ON FAMILY

Some patients were concerned about

reaction to their test results, while for

many care partners learning the test results made them more aware of their

their family and friends' potential

future managing and caregiving

**INFORMATION FOR FUTURE** 

Some patients and care partners

expressed that having additional

information on the patients' health

helped with planning for the future

 $\bigcirc$ 

### PATIENTS (n=27)

12 (44%)

"Makes me know that I'm not crazy. It's a potential medical condition"

11 (41%)

"I say to myself, this is my new normal. I have learned how to cope with what has happened in my brain, and so I keep things very positive"

#### 6 (22%)

"I am worried that my children will insist that I go into care. I value my independence"

#### 3 (11%)

"I just wanted to know the truth because you only have so many good years [...] to get all the things done that you want to get done, and then you are really dependent on others, and so it is very important to know what is happening so that you can plan"

#### CARE PARTNERS (n=27)

#### 17 (63%)

"Being able to put a definitive label to it, which probably makes it a little bit easier"

#### 8 (30%)

"I'm obviously a little bit frightened because at this point, we don't know if it is going to be months or years [...] before he has, you know, severe difficulties or death"

#### 10 (37%)

"I have a little more responsibility for her, like paying her bills. I do call her every day to remind her of her appointments, so it definitely has brought on more responsibility into my life"

#### 7 (26%)

"It motivated me to really get on top of things financially, things where he still needs to be cognitively healthy enough to make certain decisions"

**FIGURE 4** Major themes and representative quotes from patient and care partner responses when asked about the effect of AD biomarker testing and result disclosure. Values represent the number and percentage of responses in each theme relative to the total number of relevant patient or care partner responses. AD, Alzheimer's disease.

giving physicians the opportunity to judge the patients' receptiveness to testing, preparedness to receive their biomarker result and tailor the disclosure to individual needs.<sup>28</sup> This underscores the need to assess post-disclosure anxiety and depression in environments reflective of the intended application. It also highlights opportunities to adapt and translate positive components of the patient and care partner experiences we observed in specialized practice to inform utilization in other/broader contexts, including clinical trials and primary care. This is particularly valuable in the context of the availability of DMTs and the progress in blood-based AD biomarkers, which unlike CSF testing, have the potential for implementation in primary care.

We found that AD biomarker testing primes patients', caregivers', and other family members' interest in addressing modifiable risk factors. Patients were motivated to implement healthy lifestyle changes and desired more information on risk factors as a result of testing. Family members also made positive health behavior changes, similar to findings from amyloid PET disclosure.<sup>29</sup> Thus, the time post-disclosure is a favorable window when patients and care partners are highly receptive to positive lifestyle interventions. With evidence-based benefits of early lifestyle modifications in dementia prevention,<sup>30,31</sup> positive experiences of participants at-risk for dementia in a multidomain lifestyle intervention trial,<sup>32</sup> and biofluid biomarker testing enabling

more timely diagnosis, our findings indicate the value of biomarker result disclosure in encouraging the uptake of research-informed lifestyle modifications.

We observed that patients prioritized financial planning postdisclosure, and while a relatively smaller number planned for long-term care (likely attributable to the majority of participants being in the early stages cognitive impairment), this proportion of patients was comparable to that of cognitively unimpaired individuals engaged in care planning following amyloid PET disclosure.<sup>15</sup> The motivation for early planning we observed is in contrast to the hesitancy observed among families of individuals with young-onset dementia, where family members attributed the resistance to planning to their perception that the patient may find it distressing or difficult.<sup>33</sup> Given that the majority of the patients in our study were living at home and largely caring for themselves, it is important for future work to investigate how care planning varies across the AD continuum. The modest changes in financial and care planning between initial and follow-up interviews may be reflective of disease stage and immediate and longer-term planning priorities, and we anticipate the need for tailored pre- and post-test counseling and result disclosure by disease severity.

Biomarker result disclosure enabled care partners to recognize the need for caregiver-specific support, and many valued the ability to involve the patient in decisions about the future having early knowledge of the patients' cognitive health. With female caregivers of people living with dementia experiencing a greater caregiving burden,<sup>34</sup> it was not surprising to find that themes regarding future caregiving and planning were largely voiced by female care partners. This calls for further research to understand the unique challenges in future planning experienced by male and female care partners. We also observed a disconnect between patients' and family members' perceptions of the impact of result disclosure and diagnosis. While some patients expressed reticence to share feelings about their diagnosis with family to avoid burdening them, family and friends valued the information to better support the patient. As such, post-disclosure counseling should encourage patients and their families to engage in meaningful discussion about future planning, care, and support, including any caregiver-specific resources.

The observational study design ensured unscripted result disclosure by physicians (as would occur in routine practice), and participant feedback that reflects the experiences of individuals undergoing testing in secondary and tertiary care. The racial composition of the interviewed sample closely resembled that of the overall study cohort, and was similar to that of the Canadian population which is 74% White, 17% Asian, 5% Indigenous, and 4% other.<sup>35</sup> The proportion of interviewed patients having completed post-secondary education was similar to that of Canadians over the age of 55 years (50% vs. 53%, respectively).<sup>36</sup> A limitation of this study is that we did not capture the perspectives of individuals that chose not to undergo testing. As a first-of-its-kind study, this work was intended to provide insights into the testing process from the patient and family member perspectives, and with that new perspective, reveal future opportunities for research.

The patient population in this cohort can be characterized as individuals actively seeking answers regarding their cognitive health concerns, and that have trust in the knowledge of their care provider about AD biomarker testing. The physician cohort for their part are experts in dementia care, and as such can provide informative and accurate counseling regarding the decision to undergo testing as well as communicate the relevance of the biomarker findings to the patient's overall care plan. As AD biomarker testing expands to less specialized practice (e.g., with the availability of blood tests), one should consider how changes in this patient-physician dyad may affect positive impacts observed in this study. Nonetheless, the findings herein point to strategies patients, families, and health care providers can strive for to help maximize positive impacts and minimize undesirable impacts related to biomarker testing.

In summary, diagnostic certainty was the major driver of patients' decisions to undergo AD CSF biomarker testing, and both patients and care partners used the biomarker results to their benefit in making wellness and lifestyle changes, and planning decisions. These perspectives of persons with lived experience provide new insight into the value of biomarker testing and should be included as part of evidence-guided considerations for pre-test counseling and result disclosure. Moreover, study findings identify an interval when patients and care partners are highly receptive to positive lifestyle and medical interventions.

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#### CONFLICT OF INTEREST STATEMENT

David Yang, John R. Best, Emily Dwosh, and Julie M. Robillard declare no conflicts of interest. Outside of the submitted work, the authors report the following disclosures. Khushbu J. Patel reports speaker fees from Roche. Howard H. Feldman reports grant funding from Annovis, Vivoryon, AC Immune, Biohaven Pharmaceuticals, and LuMind; consulting with all payments made to the University of California San Diego (UCSD) with LuMind, Axon Neuroscience, Genentech, Roche/Banner, Tau Consortium, Biosplice Therapeutics, Novo Nordisk, Janssen Research & Development, and Arrowhead Pharmaceuticals; an issued patent with royalties paid (Detecting and Treating Dementia, PCT/US2007/07008); and a philanthropic donation to UCSD from the Epstein Family Alzheimer's Disease Collaboration. Ging-Yuek R. Hsiung reports grant funding from Biogen, Roche, Cassava Sciences, and Eisai; consulting for Biogen, Roche, Novo Nordisk, Eisai, and Eli Lilly; Ging-Yuek R. Hsiung serves as President of the Consortium of Canadian Centres for Clinical Cognitive Research. Haakon B. Nygaard reports consulting for Roche. Mari L. DeMarco reports consulting for Siemens and Eisai, and consulting and lecturing fees from Roche. Author disclosures are available in the Supporting information.

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#### SUPPORTING INFORMATION

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