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**Family Members' Perspectives on Learning Cognitively Unimpaired  
PET Scan Results**

**RUNNING TITLE: Family Members' Perspectives**

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## KEY POINTS

### Key Points

- Family members generally understood the cognitively unimpaired dementia risk information and considered it valuable.
- Alzheimer's disease risk information perceived as favorable elicited happiness and relief; unfavorable information elicited disappointment and increased awareness of cognitively unimpaired older adult's nascent incipient changes in cognition.
- Family members encouraged others to reflect on their capacity to understand cognitively unimpaired older adult's dementia risk information as different than other medical information.

**Why does this matter?** Guidelines for the appropriate use and disclosure of research results to cognitively unimpaired older adults should recognize the family's role for the needs and interests of both the individual and family.

## ABSTRACT

**Background/Objectives.** Disclosure of Alzheimer's disease (AD) risk information to cognitively unimpaired older adults may become more common if preclinical AD is more detectable and amenable to treatment. Little, however, is known about how far disclosure of risk information goes and what information is needed.

**Design and Setting.** Semi-structured telephonic interviews.

**Participants.** 70 study partners (mean age = 68 ( $\pm 11$ ); 50% female; 70% spouses; 18% children, siblings; 12% friends) of cognitively unimpaired older adults who received a personalized AD dementia risk estimate and an amyloid- $\beta$  PET scan recommendation. We explored their participation in preclinical AD research.

**Measurement.** Interviewees were asked about their desire for information about their own and family member's AD dementia risk, baseline expectations of risk, and

awareness of the participants' memory and monitoring for incipient d  
While noting that AD dementia risk information was not medically ac  
to the lack of disease-modifying therapies, some interviewees describ  
members' and their own health behaviors and future plans.

**Conclusion.** Guidelines for the disclosure of AD dementia risk estimat  
to cognitively unimpaired adults should account for the needs and int  
their family members, who may step into a pre-caregiver role.

#### **KEY WORDS**

amyloid- $\beta$ , dementia, patient education, preclinical Alzheimer's disea

Alzheimer's disease (AD) is now conceptualized as a continuum that includes a preclinical stage in which individuals have abnormal AD biomarkers but are not yet cognitively impaired. Preclinical AD is validated and found amenable to interventions that may delay or prevent the onset of cognitive impairment, testing for AD biomarkers in cognitively normal individuals will likely become part of clinical practice.<sup>2,3</sup> This will have wide implications for an estimated 46.7 million Americans have preclinical AD.<sup>4,5</sup>

Receiving a preclinical AD diagnosis will arguably transform what it means to live with AD: many individuals will become "patients-in-waiting," "hover[ing] in a limbo of time...between sickness and health."<sup>6</sup> Studies of the experiences of cognitively normal persons who learn they have AD biomarkers indicate that this is particularly challenging information weighted with implications for identity, privacy, and self-worth. Preclinical dementia risk information precipitates changes in health behaviors and social interactions, and concerns around stigma and discrimination.<sup>7-14</sup>

This suggests the need to understand the preclinical AD experience of

partner.”<sup>18,19</sup> Study partners serve as knowledgeable informants—providing information about the participant’s cognition and function—but also providing information about the participant’s risk of dementia caused by AD.

Here, we report results from interviews with study partners who participated in the REVEAL-SCAN study (Revelation and Education of Alzheimer’s Disease: The Study of Communicating Amyloid-β) (REVEAL-SCAN; NCT02959489).

## Methods

Interviewees were study partners in REVEAL-SCAN, a multi-site randomized controlled trial examining the psychological and behavioral impact of disclosing “elevated” amyloid-β neuroimaging results to cognitively unimpaired adults aged 65 and older and one first-degree relative with AD. Eligibility criteria mirrored other previous studies. In addition, by extension, a patient population likely to be screened to determine eligibility for disease-modifying therapies. REVEAL-SCAN participants had to enroll

amyloid- $\beta$  PET scan results were not included in this personalized risk information. All study participants underwent amyloid- $\beta$  PET scans and were randomized to receive their results either at their next study visit or at a study visit 6 months later. Personalized amyloid- $\beta$  PET scan results (“elevated” or “not elevated”) were disclosed to participants through a series of decision-making processes.<sup>21</sup> Study partners’ presence was not required for disclosure of results.

Study partners were purposively recruited for this interview study based on their interest in their participants’ amyloid- $\beta$  PET scan results, participant-study partner relationship, and study partner self-reported gender. Figure 1 details the recruitment flow.

A semi-structured interview guide was developed following a review of the literature. The interview guide examined: the study partner’s desire for information, the study partner’s understanding of the participant’s AD dementia risk, baseline expectations, understanding of the study partner’s role in the study, and impact of AD dementia risk information.

Telephonic interviews were conducted between July 2019 and July 2020.



rectified through discussion, and the codebook was revised to account for codes that were not adequately captured and to adjust codes lacking clarity. Having developed a codebook and reached agreement on its application, MA coded the remaining transcripts.

The University of Pennsylvania Institutional Review Board approved the study.

## Results

Demographics of the 70 interviewees are included in Table 1. Nearly 50% were spouses or significant others; the remainder were adult children, siblings, or friends. Of the 35 spouses or significant others, seven had learned their partner's "elevated" amyloid- $\beta$  PET scan result, and 28 had learned a "not elevated" result. The average time between amyloid- $\beta$  PET scan and study interview was 1.5 years (minimum 1.8 months, maximum 33 months).

*Desire for information*

favorable information would be “a reassurance,” offer “some inner peace and more security,” or “allay some of the fears.” Conversely, several expressed receiving information indicative of higher risk. For instance, one woman about her husband’s enrollment in REVEAL-SCAN she had worried about “if his reaction would be and mine as well...what it would mean for us going

Consistent with the expressed desire for information, all but six interviewed between “elevated” and “not elevated”—knew their family member’s scan result. Only a third, however, reported being present for disclosure and wanted to offer “support.”

### *Baseline expectations for amyloid- $\beta$ PET scan results*

Among interviewees who learned a “not elevated” amyloid- $\beta$  PET scan result, most had no expectations “one way or the other” at baseline. A third indicated they were not in line with their baseline expectations, which often reflected a sense that the

One interviewee clarified, “[W]hat I was hoping and what I was expecting things.”

About 15% of all interviewees reported being “kind of surprised” that their scan result diverged from their baseline expectations. Like others’ expectations “based on family history” and perceptions of memory and thinking.

#### *Understanding of AD dementia risk*

Of the 43 interviewees who learned a “not elevated” amyloid- $\beta$  PET scan result, 10 understood it to mean that their family member’s or friend’s AD dementia risk had decreased. Two mistakenly believed the “not elevated” result signified a 100% correlation. 27 interviewees who learned an “elevated” amyloid- $\beta$  PET scan result understood it to indicate an increased but uncertain risk of AD dementia. The following interviewee stated, “[T]here seems to be some relationship [between amyloid- $\beta$  and AD dementia]. It’s not a 100% correlation.” Three reported the result was ambiguous. For example,

As noted above, the amyloid- $\beta$  PET scan result was not figured into the risk estimate but offered as a separate piece of information. Overall, interviewees interpreted the two pieces of information—though there were differences in how they related to one another. For example, a wife explained that because her husband's risk estimate did not incorporate his “elevated” PET scan result, “[H]er [risk estimate] mathematics showed.” A husband whose wife ultimately received an “elevated” PET scan result recounted “feeling pretty good about the fact that she was she’s at low risk for getting Alzheimer’s. So I really wasn’t concerned about getting a test at that point.” In several cases, interviewees seemingly conflated the PET scan information. For instance, one husband whose wife received an “elevated” PET scan result explained the meaning of that result in terms of the personalized risk estimate: “there's a possibility that she will develop Alzheimer's. There's also a possibility that she won't since she was only 35%.”

*Reactions to AD dementia risk*

saying things like “That’s a beautiful car. What color is that?” He was given favorable information “helped me a lot.”

In select instances, interviewees’ positive feelings also reflected a new awareness of their own or others’ AD dementia risk. For example, one individual was “eased by his brother’s AD dementia risk because it indicated his own risk might be lower than his brother’s...but I don’t really have to dwell on Alzheimer’s.” A woman described how information had given her mother’s “siblings some kind of hope as well.”

In contrast, many interviewees who felt their family member’s or friend’s risk was increased experienced negative emotions. Nearly a quarter were “sad,” “I was sad. And it’s sad for me, and it was sad for him.” A significant number were “number one, ... disappointed because it’s not great news.” One in five was “feeling ‘a little more concerned’ or ‘20% more worried’ than before.” One family member developing AD dementia. A daughter added, “I think it’s more hereditary, then I could just as well be behind her doing the same [genetics].”

Most interviewees (61%) denied that learning their family member's risk had any effect on their perceptions of that individual's memory; however, it was more common among those who learned a "not elevated" amyloid- $\beta$  PET scan result.

Some interviewees described having concerns about their family member's memory at baseline, though individuals had to have a CDR of 0 (i.e., a score indicating memory and functioning) to participate in REVEAL-SCAN. A "not elevated" amyloid- $\beta$  PET scan result offered reassurance and led to reframing of those baseline concerns. For example, one individual who had "attributed memory lapses ... to the onset of Alzheimer's, the scan result was reinterpreted them as "normal aging." By comparison, learning an "elevated" amyloid- $\beta$  PET scan result served to validate concerns. One woman stated it was "not surprising" that she was "a little off" in light of what she learned.

Additionally, after learning an "elevated" amyloid- $\beta$  PET scan result, a few interviewees described themselves as being "just a little bit more aware of" their family member's memory and thinking or watching for "developing symptoms." One individual

A third of all interviewees reported their family member or friend had changed their health behaviors after learning their AD dementia risk. The most frequent changes were in physical exercise, followed by cognitive activities—“memory games,” “reading ... puzzles,” “taking Spanish online,” or “reading ... brain teaser magazines.” Interviewees attributed these changes to various causes, including “getting older,” as well as the AD dementia risk information.

A third of interviewees—primarily spouses and significant others—reported changes in their own health behaviors. The most frequent changes were in diet, physical activity; several described taking dietary supplements. Many interviewees with an “elevated” amyloid- $\beta$  PET scan result attributed the changes to learning their own or friend’s AD dementia risk information. One man, whose wife had an “elevated” result, explained, “If we’re living together, we eat the same foods and so I eat more salads.” Another spouse explained, “For my health, I [have a] better chance of being able to help her if she needs it.” Interviewees who learned a “not elevated” result, changes were more likely to be made

had learned a “not elevated” result (30% vs. 12%). The most common groups were in financial planning, legal planning, use of leisure time, and travel. A man explained that after receiving an “elevated” result, his friend “helped me get everything organized.” One son described his dad “looping me in more on financial planning and planning “to visit [family] more often” after getting an “elevated” result. Interviewees reported that their friends or family members who received a “not elevated” result felt “freer to make plans.”

A fifth of spouses and significant others reported that their own future plans were affected by the AD dementia risk information. One wife described how the “elevated” scan result made her and her husband “a little more mindful like, ‘Okay, we can put off for another 10 years.’” Another wife described that after receiving a “not elevated” result “we feel freer” planning for the future.

#### *Comparing amyloid- $\beta$ PET scan results to other test results*

Two-thirds of interviewees described the amyloid- $\beta$  PET scan result as



diagnosis of dementia is temporally distant: “If you’re going to get Alzheimer’s, it’s probably going to be 8 to 10 years [from now].”

About 10% of interviewees focused not on the amyloid- $\beta$  PET scan results but on the lack of actionability to differentiate it from other medical test results. One woman explained, “Medical tests often have a remediation for the result if the result is not what you want. In this case...it's finding out that you very likely might have a disease for which there is no cure. My husband echoed, “[M]edical tests are frequently things that you can act on. [T]here's no cure for Alzheimer's, ... that's the disease we don't want to know about.” She then questioned, “[W]hy do the test if there's no treatment?”

### *Advice to others*

Many interviewees described the opportunity to learn AD dementia results as “helpful.” One explained, “[H]aving knowledge is better than not having it, even if it means the possibility of acting on it.” Yet, they cautioned others to reflect on

this particular person. Don't go out and tell anyone else about the re something...negative..., try to be as helpful [as possible] to the person

## **Discussion**

Prior studies have examined the effects of disclosing AD dementia risk to cognitively unimpaired persons and also to care partners of adults with mild cognitive impairment (MCI).<sup>22,23</sup> This study is the first to examine how such disclosure affected cognitively unimpaired persons' family members and friends; we find important parallels with previous results suggest that, if adults with preclinical AD become "patients in waiting," their family members become "pre-caregivers," offering support in the present and preparing for future responsibilities.<sup>15</sup>

Consistent with other studies showing that cognitively unimpaired adults are often uncertain about the meaning of amyloid- $\beta$  PET scan results, we found high levels of uncertainty among cognitively unimpaired (mostly highly educated) interviewees.<sup>7</sup> Their emotional reactions to

important facet of their identity, and if others learn the result, they may experience stigma and discrimination.<sup>9,14</sup> The individuals we interviewed compared their PET scan result as different. Notably, however, they compared the result favorably to other medical test results, as the presence of amyloid- $\beta$  was a precursor to onset of dementia, and if cognitive impairment occurred, it was likely to be less severe than that which would invoke stigma to the extent cognitively unimpaired persons with AD experience.

Interestingly, multiple interviewees questioned the utility of disclosing dementia risk information given the lack of medical actionability. This suggests a concern that disclosing dementia risk information may affect family members' desire for and the perceived utility of dementia risk information. Interviewees' answers resonate with both clinical guidelines recommending against AD biomarker testing and APOE genotyping in cognitively unimpaired adults, as well as with ethical debates over the propriety of disclosing dementia risk information to cognitively unimpaired individuals.

Many interviewees, however, noted that AD dementia risk information, even if not *medical* actionability—is nevertheless actionable. They valued the information

Past work with cognitively unimpaired adults suggests that learning a scan result can validate existing subjective cognitive complaints or raise concerns. We found that AD dementia risk information can also influence family members' perceptions of memory and thinking. Relatedly, prior studies suggest that cognitively unimpaired individuals share their AD biomarker results with others to be monitored for changes in cognition.<sup>14,31</sup> Others, though, perceive this as intrusive.<sup>14,32</sup> We found disclosure of AD dementia risk information could be suggesting a point of friction if patients and families do not agree on

### *Limitations*

This small, relatively homogenous sample was highly educated, affluent, and White, which constrains generalizability. Interviewees were recruited through participation in REVEAL-SCAN was complete; therefore, time from disclosure to the no pre-disclosure interview, which may introduce recall bias. All REVEAL-SCAN participants underwent a standardized education and risk disclosure process; which

examine this role in broader populations and explore how the experience varies, particularly with the onset of cognitive decline. These results will assist in understanding the impact AD risk information has on family members and help to consider these different reactions when communicating such information.

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### **Conflict of Interest**

The authors have no conflicts to report.

### **Author Contributions**

Concept and design: Largent, Karlawish, and Roberts

Acquisition of subjects and/or data: Abera, Harkins, Uhlmann, Feldman

Analysis and interpretation of data: Largent, Abera, Harkins, Karlawish

Preparation of manuscript: Largent, Abera, Harkins, Uhlmann, Feldman

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The funders had no role in design and conduct of the study; collection, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; or to submit the manuscript for publication.

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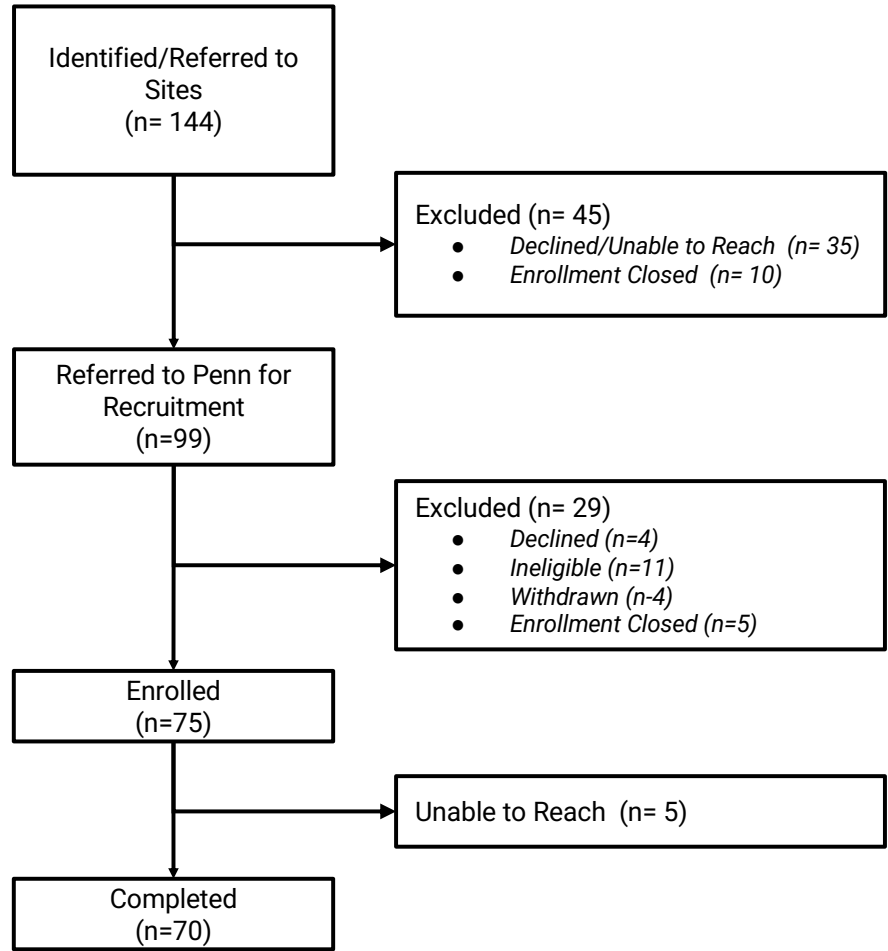
## LEGENDS

Figure 1. Recruitment flow.

Figure 2. Representative quotes from family members who learned an older adult's amyloid- $\beta$  PET scan result and a personalized estimate of Alzheimer's disease (AD) dementia by age 85 based on age, race, sex,

Table 1: Demographic Characteristics of Interviewees (N=70)

Characteristic	Not Elevated (n=43)	Elevated (n=27)
<b>Age, mean (SD)</b>	<b>67.9 ± 10.9</b>	<b>68.2 ± 10.9</b>
<b>Sex, n (%)</b>		
Male	22 (51%)	13 (48%)
Female	21 (49%)	14 (52%)
<b>Race, n (%)</b>		
Caucasian	32 (74%)	22 (81%)
Black	11 (26%)	4 (15%)
American Indian/Native Alaskan	0 (0%)	1 (4%)
<b>Ethnicity, n (%)</b>		
Non-Hispanic/Latino	43 (100%)	27 (100%)
<b>Participant REVEAL-SCAN Arm, n (%)</b>		
Disclosure	25 (58%)	12 (44%)
Delayed Disclosure	18 (42%)	15 (56%)
<b>Education, n (%)</b>		
Grade School	1 (2%)	0 (0%)
High School	2 (5%)	1 (4%)
Some College	5 (12%)	3 (11%)
Associate Degree	2 (5%)	3 (11%)
4 Year College Degree	10 (23%)	9 (33%)
Post Graduate Education	23 (53%)	11 (41%)
<b>Family history of Alzheimer's disease, n (%)</b>		
Yes	25 (58%)	10 (37%)
No	18 (42%)	17 (63%)
<b>Relationship to Participant, n (%)</b>		
Spouse	28 (65%)	16 (59%)
Significant Other	3 (7%)	2 (7%)
Relative: Child	5 (12%)	4 (15%)
Relative: Sibling	3 (7%)	1 (4%)
Close Friend	4 (9%)	4 (15%)
<b>Annual Household Income, n (%)</b>		
<\$10,000	1 (2%)	1 (4%)
\$10,000 - \$29,999	1 (2%)	0 (0%)
\$30,000 - \$49,999	4 (9%)	9 (33%)
\$50,000 - \$69,999	6 (14%)	5 (19%)
\$70,000 - \$89,999	9 (21%)	2 (7%)
≥ \$100,000	20 (47%)	9 (33%)



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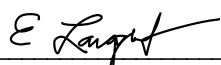
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### EMOTIONAL REACTIONS

Information that led family members to perceive AD dementia risk as increased (cf. average person or baseline expectations) was associated with negative emotions; information that led family members to perceive AD dementia risk as average or decreased was associated with positive emotions.



### PERCEPTIONS OF MEMORY

Information that led family members to perceive AD dementia risk as increased confirmed existing memory concerns, introduced new ones, and resulted in monitoring; information that led family members to perceive AD dementia risk as average or decreased offered reassurance.



### HEALTH BEHAVIORS

A third of all family members reported changes in health behaviors, though the reasons given for these health behavior changes varied with perceived AD dementia risk.



### FUTURE PLANS

Family members who perceived AD dementia risk as increased were more likely to report changes to future plans than family members who perceived AD dementia risk as average or decreased.



## PERCEIVED AD DEMENTIA RISK

“ I was surprised ... and it's sad for me, and it was sad for him.”

“ It just makes me a little more aware of [my mom's] memory, just watching that in the back of my mind a little bit more. ... My sister watches out, too.”

“ Even though I don't ... have family history of Alzheimer's, if I'm in better health, I [have a] better chance of being able to help her if she needs it.”

“ [We're] a little more mindful like, 'Okay, this isn't something we can put off for another ten years.' Maybe our timeline has been pushed up a little bit.”



## PERCEIVED AD DEMENTIA RISK

“ [H]e called me on the phone right away and seemed relieved. And I was relieved. ... We were happy.”

“ [I]f some memory lapse occurs, we say, 'This is [the] normal aging process. This isn't Alzheimer's that you forgot this.'”

“ Even though I haven't been tested about my brain plaque, we still say ... , 'Hey, we both have to do this [brain exercise] just in case.'”

“ Since learning his [AD dementia risk] ... we feel freer to make plans.”