


Original Investigation

Attitudes of Research Participants and the General Public Regarding Disclosure of Alzheimer Disease Research Results

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IMPORTANCE Results of Alzheimer disease (AD) research assessments typically are not disclosed to participants. Recent research has suggested interest in disclosure, but, to our knowledge, few studies have accounted for awareness of potential benefits and limitations of disclosure.

OBJECTIVE To determine the attitudes of cognitively normal research participants and members of the general public regarding disclosure of AD research results.

DESIGN, SETTING, AND PARTICIPANTS Participants in a longitudinal aging study were given preintervention and postintervention surveys about disclosure attitudes. In a general public sample, participants responded to a similar survey about disclosure attitudes. The setting was a federally funded Alzheimer Disease Research Center (ADRC) and general public participants in a monthly panel survey (The American Panel Survey). Cognitively normal ADRC participants (n = 219) were recruited from a longitudinal aging and dementia study at the Knight Alzheimer Disease Research Center at Washington University in St Louis and were 60.7% (n = 133) female, 83.6% (n = 183) of white race, and reported a mean of 15.91 years of education. Twenty-nine individuals refused participation. The American Panel Survey participants (n = 1418) indicated they did not have AD and were 50.5% (n = 716) female, 76.7% (n = 1087) of white race, and reported a mean of 13.85 years of education. Overall, 77.6% of eligible participants (1583 of 2041) completed the survey in July 2014.

INTERVENTIONS Participants in the ADRC sample were randomly assigned to a group (n = 119) that read an education intervention about the usefulness of AD biomarkers or to a placebo group (n = 100) that read as its intervention general information about the ADRC. Participants in the general public sample read a brief vignette describing participation in a longitudinal AD study.

MAIN OUTCOME AND MEASURE Interest in disclosure.

RESULTS Interest in disclosure was high among ADRC participants (55.1% [119 of 216] were "extremely interested"). Viewing the education intervention predicted lower interest in disclosure (odds ratio, 2.01; 95% CI, 1.15-3.53; $P = .02$). High subjective risk of AD, a family history of AD, and minimal attendance at research meetings were associated with high interest after the intervention. In the general public, interest was lower overall (12.5% [174 of 1389] were "extremely interested"), but the subset of participants most likely to join an AD research study reported higher interest (43.5% [40 of 92] were extremely interested).

CONCLUSIONS AND RELEVANCE Experience with AD appears to increase interest in disclosure. Learning about potential limitations of disclosure somewhat tempered interest. These findings should inform the development of disclosure policies for asymptomatic individuals in AD studies.

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Advances in Alzheimer disease (AD) research suggest a preclinical phase of the disease in which biomarkers of AD pathology are detectable many years before the onset of symptoms.¹ Longitudinal studies use several tools to assess the molecular pathology of the disease as well as the subsequent risk of progression to symptomatic AD when such pathology is present in cognitively normal individuals. The tools used include sensitive cognitive tests, genetic testing (eg, apolipoprotein E [APOE] allele status), measurements of AD-related protein concentrations in the cerebrospinal fluid, and results of neuroimaging studies to determine brain amyloid deposition or tau aggregation using positron emission tomography, as well as volumetric and metabolic imaging. Ongoing research aims to validate and standardize biomarker assays, improve risk prediction, and discover a disease-modifying treatment for individuals with preclinical AD. These advances have contributed to an evolving debate about whether researchers should disclose individual results to asymptomatic research participants. Disclosure of results could help individuals and families plan for the future and could motivate beneficial lifestyle changes. Research² has suggested a broad interest in disclosure among research participants and the general public. However, current assessment results carry questionable clinical usefulness without a disease-modifying treatment,³ and disclosure of biomarker results could have psychological, social, financial, or legal consequences.² Given the need to maintain sound ethical policies, prepare for advances in the usefulness and reliability of current assessments, and recruit and retain participants for clinical trials, it is imperative to examine participant preferences regarding disclosure of results.

Surveys of the general public suggest that most people (60%-70% in multiple studies⁴⁻⁶) would like to learn their risk of AD. Among participants in AD investigations, interest in learning results is higher (approximately 80% of participants).^{7,8} Yet, there is no consensus among researchers to disclose results to asymptomatic individuals. These differing perspectives may partially stem from how researchers and the general public perceive the usefulness of learning results.⁹⁻¹¹ Expert statements on the appropriate use of biomarker¹² and genetic¹³ testing for AD do not recommend disclosure of results to asymptomatic individuals because of the limited reliability and poor clinical usefulness. Furthermore, a survey of AD investigators⁹ found that only a small majority favored returning amyloid imaging results to cognitively normal research participants, with those opposing disclosure citing concerns about negative psychological outcomes and potential harm to the validity of ongoing data collection.¹⁴ The extent to which research participants and members of the general public are aware of these issues has received little attention in previous studies.

Many of the findings concerning the attitudes and preferences of participants are from the Risk Evaluation and Education for Alzheimer's Disease (REVEAL) study,¹⁵ which investigates disclosure of APOE status to first-degree relatives of individuals with AD. Findings from the REVEAL study⁷ suggest that individuals pursue genetic testing for a variety of reasons, including to contribute to AD research, arrange per-

sonal affairs, and prepare long-term care options. Other studies^{6,8} in a general public sample report interest in disclosure despite the absence of a disease-modifying treatment, suggesting gaps in knowledge about treatment options, lack of belief in the personal usefulness of results, or both. Finally, there are no reports of significant adverse psychological reactions from disclosure of AD results,^{2,16} although the implications of receiving biomarker (vs genetic) results have not been adequately studied. The increased suicide rate in neurodegenerative diseases with pathogenic dominant mutations¹⁷ should also be considered as risk detection for AD improves.

The present study extends previous findings by examining disclosure attitudes of current participants in a longitudinal AD study conducted in a federally funded Alzheimer Disease Research Center (ADRC), among persons in the general public likely to participate in AD research, and in a broader sample of the general population. The study had 2 aims. First, we assessed the attitudes and preferences of ADRC participants regarding disclosure before and after an education intervention that addresses potential benefits and limitations of learning AD research results. Second, to address the limited generalizability in previous disclosure studies and investigate the attitudes and preferences of individuals who are likely participants in future clinical trials, we assessed several samples of individuals from the general public who vary in their stated interest in AD research participation.

Methods

Participants

Cognitively normal adults (with a Clinical Dementia Rating¹⁸ of 0 at the most recent study visit) enrolled in longitudinal aging studies at the Knight Alzheimer Disease Research Center (KADRC) at Washington University in St Louis were invited to participate in the present study during one of their annual study visits. Written informed consent was obtained from all participants in the study, which was approved by the Washington University Human Research Protection Office. Participants enrolled in longitudinal studies at the KADRC sign a consent form that specifies they will not receive their research results unless there is a clinically significant incidental finding that could meaningfully affect their health care. As part of their participation in the KADRC longitudinal studies, participants undergo biomarker (eg, positron emission tomography and cerebrospinal fluid) assessments, genetic testing for APOE (OMIM 104310), cognitive evaluations, and evaluations of self-reported health and psychological changes. Participants are also invited to an annual research meeting (3-hour duration) during which the KADRC investigators (J.C.M. and other nonauthors) present updates relevant to the research in which they participated.

To evaluate the generalizability of results from the KADRC sample to the population of potential research participants, a module pertaining to disclosure of AD results was added to The American Panel Survey (TAPS), a US probability-based representative sample of approximately 2000 participants who re-

spond to monthly questionnaires. In July 2014, TAPS participants were invited to complete the disclosure module.

Materials and Study Design

We designed a pre-post randomized controlled survey experiment. Materials were developed in collaboration with the KADRC physicians and researchers and were pilot tested with 31 KADRC participants and revised for content and clarity. Results from the pilot study are not included in the final data set. The paper-and-pencil survey instrument included questions about the attitudes toward disclosure of research results (eFigure 1 in the Supplement). At the conclusion of the battery of questions, participants were randomly assigned to an education intervention about potential benefits and limitations of learning one's results or to a placebo presentation consisting of general information about AD and the KADRC. The education intervention and the placebo information were each presented on printed documents in a binder, and each took approximately 10 minutes to view. The education intervention consisted of 21 slides that included information on potential benefits (eg, the usefulness for detecting pathologic changes related to AD) and limitations (eg, the possibility of ambiguous results) of AD biomarkers at present (eFigure 2 in the Supplement). The placebo presentation consisted of 20 slides and included information about the organization and mission of the KADRC. None of the placebo slides addressed research results associated with AD. Immediately after the education intervention or placebo presentation, participants were readministered the battery of questions to determine whether initial attitudes about learning one's results had changed. All study activities were completed in one visit and lasted approximately 20 to 30 minutes.

For TAPS samples, participants read a brief vignette describing a longitudinal AD study comparable to observational studies conducted at the KADRC (eg, "Such studies often involve a 2-hour to 3-hour interview at a medical center, where the person tells his or her medical history, completes tests of memory and thinking, and has a physical examination" and undergoes a "brain scan [magnetic resonance imaging] and a spinal tap."). The vignette also described the current KADRC disclosure policy (eg, "The test results are kept confidential and are not typically shared with the study participants."). After the vignette, participants were asked whether they would participate in such a study. Participants were then asked to assume they were to join such a study and responded to a subset of questions also administered to the KADRC sample.

Statistical Analysis

For TAPS samples, we analyzed data from the following 3 subsets of participants based on different assumptions about the likelihood that respondents would join a longitudinal research study similar to that of the KADRC: the entire sample of respondents, a subsample consisting of individuals who reported strong interest in participating in a study ("likely" sample), and participants who expressed strong interest in participating in a study and reported having a relative (biological parent, grandparent, or other relative) who has or had dementia ("specialized" sample). In each sample, persons who re-

ported they currently had AD were excluded. A weighting developed by TAPS statisticians was applied to make the survey generalizable to the population of English-speaking adults in the United States.

Data analysis was performed in 4 stages using statistical software (SPSS, version 21; IBM). First, we computed descriptive statistics to outline participants' demographics and perceptions of disclosure. Second, we performed a series of ordinal logistic regressions to investigate the factors predicting postintervention interest in disclosure. Third, we used the McNemar test for matched pairs to analyze survey items with binary responses. Fourth, descriptive statistics were computed for participants in TAPS samples for comparison with the KADRC sample.

Results

Participant characteristics for the KADRC sample (N = 219) are summarized in Table 1. After random assignment, the resulting 2 experimental groups were statistically similar on demographic variables. Twenty-nine individuals refused participation. Participants and those who declined participation did not differ on demographic and background variables. However, participants reported completing slightly more education than those who declined participation (mean, 15.91 vs 14.35 years; $t_{243} = 3.04, P = .003$). Participant characteristics for each TAPS sample are also summarized in Table 1. Overall, 77.6% of eligible panel participants (1583 of 2041) completed the survey in July 2014, the month in which the disclosure module was administered. Of those individuals, we excluded from the study 40 (2.5%) who reported having AD, 57 (3.6%) who did not know if they had AD, and 68 (4.3%) who refused to indicate whether they had AD.

KADRC Preintervention Findings

Most KADRC participants reported interest in learning their results and agreed that a person has the right to access his or her own research data (Table 2). Participants reported interest in disclosure in a variety of scenarios (eg, 49.1% [106 of 216] "strongly agree" that information would help prepare their family for the future). Participants reported interest in participating in a clinical trial (36.9% [80 of 217] were "extremely interested") and adopting a healthier lifestyle if found to be at high risk of AD (34.7% [75 of 216] were "extremely interested") (Table 3). Most participants disagreed with the statement that "life would not be worth living," and participants reported little intent (from "no change" to "very little change") to make any changes regarding finances, education, employment, and other life domains if they learned they were at high risk of developing AD.

TAPS Findings

Table 3 summarizes TAPS results, with matching KADRC results. A small proportion of participants in the overall TAPS sample expressed strong interest in disclosure regardless of the availability of a treatment (12.5% [174 of 1389] were "extremely interested"). However, the subsets of respondents

Table 1. Participant Characteristics Overall and by Subgroups for the KADRC and TAPS Samples^a

Characteristic	Overall	Subgroup	Subgroup
	KADRC Overall (N = 219)	KADRC Education Intervention (n = 119)	KADRC Placebo Presentation (n = 100)
Age, mean (SD), y	74.58 (8.05)	73.87 (8.58)	75.42 (7.33)
Female sex, No. (%)	133 (60.7)	76 (63.9)	57 (57.0)
White race, No. (%)	183 (83.6)	98 (82.4)	85 (85.0)
Education, mean (SD), y	15.91 (2.45)	16.06 (2.33)	15.74 (2.58)
MMSE score, mean (SD)	29.19 (1.15)	29.14 (1.24)	29.25 (1.03)
Subjective risk of AD, mean (SD), %	43.89 (26.55)	45.34 (26.68)	42.16 (26.44)
Parent history of AD, No. (%)	110 (50.2)	56 (47.1)	54 (54.0)
APOE4 positive, No. (%)	81 (37.0)	48 (40.3)	33 (33.0)
	TAPS Overall (N = 1418)	TAPS "Likely" Sample (n = 208)	TAPS "Specialized" Sample (n = 92)
Age, mean (SD), y	46.62 (16.37)	45.18 (15.25)	45.08 (15.47)
Female sex, No. (%)	716 (50.5)	105 (50.5)	46 (50.0)
White race, No. (%)	1087 (76.7)	162 (77.9)	72 (78.3)
Education, mean (SD), y	13.85 (2.57)	14.29 (2.58)	14.61 (2.40)
Parent history of AD, No. (%)	91 (6.4)	32 (15.4)	32 (34.8)

Abbreviations: AD, Alzheimer disease; APOE4, apolipoprotein E4; KADRC, Knight Alzheimer Disease Research Center; MMSE, Mini-Mental State Examination; TAPS, The American Panel Survey.

^a The MMSE and APOE status were not available for TAPS samples. TAPS "Likely" Sample consists of TAPS participants who are extremely interested in participating in AD research and may or may not have a family history of AD. TAPS "Specialized" Sample consists of TAPS participants who are extremely interested in participating in AD research and have a family history of AD.

likely to participate in a longitudinal AD study expressed considerably higher interest in disclosure than in the overall general public. Approximately one-third (34.6% [71 of 205]) of participants in the "likely" sample reported extreme interest, and a larger proportion (43.5% [40 of 92]) of the "specialized" sample reported extreme interest in disclosure regardless of the availability of an effective treatment. Other attitudes followed a similar pattern, including interest in disclosure with the availability of an effective treatment, as well as interest in joining a clinical trial, purchasing or increasing long-term care insurance, or living a healthier lifestyle if found to be at high risk of AD.

KADRC Education Intervention Findings

Interest in disclosure of research results (dichotomous measure) declined significantly after the education intervention (from 94.9% [111 of 117] before the intervention to 81.0% [94 of 116] after the intervention, $P < .01$) (Table 4), whereas interest in disclosure remained unchanged among individuals who viewed the placebo presentation (from 96.9% [95 of 98] before the intervention to 96.9% [94 of 97] after the intervention, $P < .01$). Controlling for preintervention level of interest, an ordinal logistic regression showed that experimental group assignment (education vs placebo) significantly predicted postintervention level of interest in disclosure of research results (odds ratio [OR], 2.01; 95% CI, 1.15-3.53; $P = .02$) (Table 5). Similarly, ordinal logistic regressions showed significant declines in interest after the education intervention in learning APOE status (OR, 2.23; 95% CI, 1.28-3.90; $P = .005$), positron emission tomography findings (OR, 2.84; 95% CI, 1.60-5.05; $P < .001$), and cerebrospinal fluid results (OR, 2.55; 95% CI, 1.43-4.55; $P = .002$). However, interest in learning cognitive testing results remained high for the education and placebo groups (OR, 1.48; 95% CI, 0.83-2.63; $P = .19$).

The education intervention was not associated with reduced interest in disclosure in 3 subgroups of study participants. Participants who estimated their subjective risk of AD

at greater than 50% (the mean), participants who reported having at least 1 parent with a history of AD, and participants who attended 0 or 1 annual KADRC participant meeting (less than the median) reported similar levels of interest in disclosure before and after the education intervention.

Discussion

Dementia researchers face an ethical dilemma. While biomarker assessments reveal AD pathology in advance of clinical symptoms,^{19,20} individual risk prediction is not yet possible.^{21,22} At the same time, prior research^{4,5,8} indicates widespread interest among participants in learning the results of these assessments. The present study examines the perceptions of a cohort of current AD research participants for whom biomarker disclosure is germane and several subsamples of the general public. These results are relevant to the development of disclosure policies and recruitment efforts that incorporate the preferences of current and likely research participants.

The cognitively normal participants in the KADRC are similar in their mean age, sex distribution, educational attainment, and baseline Mini-Mental State Examination score to all cognitively normal participants in other ADRCs in the United States, but they have a slightly increased proportion of APOE4 carriers (37%) than the other ADRCs (28%).²³ Hence, results of this study are likely to inform disclosure policies regarding a broad set of current asymptomatic participants engaged in AD research. Consistent with previous findings,^{4,5,8} most cognitively normal participants in the KADRC reported high interest in learning their research results. Interest in disclosure declined somewhat among participants who were alerted to benefits and limitations related to biomarker measurement, although a large majority of participants remained interested in learning their results after viewing the education intervention. Participants who reported high subjective risk of AD, who

Table 2. Interest in Disclosure of Particular Test Results and Under Various Scenarios for All Participants in the Preintervention KADRC Sample

Item	Mean (SD) ^a	% (No./Total No.) ^b
Interest		
In amyloid imaging results	4.02 (1.14)	45.5 (95/209)
In cerebrospinal fluid protein levels	4.03 (1.15)	46.6 (96/206)
In APOE genotype	4.15 (1.10)	51.9 (109/210)
In cognitive test results	4.23 (0.99)	49.8 (108/217)
Knowing there might be false-negative or false-positive results	4.08 (1.15)	48.6 (104/214)
If I knew my estimated risk of developing AD dementia		
I could better prepare my family for the future	4.33 (0.80)	49.1 (106/216)
I would be comfortable disclosing my risk to my employer	2.32 (1.18)	4.9 (10/204)
I would be comfortable disclosing my risk to my health insurance company	2.39 (1.25)	6.9 (15/216)
If I learn or suspect I am at high risk of AD dementia		
I would consider that life is no longer worth living	1.67 (0.87)	<0.01 (1/216)

Abbreviations: AD, Alzheimer disease; APOE4, apolipoprotein E4; KADRC, Knight Alzheimer Disease Research Center.

^a On a 5-point Likert-type scale, ranging from 1 (not at all interested or strongly disagree) to 5 (extremely interested or strongly agree).

^b Refers to the proportion of respondents reporting the upper response choice (extremely interested or strongly agree).

had a family history of AD, and who attended few or no participant meetings remained interested in disclosure at roughly

Table 4. Change in Interest (Yes or No) in Disclosure of Research Results in the KADRC Sample^a

Variable	Interested in Disclosure, % (No./Total No.)	
	Preintervention Interest	Postintervention Interest
Education intervention	94.9 (111/117)	81.0 (94/116)
Placebo presentation	96.9 (95/98)	96.9 (94/97)

Abbreviation: KADRC, Knight Alzheimer Disease Research Center.

^a $P < .01$ (McNemar test) for change in the education group and for difference between the education and placebo groups before the intervention to after the intervention.

the same high rates before and after viewing the education intervention. Because these individuals might be convinced that they will develop AD or might not be familiar with research findings, any limitations regarding the predictive value and clinical usefulness of results could have been discounted.

Most participants reported potentially positive consequences of disclosure (ie, they would adopt a healthier lifestyle), although participants in the KADRC sample reported little desire to make changes in several life domains if told they were at high risk of developing AD, consistent with a prior REVEAL study²⁴ of the behavioral consequences of disclosure. Reluctance to make changes in response to disclosure may stem from difficulty in accurately predicting one's own behavior, retrospective reporting bias, or lack of knowledge and reliable information regarding the appropriate actions to take in response to learning about risk of AD. Consistent with prior research,^{16,25} there was little suggestion of negative effects of risk disclosure on mental health.

The present study provides insights into the generalizability of disclosure attitudes among the KADRC participants to

Table 3. Comparison Between All Preintervention KADRC and TAPS Participants on Disclosure Preferences

Item	KADRC Overall		TAPS "Specialized" Sample	
	Mean (SD) ^a	%(No./TotalNo.) ^b	Mean (SD) ^a	%(No./TotalNo.) ^b
Interest in disclosure				
Regardless of whether there is a treatment	4.26 (1.01)	55.1 (119/216)	3.90 (1.23)	43.5 (40/92)
If there was an effective treatment	4.47 (0.87)	64.8 (140/216)	4.43 (0.92)	64.8 (59/91)
If I learn or suspect I am at high risk of AD dementia				
I will pursue participation in a clinical trial	4.05 (0.93)	36.9 (80/217)	4.08 (1.17)	48.9 (45/92)
I will consider purchasing or increasing long-term care insurance	3.31 (1.15)	18.7 (38/203)	3.85 (1.11)	30.8 (28/91)
I would adopt a healthier lifestyle	4.00 (1.00)	34.7 (75/216)	4.31 (0.75)	46.7 (43/92)
		TAPS "Likely" Sample	TAPS Overall	
Interest in disclosure				
Regardless of whether there is a treatment	3.50 (1.45)	34.6 (71/205)	2.90 (1.25)	12.5 (174/1389)
If there was an effective treatment	4.17 (1.23)	59.9 (124/207)	3.51 (1.33)	30.8 (431/1399)
If I learn or suspect I am at high risk of AD dementia				
I will pursue participation in a clinical trial	4.05 (1.07)	43.0 (89/207)	3.54 (1.02)	16.8 (235/1399)
I will consider purchasing or increasing long-term care insurance	3.90 (1.07)	34.1 (70/205)	3.67 (0.91)	17.0 (235/1381)
I would adopt a healthier lifestyle	4.24 (0.86)	46.6 (95/204)	3.99 (0.85)	29.1 (405/1391)

Abbreviations: AD, Alzheimer disease; KADRC, Knight Alzheimer Disease Research Center; TAPS, The American Panel Survey.

^a On a 5-point Likert-type scale, ranging from 1 (not at all interested or strongly

disagree) to 5 (extremely interested or strongly agree).

^b Refers to the proportion of respondents reporting the upper response choice (extremely interested or strongly agree).

Table 5. Ordinal Logistic Regression of Variables Predicting Postintervention Interest in Disclosure in the KADRC Sample

Predictor	Estimate (SE)	Exponentiated β	P Value
Preintervention interest ^a	1.36 (0.18)	3.91	<.001
Experimental group assignment	0.70 (0.29)	2.01	.02

Abbreviation: KADRC, Knight Alzheimer Disease Research Center.

^a On a 5-point Likert-type scale.

the broader population. Compared with the KADRC sample, participants in the full TAPS sample reported lower interest in disclosure, potentially because of less knowledge about the disease, young mean age (and therefore lower perceived threat of dementia), or minimal experience with AD (eg, 6.4% [91 of 1418] reported a parent with AD compared with 50.2% [110 of 219] of the KADRC sample). Interest among participants in the “likely” and “specialized” samples was higher, with the latter group resembling the KADRC sample in disclosure attitudes (Table 3). Furthermore, TAPS study results suggest that the KADRC sample is generalizable to the pool of potential AD research participants. Because these individuals are generally in favor of disclosure, it is possible that continuing policies in which results are not disclosed to participants may lead to difficulty in recruiting large cohorts of research participants from the general public.

The debate surrounding disclosure of research results is evolving as biomarker tests are refined. Although biomarker results can become positive as much as 20 years before symptom onset,^{19,20} there are emerging cohorts of older participants who remain cognitively normal despite long-standing biomarker positivity, raising important questions about the validity and reliability of current measurements.^{21,22} However, other research has produced continued improvement²⁶⁻³¹ in the reliability and validity of biomarkers commonly used in research settings. A central challenge for researchers will be to design education materials that reflect the scientific and ethical complexity of disclosing results. Educational programs could incorporate levels of prior knowledge, experience with AD, and subjective risk by tailoring material to individual needs and preferences.³² In addition, participant meetings could be an effective and inexpensive method to educate participants

about potential benefits and limitations of learning research information and to create a forum for participants to express evolving attitudes and preferences about receiving results.

This study has some limitations. First, because the KADRC currently operates under a policy of nondisclosure of research results, it is not possible at this time to know whether participants might have responded differently if provided the opportunity to learn their results. Additional longitudinal behavioral research is needed to understand how participants react to actual biomarker disclosure. Second, the design of the survey and intervention for the KADRC sample may have influenced participant responses. The preintervention survey included questions that might have primed participants to some of the content of the education intervention. This sensitization could have affected participants' perception of the education intervention and influenced responses on the postintervention survey. Future research should reflect how disclosure is likely to operate in practice (ie, presentation of an education program, followed by solicitation of disclosure preferences).

Conclusions

Researchers rely on participation of cognitively normal individuals who may be at risk of AD. The present study addresses the limited generalizability of previous disclosure studies by comparing the attitudes among groups of individuals who vary in their likelihood of participating in longitudinal AD research. Successful recruitment and sound ethical policies will depend, in part, on investigators' consideration of the preferences of current and potential research participants.

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