

Featured Article

A survey of knowledge and views concerning genetic and amyloid positron emission tomography status disclosure

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Abstract

Introduction: This survey characterizes viewpoints of cognitively intact at-risk participants in an Alzheimer Prevention Registry if given the opportunity to learn their genetic and amyloid positron emission tomography (PET) status.

Methods: A total of 207 participants were offered a 25-item survey. They were asked if they wished to know their apolipoprotein E (APOE) and amyloid PET status and if so, reasons for wanting to know, or not, and the effects of such information on life plans.

Results: One hundred sixty-four (79.2%) of the registrants completed the survey. Among those who were unaware of their APOE or amyloid PET results, 80% desired to know this information. The most common reasons for wanting disclosure were to participate in research, arrange personal affairs, prepare family for illness, and move life plans closer into the future. When asked if disclosure would help with making plans to end one's life when starting to lose their memory, 12.7% versus 11.5% responded yes for APOE and amyloid PET disclosures, respectively. Disclosure of these test results, if required for participation in a clinical trial, would make 15% of the people less likely to participate. Likelihood of participation in prevention research and the desire to know test results were not related to scores on brief tests of knowledge about the tests.

Discussion: These results suggest that stakeholders in AD prevention research generally wish to know biological test information about their risk for developing AD to assist in making life plans.

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Keywords:

Alzheimer; Prevention; Amyloid; PET; Apolipoprotein E; Survey; Clinical trials

1. Background

Owing to the advent of potentially disease-modifying drugs that are now in clinical trials for Alzheimer's disease (AD), there is great interest in identifying those in the prodromal [1] or preclinical [2] stage of the illness who may benefit most from such interventions. Identification of the most appropriate and willing subjects for these trials requires

large outreach programs and prescreening activities by research sites. Family members of those afflicted with AD are among the largest segment of stakeholders who are most interested in possibly participating in these trials.

To accomplish the major task of identifying potential participants for prevention trials from the population, a number of centers have established registries, either using large scale web-based outreach, such as the Alzheimer's Prevention Initiative based in Arizona [3,4], or more localized community efforts, such as the Alzheimer's Disease Prevention Registry at Duke University [5] and the Wisconsin Registry for Alzheimer's Prevention [6].

Selection of prevention trial participants from such registries then rely on risk stratification. Diagnostic biomarker

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tests, such as amyloid positron emission tomography (PET) imaging, and genetic risk factor tests for apolipoprotein E (*APOE*) genotype offer a means of reliably identifying people at significant risk of developing Alzheimer's disease, but it is unclear how potential and already enrolled research participants feel about their use if and when they personally learn of the results [7,8]. Furthermore, ethical concerns have been raised [9], including enablement for pre-emptive suicide when people learn of risk information while they are still cognitively intact enough to make such plans [10]. On the other hand, there is also the potential benefit that learning about risk for the disease will motivate individuals to make important lifestyle changes to reduce risk.

Therefore, we carried out a survey of people in the Rhode Island Alzheimer Prevention Registry (RIPR) aiming to understand the viewpoints of cognitively intact people if given the opportunity to learn their *APOE* genetic status and amyloid PET status in a research setting. Although previous surveys have begun to address these topics in more general samples, our study examined individuals who were specifically interested in participating in prevention research and who had high rates of concern about developing Alzheimer's disease or dementia.

2. Methods

RIPR was established in 2012 with the support of an infrastructure grant under the Alzheimer's Disease Cooperative Study with the goal of enlisting people in the community with normal cognitive and daily living function who are interested in participating in Alzheimer prevention research. The RIPR is included in the Rhode Island State Plan for Alzheimer's Disease [11] that was instituted in response to the National Plan to Address Alzheimer's Disease [12]. Participants are recruited by various community outreach efforts such as public presentations and advertisements as well as directly from the family and friends of patients attending the Rhode Island Hospital Alzheimer's Disease and Memory Disorders Center, a large hospital-based tertiary diagnostic and treatment center that receives referrals from the southeastern New England area.

Participants are invited to come for an office visit, for cognitive and *APOE* genetic testing, but this office visit is not required. Of the people who have enlisted in the RIPR, 90.2% have completed the office visit to date, with the remainder yet to be scheduled or refused due to inconvenience on the part of the participant. All participants sign an informed consent approved by the Rhode Island Hospital Institutional Review Board. All participants are interviewed by phone, and basic demographic information is collected as well as information on exercise, diet, and family history of dementia. Medical and psychiatric history and medication usage data are collected as well. Exclusion criteria include diagnosis of Alzheimer's disease or any dementia disorder, diagnosis of a major psychiatric condition that could impair cognition, including alcoholism by *Diagnostic and*

Statistical Manual of Mental Disorders, 4th Edition criteria, diagnosis of mental retardation, Down's syndrome, or other major learning disability, education <6 years, non-English speaking, other neurologic disorder that affects cognitive (e.g., traumatic brain injury, stroke, Parkinson's disease), and age <45 years.

The Minnesota Cognitive Acuity Screen (MCAS) [13] is a cognitive screening instrument administered by phone to further exclude those likely to have dementia. Those in the range of mild cognitive impairment on this scale are not excluded. The MCAS has been shown to have good discrimination function between AD, mild cognitive impairment (MCI), and normal subjects [14,15] when used by telephone, and it has also been shown to have predictive ability for functional decline and conversion to dementia in one longitudinal study [16]. Among current registry participants, 16.7% are classified as MCI and the rest as being cognitively normal, using established cutoff scores for the MCAS.

The 207 people enrolled in the registry as of October 2014 were offered an anonymous 25-item survey to complete on paper or online. No standard educational materials were provided to participants before completing the survey. Questions were asked about whether participants knew or wished to know their *APOE* genetic status and amyloid PET status and if so, their reasons for wanting to know, or not, and the effects of such information on their beliefs and life plans.

Other questions assessed demographic items as well as their knowledge about *APOE* and amyloid PET. Knowledge questions about *APOE* status included these true or false statements about *APOE*: (1) Is a genetic risk factor for Alzheimer's disease. If you have this risk factor, you will definitely get Alzheimer's disease if you live long enough; (2) Is a genetic risk factor. If you have this risk factor, you are more likely to get Alzheimer's disease than those who do not; (3) Has not yet been established to be a risk factor for developing Alzheimer's disease; (4) Is commercially available; and (5) Is routinely done as part of the diagnostic evaluation for Alzheimer's disease performed by most physicians. Knowledge questions about amyloid PET included these true or false statements about *APOE*: (1) Is a brain imaging test that is used to diagnose dementia; (2) Is a brain imaging test that can be used to help rule out or exclude Alzheimer's disease as the cause of dementia; (3) Is a brain imaging test that can reliably demonstrate if there are significant amounts of amyloid plaques in the brain; (4) If showing no amyloid in the brain, means you will not develop Alzheimer's dementia; (5) Is commercially available; and (6) Is routinely done as part of the diagnostic evaluation for Alzheimer's disease performed by most physicians.

Before development of the survey questions, the medical literature on the topics of disclosure of *APOE* and amyloid PET status was reviewed by examining all articles in the English language from a search of PubMed over 10 years plus meeting abstracts during the past year. For sake of comparison, questions regarding reasons for wanting to know

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