Prevention Registry website (www.endALZnow.org) provided us the opportunity to determine levels of interest in the general population for presymptomatic testing and to correlate interest with basic demographic characteristics. Results: Of 2135 total respondents in its first month, 99% were high school graduates and 70% were college graduates. 68.5% were self-described as professional, and another 21% as managers or self-employed. 92.7% reported a parent and 58.8% a sibling with AD. Fear of AD (80.6%) exceeded cancer (12%), stroke (5.3%), and heart attack (2.1%). 80% wanted genetic testing if paid by insurance; 54% if it would cost them at least \$100. The most common reasons for not wanting genetic testing were personal fear of the possible results (29.6%) and fear it might hurt their insurability (15.7%). 78.2% stated they would want biomarker testing (mainly PET but not spinal taps) to detect signs of AD years before the onset of symptoms even in the absence of an effective prevention therapy. If found to be at high risk for Alzheimer's disease, 13.2% would "seriously consider suicide," 18.8% would spend all their money doing what they always wanted. 75.7% would obtain long term care insurance and 89.2% would pursue a healthier lifestyle. The implications of a positive APOE test were incorrectly understood by 12.7%; and 17.6% would interpret a positive biomarker test as evidence of having AD now. Conclusions: Responders were highly educated, specifically interested in AD, and generally wanting preclinical testing. However over 10% misunderstand the implications of genetic and biomarker testing, and over 10% would "seriously consider suicide" if given "bad news."

O3-12-02

PERSPECTIVES ON THE BENEFITS AND HARMS OF PRECLINICAL TESTING FOR ALZHEIMER'S DISEASE

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Background: Patient and family perspectives regarding potential benefits or harms of beta-amyloid biomarkers for Alzheimer's disease in asymptomatic individuals are currently unknown. Recently published criteria deem the use of PET amyloid for asymptomatic individuals inappropriate at this time point. Yet, consideration of patient and family member perspectives is critical as clinicians and researchers contemplate asymptomatic testing. A positive amyloid test could have psychological, financial, legal and social consequences for patients and families. Patient and family perspectives (including goals, values, and concerns) will serve an important role in determining the potential benefit of preclinical information. This exploratory study identifies core themes relating to family members' perspectives about potential benefits and harms of asymptomatic testing for biomarkers associated with Alzheimer's disease. Methods: 14 semi-structured interviews were conducted and analyzed for family members of patients diagnosed with Alzheimer's dementia or mild cognitive impairment. Using inductive qualitative methods investigators analyzed recorded and transcribed interviews to identify themes given by interviewees including whether participants classified knowing of a preclinical status as beneficial. Research was conducted with IRB approval. Results: Half of the participants reported that preclinical testing would be beneficial, where beneficial is defined as the potential benefits of knowing the information would outweigh potential harms. Participants identifying potential benefits focused on what they could do with the information. Classification of benefits included themes of seeking treatment, altering lifestyle, and preparation for loss of cognition. Participants identifying harm focused on the psychological impact of the information. Classification of potential harms included worry, anxiety, or depression. Life philosophy and experiences shaped participants' perspectives. Conclusions: Family members provide unique insight into how potential benefits and harms may relate to patient and family outcomes. These outcomes and patient and family perspectives should be foundational to implementing clinical amyloid testing in asymptomatic individuals. These perspectives can inform: (1) the importance of treatment options in justifying asymptomatic testing, (2) the informed consent process, and (3) the disclosure process. O3-12-03

THE PSYCHOLOGICAL IMPACT OF GENETIC RISK INFORMATION ON INDIVIDUALS WITH MILD COGNITIVE IMPAIRMENT AT IMMINENT RISK FOR CONVERSION TO ALZHEIMER'S DISEASE DEMENTIA: FINDINGS FROM THE REVEAL STUDY

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Background: Given advances in AD treatment, APOE genotyping may aid clinical practice by identifying patients at different levels of risk for AD conversion. Prior work showed that AD genetic risk information did not pose psychological risks to volunteer populations who are many years away from disease onset, but little is known about its impact on MCI patients at substantially increased risk of AD conversion in the near future or their care partners. Methods: Amnestic MCI patients were randomized to receive 3-year AD risk estimates (range: 8-57%) based on age and MCI diagnosis alone, or based on those factors and APOE genotype. To date, 6-week follow-up data has been collected from 61 patients (mean age 72; 46% male; 18% Black) and study partners (typically a spouse or adult child, mean age: 64, 32% male, 16% Black). Anxiety and depression were assessed using short forms of the State-Trait Anxiety Inventory (STAI) and the Geriatric Depression Rating Scale (GDRS). Test-related distress was assessed using the Impact of Events Scale (IES). Results: Among patients, 6-week mood scores were substantially below cutoffs for concern for both the genotyped group (STAI=11.7, GDRS=1.9, IES=11.4) and control group (STAI=11.9, GDRS=2.7, IES=15.7). Differences in changes to STAI and GDRS scores by randomization arm or genotype were not observed. However, IES scores 3-days post-disclosure were greater among \(\varepsilon 4\)-positive patients than control arm patients $(\Delta=5.9, p=.04)$ and ε 4-negative patients ($\Delta=7.3, p=.02$), while differences were not observed at the 6-week follow-up. Among study partners, differences to changes in STAI and GDRS scores were not observed by randomization arm, but IES scores of e4-positive patients were greater than e4-negative patients 3-days post-disclosure (Δ =8.4, p=.01). Differences in IES scores by randomization arm or patient genotype among study partners were not observed at the 6-week follow-up. Conclusions: Genetic risk information about imminent AD conversion does not pose significant short-term psychological risks to MCI patients or study partners. Test-related distress in the immediate aftermath of risk disclosure was greater among \(\epsilon 4-\text{positive partici-} \) pants and study partners, but this effect was transient. Results are consistent with prior work on healthy adults, and extend those findings to potential caregivers.

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USING A COMMON SENSE MODEL TO PREDICT WILLINGNESS TO BE SCREENED FOR MILD COGNITIVE IMPAIRMENT IN A COMMUNITY SAMPLE OF AFRICAN-AMERICANS

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