Penn expert addresses ethical implications of testing for Alzheimer's disease risk

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Diagnostic tests are increasingly capable of identifying plaques and tangles present in Alzheimer's disease, yet the disease remains untreatable. Questions remain about how these tests can be used in research studies examining potential interventions to treat and prevent Alzheimer's disease. Experts from the Perelman School of Medicine at the University of Pennsylvania will today participate in a panel at the Alzheimer's Association International Conference 2012 (AAIC 2012) discussing ways to ethically disclose and provide information about test results to asymptomatic older adults.

In contrast to diseases like cancer - where tumor progression and genetic markers can be measured to determine appropriate preventative steps or targeted treatments - Alzheimer's disease tests has improved diagnosis and assessment of risk, but no treatments or preventative measures are available to alter the disease progression.

Previous research has suggested that knowing biomarker results can be harmful to people at increased risk for Alzheimer's disease, potentially causing anxiety or depression.

"It is important to track the impact of revealing biomarker results to asymptomatic individuals, so we can develop and disseminate best practices," notes panelist Jason Karlawish, MD, professor in Geriatric Medicine as well as Medical Ethics and Health Policy in the Perelman School of Medicine at the University of Pennsylvania.

Since an increased risk does not mean someone will definitively get the disease, safeguards are needed to ensure individuals aren't marginalized or mistreated. While having tests available to assess risk can be helpful in diagnosing or ruling out Alzheimer's disease, there is still no consensus on how the test results will be shared with individuals, with insurance companies, and even with employers. And for those with early stages of the disease or mild cognitive impairment, standards on workplace accommodations will need to be implemented.

As researchers look to intervene in the disease as early as possible, prevention trials will need to enroll people who are at high risk for developing AD but are not suffering from symptoms. One planned prevention study will select people found to be at high risk based on amyloid imaging tests, therefore revealing test results to eligible participants. The prevention trial will also include an ethics sub-study, to gauge the emotional impact on patients learning their positive or negative amyloid status.

"This prevention trial is an excellent opportunity to better understand how older adults make sense of biomarker results and how the results impact health and overall well-being," said Karlawish, associate director of the Penn Memory Center. "Methods used for revealing genetic test results provide a template to disclose risk information to asymptomatic individuals."

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