ETHICS OF ALZHEIMER’S DISEASE TESTING

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Plasma phospholipids identify antecedent memory impairment in older adults


A blood test that may predict onset of clinical Alzheimer’s disease in 2 to 3 years with 90% accuracy. Do you want it??
Alzheimer’s disease is a complex disease with long asymptomatic preclinical phase.

The continuum of Alzheimer’s disease:

- Asymptomatic
- Early symptomatic
- Preclinical
- MCI
- AD Dementia

Source: Neurologist © 2013 Lippincott Williams & Wilkins

Sperling et al. *Alzheimer & Dementia* 2011
NIA-AA Preclinical Workgroup
Goals of testing

• Early disease identification
• Early disease treatment
• Better health care planning
Early disease identification
Early disease treatment
Advanced care planning

GOALS OF TESTING
Alzheimer’s disease testing

• Genetic testing
  – Rare autosomal dominant inheritance
  – Susceptibility gene for common form of AD (Apo E)

• Biomarkers of neurodegeneration
  – PET scan
    • Amyloid deposition
  – CSF
    • Amyloid and Tau levels
  – MR scan
    • Hippocampal atrophy
  – Peripheral markers
    • Protein
    • Micro-RNA
  – Cognitive function
Alzheimer’s disease testing

Genetic testing

Predictive test - Rare early onset cases

Susceptibility – Common late onset cases

Positive test for susceptible gene increases risk of AD for 3 to 10 folds with earlier age of onset – **NOT definite for clinical disease in a lifetime**
Alzheimer disease testing

- The most sensitive test may show neurodegeneration 20 years before symptoms occur.
- The markers that show high predictive value in a few years are likely to be associated with subtle impairments already.
- Some test are invasive, some are expensive and radioactive.
- Some people with positive biomarkers are normal in cognition.
GOALS OF TESTING

Early disease identification
Early disease treatment
Advanced care planning

Why early identification?
Curative treatment not yet available

- Available treatment is only symptomatic with no disease modifying effects
- Some protective factors
  - Lifestyle activities
  - Physical exercise
  - Cardiovascular fitness
  - Absence of depression
- Would testing results influence lifestyle or risk factor modification? Or
- Do we need a positive test result to change to a healthier lifestyle?
Curative treatments may be available??

- Earlier knowledge with special attention to research and new treatment options
- For those with availability & resources, probably a selected group in the foreseeable optimistic future
GOALS OF TESTING

Early disease identification
Early disease treatment
Better health care planning
Better Health Care Planning

- Advanced Health Care Planning
- Financial arrangements & Enduring power of attorney
- Advanced Directives
- Insurance
The other side of the story

- Psychological reactions towards positive test results
  - Depression
  - Anxiety
  - Sensitivity to subjective cognitive problems
  - Chronic depression is a risk factor for Alz Disease
- Poorer objective cognitive test results in people with known positive genetic tests
- Stigmatization
- Logistic issues
  - Health Insurance
  - Mental Capacity
Considerations

- Strong Family history
- Age
- Current cognitive functional status
- Specific concerns
  - Early treatment
  - Finance planning
- Testing
  - Sensitivity and specificity
  - Predictive value and time frame
  - Cost
  - Invasiveness
  - Potential harm (radioactivity)
Considerations – Hong Kong Chinese Community

- Strong family history
- Age
- Current cognitive functional status *(Early detection not widely known)*
- Specific concerns
  - Early treatment *(Disease modifying agents not yet available)*
  - Finance planning *(Limited community awareness)*
- Testing
  - Sensitivity and specificity
  - Predictive value and time frame *(Low prevalence of genetic susceptibility gene, Apo E, in Chinese population)*
  - Cost *(High cost prohibitive)*
  - Invasiveness *(CSF not acceptable)*
  - Potential harm *(radioactivity) *(Relative but not absolute consideration)*
THANK YOU