Ethical issues in disclosing AD biomarker results

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Conflict of Interest: Nil
• New diagnostic guidelines for “preclinical AD” of NIA-AA working group (Sperling et al, 2011) useful for research and development of disease modifying treatment => Excitement
  But
• Ethical concerns
With new imaging techniques, it is now possible to identify changes in the brain before symptoms occur. Is it ethical to provide an early diagnosis to those who do not show clinical symptoms?
Benefits of disclosure of AD biomarker results

- Subject’s right to know
- Clinical implications, e.g. early interventions
- Life planning
Ethical Concerns

Chiu & Brodaty, 2013 –

• Clinical utility of very early diagnosis, at preclinical stage is limited
• No effective disease modifying treatment
• Predictive value of biomarker results in asymptomatic people uncertain
• Possible harms of disclosure of test results. e.g. fear, anxiety, depression and suicidal behaviour
• ? effects on work, insurance, driving, family relationship
Disclosure of test results of biomarkers

• Subjects may not understand or misinterpret complex disclosed information
• Not advisable for asymptomatic subjects in general
Disclosure of test results of biomarkers

• Previously participants in research including ADNI were not informed of results unless there is clinical utility

• Recent survey of ADNI researchers shows that some support disclosure of results of amyloid imaging, but would like guidance on the process, and see a need to develop and monitor disclosure process (Shulman et al, 2013)
Disclosure of test results of biomarkers

- In special research situation, asymptomatic subjects will be informed of results e.g. the A4 trial (Anti-amyloid Treatment in Asymptomatic Alzheimer’s Disease)

=> There is a need for developing procedures for disclosure

- Beware that most studies and previous experience are from developed countries
• “Safety” of disclosure of risk may not be applicable to other countries
e.g. REVEAL study to evaluate the impact of susceptibility testing on APOE4 => suggest disclosure relatively safe, but subjects from developed country, and most are well educated; subjects with high anxiety or depression scores excluded
Disclosure of test results of biomarkers

• More studies required
• The experience of dementia have facets other than the biomedical model
• “protocol” of disclosure may need to take into consideration of socio-cultural factors
Socio-cultural Factors

• Dementia is one of the most feared disease in many countries

• The local name of dementia in many Asian countries are pejorative. In China and Hong Kong, the local name means “crazy and idiotic” => images of the very late stage of the disease, great stigma and therapeutic nihilism (Chiu et al, 2014)
• Educational level in middle-aged to older people in China and developing countries usually lower than in Western developed countries => may have difficulty in understanding complex information on risks related to AD biomarkers

• How should we convey the information on risks?
Some Cultural differences

- In Confucian philosophy in China, the moral ideal of self or personhood is the Chun-tze (superior man)
- 2 dimensions: One is an autonomous person with self-activation. Another is a relational person and personhood is socially defined in a relational context. (Tsai, 2001)
- Confucian ideal of selfhood is “harmonizing relationships” (Ho, 1995)
- Highly individualistic notion of selfhood in western culture vs indistinct boundaries of the self in Chinese and Asian culture (Chiu & Tsoh, 2009)
• Family has a central role in caregiving
• Expectations of family to be involved in the disclosure process should be considered
• e.g. Traditionally, Chinese people would ask for information of Mental disorders or serious illness in the partner for 3 generations before considering marriage
My view

• Not advisable for asymptomatic subjects in general at present

• For special situations, various stakeholders, including researchers, clinicians, participants, caregivers, regulators should be engaged in developing the protocol for disclosure and monitoring, with cultural considerations