Ethical recommendations: Patient-centered and cultural-sensitive communication about dementia prediction

Silke Schicktanz & Perla Werner

Online Symposium: Dementia Prediction and Risk Reduction – Socio-cultural Insights, Ethical Reflections and Future Developments
December 7-8 2020
Our Agenda Today

• To develop ethical guidance for clinical practice and to inform policy makers

• Preliminary: grateful for feedback
Adressing Ethical challenges

• Balancing beneficence/autonomy vs. maleficence
• Being prepared for the implementation of biomarkers in clinical routine
4 Levels of Interaction

(1) Doctor - Patient - Family
(2) Inter-professional Cooperation
(3) Public Health Promotion & media
(4) Research
(1) Doctor – Patient – Family

Communication:

• Using *sensitive language*, avoiding negative stereotypes
• Using *graphic tools* for risk information
• Conceptualizing Alzheimer’s disease as *process* & stressing *possibilities*
• Involving family: important, but the patient must authorize information sharing
Multi-step Approach to Professional Counseling

a) Flyer with basic information beforehand
b) Pre-test counseling
c) Post-test counseling
d) Evaluation of Counseling process

→ No direct-to-consumer testing
(2) Inter-professional Cooperation

- Specialized memory clinics: considering telemedicine care
- General practitioner: receiving specialized training and tools for information procedures
- Across disciplines: updating knowledge
- Social workers/psychologists: improving access for minority ethnic groups
(3) Public Health Promotion & Media

• Refraining from stigmatizing language or misleading salvations
• Explaining uncertainty and risk
• Providing evidence-based information
• Developing specialized training for journalists
• Avoiding blaming strategies or fear-based campaigns
(4) Research

• Exploring systematically short and long-term impacts on affected persons
• Examining various levels of stigma
• Paying attention to minority ethnic groups
• Clarifying ethical-legal issues of insurances
• Including target groups (healthy lay persons, relatives with/out family history, persons with MCI/SCI)
Brief Summary

• Ethical guidance for **practice-oriented** approaches

• **Procedural adaption** as part of standardization to address national and group specificities

• Broad exchange on ELSA issues: identification of consensus areas for **international** guidance
Thank you for your attention!

Project Grant No: G-1413-119.4/2017:
*Why to Know or Not to Know? Stakeholders’ Attitudes Towards Prodromal Dementia Diagnosis: Psycho-Social and Ethical Implications in Cross-Cultural Comparison* (funding period 1/2018 – 3/2021)

For more information: