



German-Israeli Foundation for Scientific Research and Development

הקרן הגרמנית ישראלית למחקר ופיתוח מדעיים

Deutsch-Israelische Stiftung fuer Wissenschaftliche Forschung und Entwicklung

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

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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

Addressing 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!



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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:

<https://egmed.uni-goettingen.de/en/research/prof-dr-silke-schicktanz/translate-to-english-altersmedizin-demenz//>

