



German-Israeli Foundation for Scientific Research and Development

הקרן הגרמנית ישראלית למחקר ופיתוח מדעיים

Deutsch-Israelische Stiftung fuer Wissenschaftliche Forschung und Entwicklung



What lies beneath?

Moral motivation regarding predictive biomarker testing and preclinical diagnosis among affected persons in Germany and Israel

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Online Symposium on Dementia Prediction and Risk Reduction
(7-8 December, 2020)



Background

- Possibility to identify persons at risk of late onset AD during the earliest, preclinical stage (Sperling et al. 2011; Dubois et al. 2016)
- Development of inexpensive blood tests for the prediction of AD
- (Rodriguez 2019; NIH 2020)
- Growing public interest



Alzheimer's blood test could predict onset up to 20 years in advance

US scientists say their blood test can be 94% effective in spotting those at risk of the illness

Kolata G. A Blood Test for Alzheimer's? It's Coming. *Scientists Report: The New York Times* 2019. <https://www.nytimes.com/2019/08/01/health/alzheimers-blood-test.html> (Accessed 26 March 2020).
Rawlinson K. Alzheimer's Blood Test Could Predict Onset up To 20 Years In Advance. *The Guardian* 2019. <https://www.theguardian.com/society/2019/aug/02/alzheimers-test-predicts-onset-up-to-20-years-in-advance> (Accessed 26 March 2020).

The New York Times

A Blood Test for Alzheimer's? It's Coming, Scientists Report

A test that measures beta amyloid protein in the blood is more accurate than a brain scan and may indicate trouble years earlier.

Study Objectives

- To explore empirically affected persons' attitudes towards dementia risk information
- To illuminate affected persons' counselling needs
- To examine whether the differences in attitudes towards AD testing exist on a cultural level

Zümrüt Alpınar-Sencan*, Silke Schicktanz*, Natalie Ulitsa, Daphna Shefet, and Perla Werner (*shared first authorship). "Moral Motivation regarding dementia risk testing among affected persons in Germany and Israel" (under review)

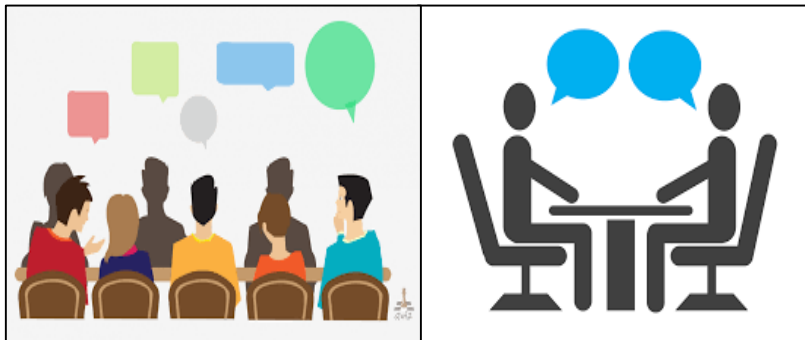


Methods

Qualitative research methods

- Focus groups and semi-structured interviews with 44 participants in Germany and 44 participants in Israel

People with Mild Neurocognitive Disorder (P_MND)



n=12 (Germany)
n=16 (Israel)

Relatives of people with Mild Neurocognitive Disorder (R_MND)



n=12 (Germany)
n=8 (Israel)

Family Caregivers (FC)



n=20 (Germany)
n=20 (Israel)

Methods

- Interview guidelines structured to focus on:
 - a) Participants' experiences and assessments of prediction and early diagnosis of dementia
 - b) Assessments of situations in which predictive results were disclosed
 - c) The impact of this information on individuals and family life
 - d) Assessments of advance directives for future care

Data Analysis

- Qualitative thematic content analysis
- Deductive and inductive coding
- Creation of an analytical matrix of ethical categories

Ethical Categories Structuring Moral Motivation

Beneficence

Assessments of benefits, risks and costs

Future-oriented responsibility

Including hypothetical outcomes regarding future events in the short or long term

Self-determination

Making one's own life decisions and honoring one's wishes

Vision of a good life

Individual perspectives on what enhances life quality and how one should live

Findings

1. Beneficence

*“There is no cure, but there are things [medications] that can slow [the progress] down.”
(Male, R_MND, Israel)”*



PROS

Potential long-term benefits of prospective risk assessment



CONS

Futility, skepticism towards predictive value of tests

*“If there is nothing you can do and I simply rush towards such a disease, then I, of course, would prefer not to know anything about it.”
(Female, FC, Germany)”*

2. Future-oriented responsibility

Responsibility for one's family

"I have a son. I don't want to burden him. [...] I want to prepare things, to set aside funds, to prepare all kinds of things." (Female, FC, Israel)"

Family's responsibility for the affected person

"I think my children are so devoted that they know exactly what to do, let's say if something happens to me. [...] I trust them! They trust me now, I'll trust them later!" (Female, FC, Israel)"

Self-responsibility

"I think it was good that I had the test. [...] Because I think that everyone should do something for her health or illness. " (Female, P_MND, Germany)"

Findings

3. Self determination

Predictive testing seen as an opportunity to strengthen one's control over one's own life through preparation for future decisions (e.g. advance care directives, planning suicide)

“For me self-rule or self-determination is the highest good of an individual [...] and nobody has the right to revise the decision that was made out of free will.” (Male, FC, German)

“[...] [I]f you indeed have the probability [...] you can think more clearly about it with a certain distance. To organize things – If there is a pill that can end one's life immediately [...]. [A]t least, I have the option to think about it.” (Female, FC, German)

4. Vision of a good life

Knowing risk or early diagnosis would spoil joy of life

“As everything I haven’t got, which I’m diagnosed with as possible, or, let me say, that I might fall ill with. That is a strain for me! [...].” (Female, R_MND, German)

Knowing risk or early diagnosis could help to improve one’s life

“[...] [If] I know it [predictive information], great, I will plan, enjoy life, travel, I will enjoy it and seize it till the end...” (Female, R_MND, Israeli)

Impact of personality

“Here the individual’s personality really enters the picture. Someone might fight it [...]. But if she’s the type who tends to depression, it’s awful.” (Female, FC, Israeli)

Discussion and Future Directions

- A mixed picture in positions for and against predictive testing and early diagnosis
- Some participants considered predictive testing and early diagnosis as an opportunity to engage in life planning
- The spectrum of moral motivation includes:
 - Aspects of personal utility
 - Ideas of responsibility between individuals and the family
 - The desire for self-determination
 - Notions of a good life

Discussion and Future Directions

- Skepticism about the predictive value of testing
 - Clinicians should ensure that tested persons understand the limits to the validity and certainty of personal risk test results
- Cultural variation in medical ethics across Germany and Israel
 - More cross-cultural comparisons to explain national-level differences

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