

MCI-PATIENTS' AND CAREGIVERS' EXPECTATIONS TOWARDS RISK PREDICTION OF AD: PRELIMINARY FINDINGS FROM THE PREDADQOL INTERVIEW STUDY



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Transnational collaborative project **PreDADQoL**

Ethical and Legal Framework for Predictive Diagnosis of Alzheimer's Disease: Quality of Life of Individuals at Risk and their Close Others

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Aims

- Examine the specific expectations of patients and caregivers towards biomarker based Alzheimer's Disease diagnosis (CSF)
- Assess the future quality of life of patients with mild cognitive impairment (MCI) and their caregivers and describe their attitude towards their current situation
- Evaluate the ethical impact of predictive knowledge

Background

- Today, a growing number of individuals with MCI specifically ask for biomarker-based prediction of (AD) and in clinical practice, doctors increasingly offer predictive diagnosis to patients

Methods

- 10 one hour episodic Interviews (Flick 1997, 2011)
- Content analysis with a focus on thematic categories
- Linguistic approach to analyze different classes of statements (Fig. 1) and phenomena which indicate attitudes and the expression of quality of life (QoL)

Statements concerning expectations towards predictive CSF biomarker-based AD diagnosis

Caregiver B (son): "I hope the test can reveal if it is something genetic."

Patient D: "If the results are more fine-grained, one can come closer to the diagnosis of dementia. I do not hope for this, that is why I stopped thinking about possible results."

Caregiver B (son): "We have to stop the decline. I would do the same test immediately if it was possible – it could show that I'm healthy."

Caregiver A (son): "I expect that the test provides clarity. If it shows what I suspect, we can start to take part in experimental pharmacological trials. I read a lot in the media about this. For all chemical processes, one can find a counterpart."

Patient E: "I expect that we can exclude dementia after the test, so that we can concentrate on other possible diseases. I expect clarity."

Caregiver C (daughter): "I expect clarity from the doctor but it is complicated with my mother. I actually know that it is dementia. After the test I expect information and provision of aids."

Patient D: "For me it was totally clear to agree to the test. I like to do everything possible to treat my disease with all possible technological possibilities."

Caregiver D (husband): "I worry about the results. They can be a burden for our relationship. I would not agree to the test if I were her. I do not believe the results will reveal something that really helps her."

Patient B: "I expect to treat my symptoms with better medication to stay at the level I am at now."

Patient C: "I'm afraid of the results and I don't want to think about what can be a result. I hope one can help me with my headaches."

Caregiver A (daughter): "I expect to learn which form of dementia my mother has or if it is only a depression."

Patient A: "I expect that they tell me I have Alzheimer's. If this comes true, I will never leave the house again."

Caregiver E (husband): "I insisted that my wife does something like this testing. We need clarity for the future and we need to know what's up with her."

Patient E: "I think this test is a good thing. Afterwards, one knows if one has this markers which indicate if something is not alright if one can do something, I mean, if it is something physical or if it is only connected to my permanent sleep deficit."

This approach is part of the PreDADQoL study

PreDADQoL study conditions

- 36 months (start 06/2016)
- Funding: BMBF, MINECO

Population

- Clinical criteria for late amnesic MCI due to AD (according to criteria of NIA-AA)
- Single or multiple domain impairment
- Age ≥ 55 years
- Reliable caregiver

PreDADQoL procedure

- Theoretical + empirical (qualitative + quantitative) approach
- Qualitative study n = 15 + 15, 2 surveys (before + 3 months after the decision for/against prediction)
- Quantitative study n = 100 + 100, 3 surveys Cologne/Barcelona

This Pre-study

- 5 patients (4F/1M), age: 55-70
- 5 caregivers (2F/3M), 2 husbands 65-80, 2 daughters + 1 son 38-45
- all levels of education, professions: teachers, care employees, housewives, civil servants, entrepreneurs

Intermediate results

- Only one in ten participants reflected the consequences of predictive knowledge for the patient and the relationships to close others
- Patients and caregivers most frequently mentioned the expectation to attain more certainty about the patients' current and future state of health. This expectation is expressed in two directions (Fig. 2)
- Patients and no less caregivers mentioned subjective theories of the health status the patient suffers from and they are looking for a confirmation of their thoughts by exclusion (Fig. 2)
- All interviewed patients showed diffuse fear of AD and knew only little about dementia
- Some Caregivers compared the MCI patients with "small children" and mentioned a change in their behavior towards the patients

Mapping attitudes and relevant topics for the future QoL in different classes of statements

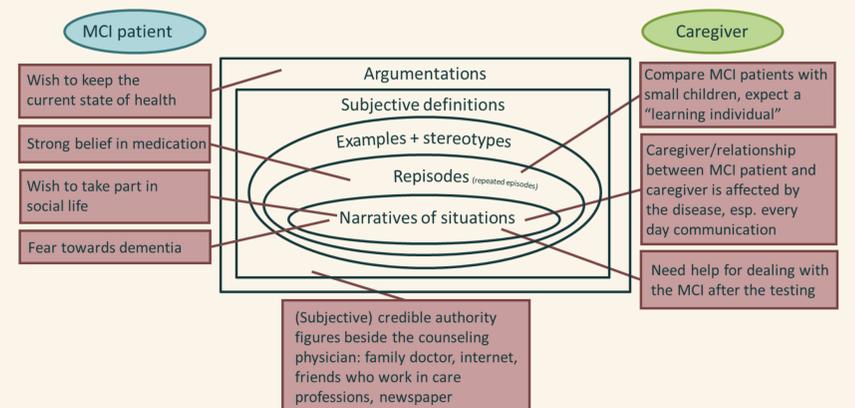


Fig. 1) Locating expressions of quality of life in different classes of statements according to Flick (2011)

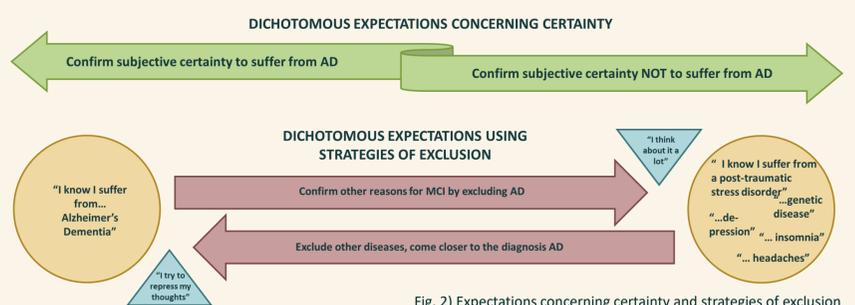


Fig. 2) Expectations concerning certainty and strategies of exclusion

Take home message

- Repression of thoughts about the consequences of predictive knowledge restricts the validity of informed consent in predictive testing. For ethical reasons, decision making with regard to possible outcomes and the impact on the life of the patients and their social environment should be an important part of the counseling process
- The counseling process for predictive testing should take into account the patients' fear and predominant expectations as well as the caregivers' need for helping information