

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

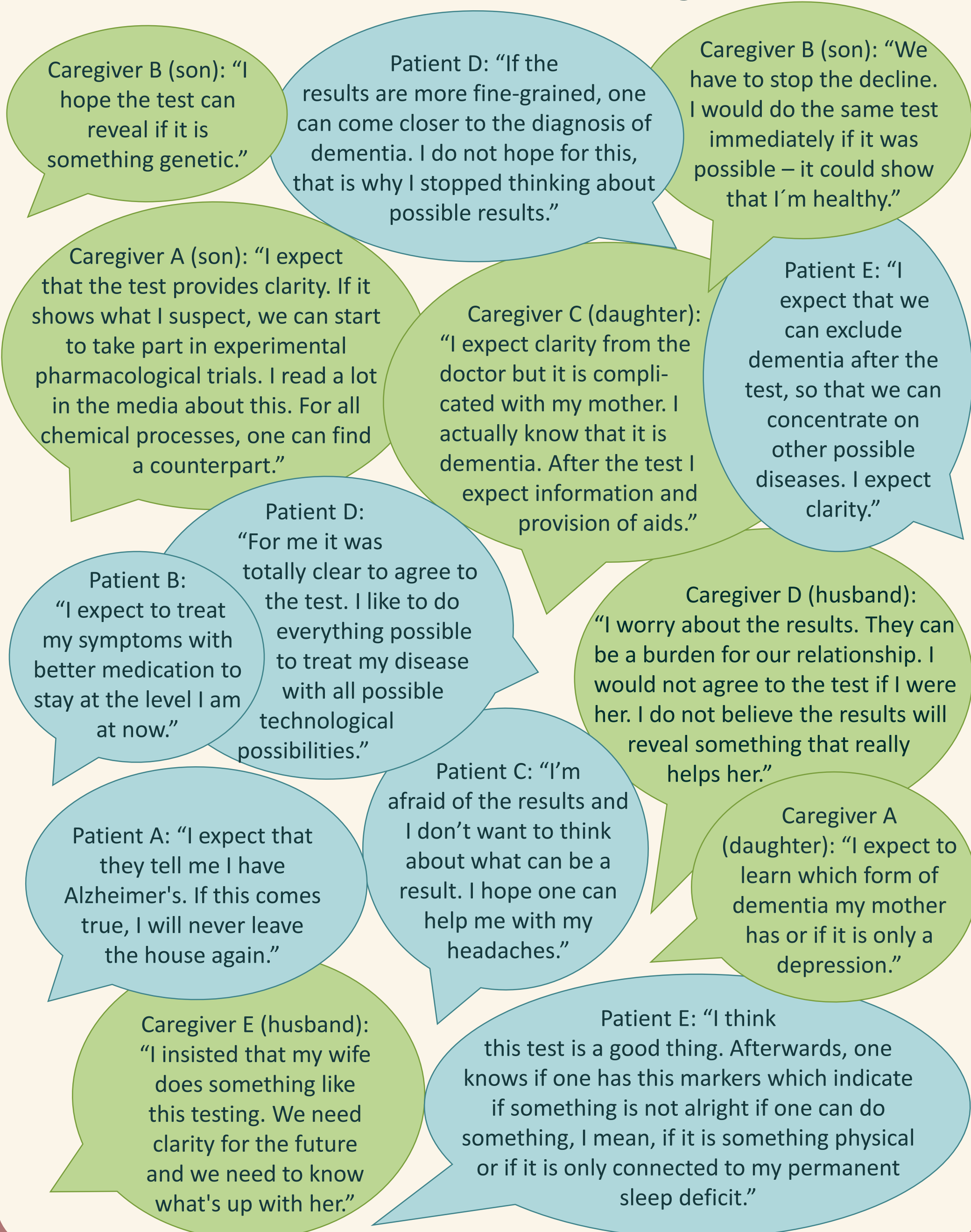
Background

- 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



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

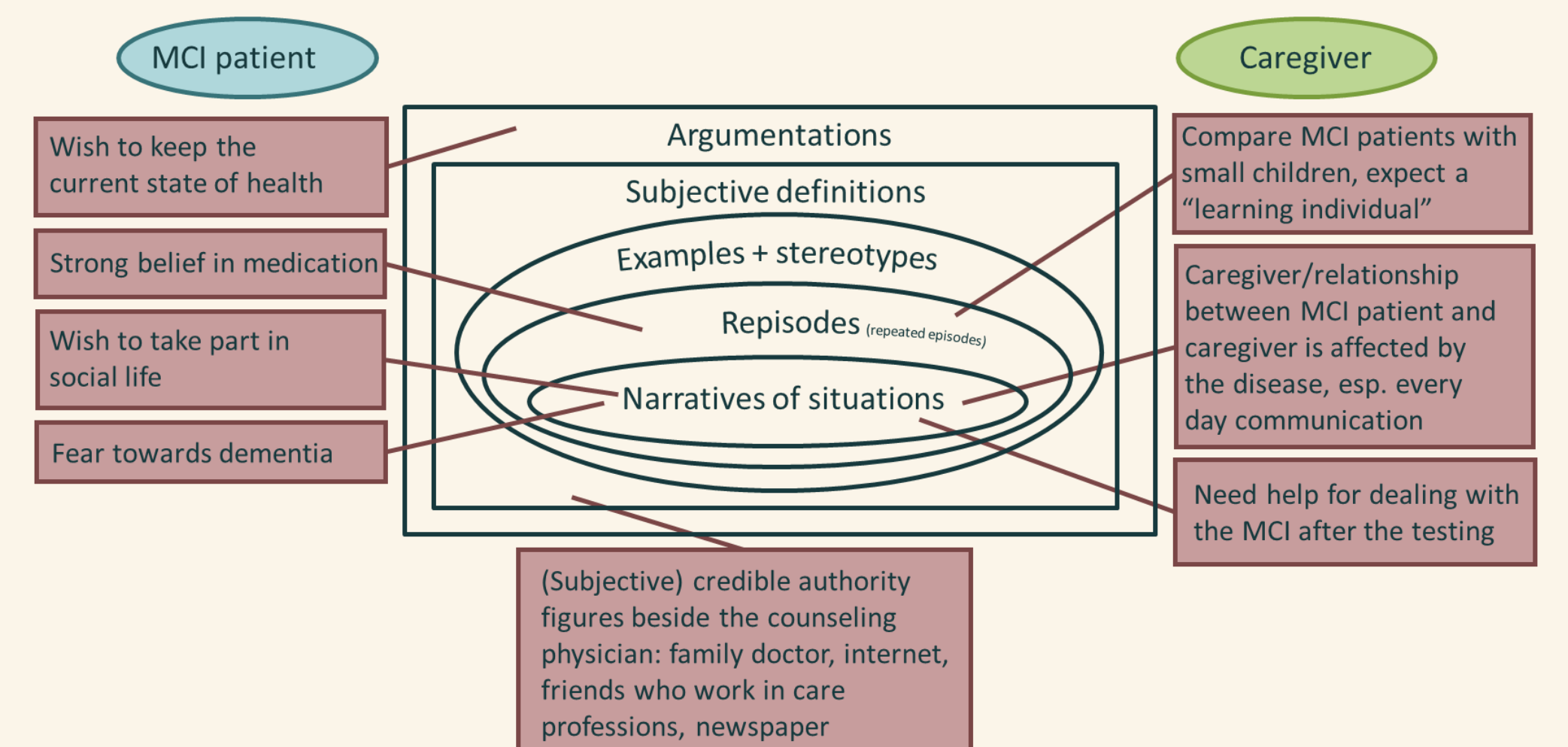


Fig. 1) Locating expressions of quality of life in different classes of statements according to Flick (2011)

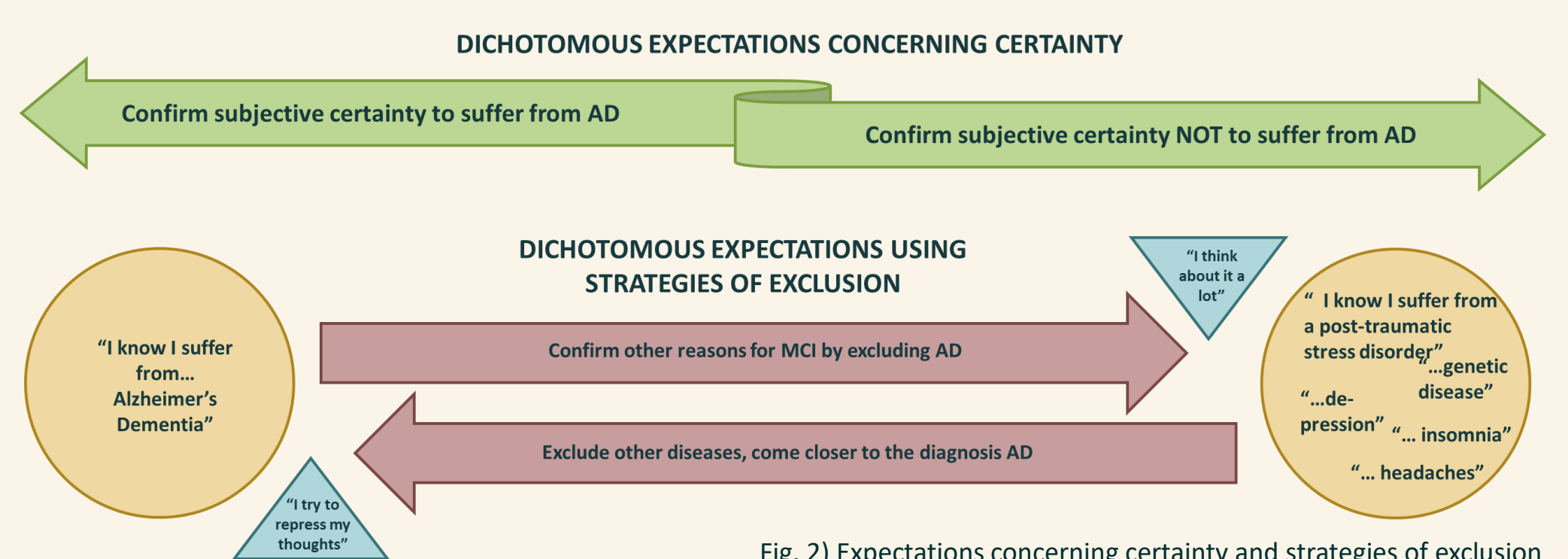


Fig. 2) Expectations concerning certainty and strategies of exclusion

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