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

- 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 it is only connected to my permanent depression.”
- Caregiver E (husband): “I expect that we can exclude dementia after the test, so that we can concentrate on other possible diseases. I expect clarity.”
- 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 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 talks.”
- Patient E: “I expect that we can stop the decline. I would do the same test immediately if it was possible – it could show that I’m healthy.”
- 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 B: “I expect to treat my symptoms with better medication to stay at the level I am at now.”
- Patient A: “I expect that they tell me I have Alzheimer’s. If this comes true, I will never leave the house again.”
- 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 talks.”

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 toward the patients

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