

Ethical and Legal Framework for Predictive Diagnosis of Alzheimer's Disease Quality of Life of Subjects at Risk and their Close Others, (PreDADQoL)

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With new bio-medical technologies, it is now possible to predict Alzheimer's Disease (AD) in elderly people with mild memory impairment. However, the prediction is not perfect; only in 80 % of the cases, the prediction is correct. Also, there is no treatment for AD available, which would delay the onset of the disease itself. Knowing in advance about a high risk to suffer from a devastating and untreatable disease can deeply impair quality of life and affects close others as well. But it can also be an important information with regard to life-decisions concerning family planning or working. On a societal level possible effects of stigmatization, discrimination and access to insurance and health care are to be considered. In this project an ethical and legal framework will be developed for prediction of AD including a guideline on how to counsel patients and their close others before and after predictive diagnosis. It will be created on theoretical grounds and based on a study in patients, which addresses the attitudes and expectations as well as the subjectively perceived consequences of predictive testing for AD in patients and their close others. The study will be performed in Germany and in Spain. A framework and guideline of this kind is urgently needed, because the worldwide usage of predictive testing in these patients is worldwide rapidly increasing.