

Participation of Stakeholders for Designing the Future in Health Decisions concerning Dementia (cumulative dissertation)

References of the published articles:

- 1) Jongsma, K., **Perry, J.***, Schicktanz, S., & Radenbach, K. (2020). Motivations for people with cognitive impairment to complete an advance research directive - a qualitative interview study. *BMC Psychiatry*, 20(1), 360. <https://doi.org/10.1186/s12888-020-02741-7>, *Karin Jongsma and Julia Perry share first authorship on this paper
- 2) **Perry, J.** (2022). Challenges of anticipation of future decisions in dementia and dementia research. *History and Philosophy of the Life Sciences*, 44(4), 62. <https://doi.org/10.1007/s40656-022-00541-8>
- 3) Wöhlke, S., & **Perry, J.** (2021). Responsibility in dealing with genetic risk information. *Social Theory & Health*, 19, 21–42. <https://doi.org/10.1057/s41285-019-00127-8>
- 4) Schicktanz, S., **Perry, J.**, Herten, B., & Stock Gissendanner, S. (2021). Demenzprädiktion als ethische Herausforderung: Stakeholder fordern Beratungsstandards für Deutschland [Dementia prediction as an ethical challenge: stakeholders demand counselling standards for Germany]. *Der Nervenarzt*, 92, 66–68. <https://doi.org/10.1007/s00115-020-00985-y>
- 5) **Perry, J.**, Brose, J., & Radenbach, R. (2023). Well Advised: The Need for Counseling in Early Stages of Alzheimer's Disease. *GeroPsych*, 36(4), 189–202. <https://doi.org/10.1024/1662-9647/a000318>

Brief outline:

1. Introduction
2. Background
 - 2.1. Dementia
 - 2.2. Medical Ethical Debates on Research Participation, Early Diagnosis, and Prediction
 - 2.3. Research Participation, Anticipation, and Counseling Needs: Decisions for the Future on the Individual Level
 - 2.4. Participation and Counseling Requirements: Decisions for the Future on the Collective Level
3. Methods
 - 3.1. In-Depth Interviews with Affected People and Caregivers
 - 3.2. Focus Groups with Experts and Lay People
 - 3.3. Qualitative Analysis
4. Results
 - 4.1. Empirical Findings (Publication 1, Publication 3, and Publication 5)
 - 4.2. Conceptual and Practical Considerations (Publication 2 und Publication 4)
5. Discussion
6. Conclusions and Future Directions

Summary:

Dementia poses social, medical, and financial challenges and has been made a global health priority. Given the current lack of effective curative treatment, the focus of dementia research has shifted towards prevention, risk prediction, and detection in very early disease stages. Standardized clinical recommendations and guidelines as well as empirical data including the perspectives of affected stakeholders are currently missing. This cumulative dissertation is made up of five scientific contributions and sets out to incorporate some of these missing perspectives by addressing ethical and social issues of dementia research participation and the use of advance research directives (ARDs), anticipation in the context of dementia and dementia research, layers of responsibility regarding predictive testing and dealing with predictive risk information, the formulation of standards in the context of dementia prediction, and concrete counseling needs for prediction and early diagnosis of Alzheimer's disease (AD).

In the first publication, I investigated how persons with initial cognitive impairment assess the introduction of ARDs, what arguments they use to support their attitudes, and, in particular, whether they can be motivated to complete such directives. In the second publication, I investigated how the practice of anticipation is challenged in the context of dementia and dementia research. For this, I considered origins and conceptual developments of anticipation in the field of sociology as well as the five key dimensions of anticipation identified by Adams et al. (2009). Further, I carried out an empirically informed analysis (see 1st publication). In the third publication, I investigated what role responsibilities play for medical laypeople in dealing with predictive testing and test results, how laypeople's responsibility and expectations are shaped in the context of predictive testing, and how different forms of responsibility become relevant for (personal and) clinical communication. In the fourth publication, relevant stakeholders' assessments of the clinical implementation of biomarkers to predict the risk of developing dementia in the future were investigated. The practical considerations are based on a stakeholder conference with experts. In the fifth publication, I investigated the current needs and expectations of affected people with initial memory disorders regarding respective counseling services in Germany after calling a provided consultation service. Further, the views of interdisciplinary counseling professionals in the context of memory clinics towards relevant aspects of counseling in prediction or early diagnosis of AD were examined.

The findings emphasize that communication and support are needed for affected individuals to make decisions that reflect their preferences and values in the context of research participation as well as in early diagnostics or prediction. Future counseling should be carried out by trained counselors and should focus on good communication so that individuals can make informed and self-determined decisions about research participation and knowing their dementia risk.