

Predicting AD Dementia Risk

An Ethical Framework for Risk Estimation in Clinical Practice

Hübner C, Braun J, Baumeister A, Schmitz-Luhn B, Woopen C, on behalf of the PreTAD Consortium
Center for Life Ethics, University of Bonn, Bonn, Germany

BACKGROUND

- Predictive approaches increasingly enable early detection of AD pathology, also in cognitively unimpaired individuals.
→ **Predictive testing is likely to expand to the broader population.**
- Deciding whether to undergo risk estimation and handling of risk knowledge affect fundamental ethical values.
→ **Currently there is no comprehensive, practice-oriented guidance for ethically sound handling of AD dementia risk estimation.**

METHODS

Empirical Analyses

- Comprehensive online survey** among the general population in Germany, Spain, and Switzerland (N=2750)
- Exploratory survey** of SCD patients and first-degree relatives (N=357)
- Qualitative interviews and body maps** with individuals with different experiences with AD dementia (N=35)

Ethico-legal Analysis

- Based on human rights and life ethics* approach
- Considered values:
 - Autonomy
 - Health
 - Privacy
 - Justice
 - Solidarity
 - Sustainability

*The ethically good means respecting or promoting the unfolding, plenitude, beauty, and embeddedness of all life (lifeethics.uni-bonn.de/en).

RESULTS

Empirical

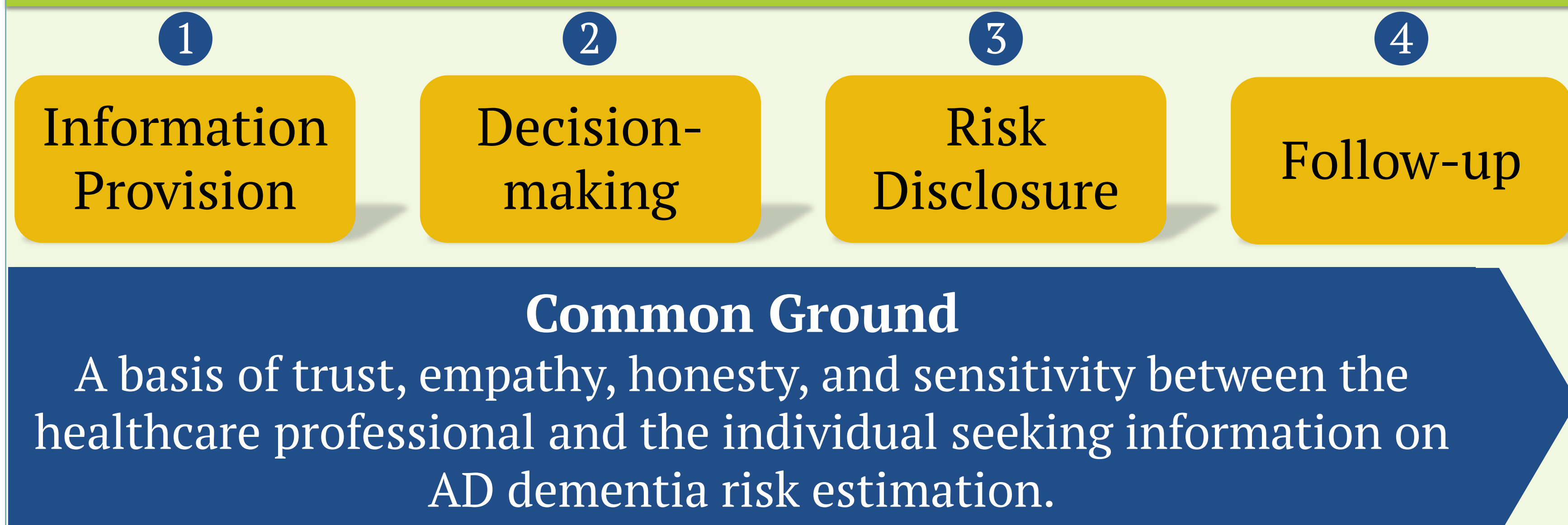
- Risk estimation and risk knowledge were perceived heterogeneously, ranging from empowerment for life planning to anticipated psychological burden, and (self-)stigmatization.
- AD dementia risk was experienced as a bodily, cognitive, and emotional phenomenon, e.g., localized in the belly or heart.

Ethico-legal

- The analysis highlighted significant uncertainties regarding indications for risk testing, standards of risk communication, and follow-up necessities relevant within clinical practice.

Therefore, we developed a...

Framework for Ethical Practice of AD Dementia Risk Estimation



CONCLUSION

- ❖ The *Ethical Framework* for handling AD dementia risk estimation in clinical practice provides practical and normative guidance along four steps of the clinical process.
- ❖ It aims to support clinicians in conducting risk estimation and communicating risk in an ethically responsible and autonomy-respecting manner.

