

Nordic AI Meet 2026

P2: AI in Health, Medicine, Care & Human Well-being

4. Data, Ethics, and Reality: AI Challenges in Late-Stage Dementia Research

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Abstract: Background. Over the past decades, Artificial Intelligence (AI) methods have been successfully applied in various domains to make predictions, assist decision making, and help understand the multitudes of data. While some accomplishments can be transferred across fields of study, certain application domains might require more caution and evaluation; this is the case for medical topics, especially when involving humans living with neurological conditions.

Objective. Identify challenges of applying AI methods in medical research for people with dementia and how it affects the study design.

Methods. The project Decoding Death and Dying in people with Dementia by Digital thanotyping (5-D) collects and utilizes data from wearable and environmental sensors in nursing homes to study the symptoms of residents with advanced dementia and investigate disease progression toward the end of life. We analyzed the compatibility of AI methods with the project hypothesis, requirements, and clinical methodology. We identified crucial points that affect the application of classic widespread approaches such as machine learning (ML) or deep neural networks (DNN).

Results. First, many AI methods depend greatly on the data they use.

5-D is centered around human-generated physiological data. Its sensitive nature makes it extremely difficult to build a large and representative enough dataset to be reliable for ML. We argue here that the understanding of "big" data in medicine can diverge greatly from the conventional. Bias (incorrect representation of demographics, varying symptoms and etiology) can lead to false generalizations, inaccurate conclusions, and faulty pattern learning. We thus underline the importance of considering and measuring the richness and informativeness of the data.

Second, quality of the data and annotations is critical. Here, we emphasize the potentially disordered and heterogeneous nature of the data. The datasets can contain a lot of noise and outliers and may be challenging to label due to subjectivity of human evaluators on aspects like symptoms. The absence of high-resolution data labels can become prohibitive to the use of supervised ML. Oftentimes, there is no "ideal" or "expected" data pattern representing a clinical outcome, as behaviors can be highly dissimilar and varied.

Third, transparency, explainability and trustworthiness must be considered. The results must be understood by clinical staff and conform to the reliability needs for decision-making. A vast majority of popular AI methods are difficult to interpret due to their black-box nature and post-hoc explainability methods (e.g., SHAP, LIME) have limitations. Furthermore, the EU/EEA legislation considers many AI applications in medicine high-risk and requires additional safety and transparency.

Conclusion. We discuss applying popular AI methods to the medical domain and urge to acknowledge the subsequent challenges.