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POSTER ABSTRACT

Social and Psychological Long-Term Consequences of NMDA Receptor Encephalitis (SAPIENCE) - from patients' views to patient-centred care

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Background and target population: NMDA receptor encephalitis is a rare autoimmune disease with severe neurological and neuropsychiatric symptoms but typically a good functional neurological outcome. Nevertheless, most patients suffer long-term cognitive, psychological, and social impairments that have a significant impact on their well-being and occupational or educational activities-this is of particular concern given the young age of patients (median 21 years). However, because the disease was only recently discovered (2007), these psychosocial effects have not been systematically studied and the resulting impact on patients is not adequately appreciated. The SAPIENCE study is an international scientific project funded by the European Joint Program that aims to characterize the long-term cognitive and psychosocial consequences of this rare disease. The leader of the consortium is Prof. Carsten Finke, Charite Berlin. The Polish team, coordinated by Prof. Donata Kurpas, is responsible for the development of standard protocols, monitoring and training of staff in the study centers where the data are collected, and the corresponding qualitative data analysis.

Study Design/Methods: Patients will be extensively studied at three European study sites in three consecutive project levels. Stage 1 includes in-depth on-site interviews and focus groups (n=30). Stage 2 develops a semi-structured short-form interview and includes on-site neuropsychological testing (n=150). Stage 3 includes an international online survey of patient-reported outcome measures (PROMs), patient-reported experience measures (PREMs), and disease progression information (n=300). Stages 1-3 will support each other in developing structured interviews, survey questions, and treatment guidelines.

Results/Outcomes: At Level 1, we will identify themes and narratives that influence patients' quality of life and their experience of coping with the disease. At Level 2, we will identify neuropsychological outcomes in the largest cohort of NMDAR encephalitis patients in the world to date, including executive function, memory, and spatial navigation performance, which have

been identified as key areas of impairment. At Level 3, we will examine subjective outcomes and individual predictors of post-acute disease progression.

Based on Stages 1-3, we will develop international consensus guidelines for post-acute care of NMDARE patients.

Impact: This project is the first to bridge the gap between standardized assessment and individual patient experience in the long-term follow-up of patients with autoimmune encephalitis. By incorporating the patient perspective into medical decision-making, current and future NMDAR encephalitis patients will benefit from the implementation of the diagnostic and treatment guidelines developed in this project for patient-centered post-acute care.