Data-Driven Personas to Inform an E-Health Tool for Mood Management in Newly Diagnosed People with Parkinson's Disease (PwPD)

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Newly diagnosed People with Parkinson's Disease (PwPD) frequently experience emotional stress following the realization of the new diagnosis [1]. They are left alone to cope with negative emotions such as fear and anxiety, which could be overlaid by disease-specific non-motor symptoms such as depression and fatigue [2]. Understanding the profiles of mood changes helps us design and develop targeted digital educational information and coaching offers to support this vulnerable population in managing their current mood changes and adopting preventive self-care strategies.
We will investigate the Luxembourg Parkinson Study cohort (LuxPARK) [3], consisting of 1020 patients and 887 controls over 9 years. The aim is to characterize mood impairments in early Parkinson's disease and understand the changes over time. We will analyze mood-related measures (e.g., BDI), motor symptoms (e.g., MDS-UPDRS), and additional relevant clinical and psychosocial metrics. The most common profiles of (mood) symptoms will be identified. This will provide a clinically solid foundation to develop data personas, i.e., typical profiles of target users, and a novel approach to the participatory design of e-health tools [4, 5].
A mixed-methods clustering analysis will be performed on 487 [3]newly diagnosed (within the past two years) PwPD and 90 follow-ups. The identified clusters will reveal subgroups of patients (fewer than 10 personas [6]) with shared characteristics and typical mood-related challenges and support needs [7].
The findings will contribute to designing targeted educational content that will increase awareness of mood management and prevention strategies thus leading to a higher QoL in PwPD.

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