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CONFERENCE ABSTRACT

Co-creating a learning curriculum for professionals working with and people living with Parkinson's disease from an integrated care approach – SUPER project experience.

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Introduction: Integrated care (IC) aims the delivery of effective management of Parkinson's Disease (PD) to minimize disability and potentially improve long-term outcomes, which would minimize long-term and costs and resource utilization.

Target Population: The target population is the members of multidisciplinary care teams to have the most detailed knowledge of IC models adapted to the real needs of PD patients and their relatives/caregivers.

Population involvement: Qualitative methods (focus groups/interviews) not only of the health and social care professionals but also other relevant key informants such as PD patients and their relatives/caregivers have promoted direct involvement in the co-creation process of the curriculum.

Methodology: Common guidelines were designed to conduct the co-production sessions, data collection, and reporting. A total of 66 participants have participated in 7 focus groups (FG) (43 participants) and in 6 interviews (I) across Spain (FG= 4), Italy (FG= 3, I=2), UK (I=3), and Ireland (I=1). Meetings were planned to be face-to-face (FG=7, I=1), but to facilitate participation they were also carried out online (I=5). By profile, 39 participants were care team members, 13 PD patients, and 14 caregivers/relatives. ISRAA (Italy) conducted the analysis and discussed, and they were discussed and agreed upon by the consortium partners, and co-validated in a final consultation with key informants.

Results: PD patients (8 men and 5 women) and caregivers (2 men and 12 women) cross-nationally reached similar agreements. The main need was about being more informed on PD. A lack of social and psychological consideration aspects and they only focused on the clinical ones. When seeking emotional support PD patients and caregivers did not feel directed to the right source. It was difficult for PD patients to assume the degenerative aspect of PD. Carers didn't receive guidelines to manage complex situations as the disease progresses, but they received good support from Parkinson's Associations. Among the care team members (22 women and 14 men). Italian professionals stated that they deliver integrated care. Professionals from Spain, Ireland, and the UK stated that they are aware of the use of an IC approach, but there is a lack in professional implementation. Professionals agree that there is a lack of training opportunities on IC for PD. Communication should be improved in a multidisciplinary way, establishing person-centred care pathways, and holistically considering patients and caregivers.

Lessons learned: A digital training curriculum for a PD professionals-based IC approach should include guidelines in three main areas: (1) PD medical, clinical aspects and treatments, (2) PD psycho-social resources for patients and caregivers, (3) IC for PD.

Next Steps: The SUPER project platform with training materials will be available to be tested with care team members.