OPTICARE

Optimizing Care for Patients with Neurodegenerative Diseases: Socially Embedded and Patient-Centered Long-Term Care

Neurodegenerative diseases such as Parkinson's disease and Alzheimer's disease are among the fastest growing causes of disability worldwide. In their advanced and late stages, these conditions are characterized not only by progressive cognitive and functional decline, but also by increasing care complexity, frequent care transitions, and a high likelihood of institutional long-term care. Across health systems, long-term care for people with neurodegenerative diseases is often fragmented, insufficiently integrated across medical, nursing, and social domains, and poorly aligned with the lived needs of patients, informal caregivers, and healthcare professionals. The systemic, ethical, and organizational determinants of these shortcomings remain insufficiently understood, particularly in cross-national comparison.

OPTICARE (Optimizing Care for Patients with Neurodegenerative Diseases) addresses this gap by developing socially embedded, patient-centered, and co-created approaches to optimize institutional long-term care for individuals with advanced neurodegenerative diseases such as Parkinson's and Alzheimer's disease. In particular, the project will look into how quality of life and care continuity in long-term care are shaped by the interaction of care structures, stakeholder experiences, and legal–policy frameworks, and what ethically informed and governance-relevant improvement can be derived from their joint analysis.

Using a mixed-methods, multi-country design across five healthcare systems, OPTICARE combines (i) comparative mapping of long-term care structures and care trajectories, (ii) qualitative investigation of lived experiences through interviews, ethnographic observation, and participatory co-design with patients, caregivers, health care professionals, and system stakeholders, (iii) standardized quantitative assessment of quality of life, cognitive status, care integration, and caregiver burden, and (iv) cross-national ethical, legal, and policy analysis. These strands are systematically integrated to identify unmet needs, structural barriers, and context-sensitive leverage points for improvement.

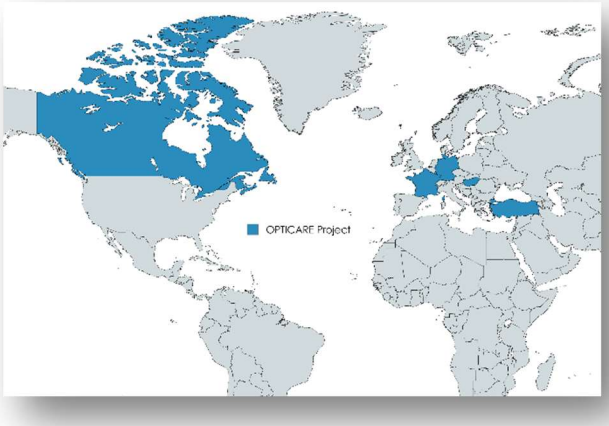
OPTICARE will generate empirically grounded, ethically robust, and policy-relevant recommendations to enhance care coordination, interdisciplinary collaboration, and governance of institutional long-term care. By translating stakeholder-informed insights into practicable models and policy guidance, the project aims to contribute to sustainable, adaptable, and rights-based long-term care systems that prioritize quality of life for people living with advanced neurodegenerative diseases and those who care for them.

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