

Neuropalliative Care in Patients with Progressive Neurological Disease in Czech Republic: Study Protocol

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Abstract : Introduction: Currently, there has been an increasing concern about the provision of palliative care in non-oncological patients in both professional literature and clinical practice. However, there is not much scientific information on how to provide neurological and palliative care together. The main objective of the project is to create and to verify a concept of neuro-palliative and rehabilitative care for patients with selected neurological diseases in an advanced stage of the disease and also to evaluate bio-psychosocial and spiritual needs of these patients and their caregivers related to the quality of life using created standardized tools. Methodology: Triangulation of research methods (qualitative and quantitative) will be used. A concept of care and assessment tools will be developed by analyzing interviews and focus groups. Qualitative data will be analyzed using grounded theory. The concept of care will be tested in the context of the intervention study. Using quantitative analysis, we will assess the effect of an intervention provided on the saturation of needs, quality of life, and quality of care. A research sample will be made up of the patients with selected neurological diseases (Parkinson's syndrome, motor neuron disease, multiple sclerosis, Huntington's disease), together with patients' family members. Based on the results, educational materials and a certified course for health care professionals will be created. Findings: Based on qualitative data analysis, we will propose the concept of integrated care model combining neurological, rehabilitative and specialist palliative care for patients with selected neurological diseases in different settings of care and services. Patients' needs related to quality of life will be described by newly created and validated measuring tools before the start of intervention (application of neuro-palliative and palliative approach) and then in the time interval. Conclusion: Based on the results, educational materials and a certified course for doctors and health care professionals will be created.

Keywords : multidisciplinary approach, neuropalliative care, research, quality of life

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