"Deep in the brain" – Individual case study on the decision-making process and the experience of deep brain stimulation (DBS) using the example of a young Parkinson's disease patient

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Abstract

Background and research objective: In a prospective qualitative longitudinal study, the chair of multiprofessional care for chronically-ill patients explored the living and care situation of a patient with young-onset Parkinson's disease (YOPD)[11]. The focus of the study is on recording various disease management strategies during the different phases of the disease. This study analyzes the process of making a decision on deep brain stimulation (DBS) from the view of a patient in order to gather information on the appropriateness of care to the patient's situation.

Methods: The patient was selected because postoperative complications occurred, necessitating further surgery, so that the patient found himself again having to decide whether to undergo additional surgery.
The data were collected during a semi-structured interview and via a case history form. Afterwards, the data were evaluated by using content structuring analysis.

Results: Due to the special constellation of the case, content-related dimensions were identified that were either in favor or against the surgery during both decision-making processes.
The decision reached by the patient aimed at reducing the symptoms and side effects of medication and maintaining his ability to work. From a risk assessment perspective, the anticipated positive effects of surgery, and the prospect of providing the longest-lasting benefit possible, clearly prevail at the present time.
Due to the patient's initial positive impressions of living with a DBS system, his confidence in repeating the surgery was not undermined by the fact that the first DBS system had to be removed owing to complications. The authentic behavior of the various physicians consulted during the preoperative phase was crucial to the decision.

Conclusion: The patient's actively gathering of information enables physicians to establish a reliable and trusting relationship with the patient.

Keywords: paraplegia, spinal cord injury, respiratory therapy, diaphragm stimulation, phrenic nerve stimulation, rehabilitation

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1 In literature, young-onset Parkinson's diseased are patients having been diagnosed before turning 45 years old. This affects approximately 10 to 15 % of the diseased.