

"I just want to be seizure free" Everyday life experiences of people with epilepsy before and after epilepsy surgery

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Introduction: People with epilepsy are coping with diversity of problems in their everyday life (physical, mental and social). In Slovenia, there is not enough data regarding the severity of problems that people with epilepsy need to deal with after the surgery. Also, working with people with epilepsy in occupational therapy practice in Slovenia is not yet very common.

Aim: The aim of the study was to explore a person's everyday life experiences before and after the epilepsy surgery, coping with chronic illness since disease onset, and experiencing the changes in everyday life within four months after the surgery.

Methods: A qualitative approach through open-ended interviews was used for gathering the data, and a constant comparative method for analysis. Two female participants were included in the research. Four open-ended interviews with each participant were done, two before and two four months after the epilepsy surgery.

Results: Findings revealed several problems participants were dealing with. They were defined in the following themes: illness controlled their life; expecting to manage life better after the epilepsy surgery; and coping with the new life situation. Managing everyday life four months after epilepsy surgery was still a problem for both participants. Participants and their families were in the phase of adapting to the new life situation, where the adaptation process could last between 1 to 2 years.

Conclusion: Epilepsy surgery for them did not mean a better, seizure free life, but rather a decision toward positive changes in their life. In spite of their good surgery outcomes, problems continue to persist. Both participants were still dependent on family members at the time of this study.

Contribution for the practice: This is the initial occupational therapy evidence with patients undergoing epilepsy surgery. It also represents a basis for the development of an occupational therapy service with people with epilepsy in Slovenia.