



**Karolinska
Institutet**

Department of Clinical Neuroscience

REHABILITATION FOR PERSONS WITH EPILEPSY- ASSESSMENT OF A COMPREHENSIVE REHABILITATION PROGRAM

AKADEMISK AVHANDLING

som för avläggande av medicine licentiatexamen vid Karolinska Institutet
offentligen försvaras i Kugelbergsalen, Karolinska Universitetssjukhuset, Solna

Onsdagen den 12 juni, 2013, kl. 13.00

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ABSTRACT

Epilepsy is one of the most common serious neurological disorders with an estimated prevalence of approximately 0.5%. In addition to the obvious medical risk associated with epilepsy, psychosocial consequences may be extensive. These can include problems related to different comorbidities and disabilities as well as cognitive impairment. Low self-esteem and self-efficacy may furthermore contribute, and result in increased unemployment rates. Besides the need to manage a situation with unpredictable recurrent seizures, people with epilepsy can be stigmatized and have to face prejudiced attitudes from their environment. To manage this wide range of problems, some persons with epilepsy are offered comprehensive multi-professional rehabilitation. Rehabilitation programs for persons with epilepsy are sparse and systematic evaluations of their effectiveness rare. Given this and our experience from the neurological rehabilitation clinic at the Stora Sköndal Foundation, we found it urgent to assess this rehabilitation program, the overall aim being to provide a basis for further development and refinement of rehabilitation programs for persons with epilepsy.

The specific aims of the two included studies were

To describe the current situation of patients who completed epilepsy rehabilitation program between 1993 and 2009, with emphasis on their employment or education (EoE) status, and to identify factors associated with a favourable development of EoE after rehabilitation (Paper I)

To identify and describe issues, experienced as essential in rehabilitation, for persons with epilepsy and for members of the rehabilitation team. (Paper II)

The first study was a long-term follow-up of 124 patients with epilepsy that had participated in the rehabilitation program. Data were collected from medical records at admission and discharge from the rehabilitation, and from a structured telephone interview 1-17 years after the rehabilitation. Participation in EoE improved from admission to follow-up in 38 patients. Tonic-clonic seizures at admission as well as decreased frequency of tonic-clonic seizure from admission to follow up were associated with increased participation in EoE in univariable analysis, but the association was no longer statistically significant in an adjusted multivariable analysis.

In the second study, we carried out five focus group interviews with patients (n=17) and one focus group interview with staff members (n=5) of the rehabilitation team. The groups were asked to discuss "What is experienced as important in rehabilitation for persons with epilepsy?" Using content analysis, two themes emerged: Life with epilepsy and Rehabilitation experiences. The result emphasizes that rehabilitation for persons with epilepsy should be designed individually, in structure and in content. Encounters between patients were important, as well as the team's attitude in the meeting with the patients. Therapeutic working alliance is essential between patients and staff for creating an individual rehabilitation.

In conclusion, while EoE participation was improved at follow-up, we could not identify specific clinical factors associated with a favorable development of EoE participation after rehabilitation, whereas focus group interviews of patients and staff revealed a number of components that were experienced as important in epilepsy rehabilitation.

Keyword: epilepsy, rehabilitation, adult, employment, education, focus groups,