



What is important in rehabilitation for persons with epilepsy? Experiences from focus group interviews with patients and staff



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ABSTRACT

This study aimed to identify the issues experienced as essential in rehabilitation for persons with epilepsy. Six focus group interviews were conducted, five groups with patients that had completed comprehensive rehabilitation for persons with epilepsy, in a day-care setting, at the Neurological Rehabilitation Clinic at Stora Sköndal Hospital, between 2006 and 2009 (total $n = 17$) and one group with staff members ($n = 5$). 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 meeting with the patients. Therapeutic working alliance is essential between patients and staff for creating an individual rehabilitation.

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1. Introduction

Persons with epilepsy can have far-reaching problems affecting everyday life independent on whether their seizures are controlled or not. These problems may include difficulties with memory and attention, depression [1–8], low self-esteem and self-image, and difficulties with education and employment [9,10]. This wide range of problems sometimes requires comprehensive and individualized rehabilitation [11–14].

Initiated in 1993, the Neurological Rehabilitation Clinic at Stora Sköndal, Stockholm, Sweden, provides an outpatient rehabilitation program for adults with epilepsy, which provides a comprehensive, intensive, and structured rehabilitation that integrates cognitive and psychological treatments [15–17]. The framework of rehabilitation of the clinic is based on WHO's International Classification of Functioning, Disability, and Health (ICF) [18,19]. The classification is divided into four domains: body function, body structure, activity and participation, and environmental factors.

Few studies have analyzed patients' opinions of important issues regarding their needs in rehabilitation. One survey investigated patients' preferences for self-management program in addition to analyzing perceived medical and psychosocial problems [14]. Other studies have asked what patients want from epilepsy service in general

[20] as well as perceived needs of rehabilitation [21]. While the need for comprehensive rehabilitation programs is frequently stressed in literature [11–14,22], qualitative studies based on patient's experiences or thoughts about rehabilitation issues have, to the best of our knowledge, not been previously carried out.

We recently published long-term follow-up data on the employment and education status of patients who had undergone epilepsy rehabilitation at Stora Sköndal [23].

The emphasis of the present report is on the experiences of patients and staff members of this rehabilitation.

This study aimed to identify the issues experienced as essential in rehabilitation for persons with epilepsy. This, in turn, can serve as the basis for further development of epilepsy rehabilitation programs.

2. Method

2.1. The rehabilitation program

Patients are usually referred to rehabilitation by neurologists, who are often specialized in epilepsy care. The rehabilitation program is aimed at persons who experience epilepsy as a hindrance in the activities of daily life and who can be expected to benefit from treatment by at least two of the professions represented in the team. The purpose of the program is to find strategies to obtain a better life with epilepsy.

The rehabilitation is performed individually and/or in groups of 5–6 patients, two to three days/week for eight weeks in a day-care setting.

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The group program consists of coping strategies that include managing neuropsychological and emotional issues, epilepsy education, training in body awareness and relaxation, and cognitive counseling/training as well as support in psychosocial issues. The individual rehabilitation can contain all or part of the group program and, in addition, often involves contact with the patient's family. A schedule of the group program is shown in Table 1.

One example of tailored interventions directly related to epilepsy and seizures is finding strategies for psychological seizure control. According to the ICF framework, this action is within the domain of body functions. Interventions, designed to address the fear of going out, can be an example of ICF-level activity and participation, where support in contacts with the workplace with appropriate information about epilepsy, can be another. Analyzing risk factors for injuries in connection to seizures, which in turn can lead to home modifications, represents a tailored intervention in the environment factors domain.

2.2. Procedure and participants

This work is a qualitative study conducted with focus group interviews. In a previous project, patients who had been admitted for rehabilitation between 2006 and 2009 were asked if they were willing to participate ($n = 42$), out of which thirty-eight ($n = 38$) accepted. Among the 38 patients who initially accepted the invitation, 7 declined participation before the interviews, resulting in 31 patients who participated in the focus group discussions. The patients were divided into five groups of 6 to 7 participants each. The groups were created with the goal that every patient should know at least one other patient in the group to enhance the feeling of security and, thereby, facilitate communication and discussion. During the time period of the interviews, another 14 patients dropped out because of increased seizure frequency ($n = 1$), other health problems ($n = 4$), problems in family ($n = 2$), and unknown reasons ($n = 7$). Thus, in total, 17 patients completed the study. Of the participating patients, 14 were female, 15 had focal epilepsy, and the duration of epilepsy ranged from 3 to 46 years. Except for one patient in retirement pension, eight patients participated in employment or education to some extent, whereas eight patients did not. The time spent in epilepsy rehabilitation varied from 15 to 122 effective treatment days. The demographic and clinical characteristics of the participating patients are shown in Table 2. There were no great differences in demographic and clinical data between the participants and dropouts. What differed between the groups was that there were more women among the participants (14/17) compared to the dropouts (16/25). Participants had also an average of more effective rehabilitation days ($n = 56$) than observed among the dropouts ($n = 39$), but the median was similar (38/37). Eight members of the staff were invited by letter to participate. Five accepted; all had worked on the day-care ward during the period of time when the participating patients were admitted for rehabilitation. The five staff members, all female, represented a range of experience (one neurologist, one neuropsychologist, one physiotherapist, one social worker, and one registered nurse) and had worked in the rehabilitation of patients with

Table 1
Schedule of epilepsy rehabilitation program at Stora Sköndal.

	Monday	Wednesday	Friday
am	Education –Neurologist –Social worker	Individual treatment	Therapy group –Psychologist
pm	Relaxation techniques Body awareness –Physiotherapist Process diary	Individual treatment Process diary	Cognitive training Activity group –Occupational therapist Process diary

Table 2
Demographic and clinical characteristics of the participants in the patients' focus groups ($n = 17$).

	n (%) or mean (median) (range)
Gender, total n (% female)	17 (82%)
Age at time of interview	40 (25–69)
Duration of epilepsy at time for interview (years)	16 (3–46)
Comorbidities	
Neurological disease/disability	3 (18%)
No neurological disease/disability	14 (82%)
Etiology of epilepsy	
Pre/perinatal neurological insult	3 (18%)
Traumatic brain injury	1 (6%)
Neoplasm CNS ^a	2 (12%)
Infection CNS ^a	1 (6%)
Idiopathic	2 (12%)
Unknown	8 (47%)
Type of epilepsy	
Generalized idiopathic	2 (12%)
Localized symptomatic	7 (41%)
Localized cryptogenic	8 (47%)
Occurrence of seizures, during preceding year ^b	
Seizure-free	3 (18%)
Nonseizure-free	14 (82%)
Antiepileptic drug (AED) ^b	
Monotherapy	5 (29%)
Polytherapy	12 (71%)
Family situation ^b	
Single	4 (24%)
Own family	11 (65%)
Living with parents	2 (12%)
Education level ^b	
Compulsory primary school	2 (12%)
Upper secondary school	10 (59%)
Higher education, e.g., university	5 (29%)
Active in employment or education (EoE) ^b	
EoE, part- or full-time	8 (47%)
Not active in EoE	8 (47%)
Retired	1 (6%)
Rehabilitation design	
Individually	1 (6%)
Group	1 (6%)
Individually and group	15 (88%)
Number of rehabilitation days	51 (38) (15–122)

^a Central nervous system.

^b At the time of the telephone interview in 2010.

epilepsy for 10 to 40 years. The staff members who declined participation included two rehabilitation assistants and one occupational therapist, one of which was male.

2.3. Data collection

The demographic and clinical characteristics were obtained from medical records and telephone interviews. The data were collected from five focus groups of patients and one group of staff members. Only two patients participated in the first focus group interview. For the subsequent interviews, the participants were sent a reminder by phone, and the following groups had 4, 5, 3, and 3 participants.

Each group met once. The interviews lasted for 60 to 90 min and took place at the clinic in the late afternoon with the participants grouped around a round table. An experienced, independent facilitator conducted all six interviews, and another person (coauthor A.E.) recorded them. Neither the facilitator nor the recorder had any prior knowledge of the participants. The question asked was "What is experienced as important in rehabilitation for persons with epilepsy?" When needed, the facilitator used probes and clarifications. The interviews were conducted during a limited time period, one month, in the same location, at the same time of day, and with the same interviewer and the same focus question.

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