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

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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,

To
my mother Gullan

LIST OF PUBLICATIONS

- I. **Ewa Wadhagen Wedlund**, Lena Nilsson, Anette Erdner, Torbjörn Tomson.
Long-term Follow-Up after Comprehensive Rehabilitation of persons with epilepsy, with emphasis on participation in Employment or Education. *Epilepsy & Behavior* 25 (2012) 219–223

- II. **Ewa Wadhagen Wedlund**, Lena Nilsson, Torbjörn Tomson, Anette Erdner.
What is important in rehabilitation for persons with epilepsy? Experiences from focus group interviews with patients and staff.
Submitted

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LIST OF ABBREVIATIONS

| | |
|-------|---|
| ADL | Activity of Daily Living |
| AED | Antiepileptic Drug |
| AVM | Arteriovenous Malformation |
| CNS | Central Nervous System |
| EoE | Employment or Education |
| ICF | International Classification of Functioning Disability and Health |
| ILAE | International League Against Epilepsy |
| MOSES | Modular Service Package Epilepsy |
| MS | Multiple Sclerosis |
| SEE | Sepulveda Epilepsy Education program |
| SLE | Systemic Lupus Erythematosus |
| T-C | Tonic-clonic seizure |
| WHO | World Health Organisation |

1 BACKGROUND

1.1 EPIDEMIOLOGY

Epilepsy is considered to be the most common serious chronic neurological disorder, having an estimated prevalence of active epilepsy of 4.5-5.0 per 1000 in Europe [1]. The annual incidence rate in Europe is estimated to 70 per 100 000 [1] being highest among young children and the elderly.

1.2 DEFINITION OF SEIZURES AND EPILEPSY

According to the 2005 proposal of the International League Against Epilepsy (ILAE) [2] an epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. The same proposal defines epilepsy as “a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure.” However, epilepsy has traditionally been defined as a condition with two unprovoked seizures with more than 24 hours apart. It can be considered that the two unprovoked seizures constitute the clinical evidence of the *enduring* predisposition. In the present study, we have used this traditional operational definition of epilepsy.

1.3 CLASSIFICATION OF SEIZURES

According to the 1981 ILAE classification [3] epileptic seizures are divided into two major categories: generalized and partial seizures. Seizures occurring in, and rapidly engaging the bilaterally distributed neuronal networks are defined as generalized, whereas partial seizures involves networks located in a limited area within one hemisphere. Generalized seizures are based on their symptomatology divided into subgroups, such as tonic-clonic (T-C), tonic, clonic, absence and myoclonic seizures. Partial seizures are divided into simple partial seizures (seizures with clinical signs such as motor, somatosensory, autonomic and psychic signs without impairment of consciousness), complex partial seizures with clinical signs including impairment of awareness or consciousness, and finally partial seizures evolving into generalized seizures. A new ILAE proposal for revised terminology and concepts for organization of seizures and epilepsies has been published, but not yet formally approved [4]. In this work, partial seizures are named focal seizures.

1.4 CAUSES OF EPILEPSY

Epilepsy is a heterogeneous condition with many different causes. Practically any disease or lesion affecting the cerebral cortex may cause epilepsy. The causes of epilepsy vary with age. Pre- and perinatal causes are more common in epilepsy of early childhood [5]. In adulthood, head trauma and brain tumours are more common in young adults whereas stroke is the most frequently occurring cause of epilepsy among the elderly, where also dementia is a common cause. [6-9]. In approximately 40% of patients with new onset epilepsy no structural lesion can be demonstrated despite thorough investigation [10].

1.5 TREATMENT

The great majority of persons with epilepsy are treated with antiepileptic drugs (AED) [11]. The treatment is symptomatic, aiming at reducing the risk of seizures, with seizure freedom as the ultimate goal. The AED treatment is often maintained for several years and not seldom lifelong. Usually, treatment is not initiated until after a second seizure, but in cases having a high recurrence risk, it may be justified to start treatment already after the first seizure [12]. There are more than 20 different AEDs available. Nevertheless, approximately 30% of the patients continue to have seizures despite systematic trials of available AEDs [13]. People that have become seizure-free as well as those who continue to have seizures can experience adverse effects from the medication, such as memory problems and fatigue [12].

Epilepsy surgery and vagus nerve stimulation are other treatment modalities that can be considered for some of those whose seizures are not controlled with medication [14, 15].

1.6 IMPACT ON EVERYDAY LIFE

As highlighted already in the 2005 ILAE definition of epilepsy [2] the condition is associated with cognitive, psychological, and social consequences.

Cognitive problems, in patients with epilepsy, can be caused by the lesion that causing the epilepsy, frequent or prolonged seizures, and to some extent by adverse effects of AEDs. Most common are memory deficits, impaired attention, difficulties to concentrate and fatigue, problems that may have an impact on daily life [16-19]. In fact, cognitive deficits are sometimes perceived as one of the major problems in having epilepsy [16].

Seizures lasting up to a few minutes occurring with long intervals are most often the only direct symptoms of epilepsy. However, the fact that seizures appear at unpredictable times and result in loss of control, can cause physical injury [20, 21] and sometimes even be fatal [22] commonly leads to the sense of insecurity, fear and limitations of daily life. These psychological reactions are highly individual and do not necessarily correlate to seizure frequency [23]. Additionally, epilepsy is associated with comorbidities, such as depression, which may further impact on the quality of life [24].

Public knowledge about epilepsy is generally low; epilepsy is still met with prejudice and associated with stigma. Apart from experiences of direct enacted discrimination and stigmatizing public attitudes, internalized stigma, i.e. the person's own feeling of shame and thoughts of other people rejecting and devaluating persons with epilepsy, is common [25].

Direct social consequences of active epilepsy include restrictions in having a driver's license with obvious consequences for professional drivers, and restrictions in some other specific occupations where epilepsy could be a risk to the affected person and/or others. Persons with epilepsy have a lower employment rate as compared to the general population [26]. Apart from the restrictions discussed above, the employers' attitude as well as the employees problems with, among other things, low self-esteem contribute to the higher unemployment rate among persons with epilepsy [27-33].

1.7 REHABILITATION FOR PERSONS WITH EPILEPSY

1.7.1 Rehabilitation

Rehabilitation is described as one of four health strategies in the care process, the other three being prevention, curative and supportive strategies [34]. World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) is an international standard used to describe and analyse consequences of a person's abilities, disabilities and health from a bio-psycho-social model. The model is divided in four domains: body function, body structure, activity and participation. Moreover, ICF includes environmental factors, then a person's functioning, and disability occurs in a context. A new conceptual description of rehabilitation based on ICF has recently been suggested [35]:

“Rehabilitation is the health strategy which, based on WHO's integrative model of functioning, disability and health applies and integrates

- approaches to assess functioning in light of health conditions

- approaches to optimize a person's capacity
- approaches that build on and strengthen the resources of the person
- approaches that provide a facilitating environment
- approaches that develop a person's performance
- approaches that enhance a person's health-related quality of life

in partnership between person and provider and in appreciation of the person's perception of his or her position in life over the course of a health condition and in all age groups; along and across the continuum of care, including hospitals, rehabilitation facilities and the community, and across sectors, including health, education, labour and social affairs; with the goal to enable persons with health conditions experiencing or likely to experience disability to achieve and maintain optimal functioning.”

In our clinical work, we evaluate the patients' situation over time on all ICF levels; body function such as seizure situation, activity performance such as personal Activity of Daily Living (ADL) and domestic work, and participation in society such as the level of Employment or Education (EoE), as we did in one of the present studies.

1.7.2 Rehabilitation for persons with epilepsy

Specialized epilepsy care is provided by all university hospitals in Sweden. These services are based on epilepsy-teams consisting of neurologists specialised in epilepsy, epilepsy nurses, social workers and psychologists, and in particular for the highly specialized epilepsy surgery programme also clinical neurophysiologists, neurosurgeons, and neuroradiologists. The teams are, however, not staffed or designed to offer more extensive rehabilitation.

Internationally, various models of epilepsy care have been developed in order to meet the more complex problems of this condition. In a Cochrane review, based on more than 4000 studies, the effectiveness of different models of care involving professionals with specialist trained in epilepsy was evaluated [36]. Two interventions were found having some evidence of benefit: specialist epilepsy nurses and self-management education. Self-management interventions, defined as chronic disease patient education programs, involving the patient as an active participant in treatment, have been developed during the past decades. The primary tasks for such intervention programmes have been to teach medical management, role management and emotional management, and were originally used for diseases like arthritis and diabetes [37] but eventually also designed for epilepsy [38]. Such educational programs are usually given as interactive lectures or discussions,

in groups of 5-15 patients, for about two hours/week over a 6-8 weeks period of time, and led by health care leaders or by lay leaders possibly with self experience of the condition. Later other formats of the structured interventions have been developed, including telephone or internet-based programs [39].

Two self-management programs for persons with epilepsy have been evaluated in randomized controlled trials, the Sepulveda Epilepsy Education (SEE) [38] and the Modular Service Package Epilepsy (MOSES) [40]. Both were given in groups lead by health care professionals during two days in several sessions and contained medical and psychosocial/emotional aspects, based on the belief that knowledge and understanding of epilepsy can help the individual to cope with the condition. SEE was found to reduce the fear of death and brain damage, to reduce medical misconception, and trends towards improved seizure frequency and compliance were observed four months after the intervention [38]. The MOSES participants showed improved knowledge, coping, active information seeking and compliance at six months follow-up [40].

Langenbahn et al [41] evaluated cognitive rehabilitation for different medical conditions affecting cognitive functions, including epilepsy. A total of 360 studies of cognitive rehabilitation in epilepsy were found, but only five met the inclusion criteria for the review. The only randomized controlled study [42], and one case series [43] with matched pre- and post-training patients, showed evidence to recommend training of attention and memory, the teaching of cognitive techniques and strategies that the patients could internalize and use.

Vocational courses and vocational rehabilitation programs designed for persons with epilepsy exist in some countries and have been shown to improve employment situation [44, 45].

1.7.3 Rehabilitation program at Stora Sköndal

1.7.3.1 Background

The Neurological Rehabilitation Clinic at the Stora Sköndal Foundation in Stockholm County has provided rehabilitation for patients having different neurological disorders since the mid 1970s. In the beginning of the 1990's the Clinic developed a rehabilitation program for adult persons with epilepsy in a day-care ward setting. The incentive was our experience that many epilepsy patients do not receive sufficient help for the deeply rooted effects of epilepsy on their self-image, effects found to greatly impact the ability to handle life and its difficulties. Hence, a proportion of patients with epilepsy may benefit from

rehabilitation that intervening at all ICF levels, with time to allow a process of change in the patient, the family and the patient's environment. To the best of our knowledge the program is still the only of its kind in the country.

The rehabilitation program is aimed at persons who experience that epilepsy is a hindrance in the activities of daily life and affects the quality of life in a negative way and can be expected to benefit from treatment by at least two professions represented in the team. Exclusion criteria for participation are substance abuse or psychiatric disorder or cognitive decline of such degree that it severely affects the person's ability to participate and communicate in a group setting. The purpose of the rehabilitation program is to find strategies to obtain a better life with epilepsy.

1.7.3.2 Approach and content

The development of the epilepsy program was inspired by principles of holistic neuropsychological rehabilitation in brain injury, i.e. comprehensive, interdisciplinary, intensive and structured rehabilitation, integrating cognitive and psychological treatment [46-48] and emphasizing the importance of the whole and the interdependence of the different parts in a therapeutic environment. An important part of the approach is the interdisciplinary teamwork, i.e. a close cooperation - including the patient as a team member – to jointly define and work with the patient's rehabilitation goals through a continuous and high level of communication [49]. The attitude of the team members – to listen, confirm, respect and invite to participation – is considered essential. The rehabilitation team consists of neurologist, neuropsychologist, physiotherapist, occupational therapist, and social worker. The patients are usually referred to the rehabilitation by neurologists. Before admission the patient, often together with family members, meets two staff members from the team, to share information about problems, expectations and the rehabilitation. Thereafter the patient and the rehabilitation team decide whether to continue with the rehabilitation or not. The rehabilitation is performed in groups of 5-6 patients, two to three days/week for eight weeks, but can also be carried out individually. The individual rehabilitation period generally lasts longer, with high intensity at the beginning that often decays somewhat as time goes by. The mean number of effective treatment days has been 33 for all patients, 185 in total so far.

The group rehabilitation contains a therapy group focusing on coping with epilepsy, education about epilepsy, relaxation training with body awareness and cognitive

counselling/training as well as support in psychosocial issues. The individual rehabilitation can contain all or part of the group program. Some contact with the patient's close family is common, and in some cases also with employer and workplace or visits in the patient's home environment in order to reduce risk of accidents and increase safety at seizures.

1.8 BACKGROUND TO THE PRESENT STUDIES

Problems and limitations in everyday life for persons with epilepsy go beyond seizure control. At the same time, structured rehabilitation programmes for persons with epilepsy are sparse and systematic evaluations of their effectiveness are even rarer. Given this and our experience from the Neurological Rehabilitation Clinic at the Stora Sköndal Foundation, we found it urgent to assess this rehabilitation program that has been in function for more than 20 years.

2 AIMS

The overall objective of this project is to provide a basis for further development and refinement of rehabilitation programs for persons with epilepsy.

Specific aims:

To describe in a systematic follow-up the current situation of patients who completed epilepsy rehabilitation program between 1993 and 2009, with emphasis on their employment or education (EoE) status. (Paper I)

To identify factors associated with a favourable development of EoE after rehabilitation. (Paper I)

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

3 METHODS

3.1 DESIGN

The methodological principles applied in the two studies are summarised in **Table 1**.

Table 1.

| Paper | Scientific approach | Design | Analysis |
|-----------|---------------------|---|--|
| I | Quantitative | Retrospective, medical record review. Structured follow-up telephone interview. | Frequencies and Logistic regression and McNemar's test. |
| II | Qualitative | Focus Group Interviews | Content analysis. Five groups with inductive approach and one with deductive approach. |

3.2 PARTICIPANTS

All patients have completed a rehabilitation period at the neurological day ward of Stora Sköndal between January 1993 and July 2009. Criteria for admission to the rehabilitation were age of 18-65, being diagnosed with epilepsy and perceived problems in life with epilepsy. Exclusion criteria were active substance abuse, psychiatric disorder or cognitive decline of such degree that it severely would affect the person's ability to participate in the rehabilitation and communicate in group settings. Patients were identified through registers at the clinic and 185 patients were assessed for eligibility. In paper II, a group of staff members, who had all been working at the day ward during the epilepsy rehabilitation program, participated in a focus group interview. **Figure 1** describes the selection process for both.

3.3 PROCEDURE AND PARTICIPANTS

3.3.1 Paper I

Out of the 185 patients that had completed the rehabilitation program, 16 had died before the data collection by medical records carried out in 2010. Hence, 169 patients were invited by mail to participate in the following structured telephone interview. The information letter described the background, purpose, and approach of the project. Patients could decline participation by returning a response letter with a pre-stamped envelope. Out of the 169, 36 declined participation and we were unable to get in contact with another nine. Hence, 124 (73%) of the eligible patients took part in the follow-up telephone interview presented in paper I.

3.3.2 Paper II

Patients that had been admitted for rehabilitation between 2006 and 2009 (n=42) were asked if they were willing to participate in a focus group interview and 38 accepted. Out of the 38 patients initially accepting the invitation, 7 declined participation before the interviews, leaving 31 patients to start in the focus group discussions. They were divided into five groups with 6 to 7 patients in each. The groups were created with the goal that every participant should know at least one other patient within the group. During the time period of the interviews, another 14 patients dropped out. Thus, in total 17 patients completed the study. Eight staff members were invited by letter to participate. Five accepted; all had worked on the daycare ward during the 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 with rehabilitation of patients with epilepsy for 10 to 40 years.

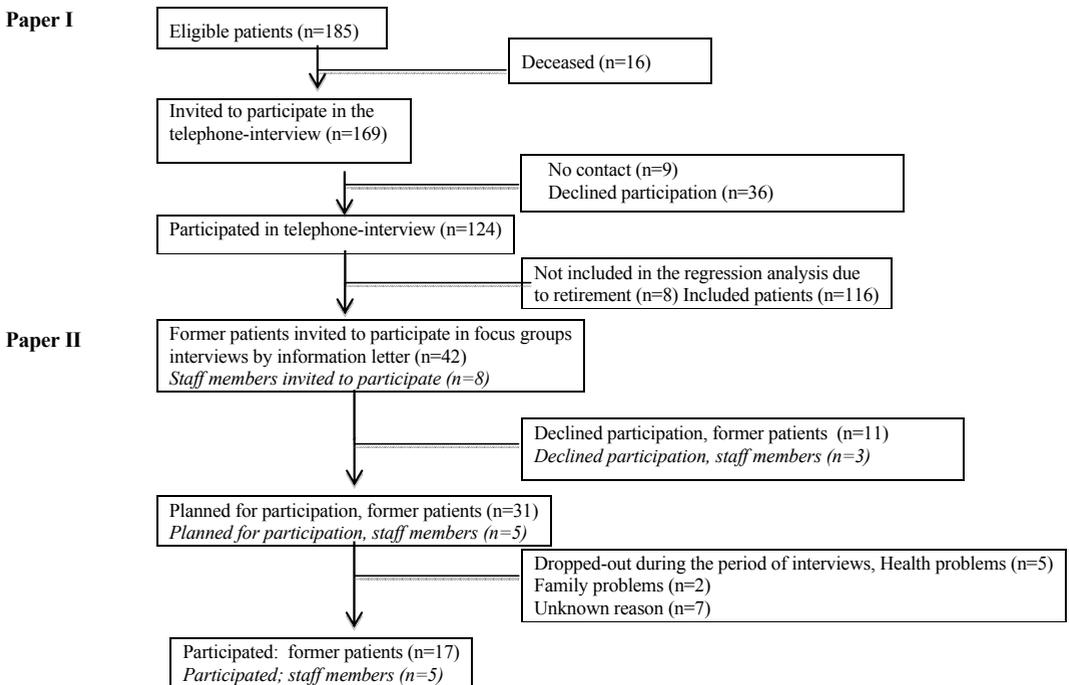


Figure 1. Flowchart for participants in paper I and II

3.4 DATA COLLECTION

3.4.1 Paper I

Medical records of all patients having fulfilled the epilepsy rehabilitation programme at least once during January 1993-July 2009 (N=185) were reviewed by one of the authors (EW). Data were collected according to a predesigned protocol, extracting demographic and clinical data as well as data concerning participation in daily living and society at admission and discharge. Epilepsy data such as etiology, type of seizures and epilepsy were also assessed by one of the neurologist in the research group (LN).

Follow-up data on current situation was obtained by telephone interview during January 2010 – October 2010. The structured interview protocol was similar to the protocol used for the medical records data collection.

3.4.2 Paper II

Demographic and clinical characteristics of participating patients were obtained from the already performed medical records review and the telephone interviews.

In this study, we chose a qualitative method to obtain the patient's and staff members own perceived experiences of what issues that are important in rehabilitation for persons with epilepsy. The data were collected from five focus group interviews of patients and one group of staff members. Each group met once and an experienced, independent facilitator conducted all six interviews and another person (co-author AE) recorded the interviews. 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 one-month period of time, in the same location, at the same time of day, with the same interviewer and the same focus question.

3.5 DATA ANALYSIS

An overview of analysis and statistical methods, variable/ content in the analysis and purpose are presented in **Table 2** for **both papers**. All quantitative descriptions and statistical analyses were performed by SPSS 19.0 and SPSS 20.0.

Table 2. Overview of analytical methods, variables/data and purpose

| Analyses | Factors/variables/data | Purpose |
|---|---|---|
| Logistic regression analysis, paper I | Increased participation in EoE ¹ Age at admission ² Age at onset ² Duration at admission ² Comorbidity ² Occurrence of T-C seizure ² Change of frequency in T-C seizures ² | Association between dependent variable and clinical factors (independent variables) |
| McNemars's test, paper I | Participation in EoE Seizure control | Proportion between base-line and follow-up |
| Independent sample <i>t</i> -test, paper I | Age at admission | Difference between participants and drop-outs |
| Fisher's exact test, paper I | Etiology of epilepsy | Difference between participants and drop-outs |
| Numbers and percentages, paper I and II | Demographic data Clinical data Rehabilitation design | Description of the participants |
| Qualitative content analysis, paper II | Statements from focus group interviews | Knowledge about persons own experiences |

EoE= Employment or Education

T-C= Tonic-Clonic seizure (in the present work including primary as well as secondary generalized tonic-clonic seizures)

¹ Dependent variable

² Independent variable

3.5.1 Paper I

Participation in employment or education (EoE) was the endpoint of primary interest in the present analysis. To examine changes in participation in EoE we compared categories of EoE levels, e.g. no EoE, 25%, 50%, 75% or full time, between admission and follow-up. Logistic regression was used to study associations between increased participation in EoE and six different clinical factors at admission and change of seizure control between admission and follow-up. We first performed a univariable analysis with the different independent factors. Thereafter, adjusted associations were calculated in a multivariate logistic model with all the independent factors, shown in **Table 2**. The associations were presented as odds ratios (OR) with 95 % confidence intervals (CI) and *p-value*.

McNemar's test was used to test the changes between admission and follow-up in proportions of patient's participation in EoE and proportions of seizure free patients.

Seizure frequency 12 months prior to admission and follow-up, was divided into four categories; 0-2 seizures, 3-52 seizures, >52 seizures, and not seizure free, but seizure frequency not possible to quantify. Change in seizure frequency e.g. increased or decreased seizure control, means change between these categories. Tonic-clonic seizures include both partial seizures with secondary generalization and primary generalized tonic-clonic seizures. To test differences between those who participated in the follow-up interview and the dropouts, i.e. those eligible but that for different reasons did not participate in the telephone interview, we used Independent sample t-test and Fisher's exact test.

3.5.2 Paper II

A qualitative content analysis was performed according to Graneheim & Lundman [50]. The interviews were recorded and transcribed verbatim and every interview represented a unit of analysis. The analytical process started with reading through the transcribed data from the patients' groups. The next step was to divide the data into meaning units based on phrases or parts of the text containing the same content. Thereafter the meaning units were condensed. Categories and sub-categories were grouped to create themes. Finally, the process of analysis was followed inversely from themes to quotations supporting the trustworthiness [50]. The aim of the research was to better understand something not already explained and the analysis was an open process, and therefore, an inductive analysis. For the analysis of the staff's statements we did a deductive analysis, using the already created themes, categories, and subcategories from the analysis of the patients groups [51].

3.6 ETICAL CONSIDERATIONS

Informed consent was obtained from all participants. The information emphasized that the participation was voluntary, confidential and that the participants could withdraw at any time without reason and that this would not affect future contacts. They were invited to call for more information, if needed. Potential participants could decline participation by returning a response letter with a pre-stamped envelope, in order to not be contacted. In study I, persons without any knowledge of the participants conducted the telephone interviews.

Each focus group interview began with information that the participation is totally voluntary, and about the right to terminate participation at any time. Independent persons made all the personal contacts with the participants, since members of the research group

(EW, LN) had been part of the rehabilitation team and thus had personal contact with nearly all participants. This was carried out in order to prevent any risk that participants may feel undue pressure to accept participation e.g. at the telephone interview. Other risks for the patients to participate could be increased anxiety due to having revealed their own opinions, but conversely many patients would like to convey their opinion and also want to contribute in developing health care. Still if the questions would bring discomfort or uncertainty among the participants, a contact person was available to answer questions and provide support. All collected data were stored in a secured cabinet. The studies were approved by the Ethics Review Board at the Karolinska Institutet, Stockholm, registration number 2008/273/31/3.

4 RESULTS

The demographic and clinical data at admission and at the follow-up interview, regarding the patients in both papers are shown in **Table 3**.

Table 3

Demographic and clinical data of the participants in paper I (n=124) and paper II (n=17)

| | Paper I | | Paper II | |
|--|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|
| | Admission n (%) /mean(SD)(range) | Follow-up n (%) /mean(SD)(range) | Admission n (%) /mean(SD)(range) | Follow-up n (%) /mean(SD)(range) |
| Gender, tot n (% female) | 124 (61%) | | 14 (82%) | |
| Age at onset | 21 (14) (0-64) | | 24 (16) (2-64) | |
| Comorbidities | | | | |
| Neurological disease/disability | 42 (34%) | | 3 (18%) | |
| No neurological disease/disability | 82 (66%) | | 14 (82%) | |
| Etiology of epilepsy | | | | |
| Pre/Perinatal abnormality | 15 (12%) | | 3 (18%) | |
| Trauma CNS | 5 (4%) | | 1 (6%) | |
| Status post stroke | 7 (6%) | | 0 0 | |
| Neoplasm CNS | 10 (8%) | | 2 (12%) | |
| Infection CNS | 11 (9%) | | 1 (6%) | |
| Idiopathic | 9 (7%) | | 2 (12%) | |
| Mesial temporal sclerosis | 3 (2%) | | 0 0 | |
| Others- MS, SLE, AVM | 4 (3%) | | 0 0 | |
| Unknown | 60 (48%) | | 8 (47%) | |
| Type of epilepsy | | | | |
| Generalized idiopathic | 9 (7%) | | 2 (12%) | |
| Focal epilepsy | 113 (91%) | | 15 (88%) | |
| Unknown | 2 (2%) | | 0 0 | |
| Duration of epilepsy (years) | 15 (12) (0-48) | 23 (14) (3-63) | 11 (12) (1-35) | 16 (13) (3-46) |
| Age | 36 (11) (18-65) | 44 (12) (24-75) | 35 (12) (19-65) | 40 (11) (25-69) |
| Changes in seizure frequency | | | | |
| Increased | | 16 (13%) | | 0 0 |
| Decreased | | 48 (39%) | | 9 (53%) |
| No change | | 41 (33%) | | 7 (41%) |
| Missing data | | 19 (15%) | | 1 (6%) |
| Changes of participation in EoE at follow-up (n=116/n=16) ^a | | | | |
| Increased | | 38 (33%) | | 5 (31%) |
| No change (retained level of (EoE) | | 12 (10%) | | 2 (13) |
| No change (retained no EoE) | | 50 (43%) | | 8 (50%) |
| Decreased | | 16 (14%) | | 1 (6%) |

CNS=Central Nervous System, MS=Multiple Sclerosis, SLE= Systemic Lupus Erythematosus,

AVM=Arteriovenous Malformation, EoE=Employment or Education

^a Not included due to retirement pension (8/124/and 1/17)

4.1 PAPER I

The follow-up interview was conducted 1 to 17 years after admission to rehabilitation (median: 7) and included 124 patients, which constituted 73% of the 185 patients who completed rehabilitation between 1993 and 2009.

4.1.1 Time and rehabilitation design

Many patients (n=61, 49%) had rehabilitation in groups as well as on an individual basis, whereas 39 (32%) had group rehabilitation only and the rest exclusively individual rehabilitation (n=24, 19%). The number of rehabilitation days displayed a large variation, from six to 122. The mean number of rehabilitation days was the same for both genders (median 26).

4.1.2 Seizure control

Changes in seizure control from admission to follow-up are shown in **Table 4**.

Table 4

Changes in seizure frequency from admission to follow-up (n=124)

| | | n(%) |
|-------------------------|--------------|----------|
| T-C seizures | Increased | 26 (21%) |
| | Decreased | 38 (31%) |
| | No change | 57 (46%) |
| | Missing data | 3 (2%) |
| Other seizures | Increased | 17 (14%) |
| | Decreased | 55 (44%) |
| | No change | 34 (27%) |
| | Missing data | 18 (15%) |
| Total seizure frequency | Increased | 16 (13%) |
| | Decreased | 48 (39%) |
| | No change | 41 (33%) |
| | Missing data | 19 (15%) |

Five (4%) had been seizure free for at least one year preceding the admission, whereas 26 (21%) were seizure free the year immediately before follow-up ($p < 0.001$).

4.1.3 Participation in employment or education

Participation in society expressed as ability to work or study was of primary interest in the present study. Thirty-eight participants (33%) had improved in EoE from admission to the follow-up interview. Another 12 patients (10%) had maintained their EoE and 66 patients (57%) had retained no participation in EoE or decreased participation (n=16, 14%) in EoE at follow-up.

Thirty-two (26%) of the 124 patients participated to some extent in EoE at the time of admission and 56 (45%) at follow-up.

There was a significantly higher proportion ($p < 0.001$) involved in EoE, at some level, at follow-up as compared to the time of admission to the rehabilitation.

Among those that were not active in EoE, the majority considered epilepsy to contribute to the work-barriers.

None of the participant with primary school as their highest level of education at follow up had improved in EoE status. Thirty-one patients (25%) went through some kind of educational programme during the follow up period, out of which 14 (45 %) also improved in EoE.

4.1.4 Clinical factors at admission and changes in EoE from admission to follow-up

In univariable analysis active epilepsy with tonic-clonic seizures at admission was clearly associated with increased participation in EoE at follow-up, as was decreased frequency of tonic-clonic seizures from admission to follow-up. However, the significance of the associations disappeared, in the multivariate analysis when adjusting for age at admission, age at onset of epilepsy, duration of epilepsy and comorbidity (**Table 5**).

Table 5
Association between factors and increased participation in EoE (n=116^a)

| Variables and categories | Total | | Unadjusted | | Adjusted [□] | |
|--|-------|-----------|--------------|---------|-----------------------|---------|
| | n | Increased | OR (95% CI) | P value | OR (95% CI) | P value |
| Age at admission | | | | | | |
| Age 18-34 | 59 | 37% | 1.5(0.7-3.3) | 0.29 | 1.0(0.4-2.7) | 0.93 |
| Age >=35 | 57 | 28% | Reference | | Reference | |
| Age at onset | | | | | | |
| Age <=17 | 63 | 40% | 2.0(0.9-4.5) | 0.09 | 1.7(0.5-6.1) | 0.40 |
| Age >=18 | 53 | 25% | Reference | | Reference | |
| Duration at admission | | | | | | |
| >=11 years | 63 | 37% | 1.6(0.6-4.0) | 0.32 | 1.2(0.4-3.7) | 0.76 |
| 0-2 years | 19 | 32% | 1.3(0.4-4.4) | 0.69 | 1.8(0.4-7.7) | 0.41 |
| 3-10 years | 34 | 26% | Reference | | Reference | |
| Comorbidity | | | | | | |
| Neurological disease/injury | 39 | 28% | Reference | | Reference | |
| No neurological disease/injury | 77 | 35% | 1.4(0.6-3.2) | 0.46 | 1.4(0.5-3.4) | 0.52 |
| Occurrence of T-C seizures, last 12 months | | | | | | |
| Seizure free | 60 | 20% | Reference | | Reference | |
| Not seizure free | 56 | 46% | 3.5(1.5-7.9) | 0.003 | 1.7(0.5-5.8) | 0.39 |
| Changes of frequency in T-C seizures | | | | | | |
| Increased/No change | 78 | 23% | Reference | | Reference | |
| Decreased | 35 | 54% | 4.0(1.7-9.2) | 0.001 | 2.6(0.8-8.8) | 0.13 |

^a 8 patients not included due to retirement pension.

^b Total number in unadjusted model, ^c Adjusted for all six variables presented, n=113

4.2 PAPER II

The demographic and clinical data of the patients are shown in **Table 3**. The staff members were all women aged between 49 and 68 (mean: 56) with experience of working with care and rehabilitation of patients with epilepsy for 10 to 40 years.

The results from the focus group interviews yielded two themes: (1) Life with epilepsy described through emotions, impact on daily living, and experiences in contact with environment and (2) rehabilitation experiences, encompassing rehabilitation structure, content and goals.

4.2.1 Life with epilepsy

Participants in patients' focus groups expressed difficulties in accepting their epilepsy, feelings of being different from others and feelings of fear of seizures and loss of control. They also described many thoughts about other people's perception of people with epilepsy.

Patients' groups talked about stress as a risk factor for seizures and expressed problems with adverse effects of medication, and its impact in daily life. They described dependency on others due to not having a driving license and in managing the family's finances. Fatigue was seen as leading to decreased ability to participate in social activities. Many patients expressed cognitive problems that influenced daily life in different ways, e.g. affecting the possibility to work or study. Negative experiences were also described in contact with authorities in society and health care, leading to lack of trust and confidence, and a wish to have continuity in such contacts.

4.2.2 Rehabilitation experiences

Both patients and staff expressed the importance of an individualized rehabilitation, i.e. based on the individual patient's problems and abilities. That includes the possibility to adjust the time spent in rehabilitation for the patient, such as duration, intensity and follow-ups, when needed. Also, the importance of getting individual strategies to handle both cognitive problems and fatigue problems, such as compensatory cognitive strategies and relaxations techniques in daily life, was emphasized.

Rehabilitation in group settings was experienced as a valuable structure in the rehabilitation. Patients in all interview groups considered it valuable to meet other persons with epilepsy, sharing experiences. The staff pointed out the importance of carefully structured treatment groups, a factor also emerging from the patients' negative experiences of being in a group where participants were too different. A rehabilitation

team with various professions and a high level of expertise was considered important both by patients and staff. The staff members described that the team must have the competence to meet patients with complex problems. The staff also talked about the frustration and fear of not having the opportunity to decide how to organize the rehabilitation work due to political changes in the health care system. The staff members also discussed the attitude between the team members towards creating cooperation as important. All interview groups talked about the team's commitment, and the importance of being listened to and met with understanding of one's problems. This was further emphasized by comments from a couple of participants experiencing the feeling of not being well understood during the rehabilitation.

Rehabilitation contents that were considered to be of importance by the patients, were that of providing knowledge about epilepsy as well as support in order to cope emotionally with the situation for the patients, but also for family members. Being introduced to different techniques, and try, practice and use these strategies to handle tiredness and cognitive difficulties were other important contents discussed in all patient groups.

Patients in all focus groups stated that rehabilitation had resulted in increased knowledge, a better understanding of their own situation, increased acceptance of their epilepsy and an improved self-image. These changes in turn led to changed attitudes towards epilepsy and the relation to other people, but most of all, it changed the attitude towards themselves.

5 DISCUSSION

5.1 METHODOLOGICAL CONSIDERATIONS

The present thesis seeks to form a basis for further development of rehabilitation programmes for persons with epilepsy. It is based on the experience of patients and staff involved in a specific comprehensive epilepsy rehabilitation programme at Stora Sköndal, Stockholm, spanning over more than 15 years. Two different scientific methods have been utilized; The outcome, with emphasis on EoE participation after completed rehabilitation, and clinical factors associated with a favourable outcome, was analyzed with quantitative methods (Paper I); Patients' and staff's experience of the epilepsy rehabilitation was analyzed with qualitative methods using content analysis (Paper II). Each method and its application have strengths and limitations, features that will be discussed in the following sections.

5.1.1 Follow-up with emphasis on participation in employment or education (Paper I)

This work is a descriptive observational study and not a randomized controlled trial. Therefore, we cannot with any certainty ascribe changes in the patients' status to the rehabilitation program as such. Although the data were collected systematically, the lag time from rehabilitation to follow-up assessment ranged from 1-17 years adding to the interpretation difficulties.

The strengths of our study are the size of the study population, the fact that we have obtained data of each patient who underwent the program since its start in 1993, and that a large proportion of eligible patients participated in the follow-up interview.

This is the only epilepsy specific rehabilitation program in the greater Stockholm region. Hence, our data likely reflect the situation for patients from the region that have been subjected to a structured rehabilitation. It is nevertheless difficult to generalize from our observations to what the effects may have been in patients that have not been referred to Stora Sköndal due to the unknown selection process for referring patients to the rehabilitation. The patients are clearly highly selected, since the large majority was referred to the program by neurologists having identified a need for multi-professional epilepsy focused rehabilitation for the patient.

As objective and quantifiable endpoint, EoE status was chosen as the endpoint of this study although this, in fact, is not the primary goal of the rehabilitation program, which does not include a formal vocational rehabilitation. However, assessment of

neuropsychological functions, activity analyses and discussions of future job plans, also together with the workplace, school, social insurance and employment services, are often included, as is referral to vocational rehabilitation or employment services at discharge when required.

5.1.2 Patients' and staff's experiences of what is important in rehabilitation (Paper II)

The main advantages of focus group interviews are that they permit an efficient qualitative data collection, richness in data, and that they stimulate the respondents and support them in remembering events, and that the discussion can lead beyond the answers of a single interviewee [52]. At the same time it may be a problem not knowing how the discussion will evolve [53]. In this study was created the theme, Life with epilepsy, which not directly answers the research question. However, given the fact that this theme clearly came out as important in the focus group interviews, and that the difficulties in everyday life expressed by the patients formed an important basis for rehabilitation interventions, we believe it was important to include.

A major limitation in our study is that only 17 out of the initially consenting patients completed the focus group interviews. The many dropouts were partly due to different, sometimes epilepsy related, health issues within the study group, which could have introduced a selection bias. Additionally, our patient focus groups turned out to comprise fewer participants than the ideal six to ten [54]. Nevertheless, the richness in the received answers to our research question indicates that the focus group approach was an appropriate and informative method. Cognitive difficulties, in particular memory problems, among the patients can be a further limitation. However, we considered focus group interviews to be advantageous in this regard, since participants can support and help each other to remember. This cross-communication did not appear to affect the validity of the result, since the statements showed broad variance and sometimes depth.

In the staff focus group, five of eight eligible, current and former team members participated. The staff members that declined to participate were one occupational therapist and two rehabilitation assistants (one male). Participating team members had all worked with epilepsy rehabilitation for at least ten years, out of which three took active part in the development of the program in the 1990:s. This large experience and knowledge is strength, but also a potential weakness as there could be a conflict of interest with the staff evaluating their own work.

We conducted all the interviews in the same manner as well as during a short period of time in order to standardize the conditions. Since the main author (EW) had been a member of the rehabilitation staff and involved in the treatment of almost every patient participating in the interview groups, another member of the research team was primary responsible for the data collection and analysis to reduce the risk of bias.

The interview with the staff was performed to obtain additional perspective on the research question, and given the team members' long experience of rehabilitation of persons with epilepsy, also valuable information. When the transcribed data from the staff's focus group were read, it was noted that it to a high degree corresponded to the patients' statements. Therefore, we used themes and categories from the patients' statements as a framework for the deductive analysis of the staff's statements. We believe that an inductive analysis would not have provided us any additional insights on our research question because the number of participants was limited and the statements were relatively concrete.

5.2 RESULTS IN RELATION TO PREVIOUS RESEARCH

5.2.1 Paper I

In this follow-up study of 124 patients that had completed an epilepsy rehabilitation programme, thirty-eight patients (33%) showed improved participation in society expressed in terms of EoE status from admission to follow-up on average 7.3 years after the rehabilitation. In our unadjusted analysis, active epilepsy expressed as occurrence of tonic-clonic seizures during the year preceding admission, and improvement in control of tonic-clonic seizures from admission to follow-up were associated with increased EoE participation. There was no significant association between improvement in EoE and age at admission, age at epilepsy onset, epilepsy duration at admission, gender, time between admission to follow-up or neurological co-morbidity. Additionally, when adjustments were made simultaneously for all these factors, the association between tonic-clonic seizures and improved EoE, OR (95% CI) 1.7 (0.5-5.8) and reduced frequency of tonic-clonic seizures and improved EoE, OR 2.6 (0.8-8.8) was no longer significant. Hence, we were unable to identify clinical factors that would have a favourable impact on improved EoE participation at follow-up after rehabilitation and that could serve as selection criteria for our rehabilitation program.

The association between occurrence of tonic-clonic seizures at admission and improved EoE status at follow-up could, however, be interpreted as an indication that our rehabilitation may be particularly effective in patients with more active epilepsy. On the

other hand, improved control of tonic-clonic seizures from admission to follow-up was more strongly associated with improved EoE. Thus, improved seizure control, rather than rehabilitation, may be the important factor for improved EoE participation. It is difficult to compare studies due to different patient populations, but a study of employment status among a community-based sample of people with epilepsy showed similar results with employment rates changing with seizure frequency [55]. That is also supported by a study evaluating the socio-occupational and employment profiles in 872 outpatients [56] where the two main factors associated with unemployment and incapacity were refractory epilepsy and occurrence of seizures. Changes in seizure control could be caused by factors unrelated to the rehabilitation program such as subsequent modifications of medication or other therapeutic interventions. Although optimization of the medical treatment is not normally included in the rehabilitation program, it is possible that the patients' improved knowledge about their epilepsy and the basic principles of treatment can enhance compliance with the treatment and also facilitate the communication between the patient and the prescribing physician. The study of the efficacy of the education treatment program MOSES [40] showed significant improvement in seizure outcome after having completed the educational program.

Yet, as discussed in a review on employment and epilepsy, there are a number of interacting problems in finding and maintaining employment [26], including feared workplace discrimination [31].

Mount et al. [57] analyzed the results of vocational rehabilitation for people with epilepsy, Missouri, USA. The only variables associated with successful vocational outcomes, were education and on-the job (epilepsy data were not available). However, studies of vocational rehabilitation and employment status are difficult to compare since conditions vary significantly in different countries and in different time periods also depending on economic or political changes in society, not only for people with epilepsy [58].

5.2.2 Paper II

Individualization, based on the patient's problems, resources, and needs, emerged as a central aspect in the rehabilitation, Thorbecke & Pfäfflin [59] used the WHO's ICF-based concept to describe the rehabilitation for persons with epilepsy tailoring assessment and interventions [59]. Tailored investigations and rehabilitation is also emphasized as key to success in a report from Norway [60]. Our results show that participants request various options of duration, intensity and follow-up's of the rehabilitation, a result that is not

surprising since some patients are likely to require more time than others to gain insight into their problems and awareness of their resources [61].

Meeting other people with epilepsy was considered as another important aspect of rehabilitation, mainly in the closed treatment group where patients shared experiences, were a cohesive group, and could trust each other and feel secure. Cohesion in groups is considered to be important for effective rehabilitation [48]. A study of 165 people with epilepsy, 74% with active epilepsy were asked to rank how they would like to have a self-management program, the majority preferred the individual face-to-face sessions, followed by face-to-face in group [62]. A study of group therapy for persons with epilepsy showed that the greatest benefit for the participants was meeting others with epilepsy and sharing experiences [63]. In a study using focus group interviews on living with epilepsy and cognitive difficulties, the authors concluded that the participants had benefited from meeting other people with similar problems and had expressed a need for group meetings [19]. The results and discussions from these findings correspond well with our participants' experiences and statements.

The team's attitude and personal encounters were considered important, together with the team holding different professions. The importance of the team's attitude and encounters between patients and staff have been described in rehabilitation of traumatic brain injury [48, 64, 65], emphasizing the creation of a therapeutic working alliance between patient and staff in order to achieve good rehabilitation results, summarized as a collaboration for change [66]. In the Randomized Controlled Trial of Holistic Neuropsychological Rehabilitation after traumatic brain injury, the participants of the Intensive Cognitive Rehabilitation Program emphasized the value of knowing that the team shared knowledge and understanding of patients' problems [48], a factor also confirmed as essential in our study. The participants stated that family members should be involved in the rehabilitation and be supported as well. Several authors emphasize the importance of involving, supporting and cooperating with family members in care and rehabilitation of persons with epilepsy [67-70].

Statements in this study, as well as in literature, show that persons with epilepsy often experience cognitive problems; these are sometimes perceived as one of the major issues with the condition [16, 18]. The participants stated the importance of individually tested strategies and tools for enhancing management of these problems in daily life. This

underscores the importance of effective compensatory cognitive strategies [19, 42, 71, 72].

Relaxation techniques were another important strategy taught to help patients' manage fatigue and as an indirect approach to seizure control. One study reported that relaxation techniques were successful [73] while a Cochrane report did not find sufficient evidence for the effectiveness of this treatment [74].

Patients in our study described the importance of support and help to accepting their situation and for changing their self-image. Pramuka et al. [61] showed that the participants who were not aware of their needs or not ready to change at the start of the psychosocial self-management program had difficulties embracing strategies for self-management. The authors suggested that self-management and self-efficacy intervention is only effective for those who are in the midst of a change.

In a postal survey, 245 outpatients with epilepsy were asked about perceived rehabilitation needs. In particular, those in the non-seizure free groups, asked for contact with social workers in rehabilitation settings in relation to employment. [75]. In our study, this is also highlighted by participants in patient focus groups who felt it was important to learn about community rights and obligations, and to have support in making contacts with authorities connected to employment or education and to other important people in society.

6 CONCLUSIONS

In this thesis we have described the current situation for patients that completed a rehabilitation program for persons with epilepsy, emphasising employment or education. We also explored whether we could identify factors that could be associated with a favourable development of participation in employment or education. We used qualitative methods to identify what patients and staff members' experience as important in rehabilitation for persons with epilepsy.

- A significantly higher proportion of patients were involved, at some level, in employment or education at follow-up compared with at admission to the rehabilitation.
- Improved participation in employment or education occurred in 33% of the patients, while 14% decreased their participation in employment or education, from admission to follow-up.
- We found an association between both (i) occurrences of tonic-clonic seizures, and (ii) decreased frequency of tonic-clonic seizures from admission to follow-up, and improved participation in EoE at follow-up in an unadjusted logistic regression analysis. However, these associations were no longer significant in a multivariable analysis.
- We found no associations between gender, age at epilepsy onset, comorbidity, age at admission and duration of epilepsy at admission and improvement of participation in EoE.

Issues experienced by patients and staffs as important in rehabilitation were:

- Individualization in both content and time and based on patient's problems and resources.
- Meetings with other persons with epilepsy in small groups to share experiences.
- Information and support to family members.
- Knowledge about epilepsy and support in emotional processing to increase self-awareness and acceptance.
- Committed rehabilitation team with different professions and high competence.
- Testing and practicing appropriate strategies for dealing with cognitive problems and fatigue in daily living and in managing work or study.
- Support in making contacts with authorities and workplace.

6.1 FUTURE PERSPECTIVES

While the work included in this thesis was carried out with the ambition to provide a basis for further development and refinement of rehabilitation programs for persons with epilepsy, it could only address a limited number of issues, and a lot remains to be assessed. We believe, however, that our present results could be used not only to refine rehabilitation programs, but also be useful in designing and planning of future studies of rehabilitation of persons with epilepsy and of the effectiveness of such programs. As any other intervention, rehabilitation programs for persons with epilepsy should ideally be evaluated in randomized studies. One possibility for the future would be to randomize referred epilepsy patients to immediate or deferred rehabilitation. Our results give clues to possible useful outcomes as well as baseline variables for stratification.

The structured interview guide developed for Paper I, can be useful directly in clinical work to improve systematisation of medical records and to support systematic follow-up.

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