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Rehabilitation for young adults with epilepsy and mild intellectual disabilities: Results of a prospective study with repeated measurements

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ABSTRACT

Purpose: A residential rehabilitation program of the Bethel Institute in Germany for approximately three years is offered to young adults with epilepsy and mild intellectual disabilities. Participants aim at epilepsy improvements and want to gain more independence. The purpose of this study was to investigate effects of the program and their stability over the course of time.
Method: Ninety-seven clients completed the program between 1999 and 2011. Data with repeated measurements (T1 = four weeks after admission, T2 = discharge, T3 = at least two years after discharge) were only available for 51 of them. Outcome variables were seizure frequency, carer-ratings on their clients' success, assistance needs after the program (supported housing vs. long-term residential care) and client-ratings on activities of daily living, problems at work, on health-related and on global quality of life (QOL), on life satisfaction and on depression and psychological distress.
Results: Seizure frequency was significantly reduced, more than half of the clients moved to supported housing. Clients reported improvements in activities of daily living and some aspects of their QOL. These improvements remained constant over at least two years. Baseline data scarcely correlated with outcome measures. Analyses of subgroups demonstrated that changes of client-ratings correspond to changes of external parameters such as seizure frequency and professional assistance.
Conclusion: Improvements with regard to more independent living, a better seizure control and more favorable self-ratings remained stable over the following years. From a social-welfare point of view, it is especially important that about half of the clients moved to supported housing after the program.

1. Introduction

People with epilepsy often suffer from psychosocial problems that are more straining than their seizures [1,2]. Besides, epilepsy is often associated with somatic and especially with psychiatric disorders [3,4]. Further frequent concomitants of epilepsy are cognitive impairments, ranging from specific cognitive disturbances to intellectual disability [5,6]. These patients with intellectual deficits have so far gained only little attention in studies about people with epilepsy [7].

Apart from seizure reduction, medical rehabilitation in Western countries primarily focuses on occupational training and (re-) integration into the regular labor market [8–10]. People with epilepsy and more profound intellectual disabilities regularly receive no medical rehabilitation but medical treatment and benefits from the social welfare system such as residential care and occupation in sheltered workshops. From their beginning the von Bodelschwinghschen Stiftungen (vBS) Bethel in Germany are providers of medical and social services for people with epilepsy and additional cognitive impairments. Since the last decade of the 20th century a special unit of the Bethel Institute offers a rehabilitation program currently called RJE[1] for young adults between 18 and 35 years of age from all over Germany. This program is conceptualized as time-limited residential living of approximately three years for people whose longer lasting professional assistance needs are still

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[1] RJE = rehabilitation for young adults with epilepsy; WJE and WHV EP 1 were former abbreviations that directed more attention to residential living.

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unknown [11]. It is addressed to people with active epilepsy and mild intellectual disabilities who suffer from problems in vocational training, in getting a job on the regular labor market or in gaining more independence from their families. These social difficulties are often accompanied by problem behavior or even psychiatric disorders.

To the author's knowledge, the RJE program is unique in Germany and also not comparable to rehabilitation programs in other developed countries due to different health and social welfare frameworks. Two studies have already been presented for RJE evaluation indicating improvements among many clients: One of them analyzed ratings of staff and clients ($N = 85$) at the end of the program in the sense of direct change measurement in addition to changes of disease parameters [12]. The other one was a prospective pre-post-study based on 52 clients that compared client-ratings at RJE-admission with those at discharge in the sense of indirect change measurement [13]: Self-ratings were gained by face-to-face interviews with the RJE psychologist. Topics were health-related and global quality of life (QOL), depression and psychological distress.

This following third naturalistic study design aims at supplementing follow-up data to the aforementioned studies. The central goal is to investigate whether improvements remain stable in daily routine after RJE discharge. Moreover, the new evaluation may also serve as a proof of the former pre-post-study although the samples are not fully identical due to ongoing data collection.

In integrating follow-up data the following questions on the rehabilitation outcome are repeated:

- Do disease parameters, individual assistance needs and self-ratings of clients on health-related and global QOL and on psychological distress improve?
- How far are outcome parameters correlated? Especially: Are different changes on "objective" measures (i.e. professional support after RJE and seizure frequency) reflected by different changes on self-ratings?
- Can data collected at RJE admission serve as predictors of rehabilitation outcome?

Furthermore, this study is going to analyze the development of RJE clients with psychogenic nonepileptic seizures (PNES) in addition to epileptic seizures. Data of this subgroup had been excluded from the former pre-post-study [13].

2. Methods

2.1. The RJE program

RJE aims at the improvement of the medical treatment, better self-management with regard to health and more independence in daily life, emotional stability and a scheduled living structure with an occupational activity that fits to the person's abilities (= most frequently an occupation in sheltered workshops). The admission board takes care that only people with the above-mentioned criteria are admitted to the RJE. Requests are often based on recommendations of epilepsy clinics or occupational training centers following unsuccessful rehabilitation in these institutions. There were so far no final RJE rejections due to availability of residential places. Most of the staff members are social workers and each of them offers personal support to some of the clients. The rehabilitation program did not change since the beginning of data collection in 1999. Fluctuation among staff was sparse. The number of residential places was reduced from 46 in 1999 to 25 that are currently available in different accommodations. Living and occupation facilities as well as medical services for people with epilepsy and mild intellectual disabilities were improved in many regions of Germany during this period. Staff is supported by professional services such as neurologists for epilepsy treatment or psychologists for counseling staff and clients. Residents are regularly employed in sheltered workshops of the Bethel Institute with a special service to prepare integration into general work force. Every 10 months round table discussions with members of the professional services take place in order to plan and evaluate interventions for each client with regard to epilepsy, daily living, occupation or emotional stability: Such interventions include, for example, medication changes, cooking lessons, trainings to use the public transport system or to buy food, practical courses in different sheltered workplaces and psychotherapeutic counseling. Setting up a schedule for every day, job trials, personal assistance by social workers to gain competence for day-to-day life and medical epilepsy treatment are obligatory. Clients also need to participate in the eight lessons of PEPE, a psycho-educational program for people with epilepsy and intellectual disability [14]. Furthermore, living with peers having epilepsy enables social learning and staff provides support in case of conflicts. Some months before RJE discharge future living and assistance needs are subject of the round table discussion. A decision has to be taken whether the client will need further residential support or whether the client will be able to live more independently with supported housing.[2] Judgment of the social workers is crucial, supplemented by the vote of the professional services. After that, an adequate home (group home or single apartment) is looked for together with the client and the change of residence is prepared.

2.2. Data collection and sample selection

Altogether, 110 young adults with epilepsy started the RJE program between August 1999 and September 2008. About four weeks after admission they took part in an individual interview with the RJE psychologist (T1). Ninety of these clients (81.8%) also took part in a similar individual interview with the RJE psychologist at discharge, i.e. between August 2002 and December 2011. Self-rating scales were obligatory presented in these interviews as part of the rehabilitation program. Face-to-face presentations seemed appropriate due to motivational or cognitive limitations of the clients. At least two years after their discharge 54 former RJE clients were asked to participate in a voluntary follow-up interview by the Psychological service. They were still working in sheltered workplaces of the Bethel Institute in the area of Bielefeld and therefore most easily recruited for an interview. Follow-up data were collected in two waves: The first group of former RJE clients was interviewed between October 2008 and July 2009. They had been discharged from the RJE between August 2002 and December 2006. The second group of former RJE clients was interviewed between January 2013 and February 2014. They had been discharged from the RJE between June 2007 and December 2011. Fifty-one persons decided to participate in the follow-up data collection, i.e. 46.6% of those that had been admitted to the RJE in the selected period or 56.7% of those with regular discharge and participation in the T2-interview.

Fig. 1 shows the sample selection and the reasons for not participating in interviews at discharge or follow-up.

Breaking off between T1 and T2 refers to persons who did not fully attend the rehabilitation program either by their own will or by institutional initiative due to insufficient adherence. Mortality must be attributed to sudden death in epilepsy (SUDEP) due to the available information from the RJE neurologists. SUDEP sometimes happened at the Bethel Institute and sometimes during home-stays with parents and relatives. Especially among patients with epilepsy and intellectual disability, mortality is raised [15] with no

[2] Supported housing refers to living in regular accommodation with assistance of professional caregivers for some hours per week.