



Counseling and social work for persons with epilepsy: Observational study on demand and issues in Hessen, Germany



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ABSTRACT

The goal of the social management of epilepsy is to decrease the physical, psychological, and social consequences for persons with epilepsy (PWEs). The objective of this observational study was to determine the needs and issues of PWEs in the utilization of epilepsy counseling services between 2008 and 2012 in the German state of Hessen.

Sociodemographic data, employment status, counseling issues, and characteristics were collected at first and follow-up visits. An average of 492 (272 males, 55.3%) PWEs presented at counseling services per year. These were mainly children or adolescents below the age of 20 years (22.4%) and PWEs in working age between 20 and 65 years (73.6%). The majority of PWEs seeking counseling were employed (44.4%, annual average: 219 PWEs, SD: 39). However, a substantial part (114/219, 52.1%) of these employed PWEs reported problems or difficulties at their workplace associated with the diagnosis of epilepsy. We could identify four major issues addressed by the PWEs as 1) diagnosis of epilepsy, 2) employment, 3) family-related matters, and 4) social or medical aids linked with public authorities.

This study demonstrated the continuous demand for epilepsy counseling with at least one out of twenty (5.8%) PWEs in need of counseling per year. Further studies are warranted to answer questions on outcome and long-term course. Epilepsy counseling should be available to all PWEs on a national level and may be helpful in preventing long-term unemployment and early retirement while maintaining quality of care for PWEs.

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1. Introduction

The goal of the social management of epilepsy is to decrease the physical, psychological, and social consequences, so that persons with epilepsy (PWEs) have to accept as few limitations as possible because of epilepsy [1]. However, PWEs report a significant impact of epilepsy and its management on lifestyle, school, driving, family function, and social and leisure opportunities, as well as increased levels of anxiety and depression and poor self-esteem compared with people without the condition [2–6]. The unemployment rate of people with epilepsy is at least two times higher than that of the general population, and the associated costs are a major burden to society [7–10].

The aim of counseling and social work services is to address specific issues faced by PWEs and to facilitate understanding, effective

management, and coping with their disease for themselves, their families, and their social environment. The other purpose is to supply them with appropriate knowledge about legal and social support of healthcare and social agencies and institutions. Frequently, social workers assist with practical matters, such as finding and keeping employment or advice in obtaining health and disability benefits.

For more than two decades, epilepsy counseling services have been recognized and recommended by national and European guidelines as essential parts of epilepsy centers and comprehensive programs for presurgical evaluation in epilepsy [11,12]. However, access to epilepsy counseling is not ensured on a national level to all PWEs, and no data are available on the demand of counseling and social work. In 2005 and 2006, epilepsy counseling services (“Epilepsieberatungsstellen”) were established in the German state of Hessen based on charitable funding. Persons with epilepsy and their relatives were made aware of the services by their treating physicians, newspapers, internet, self-help groups, and community outreach education. These epilepsy counseling services are open to all PWEs and their relatives from the state of Hessen and other German states. The access is free of charge and independent of treatment by any specific neurologist or epilepsy center.

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Thus, the objective of this study was to determine the needs and issues of PWEs in the utilization of epilepsy counseling services between 2008 and 2012. This observational study aimed to answer the following three questions: 1) Who is and who is not seeking epilepsy counseling service? 2) What is the employment status of PWEs seeking counseling, and which problems do they encounter at their workplace? 3) What are the counseling issues in PWEs, and how do they approach the service?

2. Patients and methods

2.1. Study setting

The study was performed at the epilepsy counseling services in Giessen, Marburg, and Schwalmstadt-Treysa opened in May 2006 to children, adolescents, and adults with epilepsy. The services were open to the public during usual working hours on weekdays, and voicemail was available in between. The social workers (J.S. and A.B.) at the counseling services were financed by the charity “Aktion Mensch” and the associated hospitals Hessisches Diakoniezentrum Hephata e.V. (Schwalmstadt-Treysa, Germany) and University Hospital of Giessen and Marburg GmbH (Marburg, Germany).

The West German state of Hessen has a total of 6,074,950 inhabitants (2,983,110 males, 49.2%). The local catchment area comprised the three districts of Giessen, Marburg-Biedenkopf, and Schwalm-Eder that are located 70 to 130 km north of Frankfurt/Main and have a total of 688,758 inhabitants (338,215 males, 49.2%) according to the 2011 census (Statistical Office of Hessen, www.statistik-hessen.de). The districts lie within the postal code area 35 used previously for a population-based estimation of the incidence of status epilepticus as the population structure is representative for Germany [13].

2.2. Study population

The study population consisted of four consecutive cohorts of PWEs seeking counseling between May 1st, 2008 and April 30th, 2012. The evaluation was embedded within routine counseling on the first and follow-up visits. During the first visit, demographic data (age group, sex, marital status, and education) and employment status were collected. At all visits on site and contacts via phone, e-mail, letter, or fax, the counseling characteristics and issues were recorded. Counseling aspects were taken into consideration if they were discussed for at least 15 min. Individual, family, and other contacts were considered once the conversation time and subsequent administrative activities exceeded 30 min of duration.

2.3. Data entry and statistical analysis

Statistical analyses were performed using IBM SPSS Statistics 21 (SPSS Inc., Chicago, IL, USA). Data are presented as mean \pm standard deviation (SD) and percentages where appropriate.

3. Results

3.1. Sociodemographic characteristics

Within the study period between 2008 and 2012, an annual average of 492 (272 males, 55.3%) PWEs sought counseling at the epilepsy counseling services in Giessen, Marburg, and Schwalmstadt-Treysa. Details of sociodemographic characteristics are provided in Table 1. Approximately one quarter (22.4%) was below the age of 20, while the majority of PWEs (73.6%) were in working age between 20 and 65 years. Only a minority of less than 5% was over 65 years of age.

Table 1
Sociodemographic characteristics.

| | 2008/2009 ^a | 2009/2010 ^a | 2010/2011 ^a | 2011/2012 ^a | Annual ^b | Proportion |
|--|------------------------|------------------------|------------------------|------------------------|--------------------------------|--------------|
| Persons with epilepsy | 461 | 472 | 487 | 548 | 492 \pm 39 | |
| Sex | | | | | | |
| Male | 256 | 259 | 274 | 301 | 272 \pm 21 | 55.3% |
| Female | 205 | 213 | 213 | 247 | 220 \pm 19 | 44.7% |
| Age groups | | | | | | |
| 0–10 years | 34 | 54 | 21 | 18 | 32 \pm 16 | 6.5% |
| 11–20 years | 71 | 52 | 83 | 106 | 78 \pm 23 | 15.9% |
| 21–35 years | 148 | 160 | 154 | 178 | 160 \pm 13 | 32.5% |
| 36–50 years | 137 | 146 | 150 | 175 | 152 \pm 16 | 30.9% |
| 51–65 years | 47 | 34 | 49 | 70 | 50 \pm 15 | 10.2% |
| >65 years | 24 | 26 | 30 | 1 | 20 \pm 13 | 4.1% |
| Marital status | | | | | | |
| Married/living in relationship | 191 | 193 | 215 | 210 | 202 \pm 12 | 41.1% |
| Divorced | 31 | 28 | 44 | 70 | 43 \pm 19 | 8.9% |
| Single | 113 | 113 | 103 | 144 | 118 \pm 18 | 24.0% |
| Widowed | 19 | 9 | 33 | 47 | 27 \pm 17 | 5.5% |
| n.a. or <18 years | 107 | 129 | 92 | 77 | 101 \pm 22 | 20.6% |
| Highest school education | | | | | | |
| Ongoing school education | 90 | 113 | 82 | 93 | 95 \pm 13 | 19.2% |
| Completed special needs school | 29 | 46 | 39 | 58 | 43 \pm 12 | 8.7% |
| Completed school with <11 school years | 217 | 223 | 303 | 339 | 271 \pm 60 | 55.0% |
| Completed school with >12 school years | 33 | 37 | 33 | 44 | 37 \pm 5 | 7.5% |
| No school degree | 19 | 33 | 30 | 8 | 23 \pm 11 | 4.6% |
| n.a. | 73 | 20 | 0 | 6 | 25 \pm 33 | 5.0% |
| Catchment area | | | | | | |
| Local ^c | 277 | 160 | 190 | 199 | 207 \pm 50 | 42.1% |
| State of Hessen | 158 | 251 | 247 | 293 | 237 \pm 57 | 48.2% |
| Germany, outside state of Hessen | 26 | 61 | 50 | 56 | 48 \pm 16 | 9.7% |

Bold values represent annual averages.

^a May 1st–April 30th.

^b Mean \pm standard deviation.

^c Districts of Giessen, Marburg-Biedenkopf, and Schwalm-Eder.

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