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# Counseling and social work for people with epilepsy in Germany: A cross-sectional multicenter study on demand, frequent content, patient satisfaction, and burden-of-disease

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ABSTRACT

*Background:* The diagnosis of epilepsy is accompanied by relevant personal, interpersonal, and professional restrictions for patients and their caregivers. Specialized epilepsy counseling services (ECS) have been introduced to inform, advise, and support patients with disease-related problems.
*Aim and scope:* The objective of this cross-sectional, multicenter study was to determine the demand, typical content, and outcomes of ECS in children, adolescents, and adults in two adjacent German regions of Hessen and Lower Franconia. All ECS sites in these regions participated in 2014 and 2015, offering a total population of 7.5 million inhabitants.
*Results:* A total number of 435 patients [323 adults (74.3%), 51.7% female, mean age: 40.3 ± 14.7 years and 112 children/adolescents (25.7%), 52.7% female, mean age: 9.4 ± 4.6 years] were enrolled at six ECS sites. The most common reasons for counseling were general information needs (n = 304; 69.9%), administrative help (n = 208; 47.8%), problems with education or work (n = 176; 40.5%), and recreational activities (n = 119; 27.3%). In addition, 6.2% reported epilepsy-related questions on family planning as a specific reason for desiring counseling. Recommendation by the treating physicians was the most frequent reason for receiving counseling through ECS (62.5%), and most patients preferred to receive a personal consultation (73.1%). Patient satisfaction as measured by the ZUF-8 client satisfaction score was high with a mean of 29.7 points (standard deviation: ±2.7 points, median: 29.9 points), and 83.9% of patients said they would recommend ECS. Disease-related job loss or change in school was avoided in 72% of 82 patients. Suggestions for improvement of ECS included an extension of service hours (58.6%) and a better availability of more sites located nearby (32.8%).
*Conclusion:* Epilepsy counseling services are necessary, valued, and effective institutions for people with epilepsy complementing outpatient and inpatient care. To improve the care for people with epilepsy, access to and availability of ECS should be improved.



## 1. Introduction

Epilepsy is a common and chronic neurological disease with the clinical hallmark of recurrent seizures [1]. The diagnosis of epilepsy is often accompanied by relevant restrictions for patients and caregivers. The most frequent disease-specific constraints for patients with epilepsy include the loss of their driving aptitude, the incapacity for specific recreational sports, or limitations in the supervision of children. However,

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restrictions do not only affect private life; they may also impact vocational training and work life [2–6]. On days with high demands of temporal and spatial flexibility from employers, losing permission to drive can have devastating effects including the loss of employment and can result in a dependency on transfer payments [7,8]. Unemployment rates of patients with epilepsy are more than two times the rate of the general population [9,10]. Moreover, patients with epilepsy may need special medical aids or therapies, which have to be individually applied for. For these reasons, many patients with epilepsy struggle with the diagnosis and with its further consequences, resulting in a significantly reduced health-related quality of life (QoL), increased depression rates, therapy incompliance, and a feeling of being stigmatized [11,12].

To address these problems and achieve a better QoL, people with epilepsy ideally have to accept as few disease-related limitations as possible. Specialized outpatient epilepsy counseling services (ECS) sites were introduced beginning in 2005 in the German states of Hessen and earlier in Bavaria. Most of these locations are run by trained social workers; financed by the government, charities, or hospitals; and are free of charge and accessible independently from other medical services. The comprehensive availability of ECS has been recommended by both national and international (European) guidelines as well as medical societies for more than two decades [13,14]. However, the number and spatial availability of ECS sites remain still limited. Importantly, the main goals of ECS are to address issues of people with epilepsy, provide an independent source of information, and offer fast and unbureaucratic help for both disease-related and administrative problems. Since the introduction of ECS, only a few studies have been published on the subject to date, but all have consistently demonstrated the broad acceptance of ECS and other counseling services by adults as well as children, adolescents, and their caregivers [15–17].

The objective of the present study was to evaluate the demand, typical content, and outcomes of ECS in the German regions of Hessen and Lower Franconia in 2014 and 2015.

## 2. Patients and methods

### 2.1. Study settings and design

This study was designed as a cross-sectional multicenter survey and enrolled patients over a 12-month observation period in two German states (Hessen and Lower Franconia as part of Bavaria, together representing more than 7.5 million inhabitants) at all ECS sites in these regions. Both states offer comparable infrastructural settings with large rural and metropolitan regions and a standardized, comprehensive medical supply. Data acquisition was performed independently by six ECS sites [Bad Neustadt a.d. Saale, Frankfurt am Main, Gießen, Marburg (Lahn), Treysa, Würzburg] between July 2014 and June 2015. After receiving written informed consent from adult patients, parents of affected children, and adolescents or their legal guardians, all patients with epilepsy were deemed eligible for inclusion. The seizure and epilepsy syndrome classifications were adapted according to the latest definitions of the International League Against Epilepsy [18,19]. Patients were excluded when a diagnosis of epilepsy could not be determined without doubt. Patients with intellectual disabilities were also included. Strengthening The Reporting of Observational Studies in Epidemiology guidelines were adhered to [20].

### 2.2. Data assessment, entry, and statistics

Validated and age-adjusted questionnaires were used to assess sociodemographic and disease-specific information [21–23]. In line, the demands, content, patient satisfaction with, and possible suggestions for improvement of ECS were determined. In the case of an underage patient or patient with disability, the main caregiver was asked to complete the questionnaire “by proxy.” Patient satisfaction was measured using the ZUF-8 satisfaction score, which is based on the Client Satisfaction Questionnaire by Attkisson and Zwick [24] and relies on data from eight different items [25]. The QoL was measured using age-specific and validated questionnaires in children and adolescents (KINDL$^R$, generic instrument for assessing health-related QoL in children and adolescents aged 3 years and older) [26] and adults (QOLIE-31, Quality of life in epilepsy-31), respectively [27]. The QoL in the caregivers of children and adolescents was measured using the EuroQol EQ5-D questionnaire [28]. Adult patients were also asked to complete the Cambridge Worry Scale [29], the Stigma Scale for Epilepsy [30], the Neurological Disorder Depression Inventory for Epilepsy (NDDI-E) [31], and the Liverpool Adverse Events Profile (LEAP) [32]. For more information on the employed scales, inventories, and profiles, please refer to the references cited.

Data were entered using the FileMaker Pro 8.5 database software (Filemaker Inc., Santa Clara, CA, USA) using a double-entry procedure to minimize entry errors. Statistical analyses were performed using the Statistical Package for the Social Sciences version 22 software program (IBM Corp., Armonk, NY, USA). Statistical comparisons were conducted using Pearson's Chi-square test for the analysis of categorical data. In the case of a number of less than 60 subjects, Pearson's Chi-square test with Yates correction was performed. For the comparison of ZUF-8 results, Welch's *t*-test for unequal variances was employed. P-values of $<0.05$ were considered to be statistically significant. The study received an ethics commitee approval. Informed consent was obtained from all participants for being included in the study.

## 3. Results

### 3.1. Sociodemographic and disease-specific aspects of the cohort

A total number of 435 patients with epilepsy were enrolled during the recruitment period, with 112 (25.7%) being children and adolescents and 323 (74.3%) being adults. In both age groups, gender distribution was nearly balanced at 52.7% and 51.7% female patients, respectively.

In the subgroup of children and adolescents, the mean age was 9.4 years (±4.6 years, range: 1–17 years) with a mean epilepsy onset occurring at 5.0 years (±3.7 years, range: 1–17 years), resulting in a mean disease duration of 4.6 years (±4.2 years, range: 0–16 years). Seizure freedom for ≥12 months was reported in 31.3%, while half of patients reported ongoing seizures. In 18.7%, no information on seizure frequency was available. A developmental delay was reported in 23 patients. Regarding the use of anticonvulsants (AEDs), 54.5% reported a polytherapy regimen, 33.9% reported a monotherapy regimen, and 11.6% reported no intake of AEDs. The mean QoL value of children and adolescents was 66.5 (±14.7; range: 29.3–92.8; reference for healthy children: 76.3–76.9 [33,34]) according to KINDL$^R$. Separately, the mean QoL of their caregivers was 0.88 (±0.2, range: 0.1–1.0, reference for German adults: 0.90 [35]) according to the EQ5-D questionnaire.

In the cohort of adult patients, the mean age was 40.3 years (±17.7 years, range: 18–76 years), and the mean age at epilepsy onset was 24.1 years (±17.5 years, range: 18–76 years), while mean epilepsy duration was 17.5 years (±15.7 years, range: 0–64 years). Approximately half of patients had been seizure-free for more than 12 months (40.6%) or reported ongoing seizures (42.7%), while, in 16.7%, no information on seizure frequency was available. An intellectual disability was reported in 5 patients. No intake of AEDs was reported by 9.3% of this subgroup, while 42.7% reported the intake of one, and 48.0% reported the intake of two or more AEDs, respectively, for details please refer to Table 1. The mean QoL value in adult patients was 60.3 (±22.6, median: 60.0, range: 0–100) on the QOLIE-31 scale and 54.5 (±16.5, median: 53.5, range: 14–90) according to QOLIE-31 score. Depression was assessed using the NDDI-E inventory and revealed hints for clinically relevant depression in 118 cases (36.5%, cutoff: ≥ 14). The LEAP profile revealed substantial adverse events in 128 patients (39.6%, cutoff: ≥ 45). The mean score of the Cambridge Worry

**Table 1**
Sociodemographic and disease-specific characteristics of the patient cohort (n = 435).

| | Total (n = 435) | Children & adolescents with epilepsy (n = 112) | Adults with epilepsy (n = 323) |
|---|---|---|---|
| Sex[ns] | % (n) | % (n) | % (n) |
| Female | 52.0 (226) | 52.7 (59) | 51.7 (167) |
| Male | 48.0 (209) | 47.3 (53) | 48.3 (156) |
| Age, years | % (n) | | |
| Mean ± SD | 32.3. ± 18.6 | 9.4 ± 4.6 | 40.3 ± 17.7 |
| Range | 1–76 | 1–17 | 18–76 |
| Epilepsy onset, years | % (n) | | |
| Mean ± SD | 18.9 ± 17.5 | 5.0 ± 3.7 | 24.1 ± 17.5 |
| Range | 0–73 | 1–17 | 0–73 |
| Epilepsy duration, years | %(n) | | |
| Mean ± SD | 13.5 ± 13.8 | 4.6 ± 4.2 | 17.5 ± 15.7 |
| Range | 0–64 | 0–16 | 0–64 |
| Seizure frequency | % (n) | % (n) | % (n) |
| Seizure freedom ≥12 month | 38.2 (166) | 31.3 (35) | 40.6 (131) |
| Active epilepsy | 44.6 (194) | 50.0 (56) | 42.7 (138) |
| Not provided | 17.2 (75) | 18.7 (21) | 16.7 (54) |
| Anticonvulsant drugs (AED) | % (n) | % (n) | % (n) |
| No AEDs | 9.9 (43) | 11.6 (13) | 9.3 (30) |
| Monotherapy | 40.5 (176) | 33.9 (38) | 42.7 (138) |
| Polytherapy | 49.7 (216) | 54.5 (61) | 48.0 (155) |

SD = standard deviation; ns = no significant difference (P > 0.05).

Scale obtained was 42.2 (±11.8, median: 42.0, range: 19–71), while the mean score of the Epilepsy Stigma Scale obtained was 5.0 (±1.7, median: 5, scale: 1), indicating subjective stigmatization in 57.5% of patients.

### 3.2. Utilization and counseling content

Patients reported between one and 20 appointments per year, resulting in a median annual counseling frequency of 2.0 appointments (±2.8 appointments, mean: 2.5 appointments). The ECS were most frequently used for counseling (69.9%), focusing on general information about epilepsy (54.7%) or special education on epilepsy-related problems (43.0%). Requests for administrative help were required by 47.8%, and a special counseling session on education or work-related problems was requested by 40.5% of the cohort. Moreover, 27.3% reported family planning or recreational activities as a reason for counseling. Most of the patients attended the ECS in person at one of the different sites (73.1%), but also made contact via telephone (46.0%), email (17.7%), or letter (5.5%). Most patients were referred to ECS by their treating physicians (62.5%), though in some cases, patients'

**Table 2**
Demand of and reasons for epilepsy counseling.

| | Total (n = 435) | Children & adolescents with epilepsy (n = 112) | Adults with epilepsy (n = 323) |
|---|---|---|---|
| Demand frequency/year | % (n) | | |
| Mean ± SD | 2.4 ± 2.8 | 2.4 ± 2.2 | 2.9 ± 1.3 |
| Range | 1–20 | 1–11 | 1–20 |
| Reasons for counseling | % (n) | % (n) | % (n) |
| General counseling | 69.9 (304) | 83.9 (94) | 65.0 (210) |
| Disease-specific information | 54.7 (238) | 51.8 (58) | 55.7 (180) |
| Special education | 43.0 (187) | 41.4 (46) | 43.4 (141) |
| Administrative help | 47.8 (208) | 50.9 (57) | 46.7 (151) |
| Education & work | 40.5 (176) | 42.0 (47) | 39.9 (129) |
| Kindergarten | 3.0 (13) | 11.6 (13) | 0.0 (0) |
| School & training | 14.9 (65) | 31.3 (35) | 9.3 (30) |
| Work | 26.0 (113) | 0.9 (1) | 34.7 (112) |
| Threatening job loss | 12.2 (53) | 0.0 (0) | 16.4 (53) |
| Recreational activities | 27.3 (119) | 9.8 (11) | 33.4 (108) |
| Driving license | 189.5 (82) | 4.5 (5) | 23.8 (77) |
| Sport, hobby | 8.3 (36) | 5.4 (6) | 9.3 (30) |
| Family planning | 4.6 (20) | 0.0 (0) | 6.2 (20) |
| Consultation type | % (n) | % (n) | % (n) |
| Appointment | 73.1 (318) | 70.5 (79) | 74.0 (239) |
| Telephone | 46.0 (200) | 49.1 (55) | 44.9 (145) |
| Email | 17.7 (77) | 16.1 (18) | 14.2 (59) |
| Letter & facsimile | 5.5 (24) | 4.0 (6) | 5.4 (18) |
| Recommendation | % (n) | % (n) | % (n) |
| Treating physician | 62.5 (272) | 65.2 (73) | 61.6 (199) |
| Newspapers, magazines | 7.8 (34) | 4.5 (5) | 9.0 (29) |
| Family, friends, patient advocacy groups | 7.6 (33) | 4.5 (5) | 8.7 (28) |
| Information meetings | 7.6 (33) | 4.5 (5) | 8.7 (28) |
| Internet | 7.4 (32) | 11.8 (11) | 6.5 (21) |

SD = standard deviation.

interest in ECS was aroused by newspapers (7.8%), personal recommendations (7.6%), information meetings (7.6%), via an Internet search (7.4%), and by way of patient advocacy groups (0.1%). More details on the utilization and most typical content of ECS and results for both subgroups of this cohort are displayed in Table 2.

### 3.3. Outcome and patient satisfaction

A total of 18.9% (n = 82) reported problems at work or school. Among adults, 16.4% reported an acute threat of losing their job or vocational training (n = 53) and, in 25.9% of children and adolescents (n = 29), the continuation of schooling was at stake. In 72.0% of the cases (adults: 66.0%, children: 82.8%), patients or caregivers reported that counseling helped the individual to continue their employment, training, or schooling. In 17.1% (n = 14), a change within the institution or workplace or of class in the same school was required, while, in 12.2% (n = 10) a change of employer or school but not the kind of school was necessary. In 4.0% (n = 18) of the affected adult patients, no further employment could be achieved, while, in 17.2% (n = 5) of the affected children and adolescents, despite counseling, a shift of schooling toward a lower attainment institution was necessary.

Patient satisfaction regarding ECS was measured via ZUF-8 score, resulting in a mean score of 29.0 (±2.7, median: 29.0, range: 24–32). Overall, 83.9% reported that they would recommend ECS to other patients, and 83.9% would consider the use of ECS for the management of further problems.

The results of each ZUF-8 item are displayed as a Likert plot in Fig. 1 for adults and for the caregivers of children and adolescent patients. Further details are plotted in Table 3.

### 3.4. Suggested improvements

Most of these patients (n = 255/435; 58.6%) proposed an expansion of the range of services provided by ECS (e.g., workshops and site visits in schools, nursery homes, kindergartens) or an increase in the available information or educational material. When asked for improvements in detail, only 13.3% (n = 58) made suggestions as to how to improve ECS in the future. The lack of a general availability of ECS was criticized by 19 patients (32.8%), while an increased number for ECS sites nearby was also demanded. Furthermore, six patients (10.3%) suggested increasing the duration of counseling appointments. In addition, increased public relations work (19.0%) and better networking between the ECS, clinics, epilepsy centers, physicians, and patient advocacy groups were demanded (13.8%), for details please refer to Table 4.

## 4. Discussion

The aim of this study was to determine the demands, content, and outcomes of specialized epilepsy counseling and social work in Germany based on a multicenter survey conducted in the two German regions of Hessen and Lower Franconia. Both regions include large rural and metropolitan regions as well as a comprehensive epilepsy care with three large epilepsy centers and several specialized medical practitioners focused on epilepsy (www.izepilepsie.de).

Indisputably, the diagnosis of epilepsy is accompanied by miscellaneous restrictions affecting private, social, and work life aspects as well as mobility [2,5,7,36–39]. In line with previous publications, the investigated cohort showed increased depression rates, decreased QoL as well as increased measures for worry and stigmatization underlining the diversity of epilepsy-related burdens for patients, caregivers, and society [5,40–43]. The depression rate of 39.6% was in line with a recent review that showed prevalence rates in unselected samples between 17% and 22% and up to 55% in patients with drug-resistant epilepsy [44].

In the German medical care system, the treatment and management of patients with epilepsy is historically divided into the categories of inpatient (e.g., treatment given by hospitals or specialized epilepsy centers) and ambulatory (e.g., treatment given by neurologists or general practitioners). However, both sectors mainly focus on medical issues, with a smaller focus placed on the social or administrative aspects of the disease [15,45]. To close this treatment gap, ECS were introduced in several German states following the recommendation of national and international epilepsy societies, but are still not comprehensively available or established as part of the statutory healthcare system [13,14]. In spite of more than 10 years of ECS being available and there being thousands of counseled patients, studies on the demands, reception, typical content discussed, and outcomes of these highly specialized healthcare services are rare. A pilot study by Schulz et al. analyzed the demand of ECS, showing that at least one of 20 (5.8%) patients use

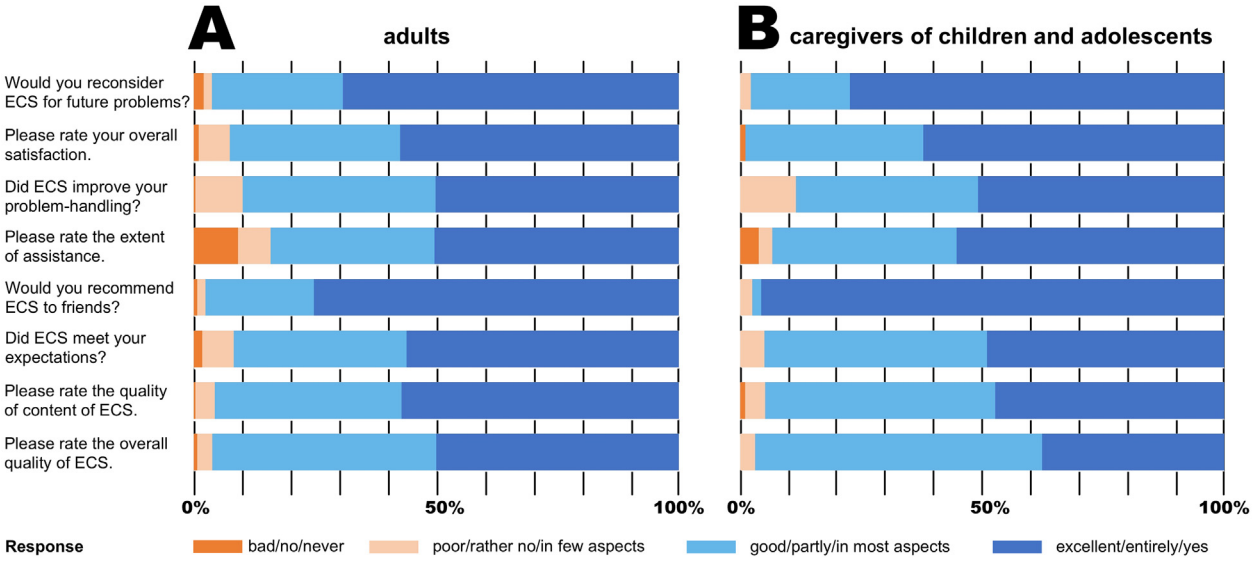


**Fig. 1.** Likert plot of the results of the patient satisfaction questionnaire ZUF-8. Adults (A) as well as children and adolescents (B) throughout rated all items of the ZUF-8 questionnaire as helpful, with a minimum share of positive feedback of 85%. In detail, more than 90% of the enrolled patients would reconsider or recommend ECS and stated that their expectations were met. More than 95% of the cohort regarded the quality of ECS to be good or excellent.

**Table 3**
Epilepsy counseling—outcome and satisfaction of those counseled.

| | Total (n = 435) | Children & adolescents with epilepsy (n = 112) | Adults with epilepsy (n = 323) |
|---|---|---|---|
| ZUF-8 score[ns] | %(n) | | |
| Mean ± SD | 29.0 ± 2.7 | 29.1 ± 2.6 | 29.0 ± 2.7 |
| Median | 29.0 | 29.0 | 29.0 |
| Range | 22–32 | 24–32 | 22–32 |
| Recommendation of epilepsy counseling[ns] | % (n) | % (n) | % (n) |
| Recommendation | 83.9 (365) | 81.3 (91) | 84.8 (274) |
| No recommendation | 3.0 (13) | 1.7 (2) | 3.4 (11) |
| Not provided | 13.1 (57) | 17.0 (19) | 11.8 (38) |

SD = standard deviation; ns = no significant difference (P > 0.05).

epilepsy counseling per year [15]. Extrapolating these findings from the regional level to the federal level results in a demand of up to 40,000 patients seeking appointments at ECS per year. In July 2018, there was a total number of 19 registered ECS sites in seven of the 16 German states (https://www.stiftung-michael.de, accessed date 08/08/2018). Given the fact that most of the patients in our study preferred to receive individual counseling during a personal appointment, the demand for services by far exceeds the current capacities. In line with these considerations, some of the most frequent suggestions for improvement were better availability, a greater proximity to the place of residence, and more ECS sites. (See Table 4.)

In line with the study by Schulz et al., the most frequent reasons for the use of ECS included the need for general information about diagnosis and disease-related problems with employment, with family-related matters or with social and medical aids linked with public authorities, respectively [15]. However, most reasons for the use of ECS relate to more than one problem area, such as driving restrictions, which normally affects both one's private and work life. It has been shown that driving and mobility are very important for many patients with epilepsy and that a relevant amount of patients with epilepsy disregard their legally imposed driving restrictions to maintain their employment or stay competitive (in the case of self-employed workers) [7,46–48]. Here, ECS may share their expertise on employee protection, in-house relocation, and job placement to help patients being threatened with disease-related job loss. In addition, imparting social security assistance may help to increase mobility for people with epilepsy who are not able to drive [49]. In our cohort, job loss could be prevented after ECS in more than half of the affected patients, which underlines the value of a qualified additional counselor. In view of several German cost-of-illness studies revealing unemployment and early retirement as relevant indirect cost-driving factors, individual and specialized work-counseling may additionally reduce the economic burden of epilepsy [9,10,50,51]. In children and adolescents, epilepsy-related stigmatization and restrictions may have a severe impact on self-determination, QoL, personal development, and career planning [3,52–56].

The early and accompanying use of ECS may have a sustainable positive effect on living conditions, school, and vocational training, a possibility that is supported by several prior studies on the use and satisfaction of several large German psychoeducational programs for children with epilepsy and their caregivers (i.e., FAMOSES, MOSES) [16,17,57,58]. In addition, positive effects of specialized epilepsy rehabilitation programs have been revealed [59,60], about which ECS can provide information and access. In general, patient satisfaction was high in both adults and children or adolescents, and nearly all patients or their caregivers would reconsider ECS for further problem-solving or recommend ECS to other people with epilepsy-related problems or counseling needs. Also, the quality and context of counseling as well as its relevance and usefulness for daily practice were rated as good or excellent by more than 85% of the patients involved (Fig. 1), which is in line with the findings of other publications investigating epilepsy-specific counseling programs [16,17].

**Table 4**
Epilepsy counseling—suggestions for improvement by those counseled.

| Suggestions for improvement | Patients suggesting improvements (n = 58) %(n) |
|---|---|
| More workshops, school visits, information material | 58.6 (34) |
| More and nearby epilepsy counseling sites | 32.8 (19) |
| Suggestions for content improvement | 22.4 (13) |
| Increased public relation | 19.0 (11) |
| More networking with clinics, physicians, and patient advocacy groups | 13.8 (8) |
| More time/appointment | 10.3 (6) |

Despite its cross-sectional multicenter design and total number of 435 enrolled patients, this study suffers from certain methodological limitations. In spite of the ongoing enrollment at multiple sites in two German regions with an established and well-functioning epilepsy care system, possible local characteristics may have influenced or biased our results. The ECS were generally free of charge, anonymous, and optional, which should help to reduce possible false statements to a minimum. However, social desirability bias due to social expectancies cannot be excluded. Furthermore, regarding the avoidance of epilepsy-related job loss, we have relied on patients' answers, and we were not able to assess that question in detail.

## 5. Conclusion

The ECS have been proven to be widely accepted and valuable offer for children, adolescents, or adults with epilepsy who struggle with disease-related problems or who have specific troubles affecting their social, family, or work life. The vast majority of patients reported they would reconsider ECS in the future and would recommend it to other people with epilepsy. Taken together, there is a much higher demand on ECS than today's infrastructure can sufficiently cover. A comprehensive and demand-driven introduction of ECS seems to be a promising way to effectively reduce the epilepsy-related burden of patients and their caregivers.

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## Conflicts of interest

S. Knake reports honoraria for speaking engagements from Desitin and UCB as well as educational grants from AD Tech, Desitin Arzneimittel, Eisai, GW, Medtronic, Novartis, Siemens, and UCB.

S. Schubert-Bast reports personal fees from UCB, Desitin Pharma, and Shire.

T. Kniess reports honoraria for speaking engagements from Eisai, UCB Pharma.

F. Rosenow reports personal fees from Eisai, UCB, Desitin Arzneimittel, Novartis, Medtronic, Cerbomed, Sandoz, GW-Pharma, BayerVital, vfaand Shire, grants from the European Union, Deutsche Forschungsgemeinschaft, and the Detlev-Wrobel-Fonds for Epilepsy Research.

A. Strzelczyk reports personal fees and grants from Desitin Arzneimittel, Eisai, GW Pharma, LivaNova, Medtronic, Sage Therapeutics, UCB Pharma, and Zogenix.

None of the other authors report conflicts of interest.

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