Diagnosis of epilepsy – consequences for work and professional activities

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SUMMARY

Introduction. The correct diagnosis of epileptic seizures and non-epileptic attacks has a decisive influence on treatment, counseling and duration of possible work limitations.

Diagnostic efforts should aim towards classifying the seizure as precisely as possible. For risk assessments, e.g. at the workplace, a close cooperation and networking of all professionals involved in the epilepsy treatment, care and consultation processes is required.

Aim. To present guidelines for assessment of occupational capacity of persons with epilepsy and to discuss their value in clinical practice.

Method and Material. The German employer's liability insurance association has recently published the new revised BGI 585 Risk Assessment Guidelines (DGUV information 250-001) framework and assistance in epilepsy in view of protection against unfair dismissal. These guidelines provide information on safety and health in the workplace.

Throughout all the German federal states, 24 Network teams were established. During the period January 2010 and December 2013, 374 employees with epilepsy were consulted by an expert member of Network Epilepsy and Work (NEA) Team, of which 80 were prospectively included in a study and scientifically evaluated.

Guidelines and discussion. While conducting the risk assessment, a special medical fact check in accordance with the guidelines was used. In addition to medical aspects, the individual vocational and occupational situation was considered. Based on this assessment an individual recommendation was made relating to continuation of employment. The project NEA established regional teams of physicians, therapists, consultants from social services, employment offices and rehabilitation authorities across Germany in order to link by networks the complex medical and social aspects of reducing the risk of people with epilepsy losing their job.

Results. It was shown that support and consultation through the NEA team led to an endangered position of employment being maintained in 70% of cases.

Conclusion. In many cases, loss of employment can be prevented by consequent application of DGUV information 250-001 (recently revised from BGI 585) for risk assessment of epilepsy in employment, together with improved networking between medical professionals, occupational health professionals and social services.

Key words: community health workers • employment supported • occupational health services

INTRODUCTION

Following the occurrence of an epileptic seizure at work a precise diagnosis is necessary to clarify whether the event is attributable to a single seizure or to previously existing epilepsy. The correct diagnosis has a decisive influence on treatment, counseling and duration of possible limitations at work.

Even a single seizure may have negative consequences with regards to driving motor vehicles and for working in general (Martikainen et al., 2011). Experience shows that the occurrence of both single seizures and chronic epilepsy can lead to strong feelings of insecurity in the affected person and those around them, manifesting in social withdrawal and stigmatization, and results disproportionately frequently in unemployment (Smeets et al., 2007).

Diagnostic efforts should aim towards classifying the seizure as precisely as possible, and to precisely define seizure semiology and the epileptic syndrome. In the case of repeated seizures, an assessment of possible risks requires comprehensive documentation of seizure frequency and individual characteristics such as precipitating factors and reliably occurring auras. In the case of pre-existing epilepsies where etiology and syndrome classification are insufficient, diagnostic as well as etiological clarification should be made prior to any occupational health assessment. These characteristics, along with information about previous and current treatments, must be examined in order to provide a sound statement regarding seizure recurrence prognosis. Precise and extensive information on medical and social factors, and a patient being well-informed about their condition, provide the basis of effective and sustainable recommendations regarding professional activities. In Germany the interpretation of risk and danger in working life includes recommendations by the employer's liability insurance associations according to the BGI 585, recently revised into seizure classifications into the new DGUV information 250-001 published in March 2015 (recommendations for assessment of the occupational capacity of people with epilepsy) for reducing the risk of losing work or becoming permanently unemployed (De Boer, 2005; Bautista et al., 2014; Thorbecke et al., 2014). These guidelines can additionally be used for providing advice regarding driving license, leisure time, hobbies, family, school, etc.

Support systems in Germany have developed over decades and have still not become integrated. Employees suffering from epilepsy are therefore not provided with assistance by a single entity. Health insurance companies, pension companies, employees associations, welfare offices and integration offices are some of the possible sources of financial assistance for medical and occupational rehabilitation services. Patients with epilepsy are supported by professionals in neurology, occupational health, occupational safety, psychology and social pedagogy, amongst others. These experts work either within the context of organisations responsible for distributing financial support, or within independent organisations (rehabilitation clinics, integration services, advice centres etc.), or are self-employed as registered practitioners (in particular neurologists, occupational health practitioners and lawyers). Employees with epilepsy can also ultimately turn to support structures within their occupational context, such as disability representatives or occupational medics, or to occupational safety officers. While the expertise of these various organisations is high, the degree of networking between individual experts must often be described as 'low'. The employee suffering from epilepsy often does not have a sufficient overview of available support services, and usually the experts can only effectively support patients with regard to only a few facets of an often complex problem. Against the background of these problems, the project NEA was initiated in Germany, with the goal of improving networking and support for epilepsy-related problems in the workplace.

AIM

This paper aims to:

- present guidelines for assessment of occupational capacity of persons with epilepsy and to discuss relevant clinical diagnostic problems of seizures classifications related to occupational capacity of patients;
- provide DGUV Information 250-001, 2015 which is a revised version BGI 585 recommendation (Berufsgenossenschaftliche Information, 2007),
- present the Project NEA with experts from results of a prospective study, in which an epilepsy risk-assessment from both epileptological and occupational health perspectives was used to produce an individually-oriented client consultation. This could be used to determine whether employment at risk of being lost could be preserved, and whether positive or negative predictors could be identified,
- discuss the value of the guidelines in practice,
- the publication of the whole study is still in progress; in this paper relevant excerpts will be presented on the basis of specific examples.

METHOD AND MATERIALS

The guidelines are presented in the form of tables and figures.

The prospective study commissioned by NEA intended to use screening questionnaires to collect da-

ta necessary for a professionally determined risk assessment. Most importantly, data were collected relating to epileptic syndromes, occupational health difficulties, specific occupational responsibilities and relevant risk assessments. Based on this a service and advice plan was developed, and further questionnaires were used to document progress throughout the whole process. The screening questionnaire was used to determine which patients would participate in the study and to select a case manager. Patients were invited to participate in the project when they suffered from epileptic seizures and were in full-time or part-time employment. Patients were not included in the study if the seizures were not attributable to an epileptic syndrome, or the patient was not willing to be involved in the case management.

24 Network teams in Germany were established between the years 2010–2013. 374 employees with epilepsy were consulted by an expert (member of NEA Team) of which 80 could be prospectively included in a study and scientifically evaluated.

GUIDELINES AND DISCUSSION

The problem of misdiagnosis

According to the new definition of ILAE from 2013, the diagnosis of epilepsy is applicable after 2 spontaneously occurring seizures or after 1 seizure and proof of an additional risk factor, for instance pathological findings in MRI and/or EEG (Fisher et al., 2014). Misdiagnoses of epilepsy (both positive and negative) are not infrequently made (Scheepers et al., 1998; Zaida et al., 2000; Josephson et al., 2007). This is especially the case if the diagnosis is made by a non-epileptologist. There may also be seizure-precipitating factors which, whilst being causally unrelated to the epileptic condition, can make seizures more likely (Stefan, 1999; Balamurugan et al., 2013; Chowdhury et al., 2014; Wassenaar et al., 2014) and non-epileptic psychogenic pseudoseizures – wrongly diagnosed in up to 40% of cases – which are also relevant for differential diagnosis (Reuber and Elger, 2003; Sigurdardottir and Olafson, 1998; Lesser, 1996; Benbadis, 1999). A unique range of causal, inductive and risk factors involved in an epileptic condition means that the consequences for prognosis, risk prevention and therapy are just as unique. Since each case involves such a high degree of complexity, in order to account for all medical aspects and social context factors, in particular with regard to working life, the close cooperation and networking of all professionals involved in the treatment, care and consultation processes is required.

From clinical day-to-day experience we know that some employers, neurologists, occupational physicians and rehabilitation experts have difficulties in assessing seizure related risks in working life. On the one hand this may lead to a situation where work is unnecessarily prohibited or, on the other hand, where seizure related risks in the workplace are overlooked, in some cases leading to irreversible injuries or even death.

The German employer`s liability insurance association has published the BGI 585 Risk Assessment Guidelines (since 3/2015; DGUV information 250-001) in view of protection against unfair dismissal framework and assistance in epilepsy. These guidelines provide information on safety and health in the workplace.

On the basis of the DGUV information 250-001 criteria, a relevant risk assessment and evaluation for professional occupation can be implemented.

Setting of risk assessment

A risk assessment must always take into account the individual disease characteristics, the specific vocational environment as well as the legal occupational situation and individual work characteristics in order to establish a realistic assessment of potential risks.

Medical fact check

When employers, occupational physicians or other individuals engaged in consultation with epilepsy patients are first contacted by them, a neutral analysis and documentation of medical facts should be conducted with the patient in a confidential environment, and confidential handling of the patients` data should be ensured.

An essential first step is the classification of seizure types according to their severity listed in DGUV information 250-001 (fig. 1 and fig. 2). Should a reliable assessment of the medical report not be possible then an experienced physician should be involved in establishing a detailed case history by a third person.

Having classified the seizure type according to the DGUV information 250-001 classification scheme (fig. 1), seizure intensity and seizure frequency should be clarified in order to allow a prognostic evaluation (tab. 1). When evaluating the severity of epilepsy the therapeutic efficacy and the time of seizure occurrence must also be considered: for instance, the occurrence of only sleep-related seizures with an observation time of

O – consciousness, control over posture and ability to act retained
Note: seizures exclusively with mental disorders without symptoms relevant for occupational health; actions may be actively disrupted until subjective symptoms end

A – ability to act impaired, consciousness and control over posture retained
Note: Seizures with convulsions, tensing or slackening of individual groups of muscles

B – actions and ability to act disrupted, control over posture retained
Note: sudden hesitation, at most minimal movements without recognizable action

C – inability to act with/without disruption of consciousness with loss of control over posture
Note: sudden fall without protective reflex, slow slumping, tumbling and falling

D – inappropriate actions with disrupted consciousness and with/without control over posture
Note: uncontrolled complex actions or movements, often not related to situation

Figure 1. Seizure categories according the risk assessment Guidelines DGUV information 250-001 by the German employer's liability insurance association.

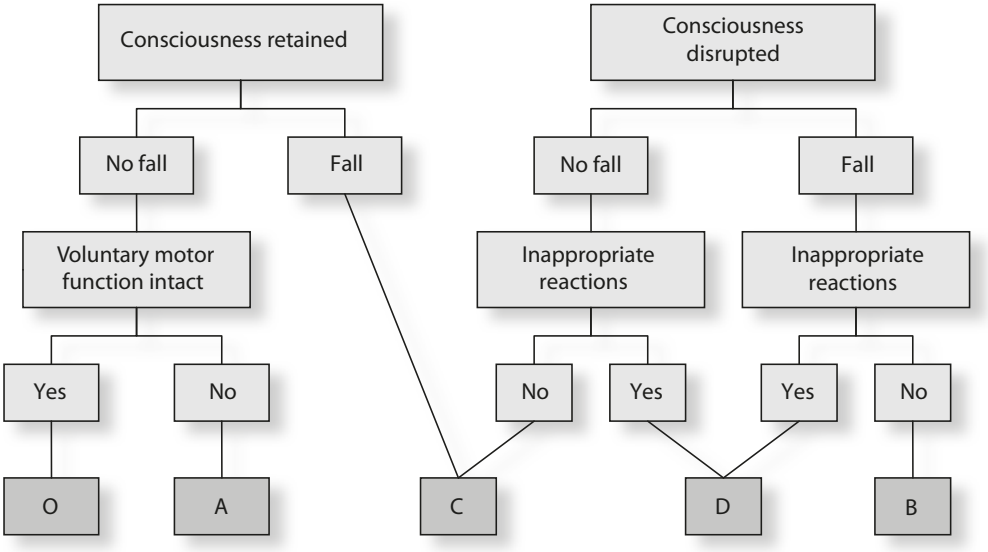

Figure 2. Algorithm of seizure severity categories according to the risk assessment Guidelines DGUV information 250-001 by the German employer's liability insurance association.

3 years and no seizure occurrence during the daytime suggests a positive prognosis; in Germany driving permits for motor vehicles are usually issued, and occupational tasks with medium risk potential (such as operating lathe machines and driving forklift trucks in low-risk environments) are permitted.

Prognosis and state of medical treatment

When seizures are still occurring, further therapeutic options involving drug treatment should be explored in an attempt to reduce seizure frequency. The possibility of surgical intervention should also be considered. In this respect a referral to a certified epilepsy center is recommended. In particular patients with a questionable

Table 1. Time defined as seizure free and seizure frequency classifications according to the risk assessment Guidelines DGUV information 250-001 as a function of the severity of epilepsy

Severity of epilepsy	
Long-term seizure free	**≥ 5 years without medication**
Medium-term seizure free	≥ 1 year (after surgery or medication)
	≥ 3 years with only sleep associated seizures
	seizure category "0" ≥ 1 year
Rare seizure frequency	**≤ 2 seizures/year**
High seizure frequency	≥ 3 seizures/year

Table 2. Checklist for the risk assessment before consultation

Medical facts for risk assessment	**Check**
Severity of seizure	category 0, A, B, C, D according to DGUV information 250-001
Severity of epilepsy	frequency of seizure?
Prognosis and state of treatment	stable situation of seizure activity? therapy adherence? medication side effects?
Trigger factors for seizure relapse?	working at night, photosensitivity, etc.?
Protective factors?	auras? mechanism of seizure self-control?

diagnosis should be referred to these centers. In cases of complex social medical questions, considerable endangerment of working capacity, complex associated partial deficits in occupational capacity, or concomitant psychological disorders, a medical rehabilitation measure may be appropriate. In this case it should be ensured that the institution in question is able to provide the necessary epileptological expertise.

Protective factors and seizure freedom

While undertaking a medical evaluation, any notable favorable prognostic factors regarding a reduction of risk potential should be evaluated: for instance, an aura can function as a forewarning of an epileptic seizure, so that the patient can get him- or herself into safety. Another aspect is self-control therapy, a special training which uses such warning signs, as described above, to enable the patient to influence seizure occurrence (tab. 2). The knowledge of individual reproducible and avoidable seizure precipitating factors may help to reduce the risk of seizure reoccurrence. These positive factors have to be well-defined for each individual patient. They should have been present over a longer period of time (1 year) and should be confirmed by a third party. In this case, the risk potential of category „0" (fig. 1) would be applicable according to the DGUV information 250-001.

Individual risk evaluation

All the aforementioned facts should be documented in an epileptological risk assessment. Ideally this risk assessment will be established by a neurologist with special expertise in epileptology, an occupational physician and, if required, a specialist for occupational safety with an interdisciplinary approach. According to the authors' experiences, only a few medical practitioners refer to the existing occupational health rules of BGI 585 and an interdisciplinary dialogue is rarely sought. For enhanced patient care in the future it would be desirable to encourage and support interdisciplinary case management.

Individual counseling

Individual counseling is primarily undertaken through occupational physicians and an occupational safety officer. They evaluate at the workplace which of the seizure related risk factors are higher than usual, both for the patient and for their colleagues. They may also recommend measures through which risk can be minimized. This may involve changes to the occupational activity itself or modifications to equipment (e.g. mounting protective devices on machines or the removal of objects which might cause injury). These measures should reduce the likelihood of injury to the patient as well as to third persons. People suffering from epilepsy

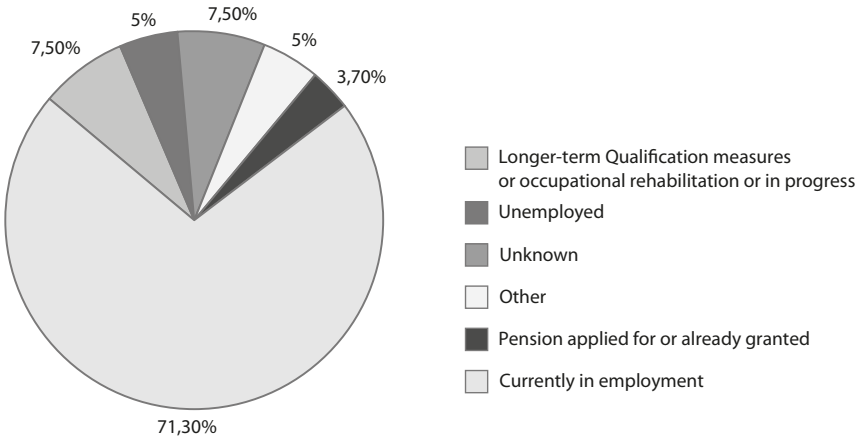

Figure 3. Current employment situation after consultation by The Epilepsy and Work Network between 2010–2013 (n = 80).

and who have a recognized severe disability can also be helped by consultation with disability-related organisations with the aim to preserve occupational capacity.

In difficult cases employers, the patient (i.e. employees), occupational physicians, safety officers and, where relevant, integration services, legal guardians for severely disabled persons, employees' union representatives, epilepsy consultation officers or certified disability managers will come together to discuss an individual case. At the end of such an interdisciplinary discussion, the occupational physician will have to establish a written consensus in which any occupational risks seen as being higher than usual are defined. This report should also describe any limitations at work and measures to minimize potential risks. The time of the next review should also be determined. Adaptation should be considered in case of improvement or worsening of the seizure situation. *Unrealistic wishes of the epilepsy patient must also be openly communicated and be related to the risk assessment.*

RESULTS

Preservation of employment is achieved through interdisciplinary dialogue

Against the background of these very complex and highly individual medical and social aspects, good direct communication and intensive networking between the many disciplines involved is necessary to provide the required support for people suffering from epilepsy. The project NEA, established across Germany, is in the opinion of the authors a promising approach. This project was successfully concluded in 2013. Throughout all German federal states, 24 Network teams were established. Between the years 2010 and 2013, 374 employees with epilepsy were consulted by an expert (member of NEA Team), of which 80 could be prospectively included in a study and scientifically evaluated (fig. 3).

The small number of cases which could be analysed is due to the case management required being very time consuming and therefore outside the scope of the work of individual NEA teams throughout Germany. If it had been possible to offer financial remuneration for the Network professionals, we would have expected a higher number of datasets available for analysis.

Those included in the study mainly suffered from resistant epilepsies and were mostly entrusted with high-risk work. It is noteworthy that more than 70% of the potentially risk-bearing occupations, according to the case management assessment criteria, could be retained. Eight percent of these patients underwent professional rehabilitation measures which included retraining or continuous vocational training. Only 5% of the epilepsy patients accompanied by the NEA lost their job, among them for example a bus driver. Only 3.7% of the patients claimed a disability pension (fig. 3). Effective networking therefore decreased the occupational problems associated with epilepsy.

Relevance of comorbidity

The presence of at least one physical or psychic disease besides epilepsy ("comorbidity") is related to employ-

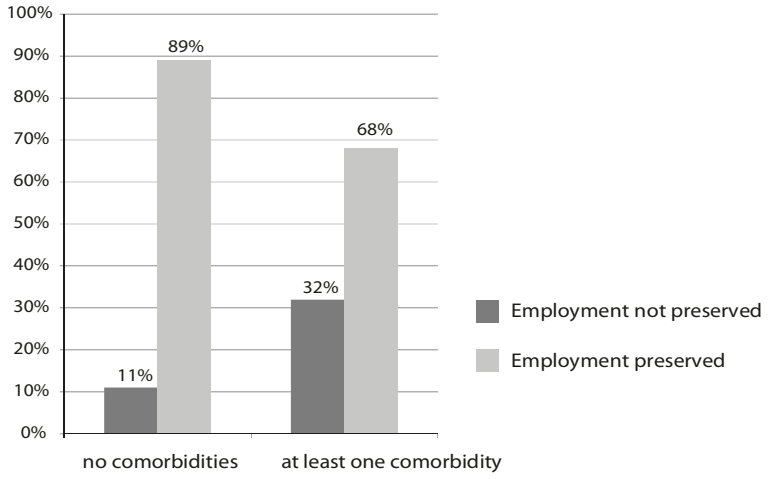

Figure 4. Relationship between preservation of employment and at least one comorbidity (N = 69, *:p ≤ 0,05).

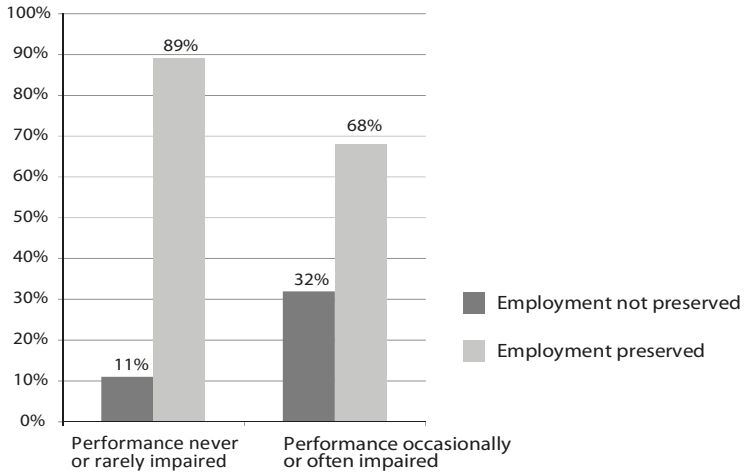

Figure 5. Relationship between preservation of employment and partial performance impairments N = 64, not significant.

ment continuity (p < 0,05). The presence of physical or psychic comorbidity diminishes the probability of remaining in employment (fig. 4).

Comorbidity was defined as the presence of at least one physical or psychic disease besides epilepsy. For instance with regard to body functions, paresis or sensoric impairment of the hand has been reported. With regard to psychologically related comorbidities, the presence of psychosomatic stress syndrome, anxiety disorders or panic attacks was recorded. Thirty three percent of the patients showing at least one comorbidity could not continue working in their previous capacity, whereas in 12% of those without comorbidities their previous occupation could be preserved.

The existence of partial performance impairments (memory and/or concentration problems) tends to be related to the preservation of employment; 16% of patients who never or rarely showed performance deficits and whose employment could not be preserved compared with 36% who occasionally or often had these disorders (fig. 5).

However, other variables such as age, gender, type of seizure, and high-risk activities at the workplace show no relation to the outcome preservation of employment.

Contrary to expectations, the type of seizure and frequency of occurrence do not seem to be the only factors involved in predicting whether or not a position of employment can be maintained.

What relevance could the results of the work carried out by Network Epilepsy and Work have for employees with epilepsy and their employers? In all cases where the assumption that 'epilepsy = occupational incapacity' is made, it should be made clear that a differentiated risk assessment, including necessary occupational safety measures, enable most positions of employment to be maintained. Since structural organisation differs substantially across states in Germany, employees with epilepsy and their employers encounter different problems when trying to organise appropriate support services.

According to the experience of the NEA, areas which do not provide professional teams specialising in epilepsy or comparable structures should be asked to justify why this is the case. In general, this is likely to happen only when initiated by support structures responsible for health, employment and rehabilitation, and also politically supported. The professional teams involved in the Network Epilepsy and Work are recognised as being particularly successful and innovative. The project itself is innovative in that the interdisciplinary professional teams form alliances which, although shown to be necessary, are not (yet) financed by the various organisations responsible for support. The German Society for Rehabilitation has awarded the Project the Kurt Alphons Jochheim medal in recognition of its future-oriented structure; a very important prize in the field of occupational medicine rehabilitation in Germany.

The following two case reports exemplify the process of NEA team work.

Case 1

Vocational school teacher for apprenticeship in mechatronics

A 42-year-old vocational teacher M.L. suffered a bilateral tonic-clonic seizure whilst teaching after many years without seizures. The lesson was interrupted by emergency aid and consequently the vocational teacher was sent on sick leave.

The directors of the vocational school questioned whether this teacher, albeit experienced and valued, could continue teaching in view of possible seizure-related injury risks in the future. A video-EEG-monitoring over several days was performed in a neurological clinic with special expertise in epilepsy, resulting in the diagnosis of generalized idiopathic epilepsy and an adjustment of medical treatment. In spite of these measures, the patient's professional future as vocational teacher was not secured. Therefore, a local meeting at the vocational school took place. Besides the senior school director and junior school director a technical consultant of the integration office, an official in charge of prevention, a disability representative, a safety engineer, a municipal representative for in-firm integration management as well as a representative of the local epilepsy information center and representatives of NEA participated in the discussion. Together they evaluated whether an epileptic seizure would present a danger to M.L. or to others.

According to the risk evaluation of BGI 585 (2007) a tonic-clonic seizure was estimated as seizure category C, in which seizure occurrence is rare (<2/year). Etiology and the epilepsy syndrome had been classified and the treatment had been corrected according to best treatment guidelines. Favourable prognostic facts were the low seizure frequency and the good prognosis of therapy. Neither protective factors nor relevant precipitating factors were found.

In order to identify possible risks, the workplace of the teacher was evaluated: in the electronic room was a simulation of the electronics of a car with its different lamps and lights. The maximum voltage was already set at 12 V and therefore did not present a health and safety risk. In the engine compartment stood a functioning engine shielded by a steel cage to protect the students against the heat. This steel cage was also viewed to be sufficient to protect against seizure related injuries.

An overall analysis of the individual working situation of the teacher resulted in an agreement that because of the high safety and security standard at the vocational school no greater risks for teachers and their students are presented in the event of seizure occurrence: no risk factor could be identified which would prevent further employment of this vocational teacher. Only minor activities, such as the handling of fuel and oil, had to be excluded until one year had passed without further seizures occurring. As no higher risk potentials were present it was agreed that M. L. could continue his work as a vocational teacher.

Case 2

House caretaker with new onset epilepsy

Between 2008 and 2011 a 54-year-old man suffered

from two unprovoked bilateral tonic-clonic seizures with postictal aggressiveness. A cavernoma was found and comorbid arterial hypertonia and moderate depressive disorder were diagnosed. After initiation of antiepileptic drug treatment he did not drive until July 2012, because of seizure-related driving license regulations. He was working as a house caretaker in a large social institution. The employer refused continuation of his employment fearing liability claims in case of further seizure occurrence. His work tasks included activities which might endanger himself and others, such as working on ladders at a height of over 3 meters, work with machines (e.g. electric drill or electric saw, lawn-mowers and snow removal motor vehicles). However, other activities presented lower risks (administrative activities, electric and water installation, building repairs).

In February 2012, after a consultation with NEA, he was sent to medical rehabilitation. The aim was to diagnose a specific epilepsy syndrome, to clarify his new life situation and to develop coping strategies. In order for the patient to take up his employment as early as possible, an epilepsy-specific risk assessment according to BGI 585 (2007) was conducted. As part of the medical risk assessment, two unprovoked bilateral tonic-clonic seizures and postictal delirium were categorized „D" according to the BGI 585 (2007). A seizure frequency with less than two seizures per year is classified as "rare". The etiology and the epilepsy syndrome at that time allowed the assessors to predict a good prognosis with respect to treatment response and seizure frequency. There were neither putative protective nor precipitating factors.

Corresponding to the guidelines of driving suitability it was recommended to suspend his work until July 2012 (1 year after the last seizure) and to suspend moderate-risk tasks (such as works on ladders of a height of more than 3 meters, work with rotating machines or driving of vehicles). As this patient had two coworkers, it was determined that delegation of these particular activities was feasible. No other everyday risk potentials were identified and the patient was able to reach his workplace using public transport.

These results were discussed with the employer, the patient, the integration service and members of the NEA team. Unfortunately the employer could not be convinced of the result of the assessment that the patient could take up work prior to July 2012. He refused to reinstate the employment until the end of this observation period. From July 2012, the patient was able take up his regular work and has so far remained seizure free.

CONCLUSION

The assessment of severe epileptic seizures and epileptic syndromes according to DGUV information 250-001 provides the urgently needed basis for consultation and occupational risk assessment which enables employment to be maintained. This requires networking and close cooperation between physicians and social services counsellors. In order to accommodate this requirement, the project NEA was initiated in 2009 in Germany, through which independent interdisciplinary teams in every region were formed. Through this process it could be shown in a prospective study that through advice and support from members of the network, many potentially endangered positions of employment could be maintained.

Effective networking therefore decreased the occupational problems associated with epilepsy.

Therefore, every effort should be made to ensure that specialists involved in medical provision, counselling, employment and treatment are sufficiently informed and motivated to be aware of and make use of the DGUV information 250-001 guidelines, and where necessary to implement the outcome of networked consultation so that the patient is disadvantaged as little as possible due to their epilepsy.

CONFLICT OF INTEREST DISCLOSURE

Knieß, Tobias: received honoraria for talk at advisory board by EISAI. Brodisch, Peter: No conflict of interests. Prof. Hermann Stefan has received honoraria for advisory board participation and/or lecturing from the pharmaceutical companies Cerbomed, UCB, Eisai, Novartis Pharma, Desitin, Merz, Electa and Medtronic. In addition he has received grants from DFG (German Research Society), ELAN (University Foundation), Sander Foundation and royalties from Cambridge University Press. There is no conflict of interest with the content of this paper.

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