

Epilepsy: a cross-sectional study of paediatricians and general practitioners on their experiences, knowledge and handling of the disease

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Received September 27, 2018; Accepted January 29, 2019

ABSTRACT – *Aims.* Epilepsy is a life-changing disease, and patients with epilepsy may face a number of issues. Paediatricians and general practitioners are often the first to be asked for advice. This cross-sectional study was performed to gain information on the knowledge and experiences of paediatricians and general practitioners on epilepsy.

Methods. From September 2015 to July 2017, paediatricians and general practitioners in Leipzig, Germany, were asked to take part in a face-to-face interview.

Results. Overall, 40 paediatricians and 60 general practitioners participated in the study. A total of 99/100 (99%) kept emergency medication available and 96/100 (96%) would administer it during a seizure. Also, 40/40 (100%) of the paediatricians and 34/60 (57%) of the general practitioners recommended that non-professionals should administer emergency medication, and 18/40 (45%) of the paediatricians and 35/60 (58%) of the general practitioners would put an object in the patient's mouth during a seizure. With regards to safety precautions, paediatricians mentioned the risks associated with swimming (30/40; 75%) and the potential of falling from a height (23/40; 58%), whereas general practitioners focused on being around vehicles including driving regulations (43/60; 72%).

Only 5/60 (8%) of the general practitioners advised that precautions should be taken during swimming. Fatigue/exhaustion was the most common adverse drug event associated with long-term anticonvulsive therapy mentioned by paediatricians (13/40; 33%) and general practitioners

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The content of this research was presented as an oral presentation at the Neurowoche 2018 in Berlin, Germany, that took place from October 30th to November 2nd, 2018.

(27/60; 45%). Of all the participants, 23/100 (23%) recommended epilepsy training programmes for patients and families, however, none were able to name a specific programme.

Conclusion. Nearly half of the general practitioners did not recommend the use of rescue medication by non-professionals. This measure, however, can prevent the occurrence of prolonged non-treatable seizures. Both paediatricians and general practitioners should bear in mind that placing an object in the mouth during a seizure should be avoided due to the risk of additional injury. To reduce the risk of drowning, physicians should recommend safety precautions during swimming. Information on epilepsy training programmes for patients and families should be diffused to all physicians taking care of patients with epilepsy.

Key words: epilepsy, paediatricians, general practitioners, rescue medication, safety precautions, education, teaching program, curriculum

Convulsive status epilepticus is the most common neurological emergency in children with a significant effect on morbidity and has a mortality rate of up to 3% (Chin *et al.*, 2006). People with epilepsy are at higher risk of mortality than people without and are at an increased risk of injury during a seizure (Trinka *et al.*, 2013). Prolonged seizures can be prevented by the early use of rescue medication (Knudsen, 1979) that can also be applied by non-professionals (Arzimanoglou *et al.*, 2014). During a seizure, measures such as the use of an object in the mouth should be avoided due to the risk of additional injury. To prevent the risk of harm during a seizure (Camfield and Camfield, 2015; Mahler *et al.*, 2018), safety precautions concerning swimming, falling from a height, and driving regulations and precautions are recommended. Most epilepsy patients need long-term medication. However, adverse drug events can limit medication therapy (Bertsche *et al.*, 2014; Bach *et al.*, 2018). Training programmes for patients and families can help to improve coping with the disease (May and Pfäfflin, 2002; Pfäfflin *et al.*, 2012; Willems *et al.*, 2019).

Several studies have explored the extent of knowledge and experiences regarding these issues. These have focussed on teachers (Dumeier *et al.*, 2015; 2017a; 2017b), parents (Lewis *et al.*, 2010; Bertsche *et al.*, 2013; Spindler *et al.*, 2017), patients (Lewis *et al.*, 2010; Bertsche *et al.*, 2013; Spindler *et al.*, 2017), patients (Lewis *et al.*, 2010; Pauschek *et al.*, 2016; Kadel *et al.*, 2018), or the public (Fong and Hung, 2002; Kartal and Akyıldız, 2016; Jansen *et al.*, 2017).

A recent study investigated the educational needs of physicians working in paediatric epileptology with emphasis on neurologists and neuropaediatricians (Murray *et al.*, 2018). However, as (general) paediatricians/general practitioners are often the first contacts for medical problems, knowledge of possible symptoms of epilepsy, fatal adverse drug reactions associated with anticonvulsants, and safety precautions aiming to prevent, e.g. drowning, can be life-saving. Data on their experiences with patients diagnosed with

epilepsy, however, is scarce. Therefore, we conducted structured interviews amongst paediatricians and general practitioners to learn more about their role in treating patients with epilepsy. We focussed on ways in which epilepsy may be explained to patients, emergency management of seizures, safety precautions to prevent harm from seizures, adverse drug events associated with anticonvulsive long-term medication, and training programmes for patients and families.

Materials and methods

Setting

After obtaining approval from the university ethics committee, we conducted a structured interview with paediatricians and general practitioners. From September 2015 to July 2017, we invited paediatricians and general practitioners in Leipzig, by telephone, to take part in the study. To contact physicians in all districts of Leipzig, we used data provided by the Association of Statutory Health Insurance Physicians of Saxony. Interviews were conducted face-to-face in the participants' consultation room and took between 20 to 40 minutes.

All paediatricians in Leipzig at the time of the study were invited to participate. As there was a much higher number of general practitioners, we performed a sample size calculation for the general practitioners. A sample size of 61 participants was calculated according to Mayer (2013) considering a population of 368 general practitioners (N) during the study period in Leipzig (data provided by the Association of Statutory Health Insurance Physicians of Saxony), a confidence level of 95% ($t \approx 1.96$), an attribute level of 95% (p); estimated rate of participants treating patients with epilepsy), and a sampling error of 5% (d). In order to reach the sample size, general practitioners were randomly selected and contacted until the sample size was reached.

Table 1. Characteristics of the participants to the present study.

Characteristics	Paediatricians	General practitioners
Number of participants (<i>n</i> [m/f])	40 (8/32)	60 (19/41)
Median age (years [Q25/Q75])	52.5 (40/56.25)	57 (46/62)
Minimum/maximum	36/76	33/74
Median office-based working experience (years [Q25/Q75])	11 (4.75/23.25)	19 (8.75/27)
Minimum/maximum	0.5/42	2/46
Median number of treated patients per quarter of a year (<i>n</i> [Q25/Q75])	1,100 (1,000/1,400)	1,000 (900/1,400)
Minimum/maximum	800/4,000	300/2,500
Median number of treated patients with epilepsy per quarter of a year (<i>n</i> [Q25/Q75])	8 (3/20)	10 (5.5/20)
Minimum/maximum	0/125	0/150

Interview

The same person conducted all interviews. The questionnaire was prepared by an expert panel of paediatric neurologists and clinical pharmacists and was then revised and improved after advice from general practitioners, general paediatricians, and adult neurologists. Moreover, the participating paediatric neurologists were epileptologists certified by the German Section of the International League against Epilepsy. The certification includes an examination that concerns child and adult epileptology. The questionnaire was piloted by ten colleagues. Based on the pilot survey, the clarity, completeness, comprehensibility, and practicability of the questionnaire were improved. The questionnaire consisted of five parts. Most questions were designed for "yes/no" answers or multiple-choice. We also used open questions to gain a broad insight into the experiences of physicians. We performed clustering of the answers to open questions in order to increase comparability. In the first part, we asked physicians how the disease is explained, and what is the safety advice and general recommendations given to their patients. The second part concerned participants' handling of an acute seizure and the recommendations physicians give to non-professionals regarding what to do during a seizure. In the third part, we asked about adverse drug events associated with anticonvulsants observed in their patients. The fourth part included questions about recommendations for participation in epilepsy training programmes for patients and families and social/legal support, and a question concerning whether physicians needed more information about epilepsy for themselves. The final part elicited sociodemographic data. No data was requested that might lead to identification of the patients.

Statistics

Frequencies are reported as numbers and percentages and continuous data is given as median with first (25%) and third (75%) quartiles (Q25/Q75) and minimum/maximum. For comparison of paediatricians with general practitioners, we applied chi-square tests for dichotomous data. A *p* value ≤ 0.05 was considered to indicate significance.

Results

Participants

Of the 61 paediatricians and 112 general practitioners we invited to take part in the interview, 40 (66%) paediatricians and 60 (54%) general practitioners agreed to participate. Detailed characteristics of the participants are shown in *table 1*. Of the interviewed physicians, 2/40 (5%) paediatricians and 3/60 (5%) general practitioners were not currently treating any patients with epilepsy.

Explanation of epilepsy and recommendations

When asked about the way physicians explain epilepsy to their patients, the participants gave the answers presented in *table 2*. In total, 10/40 (25%) paediatricians and 6/60 (10%) general practitioners referred their patients to a neurologist for an explanation of the disease. When asked for safety precautions and general recommendations they give to their patients, significantly more paediatricians than general practitioners mentioned swimming under supervision ($p < 0.001$). Avoiding heights was mentioned more frequently by paediatricians than by general

Table 2. "How do you explain epilepsy to your patients?"

(Open question; more than one category per respondent possible; paediatricians [n=40], general practitioners [n=60]).

Explanation	Paediatricians n (%)	General practitioners n (%)	Total n (%)
Seizures/convulsions	7 (18)	34 (57)	41 (41)
Muscle twitches	3 (8)	8 (13)	11 (11)
Electrical malfunction/short-circuit in the brain	9 (23)	8 (13)	17 (17)
Increased excitability of the brain	4 (10)	12 (20)	16 (16)
Malfunction of the brain	9 (23)	19 (32)	28 (28)
Loss of control/consciousness	6 (15)	14 (23)	20 (20)
Thunderstorm/lightning in the brain	9 (23)	9 (15)	18 (18)
Other explanations	3 (8)	2 (3)	5 (5)

Table 3. "What are the safety issues and general recommendations you talk about to your patients with epilepsy?"

(Open question; more than one category per respondent possible; paediatricians [n=40], general practitioners [n=60]).

	Paediatricians n (%)	General practitioners n (%)	Total n (%)
Safety issues			
Being around vehicles (incl. driving regulations)	14 (35)	43 (72)	57 (57)
Swimming	30 (75)	5 (8)	35 (35)
Trauma avoidance	15 (38)	19 (32)	34 (34)
Falling from a height	23 (58)	7 (12)	30 (30)
Triggers	5 (13)	17 (28)	22 (22)
Alcohol	1 (3)	19 (32)	20 (20)
Riding the bike	13 (33)	4 (7)	17 (17)
Diurnal rhythm/lack of sleep	1 (3)	8 (13)	9 (9)
Operating machines	1 (3)	6 (10)	7 (7)
General issues and recommendations			
Emergency management	17 (38)	14 (23)	31 (31)
Medication	5 (13)	24 (40)	29 (29)
Social environment	5 (13)	17 (28)	22 (22)
Limitations in career choice	2 (5)	8 (13)	10 (10)
No mollycoddling	5 (13)	0 (0)	5 (5)
Fever control	2 (5)	2 (3)	4 (4)
Others	1 (3)	5 (8)	6 (6)

practitioners ($p < 0.001$). All issues mentioned by physicians, when asked about safety precautions and general recommendations they give to their patients with epilepsy, are shown in *table 3*. Of the participants, 21/100 (21%) indicated that the safety precautions they recommend depend on the type of epilepsy the patient suffers from, the age of the patient, and freedom from seizures (18/40 [45%] paediatricians and

3/60 [5%] general practitioners). Referral to a specialist for safety advice was made by 8/40 (20%) paediatricians and 4/60 (7%) general practitioners.

Handling of a seizure

At least one seizure was witnessed in the consultation room by 33/40 (83%) paediatricians and 22/60 (37%)

Table 4. "Which anticonvulsive emergency medication do you keep available in your office?" (Open question; more than one answer per respondent possible; paediatricians [n=40], general practitioners [n=60]).

Medication	Paediatricians n (%)	General practitioners n (%)	Total n (%)
Diazepam iv solution	12 (30)	53 (88)	65 (65)
Diazepam suppository	39 (98)	14 (23)	53 (53)
Diazepam oral solution	0 (0)	1 (2)	1 (1)
Lorazepam iv solution	1 (3)	7 (12)	8 (8)
Lorazepam oral dispersible tablet	0 (0)	6 (10)	6 (6)
Midazolam buccal/nasal	13 (33)	1 (29)	14 (14)
Midazolam iv solution	5 (13)	4 (7)	9 (9)

general practitioners. All but one physician kept anticonvulsive emergency medication in their consultation room. All paediatricians and 56/60 (93%) general practitioners would administer anticonvulsive emergency medication during a seizure. All paediatricians and 34/60 (57%) general practitioners agreed that non-professionals should administer available emergency medication when witnessing a seizure without possible immediate medical care ($p < 0.001$). A total of 18/40 (45%) paediatricians and 35/60 (58%) general practitioners would place an object into a patient's mouth during a seizure. Moreover, this procedure was recommended to be performed by non-professionals by 47/100 (47%) physicians (15/40 [38%] paediatricians and 32/60 [53%] general practitioners; difference is non-significant). Diazepam was the most frequent drug available in the consultation room for paediatricians and general practitioners. More details about the anticonvulsive emergency medication stored in physicians' consultation rooms are presented in *table 4*. Of general practitioners, 2/60 (3%) stated that they have emergency anticonvulsive medication available but did not know which one, and 1/40 (3%) paediatricians and 2/60 (3%) general practitioners mentioned Rectodelt® (rectal prednisone) as an emergency anticonvulsive medication at hand.

Adverse drug events during long-term therapy

When asked about reported adverse drug events, fatigue/exhaustion was the most common answer for paediatricians and general practitioners. For the other top five adverse drug events, paediatricians and general practitioners provided mixed answers (*table 5*).

Living with epilepsy

Training programmes for patients and their families were recommended by 10/40 (25%) paediatricians and 13/60 (22%) general practitioners. None of the physicians could name a specific programme. Overall, 16/40 (40%) paediatricians and 13/60 (22%) general practitioners wished for further information about epilepsy.

Table 5. "What are the most common adverse drug events affecting your patients?" (Open question; more than one answer per respondent possible; paediatricians [n=40], general practitioners [n=60]).

Adverse drug event	Frequency n (%)
Paediatricians	
Fatigue/exhaustion	13 (33)
Liver toxicity	9 (23)
Personality changes/challenging behaviour	8 (20)
Exanthema/ pruritus	5 (13)
Impaired concentration/vigilance	4 (10)
Blood count changes	4 (10)
General practitioners	
Fatigue/exhaustion	27 (45)
Dizziness/unsteady gait/falls	9 (15)
Liver toxicity	8 (13)
Gastrointestinal problems	8 (13)
Impaired concentration/vigilance	7 (12)

Discussion

We interviewed paediatricians and general practitioners about their knowledge of and experiences with patients diagnosed with epilepsy. Almost all of them kept emergency medication in their consultation room and the majority would administer it when witnessing a seizure. All paediatricians, but only around half of the general practitioners, recommended that non-professionals should administer emergency medication when witnessing a seizure. When asked about safety precautions, paediatricians mainly mentioned swimming and avoiding heights; general practitioners focused on driving regulations and avoiding triggers for seizures. Only few general practitioners advised about swimming precautions. About half of all participants would practice the obsolete measure of putting an object in a patient's mouth during a seizure. Fatigue was the most common reported adverse drug event associated with anticonvulsive long-term medication. Paediatricians also mentioned personality changes and challenging behaviour as common adverse drug events, whereas general practitioners frequently observed dizziness, unsteady gait, and falls.

Epilepsy is responsible for lost years, especially symptomatic epilepsy (Gaitatzis *et al.*, 2004; Nevalainen *et al.*, 2016; Granbichler *et al.*, 2017). Any seizure lasting longer than five minutes should be treated in order to prevent further progression and damage (Knudsen, 1979; Arzimanoglou *et al.*, 2014). Consistent with this, all paediatricians and all but four general practitioners in our study would administer anticonvulsive medication to a patient having a seizure in their consultation room. As most general practitioners only kept intravenous diazepam, it is important to keep in mind that this pharmaceutical form can also be administered rectally in case of an emergency (off-label use [Chiang *et al.*, 2011]). Three of the physicians in our study reported having anticonvulsive emergency medication in their consultation room and mentioned rectal prednisone when asked for the name. As prednisone is not a recommended anticonvulsive emergency medication (McTague *et al.*, 2018), we suspect that this was due to confusion over the name of the drug. This can hinder physicians treating an acute seizure.

As well as physicians, the family, teachers, and other caregivers can also be first responders to a seizure. A recent study among teachers, for example, showed that only 15% of the teachers were willing to administer a prescribed rescue medication without any precondition. In fact, 19% of the questioned teachers did not know that epileptic seizures could be fatal (Dumeier *et al.*, 2015). In our study, all paediatricians, but only a little more than half of the general practitioners, advised non-professionals to give emergency medication. As general practitioners are often the first point of contact

for consultation with families for medical advice, their advice can have an enormous impact on daily-life decisions. Thus, it seems reasonable to encourage general practitioners to recommend the administration of rescue medication by non-professionals.

In our study, 38% of paediatricians and more than 50% of general practitioners advised putting an object into a patient's mouth during a seizure, even though this is no longer recommended. A Chinese study showed that almost 53% of people thought that putting an object into a seizing person's mouth was appropriate (Fong and Hung, 2002). Based on a study in Kuwait, this was reported to be 88% (Awad and Sarkhoo, 2008). A lack of insight into epilepsy and seizure management could lead to a deficient response to emergency and could harm patients and their families (Price *et al.*, 2015). It is important to enhance physicians' access to research, in order to ensure that no outdated information is passed on to patients.

A lack of information about safety precautions is common after discharge from hospital (Bertsche *et al.*, 2013). In our study, most paediatricians focus on safety precautions for swimming. Physicians who examine patients in a consultation room should remember to provide information on safety precautions, especially as the risk of drowning is far higher in people with epilepsy (Tian *et al.*, 2015). Few general practitioners mentioned precautions concerning swimming when asked for safety advice they give to their patients. As mentioned by some physicians, this might be due to an older patient population that does not engage in sports such as swimming or is unlikely to fall from a height. However, as people diagnosed with epilepsy have a higher risk of fatal accidents while swimming or exercising (Beghi, 2009; Mahler *et al.*, 2018), physicians should inform all patients of safety precautions such as swimming only under direct supervision of a person experienced in life support.

Our study also identified several ways in which epilepsy was explained by paediatricians and general practitioners. General practitioners treating mostly adults preferred to explain epilepsy in terms of seizures and convulsions. Paediatricians used more visual analogies, describing epilepsy as a thunderstorm or an electrical short-circuit taking place in the brain. A recent study showed that 25% of children diagnosed with epilepsy could not name their disease correctly (Pauschek *et al.*, 2016), leaving them in need of more explanation. This is the responsibility of paediatricians and general practitioners.

As a number of children with epilepsy already feel worse off than healthy children (Pauschek *et al.*, 2016), adverse drug events, such as challenging behaviour, can increase the difficulties associated with social integration. In a German study, 3% of high school students even stated that they would not want to be friends with

a person suffering from epilepsy (Jansen *et al.*, 2017). In older age, adverse drug events, such as dizziness, unsteady gait, and falls, might become more relevant, as the prevalence of falls increases with age (Peeters *et al.*, 2018). Fatigue often occurs in patients with epilepsy (Yan *et al.*, 2016). In our study, it was the most frequently mentioned adverse drug event by both paediatricians and general practitioners. Such adverse drug events can have an enormous impact on daily life (Bach *et al.*, 2018). Adverse drug events experienced by patients and their relatives increase the use of alternative therapies (Hartmann *et al.*, 2016) with a risk of stopping necessary anticonvulsive therapies. Thus, it is necessary to help patients and families to cope with adverse drug events if they are unavoidable.

Special training programmes offer helpful support for patients with epilepsy to cope with problems such as these. FAMOSES, a programme designed for children with epilepsy and their parents, increased not only knowledge about the disease but also reduced related anxiety. Even seizure frequency decreased after taking part in the training (Pfäfflin *et al.*, 2012). MOSES, an educational programme for adults diagnosed with epilepsy, has shown similar positive effects (May and Pfäfflin, 2002). A recent American study of an intervention programme for children with chronic diseases and their families demonstrated the influence on quality of life based on a significant decrease in the number of school days missed and the number of days parents needed additional help (Distelberg *et al.*, 2014). Possibly, the low number of physicians who recommended a training programme in our study reflects the assumption that the treating neurologist will tend to this problem. Patients, however, usually see their paediatrician/general practitioner more frequently than they see their (child) neurologist. Thus, patients could benefit from information about training programmes from their paediatrician or general practitioner. Indicating the existence of such programmes to patients and their families could motivate patients to seek more details from their (child) neurologists.

Limitations

The study was performed in Leipzig, a large city in Eastern Germany where neuropaediatricians and neurologists are more accessible than in the countryside. Therefore, the level of educational advice may have differed according to the location of neurologists. However, in the city, general practitioners and paediatricians are much easier to access than neurologists. Thus, many questions may arise that should be answered through consultation with general practitioners and paediatricians.

As paediatricians only treat children, whereas general practitioners treat children and adults, the

comparability of some answers may be limited. Although the participants could have differentiated between adults and children in their answers, this was not the case. Therefore, it is striking that most general practitioners did not keep rectal rescue medication in their consultation room even though they regularly treated children. It is even more striking that many general practitioners did not mention safety precautions for swimming given that drowning is one of the main reasons for death in children as well as in adults.

The quality of answers may also have been influenced by the voluntary participation of colleagues who may have been more interested in epilepsy.

Conclusions

Emergency anticonvulsive medication was shown to be widely available in the consultation room, and most physicians were confident in using it. All paediatricians and more than half of the general practitioners recommended that non-professionals should administer emergency medication. As seizures lasting longer than five minutes should be treated early, it seems appropriate to encourage the remaining general practitioners to also recommend this measure. In order to increase patient safety, it is also necessary to inform physicians about current medical recommendations, such as not placing an object in the mouth during a seizure. Paediatricians advised their patients about safe swimming and potentially dangerous activities such as climbing, however, the same advice was less frequent among general practitioners. Due to the increased risk of drowning in epileptic patients, all physicians should inform about such safety precautions.

Our study indicates that training programmes for patients and families should be diffused more actively. For example, because lack of neurologists in Latin America forces primary health care providers to manage epilepsy the International League Against Epilepsy Education Commission (2013-2017) created a low-cost, regional, virtual course with the main goal of improving diagnostic and therapeutic management of patients with epilepsy through training of physicians in the primary health care level (Carrizosa *et al.*, 2018). We believe that the data presented here will contribute to improved medical care and safety for patients diagnosed with epilepsy, as well as the interaction between patients and their physicians, in order to save the lives of people with epilepsy and increase their quality of life. □

Acknowledgements and disclosures.

We thank all participating physicians for their time and support in the study, and Prof. Dr. T. Frese and Prof. Dr. H. Sandholzer

of the Department of General Medicine, Leipzig University, for their advice.

None of the authors have any conflict of interest to declare.

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TEST YOURSELF



- (1) What are the current recommendations concerning the placement of an object in the mouth during an epileptic seizure?
- (2) Which safety precautions should be pointed out when consulting a patient with epilepsy or the parents of a child affected by epilepsy?
- (3) What are the most frequent adverse drug events associated with anticonvulsants reported by physicians?

Note: Reading the manuscript provides an answer to all questions. Correct answers may be accessed on the website, www.epilepticdisorders.com, under the section "The EpiCentre".