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ORIGINAL ARTICLE

# Epilepsy: knowledge and attitudes of physiotherapists, occupational therapists, and speech therapists

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## Abstract

Physiotherapists, occupational therapists, and speech therapists play a key role in the treatment of children with epilepsy. We performed a survey of therapists' knowledge of and attitudes towards epilepsy in two regions of Germany, the city of Leipzig and the rural district of Zwickau. Therapists of 29/68 (43%) outpatient practices and 4/9 (44%) hospitals took part. In total, 195 therapists participated: 63 (32%) physiotherapists, 74 (38%) occupational therapists, and 58 (30%) speech therapist. In 65%, epilepsy was subject of vocational training. Of all therapists, 8% claimed they had not treated epilepsy patients so far. During professional life, 43% had witnessed a seizure. Of all therapists, 44% correctly assumed a seizure could result in death. During a seizure, 42% would perform the obsolete measure of placing something solid in the patient's mouth, and 41% would administer a prescribed rescue medication. More information on epilepsy was requested by 92%.

*Conclusion*: Most therapists treat patients with epilepsy, and almost half have already witnessed a seizure. Often, however, epilepsy is not subject of vocational training. The risk of a fatal outcome of a seizure is underestimated, and many therapists would perform obsolete measures. Knowledge of seizure management should be transmitted to therapists especially during vocational training.

**Keywords** Physiotherapists · Occupational therapists · Speech therapists · Epilepsy · Seizure · Emergency management

### Abbreviations

O occupational therapists
P physiotherapists
S speech therapists

## Introduction

During the first 10 years of life, approximately 1 out of 150 children is diagnosed with epilepsy [1]. Neurodevelopmental

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comorbidities such as developmental delay, speech/language and learning difficulties, and intellectual disability are common in children with epilepsy [3]. For this reason, many children with epilepsy receive physiotherapy, occupational therapy, and speech therapy. In most cases, seizures are self-limiting and short but they can represent a potential emergency. Thus, fundamental knowledge of epilepsy and emergency treatment of seizures is essential for all members of therapeutic professions especially of those treating children.

There are data about knowledge and attitudes towards (people with) epilepsy for pediatric [9, 14] and adult [4] patients themselves, parents [17] and relatives [12], physicians [16], teachers [6], and healthy adolescents [11] and adults [10]. In studies about knowledge and attitudes of healthcare professionals in Saudi Arabia and Brazil, few physiotherapists were included [2, 18]. In total, data concerning knowledge and attitudes of therapists, however, are scarce. Thus, we conducted a survey to assess physiotherapists', occupational therapists', and speech therapists' knowledge of and attitudes towards epilepsy.

## Materials and methods

### Setting

We conducted a survey to explore the knowledge and attitudes of physiotherapists, occupational therapists, and speech therapists towards epilepsy. We invited therapists from the city of Leipzig and the rural District of Zwickau, both located in Saxony/Germany, to take part in our study. In total, 68 outpatient practices and 9 hospitals were contacted. The participation of the respondents took place voluntarily and anonymously. The study was approved by the Ethics committee of Leipzig University. Written informed consent was obtained from all participants. The survey was carried out between June 2018 and January 2019.

### Questionnaire

The survey was based on a questionnaire developed by an expert panel consisting of neuropediatricians and clinical pharmacists. The questionnaire contained questions concerning the participants' experiences with epilepsy, their knowledge of the disease, the emergency management of a seizure, and attitudes towards epilepsy. Additionally, we asked if the participants wished for more information on epilepsy and more support. The same questionnaire was used for all respondents (physiotherapists, occupational therapists, speech therapists). The questionnaire contained predefined options for ticking off answers.

### Statistics

Statistical analysis was performed using Microsoft Excel 2016 (Microsoft Corporation, Redmond, Washington, USA) and SPSS (V23.0 IBM Corporation, Armonk, NY, USA). Frequencies are reported as numbers and percentages. We analyzed whether there was a correlation between professional experience and various variables. We employed chi-square tests to compare answers across the professions. A $p$ value $\leq 0.05$ was considered to indicate significance for the correlations, and a $p$ value $\leq 0.017$ for the chi-square tests as a Bonferroni correction for multiple testing was applied.

## Results

### Characteristics of respondents and setting

We received questionnaires from therapists of 29/68 (43%) outpatient practices and 4/9 (44%) hospitals in Leipzig and the District of Zwickau that were invited to take part in the survey. In total, 195 therapists completed the questionnaire, 63 (32%) physiotherapists (P), 74 (38%) occupational therapists (O), and 58 (30%) speech therapists (S). The socio-demographic data of the participants are presented in Table 1. The age range of treated patients was from 0 to 97 years. Of the outpatient practices and therapeutic departments of hospitals, 85% stated they regularly treat as well children as adults. A high number of treated children suffered from developmental disorder of any kind.

### Therapists' experiences with epilepsy

In total, 180/195 (92%) of therapists stated they had already been confronted with epilepsy in any manner in theory or practice (P 84%, O 97%, S 95%). During vocational training, epilepsy was addressed according to 127/195 (65%) therapists (P 52%, O 78%, S 62%). Of all therapists, 16/195 (8%) stated they had not treated people with epilepsy so far (P 11%, O 9%, S 3%). The therapists' self-assessment of their own knowledge of epilepsy is displayed in Fig. 1. Of all therapists, 84/195 (43%) had already witnessed a seizure during their professional life (P 38%, O 46%, S 45%).

### General knowledge of epilepsy

In one of the questions, five different descriptions of seizure symptoms including a generalized tonic-clonic seizure and an absence (i.e., a short period of inattentiveness without any other symptoms) were presented. Of all the therapists, 68/195 (35%) correctly assigned all five descriptions to a possible seizure (P 35%, O 36%, S 33%). Death as a possible

**Table 1** Sociodemographic data of the participants

| | | Physiotherapists ($n = 63$) | Occupational therapists ($n = 74$) | Speech therapists ($n = 58$) |
|---|---|---|---|---|
| Gender ($n$) | Female | 51 (81%) | 69 (93%) | 50 (86%) |
| | Male | 12 (19%) | 4 (5%) | 8 (14%) |
| | Diverse | 0 (0%) | 1 (1%) | 0 (0%) |
| Age (years) | 18–30 | 14 (22%) | 16 (22%) | 26 (45%) |
| | 31–40 | 18 (29%) | 38 (51%) | 11 (19%) |
| | 41–50 | 18 (29%) | 5 (7%) | 13 (22%) |
| | 51–60 | 11 (17%) | 12 (16%) | 8 (14%) |
| | > 60 | 2 (3%) | 3 (4%) | 0 (0%) |
| Professional experience (years) | < 1 | 0 (0%) | 5 (7%) | 6 (10%) |
| | 1–2 | 6 (10%) | 9 (12%) | 5 (9%) |
| | 3–5 | 6 (10%) | 12 (16%) | 11 (19%) |
| | 6–10 | 7 (11%) | 13 (18%) | 8 (14%) |
| | 11–15 | 11 (17%) | 11 (15%) | 11 (19%) |
| | > 15 | 32 (51%) | 22 (30%) | 17 (29%) |
| | Not specified | 1 (2%) | 2 (3%) | 0 (0%) |
| Employment status ($n$) | Self-employed in practice | 6 (10%) | 12 (16%) | 6 (10%) |
| | Employed in practice | 18 (29%) | 47 (64%) | 30 (52%) |
| | Employed in hospital | 32 (51%) | 13 (18%) | 19 (33%) |
| | Not specified | 7 (11%) | 2 (3%) | 3 (5%) |

consequence of epilepsy was correctly assumed by 85/195 (44%) of therapists (P 49%, O 38%, S 45%).

## Emergency treatment for seizures

During a seizure, 81/195 (42%) of therapists would place something hard in the patient's mouth (P 63%, O 31%, S 31%). All answers to the question on measures therapists would perform during a patient's seizure are displayed in Fig. 2. When asked if they would administer a prescribed rescue medication, 80/195 (41%) stated they would do so (P 38%, O 51%, S 31%). On presentation of a photo of buccal midazolam, 16/195 (8%) of therapists stated they knew the medication (P 10%, O 7%, S 9%). Rectal diazepam was known to 80/195 (41%) of therapists (P 46%, O 36%, S 41%). Of all the therapists, 108/195 (55%) were afraid of legal repercussions in case of committing an error when administering rescue medication (P 43%, O 59%, S 64%).

## Attitudes towards epilepsy and wish for information and support

The impairment of epilepsy patients' quality of life as judged by the therapists is presented in Fig. 3. Of all therapists, 156/195 (80%) did not have reservations against a person with epilepsy as a coworker (P 73%, O 80%, S 88%). A wish for more information on epilepsy was expressed by 179/195 (92%) therapists (P 97%, O 88%, S 91%), and 66% of therapists would like to have more support (P 65%, O 68%, S 66%; Fig. 4).

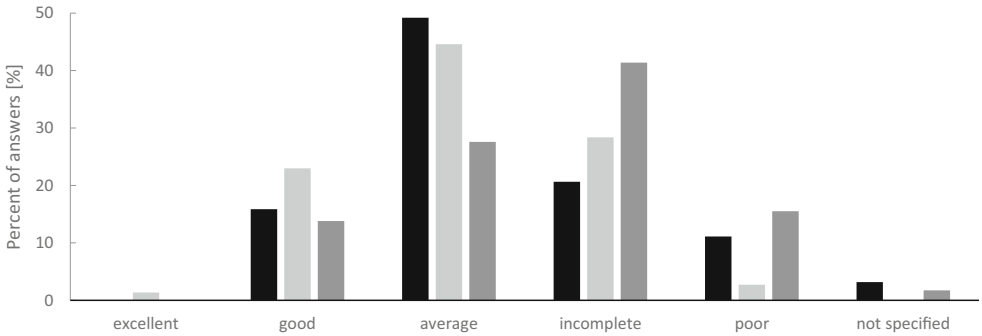


**Fig. 1** Therapists' self-assessment of their knowledge of epilepsy. Physiotherapists ($n = 63$): black bars, occupational therapists ($n = 74$): light gray bars, speech therapists ($n = 58$): dark gray bars

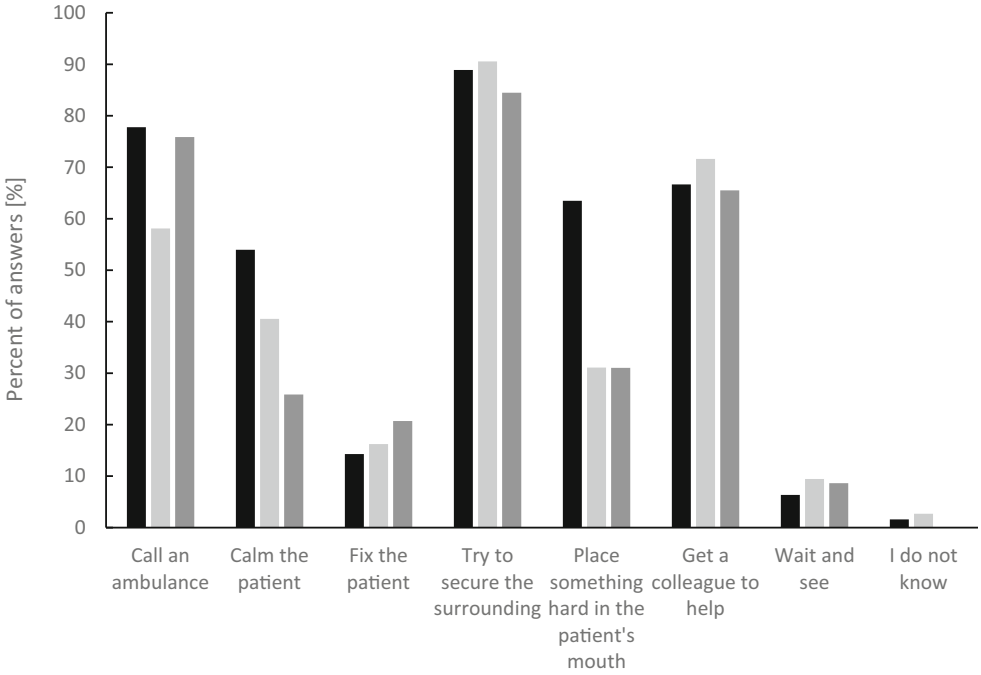


**Fig. 2** Measures therapists would perform during a seizure of a patient in their care. Multiple answers possible. Physiotherapists ($n = 63$): black bars, occupational therapists ($n = 74$): light gray bars, speech therapists ($n = 58$): dark gray bars

## Correlations with professional experience and comparisons across professions

We did not find a correlation between professional experience and the knowledge of different symptoms of an epileptic seizure, knowledge of the risk of fatal seizures, the placement of something hard in the patient's mouth during a seizure, the willingness to administer rescue medication, or the presence of reservations against a person with epilepsy as a coworker. We did not find differences between the professions concerning the following issues: epilepsy addressed during vocational training, professional experience with patients with epilepsy, willingness to administer a rescue medication, and fear of legal repercussions. More physiotherapists than occupational or speech therapists would place something hard in the patient's mouth during a seizure (P vs O, P vs S: each $p < 0.001$; O vs S: n.s.).

## Discussion

We performed a survey among physiotherapists, occupational therapists, and speech therapists on their knowledge of and attitudes towards epilepsy. The majority of the therapists taking part in the survey treated patients with epilepsy. Nevertheless, the study revealed large gaps in the participants' knowledge. Almost all participants requested more information on the subject of epilepsy.

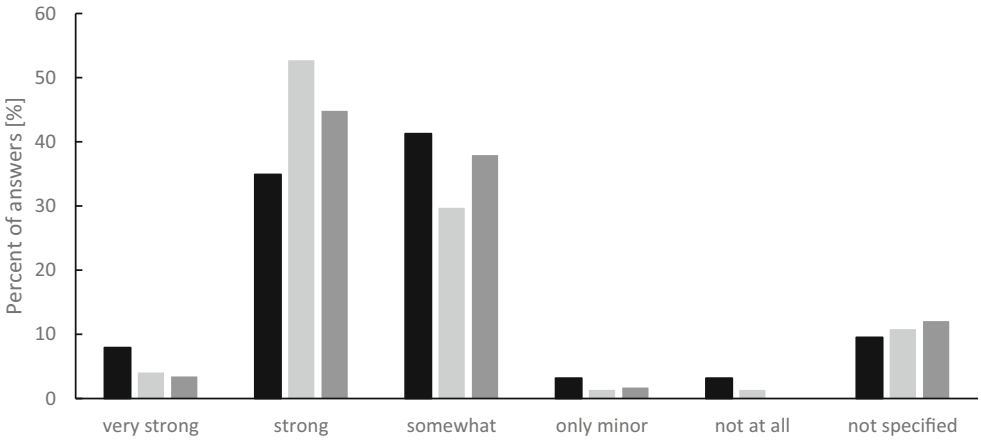


**Fig. 3** Impairment of the quality of life of people suffering from epilepsy as judged by therapists. Physiotherapists ($n = 63$): black bars, occupational therapists ($n = 74$): light gray bars, speech therapists ($n = 58$): dark gray bars

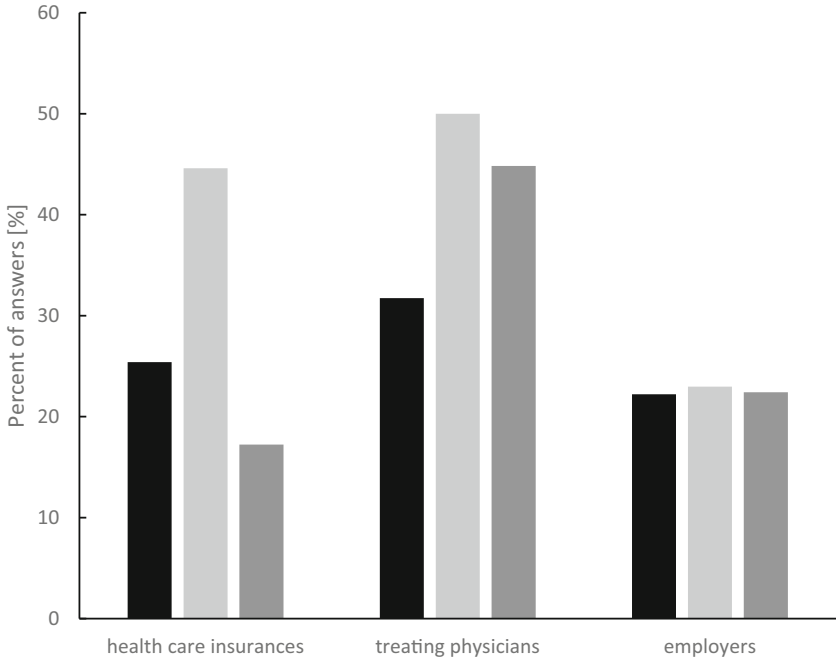


**Fig. 4** Sources of support the therapists wish to have. Multiple answers possible. Physiotherapists ($n = 63$): black bars, occupational therapists ($n = 74$): light gray bars, speech therapists ($n = 58$): dark gray bars

## Therapists' experiences with epilepsy

Most therapists treated patients with epilepsy, and almost half of them had witnessed an acute seizure during their professional life. Nevertheless, one third of therapists stated that epilepsy had not been subject of their vocational training. In a similar study in Brazil, even more than 40% of surveyed physiotherapists stated they did not have access to any information on how to deal with epilepsy during their professional graduation [18]. A survey of teachers had shown that only one out of five stated that epilepsy was subject of teacher training [6]. Trainings of teachers on epilepsy had strongly positive effects on the knowledge and attitudes of participants [7, 8]. This led to the introduction into formal teacher training in Saxony. As therapists have an even greater chance than teachers to witness an epileptic seizure due to the greater number of patients with epilepsy they are in touch with, it seems mandatory to integrate the subject of epilepsy into the vocational training of all therapists. In Germany, vocational training of physiotherapists, occupational therapists, and speech therapists consists of a 3-year school education and internships. Thus, teaching on epilepsy could easily be integrated in the school education.

## General knowledge of epilepsy

Only one third of therapists assigned all descriptions of possible seizures, including an absence, to a possible seizure. This represents a greater proportion than in a similar survey of teachers in which only 6% were able to correctly relate all symptoms [6], but the percentage share is still low. In a study of healthcare professionals in Saudi Arabia, a considerable number of participants did not assume that changes in behavior could represent a possible seizure [2]. Especially in children with inattentiveness, the possible diagnosis of an absence is frequently not considered. If people caring for patients with epilepsy such as therapists know about possible seizure symptoms, they can recommend a medical consultation at an early stage. This way, patients can be prevented from harm.

Almost half of the respondents did not know that a seizure could result in death under unfavorable conditions. Those data are comparable with those of a study of relatives of people bereaved by epilepsy in which more than half of the respondents said that they did not know people could die of epilepsy before the death of their relative [5]. In a study focusing on teachers, nearly 20% were not aware of the risk of a fatal outcome of a seizure [6]. Those who care for people with epilepsy need to know the risk of a fatal outcome. Otherwise, they might be too reluctant to take emergency measures and administer a prescribed rescue medication. Moreover, the need for safety precautions such as swimming only under direct supervision of a person trained in lifesaving only becomes apparent when one is aware of the risk of drowning or fatal accidents.

## Emergency treatment for seizures

In accordance with other studies [2, 6, 11, 16], the misconceptions that it is favorable to fix a patient suffering from a seizure and to put something hard in the patient's mouth are still widespread. Especially physiotherapists stated that they would put a solid object in the mouth of a person experiencing

a seizure. As those measures can cause additional harm to the patient, they should be avoided. Training sessions on seizure management should address this aspect.

Less than half of therapists would administer a prescribed rescue medication to an epilepsy patient. A study on teachers had already shown that many participants were reluctant to administer a prescribed rescue medication [6]. If a rescue medication is administered in the first 15 min of a seizure, the chance for successful cessation is 97%; this chance declines to 57% if the rescue medication is administered after this time [13, 15]. Thus, administration of a rescue medication is recommended for seizures lasting longer than 5 min. As an ambulance might take too long to arrive, especially in rural areas, people caring for patients with epilepsy should be prepared to administer a prescribed rescue medication. A teaching session on epilepsy increased the willingness of teachers to administer a prescribed rescue medication [7]. Such teaching sessions should be integrated in the vocational training of therapists and be repeated regularly. This is especially important as most therapists are not familiar with the epilepsy rescue medications currently licensed for use of non-professionals. Especially buccal midazolam is only known to a small number of therapists. This also applies to therapists who are generally willing to administer a prescribed rescue medication. However, the fear of legal repercussions in case of committing an error in the administration of a prescribed rescue medication cannot be solved by training sessions. This problem has to be addressed with employers and professional associations, as the risk of harm for the patient with epilepsy is much higher if the medication is withheld from him or her. Understandably, the therapists need legal certainty.

### Attitudes towards epilepsy and wish for information and support

Most therapists assumed at least some impairment of epilepsy patients' quality of life. This is in accordance with data obtained from parents [17]. Therapists can play an important role in improving the quality of life of people with epilepsy by addressing, e.g., motor, coordination, or speech problems. Most therapists would not mind having a person with epilepsy as a coworker. This reflects a positive attitude. The majority of high school students gave similar answers to the question whether they would be friends with someone with epilepsy [11]. Most therapists wished for more information and support. Considering the gaps in knowledge displayed in this study, the transmission of information seems urgently necessary.

### Limitations

As participation in our study was voluntary, participants with a particular interest in the topic might be overrepresented. Since such participants tend to have a greater need for information and consequently a higher level of knowledge, it can be assumed that the level of knowledge among all therapists is even worse than determined in this survey.

Apart from the factors mentioned above, we have not performed any analysis of factors such as own information via the media or reading specialist literature. These aspects could indeed have led to an individual improvement in knowledge. However, we believe that this factor may not have played a significant role in the overall study.

## Conclusion

Most therapists treat people with epilepsy, and almost half of them have already been involved in a seizure during their professional life. Nevertheless, only two thirds of participants claimed epilepsy was subject of their vocational training. Less than half the participants knew a seizure could result in death under unfavorable conditions. Almost half of participants would place a solid object in the patient's mouth. Less than half of participants would administer a prescribed rescue medication. Most therapists wished for more information on epilepsy. Based on the data acquired in this study, teaching sessions for therapists seem mandatory to improve safety and participation of patients with epilepsy.

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**Authors' contributions** Katharina Hackel designed the study protocol, developed the questionnaire, performed the questionnaire survey, the statistical analysis, and the interpretation of the data, and wrote the manuscript.

Martina P. Neininger was involved in the development of the questionnaire, performed the statistical analysis and the interpretation of the data, and critically reviewed and revised the manuscript.

Wieland Kiess supported the development of the questionnaire, and critically reviewed and revised the manuscript.

Thilo Bertsche was involved in the development of the study protocol and the questionnaire, was involved the interpretation of data, and critically reviewed and revised the manuscript.

Astrid Bertsche designed the study protocol, was involved in the development of the questionnaire, supervised the questionnaire survey, the recruitment of participants, and the statistical analysis, performed the interpretation of data, and wrote the manuscript.

### Compliance with ethical statements

**Conflict of interest** A. Bertsche reports grants from UCB Pharma GmbH and honoraria for speaking engagements from Desitin Arzneimittel GmbH, Eisai GmbH, ViroPharma Incorporated, and Shire Deutschland GmbH. The other authors declare they have no conflicts of interest.

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the

institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study described has been carried out in accordance with abovementioned standards and has been approved by the institutional ethics committee.

**Informed consent** Written informed consent was obtained from all individual participants included in the study.

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