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Original article

Use of complementary and alternative medicine (CAM) by parents in their children and adolescents with epilepsy — Prevelance, predictors and parents' assessment



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ABSTRACT

Background: The use of complementary and alternative medicine (CAM) is popular. Parents of children suffering from epilepsy may also consider administering CAM to their children. Systematic data about frequency of and motivations for CAM use, however, are scarce. Methods: In a university hospital's neuropaediatric department parents of patients aged 0–18 years suffering from epilepsy were consecutively invited to take part in a structured interview during 4 months in 2014.

Results: Of the invited parents, 164/165 (99%) agreed to participate. From those, 21/164 (13%) stated that they used CAM in their child. The highest independent predictive value of CAM use was the occurrence of adverse drug events (ADE) of anticonvulsants as judged by parents. Patients affected by ADE had a 5.6 higher chance of receiving CAM compared to patients without ADE. Most commonly used were homeopathy (14/21, 67%) and osteopathy (12/21, 57%). The internet was the most frequently used source of information (14/21, 67%). Of the parents, 10/21 (48%) described positive effects of CAM on seizure frequency, 12/21 (57%) on general condition of their child, and 20/21 (95%) wished to continue CAM for epilepsy therapy. From the non-users of CAM, 91/143 (66%) expressed the desire to learn more about CAM for epilepsy therapy.

Limitations: Our study was performed in a university hospital in a large urban city in Eastern Germany. CAM user rates can differ in other parts of Germany and Europe, in other institutions and for chronic diseases other than epilepsy.

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Abbreviations: CAM, complementary and alternative medicine; ADE, adverse drug events.

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Conclusion: The main reason for CAM use was the occurrence of ADE of anticonvulsants. More than half of the parents saw a benefit of CAM for their children. Almost all parents wished to continue CAM use, even those who did not see concrete positive effects.

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1. Introduction

Cerebral seizures are common in children and adolescents. In Europe, the estimated number of children and adolescents suffering from epilepsy is 900,000 and worldwide about 10.5 million. ^{1,2} Although more than 20 anticonvulsants are licensed for long-term treatment of epilepsy, a third of patients does not become seizure free. ^{3–5} In this situation, parents also search for other options to support their children and may consider the use of complementary and alternative medicine (CAM). ^{6,7} CAM includes practices such as homeopathy, osteopathy, acupuncture, EEG biofeedback, naturopathic treatment, yoga, kinesiology, vitamins and herbal remedies. ^{8–10}

The use of CAM for chronic diseases is becoming more common, but there is still a lack of population-based descriptions of its pattern and frequency of use, especially for children suffering from epilepsy. ^{11–13} Worldwide, only few data on the use of CAM in children suffering from epilepsy exist. ^{14–18} To our knowledge, only one study was conducted in Germany so far. 37% of parents of 6–12-year-old patients of a Western German university hospital who received a questionnaire by mail stated they used CAM for the epilepsy of their children. The study revealed a significant level of financial and time resources spent on CAM. Among the predictors for CAM use were duration of illness, use of CAM by parents themselves, and the parents' desire for their children to receive a holistic and natural treatment. ¹⁷

The aim of our study was to analyse incidence of and motivation for CAM use in paediatric epilepsy patients, aged 0–18 years, of an Eastern German university hospital by consecutively interviewing their parents. We also aimed at gaining knowledge of motivations of parents who did not use CAM for the epilepsy therapy of their children.

2. Patients and methods

2.1. Patients and setting

After obtaining the approval of the local Ethics Committee, this prospective observational study was performed at the neuropaediatric department of a university hospital located in the eastern part of Germany for the duration of 4 months in 2014. We performed a structured interview by using a questionnaire consisting of predefined questions. We consecutively included all patients aged from 0 to 18 years with the diagnosis "epilepsy" by ICD-10-GM that had an outpatient appointment at the neuropaediatric department or were

hospitalised at the university hospital. Parents with insufficient German language skills and parents who were not legal guardians of their child were not included in the study. Informed consent was gained from all participating parents.

2.2. Structured interview based on a questionnaire

The structured interview was developed by an expert panel including neuropaediatricians, psychologists and clinical pharmacists. By providing structured questions, we aimed to ensure that the interviewing process was consistent for all participating parents. The following aspects were included:

- Questions about complementary and alternative medicine use (pattern and frequency of CAM use, information sources, motivations for using CAM, expectations in CAM, influence on conventional therapy, monthly costs and time spent on CAM, benefits, success and undesired side effects of CAM).
- 2. Demographics of the parents and the child.
- 3. Previous therapy with anticonvulsive drugs and adverse drug events (ADE) of anticonvulsants as judged by parents. Parents were asked if their child experienced ADE of anticonvulsants. They were asked for kind and frequency of occurrence of ADE and if the quality of life of the child was decreased due to ADE.
- 4. Furthermore, non-CAM users were asked for reasons for not using such therapies and whether they had a desire for advice on CAM.

At the beginning of the interview, a list of the most common CAM therapies was shown to all participating parents ("naturo-pathic treatment", "enzyme therapy", "homeopathy", "Schuess-ler tissue salts", "vitamins", "Bach flower remedies", "herbal medicine", "kinesiology", "osteopathy", "acupuncture", "EEG biofeedback", "magnetopathy", "chiropractic", and "yoga"). We used the terminology as used by the therapy providers without any scientific confirmation of the accuracy of the terms.

2.3. Statistics

Calculations were performed using SPSS (Statistical Package for the Social Science, Version 20, IBM, USA). Frequencies are reported as numbers and percentages, continuous data as median with first (25%) and third (75%) quartile (Q25/Q75) and minimum/maximum as appropriate. For comparison of CAM users and non-users we applied Chi-square tests, Fisher's Exact tests or Mann-Whitney-U tests depending on the underlying data. In addition to these standard tests, we

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