



A longitudinal, randomized, and prospective study of nocturnal monitoring in children and adolescents with epilepsy: Effects on quality of life and sleep



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ABSTRACT

Objective: Most studies on seizure detection systems focus more on the effectiveness of devices than on their practicability in and impact on everyday life. Our study investigated the impact of a technical monitoring system on subjective quality of sleep and the lives of affected families. Furthermore, we evaluated the impact of anxiety levels on seizure monitoring and vice versa.

Methods: Forty-three patients with newly diagnosed epilepsy were included. Initially, the families decided whether they did (group 1, n = 27) or did not (group 2, n = 16) want to use a monitoring device. In group 1, patients were randomly assigned to using Epi-Care® (group 1A, n = 14) or an audio baby monitor (group 1B, n = 13). Quality of life was assessed at two points (t1, at the start of the study and t2, at 5–7 months of follow-up) using the SF-12, Kindl-R, and “Familien-Belastungs-Fragebogen” (German version of the “Impact on Family Scale”). In addition, parental anxiety was measured using the State-Trait Anxiety-Inventory, and subjective quality of sleep was measured using the Pittsburgh Sleep Quality Index. Statistical analysis focused on the possible differences between groups 1 and 2 that may influence parents' decisions and the effects of the presence and types of technical monitoring over time.

Results: Anxiety levels were not significantly different between the groups with and without monitoring (group 1 vs. group 2). We also found no statistically significant, substantial baseline differences between the Epi-Care® and audio baby monitor groups, with at least medium effect sizes (group 1A vs. group 1B). Parents' health-related mental quality of life measured via the SF-12 increased significantly over time in all groups. By tendency, the fear of further seizures as well as the frequency of cosleeping arrangements in the monitoring group decreased during the study and approached the stable values of the control group.

Significance: Individual parental anxiety levels are not crucial in the decision regarding the use of a monitoring device. A monitoring system may help some families in certain aspects of daily life. During the first months following a diagnosis of epilepsy, quality of life increases independently of the use of a monitoring system.

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1. Introduction

Upon witnessing their child's first epileptic seizure, many parents become scared that their child may die [1–4]. From a professional point of view, this fear usually has no basis. Compared with adults, children are at a substantially lower risk of sudden unexpected death in epilepsy (SUDEP), and many patients recover before reaching adulthood. In most instances, the slightly increased mortality of children with epilepsy can be attributed to the underlying neurological disease and not the epilepsy itself [5].

Nevertheless, even in the later course of their child's disease, many parents dread epileptic seizures and their unpredictability. The fear of undiscovered nightly seizures plays a particularly major role. Many parents of a child with epilepsy suffer from a reduced quality of sleep and check on their child's state of health multiple times in a single night [6]. In many families, the diagnosis of epilepsy leads to cosleeping [7] (parents and the affected child sleeping in the same room). Associations between parents' subjective quality of sleep, the mother's state of health, daytime functioning, health-related quality of life (QoL), and measures of depression and anxiety have been shown in several studies [6,8]. Parental anxiety reduces not only a parent's QoL but also that of the child [9,10]. Parental anxiety and an overly protective style of parenting may impair the child's development of autonomy as well as his or her general and social development [11].

Nightly seizure monitoring may help improve the sleep of parents and children, but it may also limit the child's or adolescent's independence and may be considered inappropriate.

While there are various tools used worldwide for nightly seizure monitoring, "Epi-Care®" is the device used most frequently in Germany. Alternatively, simple acoustical monitoring systems can be used (e.g., an audio baby monitor). The pure medical benefit of any monitoring system is difficult to estimate because few studies have analyzed the effectiveness of tools in nightly seizure monitoring. Published data to date indicate that such effectiveness is limited. All analyzed systems have showed built-in weaknesses in terms of undetected seizures or frequent false alarms [12]. To date, there are no studies investigating the impact of nightly seizure monitoring on the everyday lives of patients and their families.

In the present study, we searched for potential factors related to anxiety and QoL with respect to the decision for or against the use of a nighttime monitoring device. Effects of the presence and type of technical monitoring (Epi-Care® or an audio baby monitor) of nightly seizures on the parents' and their children's or adolescents' subjective quality of sleep and life were analyzed. Mutual influences of monitoring and anxiety during the study were investigated. The results of this study should facilitate well-reasoned counseling for affected families.

2. Methods

2.1. Patient cohort and study design

The Center for Child and Adolescent Medicine (HELIOS Hospital Wuppertal) provides neuropsychiatric care for a population of 500,000 inhabitants, covering both urban and rural areas. The study design was longitudinal, with tests conducted at two time points:

- t1: "diagnosis"
- t2: "reassessment" (after five to seven months of follow-up)

Parents of children aged from one to 18 years who had received medical care because of a first afebrile convulsive seizure or recently diagnosed epilepsy were asked if they were willing to participate in the study. We excluded patients with severe acute or life-threatening disease of the child during the previous six months (e.g., leukemia), any history of pseudoepileptic seizures, presence of additional medical circumstances that would require continuous nightly monitoring, or refusal to participate or to attend the reassessment.

Families willing to participate in the study decided for themselves whether they wanted to use a monitoring system. Families who did not wish to conduct nightly seizure monitoring but were willing to participate were followed as a control group. Families who wanted to use a monitoring system were randomly allocated to one of two monitoring groups (Epi-Care® or audio baby monitor). Randomization was based on electronically generated random numbers.

The study sample ultimately consisted of group 1, which utilized a monitoring device, and group 2, which did not utilize a monitoring

device. Subgroup 1A included patients assigned to monitoring with the Epi-Care® system, while subgroup 1B contained patients monitored with an audio baby phone.

2.2. Tools for monitoring seizures

For the duration of the study, patients in the Epi-Care® and audio baby monitor groups were provided with the monitoring systems on a free loan basis. The Epi-Care® 3000 monitor (Danish Care Technology ApS, Sorø, Denmark; Epitech GmbH, Hiddenhausen, Germany) used in patient group 1A utilizes a sensor that is fixed under the child's mattress and transmits registered movements to a local base unit. This unit records the time, duration, and intensity of emerging seizures and triggers an alarm if a seizure is identified. Parents can receive a signal via a beeper within a range of 300 m. In group 1B, the audio baby monitor H&H Babyfone MBF 8020 (Hartig & Helling GmbH & Co. KG, Bochum, Germany) was used for nightly monitoring.

2.3. Seizure diary

All parents recorded the occurrence of seizures on a daily basis. Parents in the monitoring groups were asked to document the number of nights they actually used the monitoring systems and the number of correct and false alarms.

2.4. Outcomes

The main topics of the study were possible differences between groups 1 and 2 that may have influenced the parents' decision for or against a monitoring device and the effects of the presence and type of technical monitoring over time with respect to QoL.

Parental anxiety was measured using the State-Trait Anxiety-Inventory (STAI) [13]. Its two scales capture "general" fear as a stable personality trait ("trait scale") and "current" fear as a momentary situation-specific condition ("state scale"). In our study, parental state anxiety was measured at both measurement times to assess changes over time and to examine between-group differences in those changes. Because trait anxiety was considered a stable trait, it was only captured at t1.

Furthermore, we evaluated subjective quality of sleep and health-related QoL as measured by validated, standardized, psychometric questionnaires. The participants completed these questionnaires at both t1 and t2. To assess QoL, the Short Form 12 Health Survey (SF-12) [14], Kindl-R [15,16], and "Familien-Belastungs-Fragebogen" (FaBel, German version of the "Impact on Family Scale", IFS) [17] were used. The Kindl-R yields a global score for the child's QoL. The SF-12 consists of two scores, one each for capturing physical and psychological QoL. The FaBel is a questionnaire developed to measure a family's perceived burden as a result of the child's or adolescent's disease. The "Kindl-Epilepsy" questionnaire is a supplement of the Kindl-R, developed especially for children with epilepsy. Parent's and children's perceived strain was only assessed at t2 because we expected that possible strains (e.g., financial strains or social problems) would not yet be pronounced at the time of the initial diagnosis.

Parents' subjective quality of sleep was measured using a question from the Pittsburgh Sleep Quality Index (PSQI) [18]. Each respondent was asked to rate the quality of his or her sleep during the previous four weeks.

All assessments employed in this study were established questionnaires commonly found in the research literature. To assess additional variables of potential interest in the context of quality of sleep and life, parents and children were further presented with a few statements and asked to rate the extent to which each statement applied to them on a five-point scale ("I am afraid of my child having a seizure at night"; "When my child is sleeping at night, I regularly check to make sure he or she is okay"; "My son / my daughter and I sleep in the same

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