

The importance of parental expectations of cognitive improvement for their children with epilepsy prior to starting the ketogenic diet

Sharifeh Farasat, Eric H. Kossoff*, Diana J. Pillas, James E. Rubenstein, Eileen P. Vining, John M. Freeman

Departments of Pediatrics and Neurology, The Johns Hopkins Medical Institutions, Baltimore, MD 21287, USA

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Abstract

Although the success rates and complications of various treatment options for children with intractable epilepsy have been described, the actual expectations of parents for these treatments are less clear. Since 1998, parents at our institution have written their goals in a letter before starting their children on the ketogenic diet. One hundred consecutive letters were evaluated. The most common first goal was seizure improvement, second was anticonvulsant reduction, and third was cognitive improvement. Ninety percent requested improvement in cognition or alertness. These expectations were either met or exceeded at 6 months in 52–60% of children. Achieving or surpassing parental expectations for cognitive improvement correlated with longer diet duration ($P = 0.04$), but meeting goals for seizure or anticonvulsant reduction did not. Cognitive improvement ($P < 0.001$) and >90% seizure reduction ($P = 0.04$) at 6 months positively correlated with longer eventual diet duration. Expectations for cognitive improvement need to be discussed prior to beginning the ketogenic diet.

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1. Introduction

Although epilepsy research currently focuses on a variety of treatment options and associated success rates, there is a scarcity of information regarding the actual goals and expectations of patients when their children begin one of these therapies. Swarztrauber and colleagues have explored patient attitudes toward intractable epilepsy and its therapy, particularly surgery, in adult and adolescent patients [1]. The parents of all four adolescents expressed a great deal of concern about the side effects of antiepileptic drugs (AEDs), lack of sleep, and fear of an impending seizure [1]. A recent survey of children aged 7–18 with epilepsy identified similar concerns, including excessive fatigue, emotional distress, social isolation, and fragmented learning [2]. In another study examining goals of adults with respect to epilepsy surgery, the five most frequently cited

aims for epilepsy surgery, apart from seizure freedom, were ability to work, driving an automobile, independence, socializing, and freedom from anticonvulsants [3].

Information regarding parental expectations for their children with intractable epilepsy is relatively limited. A 20-year-old study of parents of children with epilepsy found that physicians underestimated parents' psychosocial concerns [4]. A more recent study confirmed this, stating that parents and physicians do not agree on "global, medical, and everyday aspects of epilepsy" [5]. The authors concluded that satisfaction with care may be positively associated with agreement between parents and physicians. In a questionnaire study of 43 children in India, although the majority of parents hoped for seizure and anticonvulsant reduction, approximately one-third had concerns about intelligence, future marriage, behavioral problems, and mood disturbance [6]. The authors believed that "focusing simply on control of seizures may not address the full range of the child's emotional and behavioral difficulties."

* Corresponding author. Fax: +1 410 614 2297.

E-mail address: ekossoff@jhmi.edu (E.H. Kossoff).

The ketogenic diet is used for difficult-to-control childhood epilepsy, with the average child having tried more than four AEDs in studies [7–10]. Many parents and physicians see the diet as a last resort for their child; however, the diet can occasionally be used earlier in the course of epilepsy [11]. Although there exists literature on the issues faced by individual parents seeking improvement for their children through use of the ketogenic diet, no study has examined the goals of multiple families prior to starting the diet [12].

2. Method

Since 1998, all parents of the 226 children started on the ketogenic diet at Johns Hopkins Hospital have been asked to handwrite their personal goals and criteria for success on the diet. This letter was written during the first 2–3 days of the diet admission period, often during the fasting period [10]. Participation was encouraged but not required. Both parents (if present) were asked to write their goals independently and these letters were later collected. Parents were not specifically instructed to write goals in their order of importance; no further guidance was given. All letters were handwritten, legible, and in English. Letters were briefly reviewed by the treating neurologist, and then placed in the child's ketogenic diet chart.

Over the period from September 1998 to November 2004, we identified 100 children for whom there was at least one parent letter and 6 months of follow-up information. Letters were examined for a maximum of three written goals in the order of presentation within each letter, level of desired seizure reduction (seizure free, >50% reduction, any change, not mentioned), and AED reduction (AED-free, reduced, not mentioned). We classified written goals into seven groups: seizures, AEDs, cognition, happiness, injury, alertness, other.

Children were evaluated at 6 months for seizure frequency, number of AEDs, and subjective psychomotor improvement as reported by parents and neurologists, and then outcomes were correlated with the prediet goals and expectations. For letters in which “any change in seizures” was desired, achieving this goal was defined as an improvement of 1–50%, with results exceeding this goal defined as >50% seizure reduction. For an expectation of >50% reduction, only seizure freedom was defined as exceeding this goal. AED reduction at 6 months was also compared with prediet expectations, with AED freedom defined as exceeding a goal of “any reduction.”

Categorical data were analyzed using Pearson's χ^2 and for independence of rows and columns. Numerical data were analyzed using the Wilcoxon rank-sum test. The independence of outcome variables was tested for collinearity using a variance inflation factor. Logistic regression with log-transformed variables was performed on outcome variables as well. The significance level for all tests was $P = 0.05$. The study was approved by the Johns Hopkins Committee on Clinical Investigation.

3. Results

3.1. Demographics and 6-month outcomes

Prediet characteristics of the 100 children with a parent letter are listed in Table 1. No demographic information regarding the parents (e.g., socioeconomic status) was available. At 6 months, 24% of patients were seizure-free, 20% had had a >90% reduction in seizures, 26% had had 50–90% reductions in seizures, and 30% had had <50% reductions in seizures. The mean number of AEDs at 6 months was 1.3 (range, 0–4). Diet duration ranged from 0.1 to 7 years, with an average of 1.4 years; 58% of the patients are still on the diet to date.

Table 1
Pre-ketogenic diet demographics of children with parent letters available ($n = 100$)

Characteristic	Number
Gender (male)	61
Seizure type	
Multiple	41
Complex partial	18
Infantile spasms	16
Myoclonic	13
Atonic	7
Tonic	3
Atypical absence	2
Prior AEDs attempted	5.1 (1–17) ^a
AEDs used at diet onset	1.9 (0–4) ^a
Seizure frequency (per month)	2,038 (1–72,000) ^a
Age at first seizure (years)	1.5 (0–14) ^a
Age at diet onset (years)	4.4 (0.5–15) ^a

^a Mean (range).

3.2. Expectations

For 95% of the patients, mothers had written a letter; for 75%, fathers had written a letter; and for 70%, both parents had written letters. Examples of several of these written statements are included in Table 2. Of the 95 letters written by mothers, 66 (69%) cited seizure reduction as their first goal, 12 (13%) listed AED reduction as their first goal, and the remaining 18% stated cognition, happiness, injury, alertness, or other goals. The second most frequently documented goal was AED reduction (42/92, 42%), and the third, cognitive improvement (20/69, 29%). In the 75 letters written by fathers, seizure reduction and AED reduction were similarly identified as goals ($P = 0.57$ and 0.80 , respectively). Fifty fathers (67%) cited seizure reduction as the first goal, 31 of 68 (46%) named AED reduction as a second goal, and 18 of 40 (45%) cited cognition improvement as a third goal. Overall, 90% of families cited goals other than seizure or AED reduction in their top three expectations. Improvement in cognition and alertness was the most common third goal (63% of families).

Table 2
Examples of written parent expectations

Seizure reduction
“To measure seizures per month rather than per day.”
“Just one fewer seizure a day, then the diet was worth every minute.”
“No seizures would be a gift worth more than words could describe.”
Anticonvulsant reduction
“If we can get her off the drugs and perhaps not be seizure-free, I would be very happy.”
“Stop forcing medications in my child's mouth.”
“If she was dizzy or confused, it was her condition and not her medication.”
Other
“We see glimpses of the bright-eyed, willful, nature-loving girl trapped inside this neurological tempest raging in her head.”
“Be able to learn in school without constant interruptions.”
“We want our son back.”

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