



Assessing parents' attitudes towards ketogenic dietary therapies



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ABSTRACT

We aimed to assess and quantify parental beliefs regarding ketogenic dietary therapies (KDTs). We also aimed to determine whether beliefs were related to response to KDTs.

Adapted versions of the Beliefs about Medicine Questionnaire were completed by parents of children following KDTs for epilepsy. Demographic and clinical data were collected from hospital records. Ketogenic dietary therapy response was defined as $\geq 50\%$ seizure reduction compared to baseline.

Many parents had a positive perception of KDTs and were convinced of the necessity of KDTs for their children, although beliefs were wide-ranging. Over half of parents reported concerns about the potential long-term effects of KDTs. Parental beliefs about KDTs were significantly correlated with patient response.

This was an attempt to quantify parents' beliefs regarding the use of KDTs for their child's epilepsy. The questionnaire may be used to identify individuals with a less positive attitude towards KDTs and who may be less likely to report a favorable response to KDTs. It is unknown whether people who have positive beliefs about KDTs engage in less nonadherent behavior or whether beliefs regarding KDTs simply reflect outcomes. The evidence behind the long-term side effects of KDTs should be emphasized when counseling patients and their families.

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1. Introduction

Ketogenic dietary therapies (KDTs) can be an effective treatment for drug-resistant epilepsy [1,2]. Various types of ketogenic diets have been designed to improve palatability or reduce adverse side effects, and there are a range of products and resources available to help people following KDTs. However, adherence to a dietary regime may not always be easy.

Nonadherence to treatment may be unintentional, for example due to forgetfulness or limited resources, or intentional, where people make a conscious decision not to follow an agreed treatment plan [3]. Nonadherence is multifaceted and depends also on physician-related

and health-care system-related factors, but, ultimately, it is the patient who decides whether or not to adhere to treatment [4].

A key factor in understanding intentional nonadherence to treatment is the individual's beliefs about treatment – specifically their perceived personal need for treatment and concerns or worries about treatment. This relationship is described in the Necessity–Concerns Framework and operationalized with the Beliefs about Medicine Questionnaire (BMQ) [5]. These necessity and concern beliefs are related to adherence to antiepileptic drugs (AEDs) and medicines prescribed for other long-term conditions [6,7].

In clinical practice, adherence to KDTs is generally assessed by monitoring blood and urine ketone levels. These measures are imperfect and do not consistently correlate with seizure reduction [8]. Previous studies have used biochemical measures [9] or personal communication [10] to assess adherence to KDTs. Accurate knowledge of food consumption may be obtained by patient surveillance and weighing of meals [11], but this would not be feasible on a large-scale outpatient basis. Previous studies have examined reasons for starting KDTs [12] and parental expectations and factors influencing diet duration [13], but no attempts have been made to formally quantify beliefs regarding KDTs using the Necessity–Concerns Framework.

Abbreviations: KDTs, ketogenic dietary therapies; BMQ, Beliefs about Medicine Questionnaire; BMQ-KDTs, Beliefs about Medicine Questionnaire adapted for use with ketogenic dietary therapies.

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We assessed parental beliefs regarding KDTs with an adapted BMQ. We also aimed to determine whether beliefs were related to response to KDTs.

2. Material and methods

This project was reviewed and registered as an audit or service evaluation at each of the study sites: Great Ormond Street Hospital, Evelina London Children's Hospital, Young Epilepsy (Charity for Children and Young People with Epilepsy, <http://youngepilepsy.org.uk/>) in conjunction with Matthew's Friends charity (Dietary Treatments for Epilepsy: Information–Training–Research–Support, <http://www.matthewsfriends.org/>), Birmingham Children's Hospital, Cambridge University Hospital, and St George's Hospital.

2.1. Adaptation of the BMQ

A version of the BMQ used to assess people's beliefs regarding AEDs and levels of adherence at our specialist NHS inpatient evaluation facility (unpublished data) was adapted for use by parents with children following KDTs. For example, 'My tablets make my seizures better' was changed to 'The diet makes my child's seizures better'.

The BMQ-KDTs (copyright, Prof. Rob Horne) consisted of a 4-item Necessity scale, which assessed parents' perceptions of the need for their child to follow KDTs, and a 7-item Concerns scale, which assessed their concerns about the potential adverse effects of following KDTs. All BMQ-KDT items were scored on a five-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = uncertain, 4 = agree, and 5 = strongly agree). Individual item scores were summed to give a Necessity and a Concerns score for each individual. Mean Necessity and Concerns scores were calculated by dividing the overall score for each individual by the number of items in the scale.

A copy of the BMQ-KDTs is given in Supplementary material.

2.2. Participants

A cross-sectional design was adopted. Parents of children following KDTs for their epilepsy were asked to complete the BMQ-KDTs when attending specialist clinics at the six study sites. The minimum duration of KDTs was three months, as this is customarily the first time point at which response is assessed in the clinic. All children were participants in a previous ethically-approved research project, for which informed consent was obtained. All parents accepted the invitation to participate in this audit and complete the questionnaires.

2.3. Demographic and clinical data

Demographic and KDT response data had already been collected from hospital records and dietetic notes as part of the previous project. Baseline seizure frequency was determined from the last clinic letter prior to starting KDTs. Seizure frequency at the time that the BMQ was completed was determined from the clinic letter during the corresponding follow-up appointment. If an individual achieved $\geq 50\%$ reduction in seizure frequency compared to baseline (as reported by parents in clinic and relayed in clinic letters), he/she was classified as a responder.

2.4. Data analysis

Statistical analysis was undertaken using IBM SPSS Statistics v22. Descriptive statistics were used to describe the sample and illustrate frequencies, mean, and distribution of responses to the BMQ-KDT scales. The internal consistency of the BMQ-KDT scales was tested using Cronbach's alpha. As several adaptations were made to the original items, it was necessary to check whether these items still adhered to the concept of the scale.

A Necessity–Concerns differential was calculated by subtracting Concerns scores from Necessity scores. A negative differential signifies that the individual rates his concerns about KDTs higher than his beliefs about the necessity of following KDTs; a positive differential signifies that the individual's belief in the necessity of following KDTs is stronger than his concerns about potential adverse effects from KDTs.

Participants were categorized into attitudinal groups based on their beliefs about KDTs: 'accepting' of KDTs (high necessity, low concerns), 'ambivalent' (high necessity, high concerns), 'skeptical' (low necessity, high concerns), or 'indifferent' (low necessity, low concerns). Necessity and Concerns scores were classified as high or low by dichotomizing at the midpoint for each subscale: low necessity ≤ 3 and low concerns < 3 . One participant that had missing responses to many BMQ-KDT items could not be categorized.

T-tests were used to explore putative correlations between mean BMQ-KDT scores and Necessity–Concerns differentials, with KDT response. A chi-square test was used to explore correlations between attitudinal groups and KDT response.

3. Results

3.1. Cohort demographics and KDT response

Parents of 92 children completed the BMQ-KDTs.

Of the cohort ($n = 92$), 47 (51%) children were female and 45 (49%) were male. Seven children had Dravet syndrome, 8 had epilepsy with myoclonic seizures (either myoclonic–atonic seizures and/or myoclonic absences or myoclonic epilepsy unspecified), 6 had West syndrome, 1 had juvenile absence epilepsy, 2 had late infantile Batten disease, 1 had Lennox–Gastaut syndrome, and 67 had no diagnosed epilepsy syndrome.

The average age at KDT initiation was 5.7 years (range: 0.8–16.2 years). At the time of completing the questionnaires, 66 (72%) children were following the classical ketogenic diet, 15 (16%) were following the medium-chain triglyceride diet, and 11 (12%) were following the modified ketogenic diet. The average duration of KDTs at the time that the questionnaires were completed was 14.8 months (range: 3–82 months).

Fifty-seven (62%) individuals were classified as responders at the time that the questionnaires were completed; 29 (31.5%) were nonresponders; and KDT response was unknown for 6 (6.5%) individuals, as seizure frequency could not be accurately determined from hospital records at that particular time point.

3.2. Sensitivity analyses

The internal consistency of the BMQ-KDT scales was deemed acceptable despite modifications to the original items. There are varying reports regarding what constitutes an acceptable alpha: values over 0.7 are often considered acceptable [14], although values below 0.7 may be appropriate, depending on what is being measured [15].

The BMQ-KDT–Necessity scale had an alpha of 0.93 and the BMQ-KDT–Concerns scale an alpha of 0.68. Removal of specific items did not substantially improve the alphas.

3.3. Beliefs regarding KDTs

The mean necessity score for the cohort was 3.77 [standard deviation: 0.92], revealing that there was strong belief in the necessity of KDTs.

Most parents indicated that it was necessary for their children to follow KDTs, although the proportion of parents strongly endorsing the necessity of KDTs varied between individual items (see Fig. 1).

The mean Concerns score for the sample was 2.59 (standard deviation: 0.54). Examination of the individual Concerns items in the

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