

Health Technology Assessment in Epilepsy: Economic Evaluations and Preference Studies

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Valorization

Relevance

Epileptic seizures vary considerably in severity and frequency between patients, as well as in an individual patient. Some patients have multiple seizures per day, others only seldom. Worldwide, about 65 million people are estimated to have epilepsy. In the Netherlands, the prevalence of active epilepsy is approximately 84,000. Although difficult to estimate, epilepsy was considered to be the cause of death in 229 persons in the year 2010. About 30% of the patients with epilepsy suffer from uncontrolled seizures despite the use of many antiepileptic drugs (AEDs) (i.e. intractable epilepsy). Epilepsy mortality rates are related to young patients with severe intractable epilepsy in combination with other neurological problems and/or mental retardation. Living with epilepsy can be a great burden for the patient himself and those around him. Patients with epilepsy heavily depend on informal care delivered by family and friends. Since epileptic seizures mostly occur unexpectedly, they may cause physical harm, as well as psychological stress due to their unpredictability. Epilepsy can sometimes result in significant disability, social exclusion and stigmatization. People with epilepsy commonly encounter problems in the following areas: education; employment; driving; personal development; psychiatric and psychological aspects and social and personal relationships. Currently the scientific and clinical attention paid to the role of the ketogenic diet (KD) is negligible. This means that a KD is often overlooked and underutilized as a treatment option for children with intractable epilepsy. An important reason for this is that relatively few children and their parents can comply with the stringent diet. Therefore, physicians are often reluctant to initiate the diet. To offer more children the opportunity to benefit from a KD, we suggest that the diet should be initiated and monitored under strictly controlled circumstances in order to maximize compliance.

Target groups

See Table 10.1

Activities

Compliance with a KD is difficult due to its restrictive nature. Unfortunately, non-compliance limits the intended effect and increases the costs to society, resulting in a less favorable cost-effectiveness ratio. In order to overcome this problem, the children

and adolescents with uncontrolled epilepsy who are on the KD will be monitored according to a strict standardized protocol.

In order to help KD users preparing meals, a website was developed on which tasteful recipes can be found. Our master-chefs encourages menu plans that can be shared by the entire family. These tasty menus can be found at www.ketogeenmenu.nl. In order to make patients and their parents/caretakers get used to the new meals, workshops are provided.

Table 10.1 Target groups, related activities and products and an indication of innovation level and realization.

Target Group	Activity / products	Innovation	Realized
Patients	Ketogenic diet cookbooks	+	+
	Ketogenic diet website	+++	+
	Ketogenic diet stand	+	+
	Workshops	++	+
Health care professional	Presentations	-	+
	Scientific articles	+	+
	Instructions MCT-powder	++	+
	Instructions by master-chef	++	+
Health care insurance companies	Include results in guidelines	+	-
	Scientific articles	+	+
	Distribute information on effects	+	-
	Distribute information on costs	+	-
Industry	Ketogenic diet website	+++	+
	Scientific articles	+	+
	ISPOR SIG Nutrition economics	++	+
Scientists	MCT-oil explore possibilities	++	-
	Scientific articles	+	+
	Presentations	+	+
	Thesis	+	+

Innovation

Although the KD was popular in the 1920s and 30s, it was largely abandoned in favor of new antiepileptic drugs. Most individuals with epilepsy can successfully control their seizures with AEDs, however, about 30% fail to achieve such control despite trying a number of different AEDs. For this group, and children in particular, the diet has once again found a role in epilepsy management. Therefore, the innovation of our study does not lie in using the diet. However, due to the stringent diet, compliance is sometimes difficult. Therefore, our master-chef developed tasty meals by using a special MCT-powder to turn MCT oil into tasteful cream, paste and mayonnaise. Recipes are presented on our website.

Implementation

At the moment we are building a new website to replace the former ketogeenmenu.nl. The new website will have an interactive dimension in which

parents and children have their special meals get calculated based on their personal needs. Furthermore, when the patient give their permission, their treating physician and dietician can view their personal data. With this, the dietician and/or treating physician can anticipate on experienced side-effects or the level of ketosis by changing the diet. The development of this new website is sponsored by fonds NutsOhra, CZFonds, Epilepsiefonds and ZonMw.