

Health technology assessment in epilepsy

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Valorization

Epilepsy is the fourth most common neurological disorder and affects people of all ages. In the Netherlands, in 2015, roughly 180,000 were suffering from epilepsy, with 14,000 newly identified cases. Epilepsy results in various clinical manifestations, and seizure severity and frequency vary per person. In 2011, in The Netherlands, costs of epilepsy were about 248.7 million euro, that is 4.8% of the total healthcare budget spend on neurological disorders. The rising healthcare costs attributable to epilepsy in combination with an overall increase in healthcare expenditure nationwide and a constraint healthcare budget stress the need for economic evaluations with the ultimate goal to achieve an efficient allocation of resources.

To achieve a more efficient and patient-centered healthcare system, scientific research is only the first step. The second step is to reach out to various stakeholders within the healthcare sector to disseminate the results of scientific research. Scientific knowledge should benefit society as a whole and it is important to translate the value of scientific work into ideas and solutions societies face. As defined in the PhD regulations of Maastricht University in 2013, the process of valorization is *"the process of value creation from scientific knowledge by making it available for societal (or economic) use and make it suitable for translation to competitive products, services, or processes"*. Hence, this chapter provides an overview of the relevance of this thesis for the most important stakeholders and a description of the dissemination of the findings of this thesis.

Relevance for researchers

The studies described in this thesis are relevant for researchers in the field of health technology assessment (HTA). Chapter two and three provide examples of application of a discrete choice experiment and a time trade-off study in epilepsy. Chapter four provides an overview of best-worst scaling in healthcare, which may provide important understandings and insight in to the usefulness of this technique.

For researchers focusing on economic evaluations, especially in epilepsy, the performance of the EuroQol-5D-5L in adults with epilepsy described in chapter five is important as it makes them aware of the shortcomings of this instrument. As this instrument is recommended in the national guidelines for conducting economic evaluations, it is important to know what its limitations are when using the instrument. For example, these results may give rise to the development of another generic or condition-specific instrument to examine quality of life in patients with epilepsy or these results may highlight the need for additional questionnaires besides the EuroQol-5D-5L when conducting an economic evaluation in epilepsy.

This thesis also provides an overview of the current economic evaluations conducted in epilepsy, which indirectly highlights potential knowledge gaps. This may guide future researchers in developing (trial-based) economic evaluations to close these gaps. In addition, the heterogeneous methodology may give rise to the development of a reference

case for the conduct of economic evaluations in epilepsy. Lastly the two trial-based economic evaluations in which the ketogenic diet (KD) and a multi component self-management intervention are being compared to care as usual add to the current scientific knowledge of both the KD and self-management in epilepsy.

Relevance for patients and healthcare professionals

Some of the more methodological studies described in this thesis are not directly relevant for patients and healthcare professionals. However, on the long run, patients and healthcare professionals indirectly benefit from improved scientific methods as it enables researchers to perform high quality studies, resulting in results with greater certainty.

For patients and healthcare professionals, it is relevant to know what the (cost-)effectiveness is of interventions aiming to treat epilepsy is. Although it is unrealistic to assume that every patient or and healthcare professional is able to understand the studies described in this thesis in detail, the overall conclusion should be presented in a comprehensible way. It is important for patients and healthcare professionals to be aware of alternative treatments as 30% of the people with epilepsy is still not seizure free while being on anti-epileptic drugs. For example, although the retention rate of the KD is rather low, the KD was shown to be of significant importance to those who were still on the diet at the end of the study. The same holds true for the multi component self-management intervention, which (marginally) improved patients' health status.

Relevance for policy makers or healthcare insurance companies

For policy makers or healthcare insurance companies it is important to look at the (cost-)effectiveness of treatments in order to make a deliberate choice on what to reimburse. The ZMILE-study demonstrated favourable cost-effectiveness ratios, which may create a positive attitude towards self-management interventions in general, but more specifically the ZMILE intervention for adults with epilepsy. Regarding the KD, although unfavourable cost-effectiveness ratios were found, the KD was shown to be effective on the short term and was demonstrated to be effective for those who were still on the diet at the end of the follow-up period. The low retention rate may make policy makers or healthcare insurance companies willing to investigate the most optimal way of delivering the KD and which patients are best able to benefit from the KD.

Dissemination

To stimulate the dissemination among fellow researchers, it is important that the results of all scientific studies described in this thesis and the studies which are not included in this thesis, are being published in international journals. Of the nine articles described in this thesis, eight have been published so far and the remaining two are currently under review for publication in international journals. In addition, the plan is to write and publish a Dutch translation of the economic evaluation of the ZMILE study in the Dutch journal "Epilepsie,

periodiek voor professionals” to reach out to Dutch neurologists. A publication regarding the short term effects of the KD is already available in this journal. Besides this, a general (Dutch) introduction to economic evaluations in epilepsy was written (and published) in this same journal.

Besides (inter)national publications, results of the studies described in this thesis have been presented at (inter)national conferences such as conferences of the International Society of Pharmacoeconomic Outcomes and Research (ISPOR), the Lowlands Health Economics Study Group (LolaHESG), the annual CAPHRI day, the annual International Clinical Symposium of Kempenhaeghe, and a congress of the European Academy of Neurology. In addition, all researchers at epilepsy center Kempenhaeghe are required to present their results (or progress) twice a year for interested staff members of Kempenhaeghe and specially invited (inter)national experts in the field of epilepsy.

To enhance the dissemination and ease of use of the KD, a website has made available for people with epilepsy who are currently on the KD. This website contains information regarding the KD and provides daily recipes for the three different types of the KD, namely the modified Atkins diet, the MCT-diet, and the classic KD. These recipes are developed in consultation with a master chef and makes life easier for those on the KD. The menus can be found at www.ketogeenmenu.nl. In order to make patients and their parents/caretakers get used to the new meals, workshops were provided. Furthermore, when the patients 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.

Regarding the multi-component self-management intervention (MCI; the ZMILE-study), with valorization in mind, an advisory group was composed already in the designing phase of the study. This advisory group consisted of a patient representative, and people from healthcare insurances, and the industry. The advisory group was consulted/informed four times a year and the final results of the ZMILE-study were presented to them. As the ZMILE-study has been completed quite recently, we are now working on the implementation of the intervention. Fortunately, the first conversations regarding implementation of the MCI are promising and we hope to be able to offer patients the MCI at the Academic Center for Epileptology in Maastricht in the near future. In addition, a process evaluation was carried out (not described in this thesis), to evaluate patients’ view on the MCI and to identify potential barriers or facilitators for future implementation (such as the availability of the education adherence monitoring system and minor adjustments to the intervention protocol).

