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Burden of disease of people with epilepsy during an optimized diagnostic trajectory: costs and quality of life

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ABSTRACT

Background: Diagnosing epilepsy can be lengthy and stressful, potentially leading to increased use of healthcare resources and a reduction in quality of life.
Aim: This study aims to determine cost and quality of life before and after an optimized diagnostic procedure for people suspected of having epilepsy from a societal perspective with a follow-up of 12 months. In addition, this study aims to differentiate between people diagnosed with epilepsy during the follow-up of the study and the people who are diagnosed as not having epilepsy or for whom diagnosis is still uncertain.
Methods: A questionnaire regarding the use of healthcare resources was used accompanied by the EQ-5D-3 L. Multiple imputations by chained equations with predictive mean matching was used to account for missing data. To investigate the uncertainty of the results, non-parametric bootstrapped (1000 times) was used.
Results: In total, 116 people were included in the study. Total average costs per patient made in the previous 3 months had decreased from €4594 before the optimized diagnostic trajectory to €2609 in the 12 months after the optimized diagnostic trajectory. Healthcare costs were the largest expense group (52–66%) and had decreased significantly from baseline measurement to 12 months after baseline (€2395 vs €1581). Productivity costs had decreased from €1367 to €442 per 3 months. Total annual costs were similar between people diagnosed with epilepsy during the follow-up of the study and the people who are diagnosed as not having epilepsy or for whom diagnosis is still uncertain. Quality of Life had significantly increased over the course of 12 months from 0.80 to 0.84 (Dutch tariff).
Discussion: This study indicates that an optimized diagnostic trajectory has positively influenced the use of healthcare resources and the quality of life in people with epilepsy. As chronic care patients make diverse costs, future research should identify the long-term costs after an optimized diagnostic trajectory for patients with epilepsy, possibly identifying patients who are at high risk of becoming high-cost users in the future for early intervention.

1. Background

Correctly diagnosing epilepsy poses a great clinical challenge, as misdiagnosis is common and differentiation is not always a straightforward process (Chadwick and Smith, 2002). The condition has a complicated clinical appearance, as its progression varies per patient. Its symptoms are diverse and often ambiguous (Pugliatti et al., 2007), which makes distinguishing epilepsy from similar disorders a major difficulty in establishing the correct diagnosis (Chadwick and Smith, 2002).

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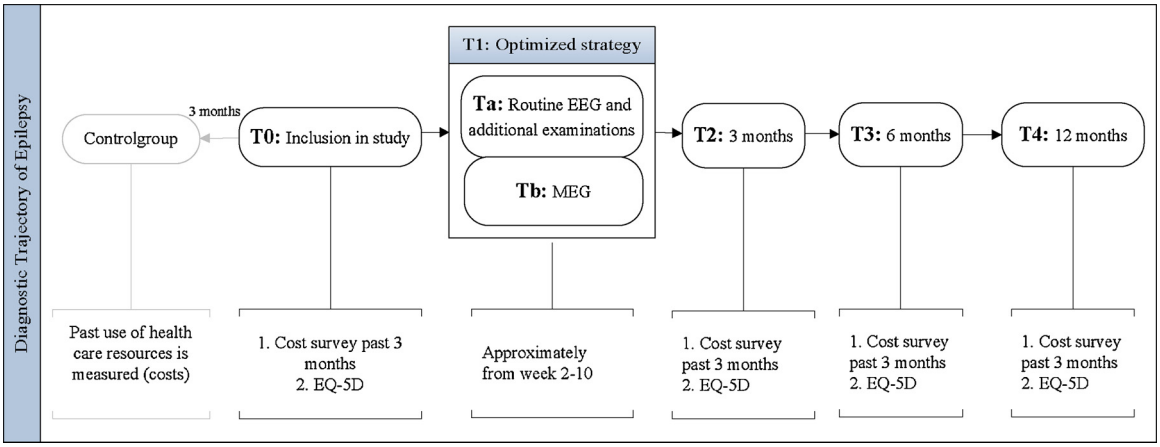

Fig. 1. Diagnostic trajectory of the study with an optimized trajectory.

Epilepsy has a considerable impact on costs and Quality of Life. It is often paired with psychological states of anxiety and depression, behavioral issues and cognitive dysfunction (Ramaratnam et al., 2008). These associated psychosocial effects as well as the uncertain clinical nature of epilepsy lead to a significant impact on a person's Quality of Life (Baker et al., 1997). Moreover, epilepsy constitutes a considerably high socioeconomic impact in Europe. For example, in 2004, the total costs of epilepsy were estimated at €15.5 billion, constituting 0.3% of the total European healthcare expenditures. Similarly, healthcare costs in the Netherlands have been estimated at €251 million in 2007 (Slobbe et al., 2011). A study by Cockerell et al. shows that the average medical costs per patient with epilepsy decreases with nearly 70% at 2 years after diagnosis (Cockerell et al., 1994).

An adequate diagnosis of epilepsy requires differentiation between seizures and other neurological disturbances (Chadwick and Smith, 2002), for example psychogenic non-epileptic seizures (PNES), which is most frequently misdiagnosed as epilepsy (Benbadis, 2006). In the search for a correct diagnosis, persons may excessively use health care resources, leading to higher health care costs, and experience lower quality of life. As a result, the diagnostic trajectory of epilepsy can be a lengthy process based on trial-and-error, often experienced as stressful and uncomfortable (Noachtar and Rémi, 2009). In addition to this shopping behavior, they can experience stress and anxiety due to uncertainty about their diagnosis, leading to a lower Quality of Life. Determining the correct diagnosis in people suspected of having epilepsy can have great consequences for their health, social behavior and employment (Angus-Leppan, 2008), and can be crucial in minimizing their healthcare consumption and in improving Quality of Life.

No studies up till now have provided insight into which costs people with possible epilepsy make during this diagnostic process and how it influences their Quality of Life, in order to determine how and where efficiency can be increased in the process of diagnosing and treating epilepsy. This study aims to quantify the Burden of Disease, in terms of quality of life and (healthcare) resource use, before and after an optimized diagnostic procedure for people with suspected epilepsy from a societal perspective with a follow-up of 12 months. In addition, this study aims to differentiate between people diagnosed with epilepsy during the follow-up of the study and the people who are diagnosed as not having epilepsy or for whom diagnosis is still uncertain. Assessing the burden of disease will consist of two components: 1) measuring cost of illness, operationalized in costs and use of (healthcare) resources, and 2) measuring health-related quality of life, operationalized in quality-adjusted life years (QALYs).

2. Methods

The study was a Burden of Disease study, which was assessed by two components: measuring the Cost-of-Illness (CoI), operationalized in cost, and measuring the Health-Related Quality of Life (HR-QoL), operationalized in utilities and Quality-Adjusted Life Years (QALYs). A CoI study aims to identify and measure all the costs of a particular disease. The output reflects the total burden of a specific disease to society (Rice, 1994). QALYs are widely used measures for health outcome that combine mortality and morbidity into a single measure (Kind et al., 2009). QALYs are generated by using health utilities, which are preference weights that reflect the value of a certain outcome (Weinstein et al., 2009).

2.1. Design and data collection

The study was a prospective, non-randomized, longitudinal study with a pre-post comparison. In this pre-post design, the same patients were measured before and several times during and after the diagnostic trajectory, i.e. patients serve as their own controls (3-month period before baseline). This study was funded by a healthcare innovation project which enabled access to the optimized diagnostic trajectory.

Data was collected at baseline and after 3, 6 and 12 months. Baseline measures were performed at the start of the diagnostic trajectory (T0). Participants received a questionnaire regarding their use of healthcare resources in the past 3 months and the Dutch EuroQol-5D 3 level version (EQ-5D-3 L) (Van Reenen and Oppe, 2015). The baseline questionnaire also included questions on general characteristics, i.e. date of birth, gender, education, civil status and whether participants autonomously filled in the questionnaire or proxies were used.

Recruited participants were derived from a larger healthcare innovation project in which an optimized diagnostic trajectory was examined that included magnetoencephalography (MEG) in addition to the standard routine diagnostic trajectory. Before the start of the study, the attendant neurologist notified the patient of the request for a routine EEG. During this conversation, the patient was asked to participate in the optimized diagnostic trajectory including the MEG procedure, provided that they met the inclusion criteria. The patient received information about the study and an informed consent form. The patient was given 2 weeks to review and ask questions. Fig. 1 gives an overview of the diagnostic trajectory. At T0, patients were included in the study. After they gave permission, the research nurse provided them with the relevant documents, including the cost questionnaire, the EQ-5D-3 L, and a reply envelope. Subsequently, the routine EEG and MEG were scheduled. During week 2–10 (T1), the optimized diagnostic trajectory took place. After 3, 6, and 12 months (T2-T4), the cost questionnaire and EQ-5D were again administered. The study protocol was approved by the Medical Ethics Committee of Kempenhaeghe.