Enhancing efficiency in epilepsy care

Citation for published version (APA):

Document status and date:
Published: 01/01/2024

DOI:
10.26481/dis.20240515hc

Document Version:
Publisher's PDF, also known as Version of record

Please check the document version of this publication:
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Download date: 17 May. 2024
Impact paragraph

Epilepsy is a widespread neurological disorder, ranking as the fourth most common globally, affecting approximately 50 million people worldwide. In the Netherlands, in 2021, around 62,500 individuals were living with epilepsy, with 10,900 new diagnoses. The financial burden of epilepsy was substantial, estimated at 192.3 million euros in 2019, which constituted 3.8% of the country's total healthcare spending. Notably, about 30% of those diagnosed with epilepsy do not respond to conventional anti-seizure medications, incurring an estimated annual cost of €39,956 per patient. More than half of these expenses stem from non-medical factors, including 50% attributed to informal care, 12% to inpatient care, and 9% to productivity losses.

Given the escalating healthcare costs and constrained budgets, there is a growing importance for economic evaluations to assist policymakers in optimizing healthcare allocation while safeguarding patients' quality of life. Value-based healthcare strives to enhance people's well-being by improving healthcare quality, increasing efficiency, and ensuring long-term sustainability, with scientific research playing a pivotal role. It is crucial to translate research findings into practical applications that cater to the diverse needs of various stakeholders.

In the following section, we will delve into how the research presented in this dissertation will impact different groups, including patients, healthcare professionals, the scientific community, healthcare insurance companies, and policymakers. This approach aims to bridge the gap between research and real-world healthcare practice, ultimately benefiting the broader healthcare ecosystem and enhancing the lives of those affected by epilepsy.

Patients & healthcare professionals

The research outcomes offer promising avenues for enhancing the well-being of patients with epilepsy. In Chapter 2, the review on the relevance of therapeutic drug monitoring of levetiracetam underscores the potential role of therapeutic drug monitoring in personalized medication management, potentially minimizing side effects and optimizing seizure control. Furthermore, in Chapter 3, the introduction of ZMILE, a multicomponent self-management intervention for adults with epilepsy, sets the stage for patient empowerment, allowing individuals to take a more active role in their epilepsy management. These chapters promote patient-centered care and better communication between patients and healthcare professionals, potentially revolutionizing the way epilepsy is treated and managed.
Scientific community

The research presents significant contributions to the scientific community by addressing critical questions in epilepsy treatment. Chapter 4, which centers on the translation, validation, and application of the Assessment of Quality of Life 8-Dimension (AQoL-8D) in individuals with epilepsy, introduces a new tool for assessing patient's quality of life. This chapter's comparison of AQoL-8D with the widely recommended EQ-5D-5L, a generic instrument in economic evaluations, underscores that a one-size-fits-all approach may not fully capture the complexities of specific patient groups, such as for people with epilepsy. This study makes researchers aware of the possible limitations of generic instruments in representing the nuanced quality of life changes in epilepsy, providing valuable insights for future studies. Moreover, Chapter 5's systematic review consolidates all available economic evaluations on non-pharmacological treatments for epilepsy, potentially identifying knowledge gaps and inspiring further research to address these gaps comprehensively. Lastly, Chapter Six's lifetime decision analytic model comparing deep brain stimulation with vagus nerve stimulation and standard care for individuals with drug-resistant epilepsy contributes novel insights into the cost-effectiveness of deep brain stimulation, a more recent non-pharmacological treatment. These findings collectively stimulate scientific discourse and exploration, advancing our understanding of epilepsy treatment and guiding future research in this domain.

Healthcare insurance companies & Policy makers

For healthcare insurance companies and policy makers, the research findings hold potential to drive cost-effective and patient-centric healthcare policies. In Chapter 5, the systematic review of economic evaluations provides crucial insights for resource allocation and reimbursement decisions, potentially enabling insurance companies to offer more comprehensive coverage for non-pharmacological interventions. Chapter 6's decision analytic model offers a long-term perspective on the cost-effectiveness of different treatment modalities, allowing policy makers to make informed decisions about funding and access to advanced therapies. These publications have the potential to reshape the landscape of healthcare financing and access for individuals with epilepsy, improving their quality of life and overall health outcomes while optimizing resource utilization.

Dissemination & Implementation

Enhancing the impact of disseminating critical research findings to both healthcare professionals and patients is a multidimensional effort. This process involves a strategic approach encompassing various channels such as conferences and tailored resources
for the implementation of innovative interventions. In the context of scientific research, widespread dissemination via (inter)national publications and academic presentations is crucial, stimulating interdisciplinary collaboration and future research.

In alignment with these principles, all five studies described in this dissertation have been published in international journals. In addition to the international publications, the results of each study within this dissertation have been presented at various (inter)national conferences, such as the Lowlands Health Economics Study Group (LolaHESG), the European Health Economics Association (EuHEA), the annual International Clinical Symposium of Kempenhaeghe, the European Academy of Neurology, and the MOSA conference.

Moreover, an extensive description of the ZMILE self-management tool has been published, offering a detailed guide accessible to all neurologists. This comprehensive documentation includes an in-depth clinical and cost-effectiveness assessment of ZMILE, presenting an adapted version ready for seamless implementation. Finally, the validation of the AQoL-8D provides new insights for adequate selection of quality-of-life assessment tools for fellow researchers. This validation and (Dutch) translation not only enhances the arsenal of available tools but also elevates the efficiency and quality of future epilepsy research.