

# Self-management in Epilepsy

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## Valorisation



## VALORISATION

Epilepsy is an invasive disease; not only does it have a psychosocial impact on persons with epilepsy (PWE) and their relatives, but it also has an economic impact on society as a whole. The costs involved include direct health care (e.g. health care visits, hospitalisation), informal care by family, friends or the community, indirect costs due to productivity losses and unemployment, and societal costs. The latter are the result of the effect that epilepsy, or epilepsy treatment, has on productivity and on independent living.

From the perspective of PWE and their relatives, as well as from a societal perspective it would seem valuable to achieve an efficient patient-centred health-care system, focusing on optimal self-management and quality of life. Self-management is defined as the ability to deal with the symptoms, medical treatment, lifestyle changes, and physical and psychosocial consequences.

In 2017, the National Health Care Institute started a programme called ‘appropriate care’ that focusses on assessing whether diagnostics and (therapeutic) interventions are being applied in a patient-oriented, effective and cost-effective manner. Part of this programme, which was setup together with patients, healthcare professionals and insurance companies, was a project that investigated whether the care of PWE was deployed in this way. It was concluded that the psychosocial care of PWE (and their relatives) is lacking, and that a psychosocial self-management intervention could be effective. The subject of this thesis is relevant in that it provides an evidence-based intervention, introducing psychosocial and self-management support not only for PWE, but also for their relatives. The multi-component intervention (MCI), which is a novel self-management intervention in the Netherlands for PWE, provides support in the development of self-management skills. To increase these skills, different strategies are applied, such as self-management education, setting goals and increasing one’s involvement in the treatment plan, thus leading to a shared treatment decision and self-monitoring.

The positive results of the effectiveness study, the process and economic evaluation of this thesis, mean that further dissemination and implementation of the adapted self-management intervention (MCI) in the clinical setting is possible.

### *RELEVANCE FOR STAKEHOLDERS*

The results of this thesis are of relevance for patients and their relatives, healthcare professionals, insurance companies and policy makers (local and nationally)

#### *Patients & Relatives*

Patients and their relatives will profit from this research, as it emphasizes the importance of their perspective on self-management and of how they perceive self-management support. From the literature we know that there is no such thing as the typical chronic patient and there is no ‘one size that fits all’, knowledge that is supported by this thesis.

To achieve an efficient patient-centred health care system, the entire system should be considered, since the demand on informal care is growing. Relatives will benefit from this research, because it emphasizes their need for support from health care professionals

#### *Researchers*

The studies described in this thesis are relevant for a broad range of researchers in the field of epilepsy and economic evaluations. Since this thesis represents the first study to look at/consider a self-management intervention for PWE in the Netherlands, many aspects of self-management (support) have not yet been investigated. For instance, what is the implication if instead of finding a significant improvement on the primary outcome (self-efficacy), significant results are found on secondary outcomes (QOL, side-effects).

The MCI is also innovative in that it includes relatives. They are stimulated to focus on their own goals, experiences and problems, which are an inherent part of living with a relative with epilepsy. The introduction of relatives within the MCI, disclosed a knowledge gap about the results relatives hope to achieve by attending an intervention and research on this subject.

The challenge for researchers in economic evaluations is to develop an instrument to measure quality of life, which will be accepted in the guidelines for economic evaluations, and which does not have the limitations of the EuroQOL-5D-5L.

#### *Healthcare professionals*

Healthcare professionals (neurologists, nurse practitioners, etc.) working with PWE can benefit from the study findings. Our study showed that personalized goalsetting of PWE, alongside personalized information and shared decision-making, plays an important role in their psychosocial functioning. By taking these factors into account, healthcare professionals will be able to support patients in achieving self-management, either by means of individual interventions or by the MCI, the latter including group sessions.

As well as improving the quality of care for PWE, the effect of stimulating self-management behaviour may also result in more efficient consultations with the healthcare provider.

In contrast to, for instance, the guideline from the United Kingdom (The National Institute for Health and Care Excellence (NICE) Epilepsies: diagnosis and management CG137), self-management and self-management support do not feature in the current national epilepsy guideline. As pointed out in the discussion (chapter 7), findings of the studies can be used to update the Dutch national epilepsy guideline to include these aspects.

#### *Policy makers & Healthcare insurance companies*

Both studies convey an important message to policy makers and insurance companies; they have to make a deliberate choice about what to reimburse.

Over the past decade, policy makers and insurance companies have emphasized the need for patients with a chronic condition to take responsibility in managing their own condition and for informal caregivers to play a larger role. Self-management, especially self-management using eHealth, was seen as a favourable option. Strategies to improve self-management in this way are based on research on chronic diseases, such as diabetes, COPD etc., and not on research on more vulnerable groups such as epilepsy, a disease known for the effect on cognition and the accompanying challenges for PWE.

The ZMILE-study demonstrated favourable cost-effectiveness ratios, which may create a positive attitude to the self-management intervention for adults with epilepsy. This thesis also offers an insight into the feasibility of this self-management intervention as perceived by PWE, relatives and healthcare professionals. In addition, our research showed that a group of PWE did not have access to or the ability to use eHealth, meaning this option is not appropriate for a subcategory of patients. The knowledge may be useful for policy makers and insurance companies in their approach to self-management for special groups.

**Table 10.1:** Overview of planned and realized products and activities per target group

Target group	Products & Activities	Realized locally	Realized nationally in 2019
Patients & relatives	MCI	x	x
	5-step framework (adapted)	x	x
	Manual - facilitators	x	x
	workgroup 'national accessibility'		x
	Project group – business case		x
Healthcare professionals	Presentations	x	x
	Scientific articles	x	
	workgroup 'national accessibility'		x
	Project group – business case		x
	National education organizations	x	x
Insurance companies	Scientific articles	x	
	Information on costs (thesis Ben Wijnen and Loes Leenen)	x	
	Information on patient & relatives perspective (process evaluation)	x	
	Project group – business case		x
Researchers	Scientific articles	x	x
	presentations	x	x
	Evaluation implementation		x
Policy makers (including local)	Information on costs (thesis Ben Wijnen and Loes Leenen)	x	
	Scientific articles	x	
	workgroup 'national accessibility'		x
	Business cases (local)	x	x
	Project group – business case		x
	Business case (national)		x
	Project plan	x	

*DISSEMINATION & IMPLEMENTATION*

The MCI was designed and validated. Based on recommendations of PWE and relatives, and considering the positive reactions from practitioners (chapter 4), the adapted intervention is ready for implementation.

As table 10.1 shows, some activities and products have already been realized and some are planned within the dissemination and implementation process. Products and/or activities focus on three levels of stakeholder:

- At a micro level: end-users (i.e. healthcare professionals, patients and relatives).
- At a meso level: managers and policy makers (e.g. insurance companies etc.).
- At a macro level: umbrella organizations (professional associations, patient support groups, national knowledge networks and national committees).

The products and activities, planned and realized per target group, are summarized in table 10.1.

*Realized locally*

In the design phase of the ZMILE-study, and of the multi-component self-management intervention (MCI), an advisory board was selected, with valorisation in mind. This board, which consisted of patient representatives, healthcare professionals, members of industry and representatives of healthcare insurances, met three or four times a year.

The results of studies were also presented on three levels:

- At a micro level: by presenting results at Maastricht University Medical Centre (vakgroep neurologie), Maastricht 2017, and in a SepiON (Stichting Epilepsie Onderwijs Nederland) course on self-management, Hoevelaken 2018. (i.e. health care professionals)
- At a meso level: by publication in international and national journals (e.g. researchers)
- At a macro level: Presentations at national and international conferences. Examples of national conferences were the 17<sup>th</sup> and 20<sup>th</sup> edition of the annual international clinical symposium Kempenhaeghe, Heeze 2015 and 2018. International conferences were the 32<sup>nd</sup> International Epilepsy Congress, Barcelona 2017, the 3<sup>rd</sup> Congress of the European Academy of Neurology, Amsterdam 2017 and the 10<sup>th</sup> ICN NP/APN Conference, Rotterdam 2018.

*Planning for realisation nationally in 2019*

As the intention is to implement the MCI in the regular care of PWE, a dissemination and implementation plan has been designed, in collaboration with various stakeholders.

The four main objectives of the dissemination and implementation plan are:

1. To optimize the MCI
2. To secure MCI financially and practically
3. To make the MCI accessible nationally (and exploring international opportunities)
4. To evaluate and produce a Business Case

To achieve these objectives in current practice, the following mix of activities / strategies are planned:

To further optimize the MCI by:

- Adjusting the MCI based on the process evaluation
- Professionalizing the available course material in terms of layout and practical applicability;
- Developing the training for course leaders, so that it is easier to implement the course at different locations;

Financially securing the MCI by:

- Remaining financially accessible for participants of the MCI;
- Composing a project team; that includes the representation of patients with epilepsy, health insurers, pharmaceutical companies and both regional and national healthcare organizations in order to prepare a business case.
- Drawing up a business case, in which the costs and benefits are calculated for the various parties

Practically securing and making the MCI accessible on a national scale by:

- Drawing up a communication plan for optimal dissemination;
- Informing stakeholders about the MCI (presentations and publications);
- Aiming at involvement in the 'landelijk leerhuis epilepsie' and SepiON at an educational level;
- Aiming at organizational change, so that the MCI is a standard part of the care of epilepsy (participation by end-users and professionals);

Evaluating by

- Monitoring the process and results with regard to all objectives

The intention is to disseminate the MCI nationally in 2019; as a first step in this process, the MCI will be offered to PWE and their relatives at the Medical University Centre Maastricht (MUMC) in the autumn of 2018.