












The Role of Digital Care Pathway for Epilepsy on Patients' Treatment Burden: Clinicians' Perspective

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Abstract. Epilepsy is a chronic neurological disorder, requiring long-term treatment. The workload and impact of treatment causes a significant burden to patients. Digital care pathways may have potential for reducing treatment burden, but there also may be concerns of additional burden caused by digital healthcare. The aim of this study is to investigate the role of digital care pathway on treatment burden for patients with epilepsy. This was a single case study with the digital care pathway for epilepsy in the Wellbeing Services County of North Ostrobothnia (Pohde), in Finland, as a unit of analysis. The data was collected by observing an expert meeting of three clinicians. The meeting focused on five pre-defined domains of treatment burden: Medication burden, Time and travel burden, Financial burden, Social and emotional burden, and Healthcare access burden. The data was analyzed qualitatively and organized based on the pre-defined categories. The results suggest that the digital care pathway supports patients with treatment burden for all the pre-defined domains. Reported benefits include reduced travel, options for remote appointments, providing informational support and easier ways to contact healthcare professionals (HCPs). The main concerns clinicians had was could the use of digital care pathway cause rushed treatment decisions, difficulties of building trust and seeking support from HCPs, and difficulties of using the digital systems. A new theme emerged from the data, Diverse burdens, highlighting the variety of patients with epilepsy with differing needs for treatment.

Keywords: Chronic Illness · Treatment Burden · eHealth · Digital health

1 Introduction

Digital healthcare has been found to be effective, accessible, and cost-effective for treating many conditions [1–3]. One way of complementing traditional health care with digital and remote treatment is through digital care pathways. Digital care pathways are web- or mobile-based healthcare interventions, where multidisciplinary teams work together to deliver care to patients, usually in a structured evidence-based way [4, 5]. Digital care pathways are used, for example, for filling in surveys, receiving feedback, reading patient instructions, and communicating with healthcare providers [6]. Oulu University Hospital has been using a web based digital care pathway for the treatment of epilepsy since 2020, and in December 2022 a mobile version was introduced to adults with epilepsy. Currently the users of the digital care pathway can keep a digital seizure diary, contact healthcare professionals, receive their replies, and record their healthcare data regarding treatments, other diagnosis, daily functional capacity, and possible depressive symptoms.

The current evidence shows that digital care pathways can improve patient outcomes, quality of care, and healthcare resource utilization [5]. People with epilepsy may specifically benefit from dynamic remote care, as it gives them easier ways to reach out when needed, and it has been suggested this could potentially reduce the number of seizures [7]. Digital care pathways can therefore offer new opportunities for improving outcomes beyond what current medication and healthcare delivery can achieve.

However, for developing digital healthcare, it is necessary to understand the unique circumstances for patients with different conditions. Epilepsy is a chronic neurological disorder characterized by recurrent seizures. The treatment of epilepsy may last through lifetime [8]. Even though the long-term prognosis for seizure cessation tends to be better in children than adults, 1/3 of children don't achieve remission [9]. To manage their condition, people with epilepsy need to adhere to their treatment and learn various self-management skills, including identifying and managing seizure triggers, minimizing seizure-related risks, and educating others what to do during a seizure [10]. These demands are often referred to as treatment burden [11]. Treatment burden can be divided on several domains, including taking medications, travelling to appointments, cost of treatments, impact to social life, and difficulties accessing healthcare services [12, 13]. Digital healthcare may support patients with their treatment burden by, for example, reducing travel and making communication with healthcare professionals (HCPs) easier [14, 15]. It can also create additional challenges and barriers, for example by being inaccessible to some patients or shifting too much responsibility of care to the patients [16, 17].

Although the development of digital healthcare aims to consider patients' needs, the research for epilepsy has been mostly focusing on health outcomes, such as medication adherence, reducing seizures, and quality of life [18–21]. Since epilepsy is a life-long disease and often requires daily long-term treatment [8], it is important that the digital care pathways support patients managing their treatment burden and promoting long term use of the program. Therefore, there is a need to evaluate how digital care pathways affect the workload and demands of treatment for the patients using the care pathway.

The objective of this study is to investigate the role of digital care pathway on the treatment burden on patients with epilepsy, from the clinicians' point of view. The study

design, procedures, and data analysis will be explained in Sect. 2, and the findings will be reported in Sect. 3. The paper is wrapped up with concluding remarks and future directions in Sect. 4 and 5.

2 Methods

2.1 Design

The study design is a single case study based on the definition by Robert Yin [22], with the digital care pathway for epilepsy (see Fig. 1) in the Wellbeing Services County of North Ostrobothnia (Pohde), in Finland, as a unit of analysis. Pohde is the wellbeing services county responsible for organizing public health, social and rescue services in North Ostrobothnia area [23]. The digital care pathway is one part of the public health services Pohde provides for patients with epilepsy in North Ostrobothnia.

Case study is a suitable method for the present study, as there is currently limited research about the impact of digital care pathways on treatment burden, and case study can be used as an exploratory phase of research to gather qualitative data [24]. We examine the role of digital care pathway on the treatment burden on patients with epilepsy and identify the potential challenges.

We followed the University of Oulu ethics process as defined in the guidelines from Ethics Committee of Human Sciences [25]. Even though the research topic is health related, the method does not involve medical research as defined in Ethics Committee of Medical Sciences [26]. Therefore, the guidelines for human sciences were more suitable.

The case study used systematic participant observation of an expert meeting for data collection. In participant observation, the researcher is a member of the group they are researching and so can better understand their situation [27]. The first author and the sixth author, who attended the meeting as participant observers, have been collaborating in the same research project as the clinicians and therefore were already familiar with them and the meeting topic. Using participant observation was selected for the present study, since it allowed the researchers to further gain familiarity with the digital care pathway development.

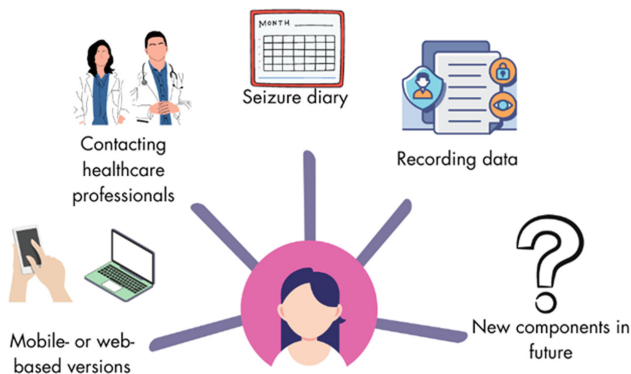


Fig. 1. Illustration of the components and functions of the digital care pathway for epilepsy in Pohde

2.2 Procedures

In December 2023, three experienced clinicians from Oulu University Hospital were invited to participate in an expert meeting. One clinician was working in the Neurocenter (Neurology) and two in the Pediatric neurology department. The purpose of the expert meeting was to discuss topics related to the treatment burden for patients and the sustainable design of the digital epilepsy care path. The invited clinicians treat patients with epilepsy in the Oulu University Hospital and have used the digital care pathway for epilepsy previously. For the purpose of this study, we have focused on the observed data relating to the treatment burden topic.

The meeting focused on five pre-defined domains of treatment burden: *Medication burden*, *Time and travel burden*, *Financial burden*, *Social and emotional burden*, and *Healthcare access burden*. These domains were identified based on two systematic reviews regarding treatment burden on people with chronic conditions [12, 13]. Prior to the meeting, the first author prepared a checklist to list and keep track of the relevant concepts discussed during the meeting. The checklist was reviewed and approved by three other authors from the research team. Clinicians were invited to discuss how the digital care pathway for epilepsy can impact these domains, considering both positive and negative impact.

2.3 Data Analysis

The online meeting was organized on Microsoft Teams. The meeting was recorded and automatically transcribed. The transcripts were analyzed with NVivo [28]. The transcripts were coded by the first author using deductive analysis approach [29] and organized according to the pre-defined categories. Inductive analysis approach [30] was used for adjusting existing categories and creating a new category from codes that did not fall under the pre-defined categories.

3 Results

Three clinicians attended the meeting on 8th December 2023. The collected data provided substantial content under five out of six pre-defined themes *Time and travel burden*, *Medication burden*, *Social and emotional burden*, and *Healthcare access burden*. The pre-defined theme *Financial burden* was moved under the theme *Time and travel burden*. The theme *Financial burden* consisted of treatment costs related to travel to appointments and other expenses, such as medications and medical operations. Even though non-travel related costs of treatment are a significant part of the overall treatment burden for the patients, the clinicians stated that the digital care pathway does not have direct impact on them. However, there can be a positive impact on reducing travel costs and loss of income due to absences from work, which are discussed in the *Time and travel burden* theme. In addition to the five pre-defined themes, a sixth theme *Diverse burdens* was discovered. *Diverse burdens* covers the discussion regarding differences between individual patients and special patient groups, that did not fall under the pre-defined themes. The findings are illustrated in a Venn diagram of the positive and negative impacts of digital care pathway on the treatment burden categories (see Fig. 2), and the identified impacts are listed in more detail in Table 1.

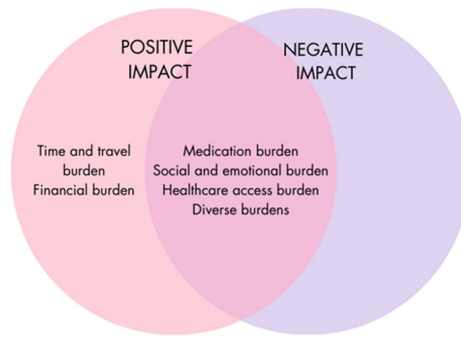


Fig. 2. A Venn diagram presenting the positive and negative impact of the digital care pathway regarding each category of treatment burden

Table 1. A list of the identified positive and negative impacts of digital care pathway on treatment burden

Treatment burden category	Positive impact	Negative impact
Time and travel burden	Less time spent on travelling to appointments Less absences from work or school	
Financial burden	Reduced cost of travel	
Medication burden	Informational support Increased effectiveness of care Faster resolving of problems	Potentially too fast decisions regarding medication
Social and emotional burden	Reduced negative emotions from hospital environment Reduced stigma and illness identity Remote appointments help to spend more time with family	Difficulties seeking support without face-to-face meetings Difficulties building trust and relationships with HCPs
Healthcare access burden	Contacting HCPs is easier Access to informational support	Inaccessibility of digital interventions to some patients Difficulties starting to use the digital care pathway
Diverse burdens	Suits some patients better than traditional care	Not suitable or accessible for all patients Life circumstances prevent the use of digital care pathway to some patients

3.1 Time and Travel Burden

The clinicians identified several burdens caused by travelling to appointments, and ways digital care pathway can alleviate those burdens. First, all clinicians discussed how travel to appointments is time consuming for patients living far away from the hospital. One clinician emphasizes that the distances can be long, especially for some patients with drug-resistant epilepsies that need treatment in a tertiary care hospital.

“[Travel] can be quite easy, so the patients and the families can just live very near to our hospital, like next door neighbors. But on the other hand, the distance between the home and the hospital might be more than 600 kilometers if the patient lives up in the north.”

-Clinician 1.

The clinician 1 continued the discussion with how travelling impacts families: more time for travelling means children and adolescents will miss school, and people with jobs need to be absent from work, leading to loss of income. Travel can be especially challenging for parents of small children who must manage childcare during hospital visits, and for parents who must accompany their children to their appointments. Another clinician complemented this with the perspective of adult patients. For adults with epilepsy, travelling can also be difficult to organize, since at least for one year from diagnosis people with epilepsy are not allowed to drive. Additional risks from traveling were mentioned. Driving to appointments increases the risk of road accidents, especially in winter. Once in the hospital, there is a risk of viral infections spreading to patients and their families, causing additional burden by the possibility to increase the risk for seizures, and absences from work.

The clinicians agreed that the digital care pathway has addressed these burdens by reducing the need for travelling. Traditional appointments can be replaced by remote online appointments, and in some cases the issues can be solved through the digital care pathway with no need for physical checkups. For example, some medication changes can be feasible organized remotely, as described in the following quote:

“Sometimes, maybe it would be easier if you can bring the situation to notice from the digital care path, and if there is no need for changing care, if it is quite stable situation, maybe it is unnecessary to come for a checkup. It is quite a big effort, and then it is easier maybe to say, just tell that yeah, it is fine. We can postpone it.”

-Clinician 3.

3.2 Medication Burden

Two clinicians suspected that the digital care pathway does not have a direct impact on the time and inconvenience of taking medication. However, they identified three ways the digital care pathway can support people with epilepsy with self-management and issues related to medication. First, the digital care pathway provides informational support. Better instructions can increase medication adherence and help people with epilepsy

with self-management, dealing with medication side-effects, and a healthy lifestyle. The following quote illustrates the clinician's experience of improvement of patients' adherence:

"The adherence to the treatment has gone way up due to the digital eHealth path. The patients used to say to me that 'my treatment plan was, there was no plan', or 'my future is a black hole'. Nowadays they do have some kind of better treatment plan and they have a method to contact us. And they know that the changes are done, and they are going to be heard, if they only contact us ... And I think that this is the like the best thing ever."

-Clinician 2.

Second, the digital care pathway may increase the effectiveness of care, which will consequently reduce the burden of self-management. Also, getting seizures during travel could be more dangerous than at home, and seizures may sometimes be triggered by mood changes, for example anxiety of going to hospital. Therefore, the option of remote appointments from home can make the management of seizures easier.

Third, two clinicians discussed that when a patient has a problem with medication, digital care pathway can help to resolve it faster. Patients can easily contact through the messaging systems and referrals and adjustments to medication can be done from there. On the other hand, reacting quickly to patients' concerns through the digital care pathway creates a risk of acting too fast. Medications can take a long time to start working, and initial side-effects can go away with time, so reactions too fast may lead to making changes to treatment when it is not necessary.

3.3 Social and Emotional Burden

Two clinicians discussed ways the digital care pathway might both increase and decrease the burden related to stigma, identity, and negative emotions. Going to hospital might cause negative feelings, such as anxiety, fear, and frustration. The digital care pathway can help by treating patients in their home, where they can feel safe and comfortable. The hospital environment might also enforce patients' identity as a sick person. When the treatment happens in a familiar environment, and it takes less time, they may feel that having epilepsy is less consuming part of their lives and therefore has less impact on their identity.

However, the clinicians also acknowledge that face-to-face meetings can be beneficial for building trust and good relationships between patients and HCPs. Having only remote appointments may make it more difficult for patients to seek and receive support from professionals, increasing their treatment burden. It can be beneficial to have some face-to-face appointments initially, for patients to build trust on HCPs and feel confident that they will take as good care of them online as face-to-face. The following quote discusses the complex impact of face-to face care on emotions:

"These negative emotions might be towards us as medical, healthcare and hospital, depending on what has happened with the person. I think all these emotional things are difficult when you're not face-to-face, but maybe it's important to see them and

to be able to show them. And if you are not face-to-face, maybe it's not good. But if you think in that way that hospital brings negative emotions, and you're happy in your home surroundings, and then that's good. There is so many ways to think about this."

-Clinician 3.

Two clinicians discussed how epilepsy treatment can be a strain for family relationships, and the digital care pathway has potential of reducing that impact. When one or multiple family members must spend considerable time away from home travelling to appointments, it can burden the whole family. Online meetings can be a great option, as they save time and can be attended from home. However, the digital care pathway can also be an additional burden for parents whose lives are already full of responsibilities. One clinician mentioned a parent, who reported being so exhausted with their everyday life, that they felt unable to start using the digital care pathway. As children with epilepsy do not use the care pathway themselves, parents must take responsibility of learning and using the system, which will add to their workload.

3.4 Healthcare Access Burden

All clinicians estimated that the digital care pathway is easy to use, and it makes contacting HCPs easier for patients. There were some concerns of patients having difficulties starting to use the care path, especially for those who recently had their diagnosis and are not yet experienced with epilepsy self-management. When an individual gets familiar with the system, organizing appointments and messaging HCPs is easy and convenient for patients. However, to allow fast contact with HCPs, the professionals need sufficient working time allocated to answering messages through the digital care path. Currently the time schedule for HCPs working with the digital care pathway is quite tight, and there are concerns of how the work time arrangements will develop if the number of users of the digital care pathway increases.

"When there are more and more users of these digital care pathways, of course [lack of time] has to be taken into account in our time scheduling. Also, it helps us to focus on those patients where there is really a need for a face-to-face meeting."

-Clinician 1.

All clinicians discussed the informational support digital care pathway can provide to patients in addition to contacting HCPs. Currently the Finnish patients can access informational resources in public online services called Health Village [31], which already covers all general epilepsy related information patients need and is regularly updated by the health care professionals from the Finnish university hospitals. The clinicians suggest that the Health Village resources are sufficient for general information, but perhaps the digital care pathway could include individual instructions, for example, for treatment of prolonged seizures.

3.5 Diverse Burdens

All clinicians agreed that the digital care pathway is not suitable for all patient groups. There are patients with cognitive challenges and epilepsies related to progressive neurological diseases, which will require clinical examinations during appointments. There are also patients going through a changing period in their epilepsy care, such as the time of getting diagnosed, or when adolescents make a transition to adult care. In these cases, face-to-face meetings are usually more suitable. The patients may also have non-epilepsy related challenges and life-circumstances that prevent them from using the digital care path. However, one clinician reminded that there is also a group of patients that can be treated exclusively through the digital care pathway and remote appointments, with no need for face-to face meetings:

“There are a group of patients that do not have needs for face-to-face meetings. So, all the things can be managed through the digital care pathway and remote visits. We have to just identify and optimize our services for different groups of patients.”

-Clinician 1.

One clinician suggested that the patient population should be seen as two groups, those that use the digital care pathway and those that do not use it. When the digital care pathway is developed, it should be done considering the needs of both groups, with understanding that not everyone can use the digital care path.

4 Discussion

The results show that the digital care pathway supports patients with treatment burden for all the pre-defined domains. Domain *Financial burden* was only relevant for travel-related costs of treatments; therefore, it was moved under *the Time and travel burden*. The clinicians had concerns for digital care pathway potentially causing additional treatment burden for the domains of *Medication burden*, *Social and emotional burden*, and *Healthcare access burden*. A new theme emerged from the data, *Diverse burdens*, highlighting the variety of people with epilepsy with differing needs for treatment. There is a considerable number of people with epilepsy to whom digital care pathway is not suitable.

Our results support the suggestions of previous research on virtual appointments [14, 15] emphasizing the advantages in alleviating patient burden by reduction of travel and easier contacting of HCPs. Additionally, we found that digital care pathway also supports patients with providing informational support, quick adjustments of medication, better treatment plan, reducing negative emotions and illness identity, and making accessing services and arranging appointments easier.

For the negative impact of digital care path, the clinicians shared the same concerns brought up in previous research [16, 17] about the digital care pathway being inaccessible to some groups of patients, and some patients having difficulties of using the care path. Clinicians strongly agreed that digital care pathways are not suitable for everyone and there should be an alternative to the traditional care path. There is a need for structured

system, where sufficient time is allocated and divided between the digital care pathway users and patients who will not use it.

If the schedule is managed responsibly considering the increasing numbers of patients using the digital care path, there is a potential of not only supporting the digital care pathway users with their treatment burden, but also increasing resources to focus more on patients who need face-to-face care. Additionally, the clinicians raised concerns of making too quick changes to treatment, and difficulties with building trust and seeking support from HCPs. These are important factors that need to be evaluated when considering the need for face-to-face appointments.

There are some limitations in the current study. First, the number of experts attending the meeting was small. More extensive qualitative research with larger sample size would be needed to support the findings of this study. Second, due to the case study design, the scope of this study was limited to the clinicians' perspective in the unit of analysis, digital epilepsy care path in Pohde. For complement the findings from the current study, it would be particularly relevant to study the patient's perspective. Therefore, further research would be needed for extending findings to broader population.

This study is part of an EpiDigi-project, which is aiming to evaluate and further develop the digital care pathway for epilepsy in Pohde. Following the exploratory qualitative findings from the current study, we are planning to conduct more extensive qualitative study, including larger number of HCPs, patients who have personal experience of using the digital care path, and their caregivers. In addition to qualitative evaluation, EpiDigi will include quantitative survey study for the patients, and developing improvements to the digital care pathway for epilepsy based on the findings of the experience of patients, caregivers, and HCPs.

5 Conclusions

The results of this study indicate that digital care pathway can support patients with epilepsy with their treatment burden. The digital care pathway for epilepsy can reduce travel, provide options for remote appointments, informational support, and easier ways to contact HCPs. The main concerns clinicians had was how the use of digital care pathway may cause rushed treatment decisions, difficulties of building trust and seeking support from HCPs, and difficulties using the digital systems. Future research from patients' perspective would be needed to better understand the impact of digital care pathways on patients' treatment burden.

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