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Decision-Making in Epilepsy Care - Are Digital Services Underutilised?

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Abstract. Digital services are increasingly utilised in healthcare decision-making (DM). There are various digital DM support tools for healthcare professionals (HCP) and to provide patient-generated health data. This qualitative study explored how HCPs utilise digital services for the purpose of sharing information with patients and evaluated the perceptions of neurologists and nurses with regard to their own and others' roles in DM, paying particular attention to the manner in which digitalisation may facilitate the sharing of health information. Focus group interviews were conducted with neurologists (n=3) and nurses (n=4), and the data were analysed using inductive content analysis. Both neurologists and nurses considered providing information to patients with epilepsy to be central to DM, with neurologists providing medical information and nurses focusing on practical, daily information. Use of digital services, for information sharing remained limited, yet nurses guided patients to them more frequently than neurologists. Information was primarily provided during face-to-face appointments, while nurses emphasised the importance of implementing digital services. Both neurologists and nurses recognised the value of reliable information in enhancing patient knowledge and promoting treatment adherence. Future research is still needed to evaluate the utilisation of digital services in clinical DM.

Keywords. clinical decision-making, healthcare professionals, information sharing

1. Introduction

The digitalisation of healthcare has enhanced clinical decision-making (DM) and patient engagement in chronic disease management, including epilepsy. DM has increasingly shifted toward patient-centred shared decision-making (SDM), involving mutual information exchange between healthcare professionals (HCP) and patients [1]. Effective information management is therefore considered vital in epilepsy care, as it supports treatment planning and the continuity of care. [2]. Still, people with epilepsy (PWE) experience unmet needs regarding accessible and comprehensive health information [3,4,5]. HCPs play a key role in meeting patients' information needs through educational

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interventions, concise communication, and personalised counselling—efforts increasingly supported by digital tools [6,7]. These tools can improve HCP–patient communication, facilitate health information exchange, enhance transparency, and help incorporate patients' values into clinical DM [8]. In epilepsy care, digital services offer diverse opportunities for information management [9,10], yet their adoption by HCPs remains uneven due to various technological and human factors [11,12].

In epilepsy care nurses play a key role in supporting epilepsy management through communication [13], while neurologists typically lead assessment and treatment planning [14]. Interprofessional collaboration (IPC) supports communication and care coordination [15], though factors such as information access, time constraints, digital tools [15]. Integrating IPC with digital services offers potential to enhance clinical DM, but patient involvement may still vary [14].

Digitalisation can enhance IPC by improving information sharing and patient engagement in clinical DM. This study explored how HCPs use digital services to share information and examined neurologists' and nurses' perceptions of their own and each other's roles in DM, with particular attention to how digitalisation may support information sharing.

2. Methods

This qualitative study explored experiences of HCPs through two focus group interviews. The study was approved by the Ethics Committee of the Tampere Region, Finland (id 18/2021). The study complied with the regulations of the Finnish Advisory Board of Research Integrity and the World Medical Association Declaration of Helsinki.

All participants worked in Finnish wellbeing services counties, which are responsible for organising public social and healthcare services. Two semi-structured focus groups for neurologists (n=3) and nurses specialised in neurology (n=4) via Teams Meeting app in November 2022 and December 2023 were arranged. The sessions lasted 90 minutes and were conducted in Finnish by two interviewers (HK&MR) and a technical support person. At the beginning of each session the participants were informed about the study, its aims, data management and the voluntary nature of participation.

Focus group questions, informed by the Ottawa Decision Support Framework [16], examined HCPs' information-sharing with patients in their clinical DM roles. The discussions were audio recorded, and anonymity was considered in the transcription. The data were uploaded to Atlas.ti software (version 23.0.7) and analysed inductively so that themes emerged directly from participants' accounts.

3. Results

The focus group interviews indicated that neurologists predominantly approached DM and information sharing from a clinical expert perspective. They emphasised the medical and evidence-based reasoning. Besides practising SDM effective communication and relevant information were seen as key determinants of treatment adherence (such as medication initiation) by neurologists. Yet only one neurologist reported utilising digital tools, i.e. external virtual hubs and websites (e.g. HealthVillage.fi, EURAP) in sharing

information with patients and considering the language skills of the patient. Another neurologist considered digital information sharing to be a nurse's duty.

"Then we take a look at reports on the EURAP website. For those who are proficient in English, I recommend checking it. And Health Village is actively used." (Neurologist 1.)

"The epilepsy nurse goes through the medication information, what epilepsy means and what kinds of things affect the success of the treatment, providing basic information about epilepsy and introducing the Epilepsy Association's website." (Neurologist 2.)

Conversely, nurses played a proactive role in sharing digital resources, introducing platforms like the Finnish Epilepsy Association, Brain Health interface, and MyKanta, a nationwide portal, during in-person or video consultations.

"Well, of course Health Village, and specifically the interface of Brain Hub. And also, to the website of Finnish Epilepsy Association." (Nurse 1.)

While written materials remained in use, especially among older patients, nurses observed a tendency among younger patients to engage with digital services.

"*These younger patients actually prefer to look things up online." (Nurse 2.)*

Figure 1 illustrates the information sharing and various tools in clinical DM in the IPC.

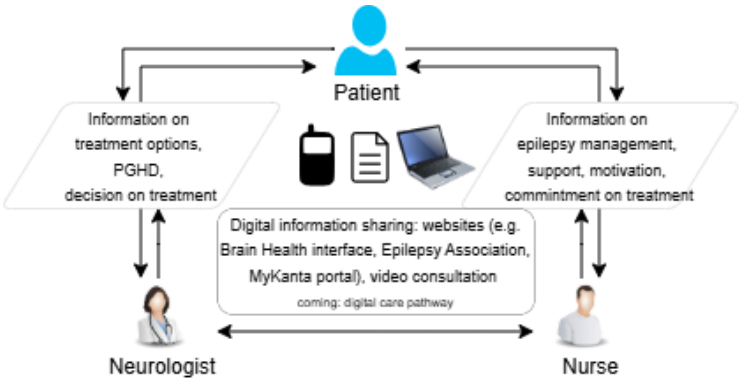

Figure 1. Illustration of how information was shared between patients with epilepsy and HCPs

Nurses saw neurologists as responsible for informing patients and making treatment decisions, while neurologists viewed nurses as key mediators and follow-up contacts. Nurses also identified themselves as intermediaries, highlighting the importance of accessible information alongside healthcare access and sufficient consultation time.

"I always make a summary of the issues and listen. To see if it's understood. If necessary, I write and give instructions to read My Kanta or contact us. The encouragement and effort often help. But also giving the opportunity for contact if needed." (Nurse 3.)

As a tool for more efficient support for epilepsy care coordination, one of the nurses expressed an urge for the implementation of a digital care pathway.

"But the epilepsy digital care pathway will then be one more tool in our selection… We try to provide information in a variety of ways, depending on how the patient most naturally wants to seek out or study that information." (Nurse 4.)

4. Discussion and Conclusions

Despite the availability of digital technologies, they remain underutilised in clinical DM, particularly for patient information sharing. In this study, information for PWE was mainly delivered during face-to-face appointments. Nurses were more active in using digital services, whereas only one of three neurologists reported utilising digital services. Nurses also emphasised the importance of a digital care pathway for PWE.

Adequate information has been identified as essential for the patient to assess the personal relevance of treatment options and express their values and preferences [3-5,13]. In our study nurses emphasised the need for adequate information to support the epilepsy management. Notably, information management may enhance patients to understand how disease affects daily life, allowing improvement in care coordination and clinical DM [17]. Inadequate information hinders effective clinical DM [13], leading uninformed or excluded patients to seek possibly unreliable sources before adhering to treatment [17].

A digital clinical pathway was mentioned as one promising tool for epilepsy care coordination between HCPs and patient. This finding aligns with evidence that patient-centred digital services may enhance information reliability and accessibility, thus reducing patients' risk encountering misleading or inaccurate information online [18,19]. Nurses regarded patient education and sharing of trustworthy information as essential also for promoting disease-specific well-being. Moreover, this has been shown to strengthen patients' motivation to engage in treatment [15], aligning with the neurologists' views in this study that SDM may enhance treatment engagement.

Although limited by a small sample size, this study suggests that the combination of traditional counselling and digital tools has the potential to improve information provision for PWE. HCPs can leverage technology to meet unmet information needs, support self-management, and enhance overall patient care coordination. Since the study was conducted, the digital epilepsy pathway has been introduced and is currently in pilot use in four Finnish hospitals. The pathway includes an interface and an app for reporting seizures, which integrates patient-generated health data into clinical DM and facilitates information sharing between a patient and HCPs [7].

Information management, especially possibility of digitally share information, offers support for both patients and IPC despite of the time and place [20]. Future research should thus focus on evaluating the effectiveness, accessibility, and user experience of these digital interventions in real-world epilepsy care among patients and HCPs.

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