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Targeted Review

Shared decision-making in epilepsy management

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ABSTRACT

Policy makers, clinicians, and patients increasingly recognize the need for greater patient involvement in clinical decision-making. Shared decision-making helps address these concerns by providing a framework for clinicians and patients to make decisions together using the best evidence. Shared decision-making is applicable to situations where several acceptable options exist (clinical equipoise). Such situations occur commonly in epilepsy, for example, in decisions regarding the choice of medication, treatment in pregnancy, and medication withdrawal. A *talk model* is a way of implementing shared decision-making during consultations, and *decision aids* are useful tools to assist in the process. Although there is limited evidence available for shared decision-making in epilepsy, there are several benefits of shared decision-making in general including improved decision quality, more informed choices, and better treatment concordance.

1. Introduction

Health care systems throughout the world face increasing challenges from demand, expectation, and austerity. *Prudent* health care faces these challenges by actively taking account of the needs and circumstances of patients and actively avoiding wasteful care. A significant part of prudent health care is promoting equity between the people who provide and who use services and ensuring patient satisfaction [1]. Patient-centered care, which is respectful of and responsive to individual patient preferences, needs, and values, is also recognized as an important component of modern health care [2].

One of the most common reasons for patient dissatisfaction is feeling not properly informed about treatment or management options [3]. Surveys of patients with epilepsy have concluded that patients welcome greater involvement in such discussions [4,5]. Despite this, there is evidence that patients are not involved to a sufficient degree in these decisions in epilepsy clinics. For example, the decision-making in selecting antiepileptic drug choices, investigation options, and treatments was perceived by patients to be clinician-dominated processes [6].

Shared decision-making helps to address these concerns by attempting to involve the patient and clinician equally in the decision-making process, providing more patient-centered care [7]. National policies and guidelines have recognized this—including guidelines on epilepsy [8]—and also recognize the potential savings on resources through greater patient involvement in decision-making. In a 2010 policy document, the UK government envisaged that shared decision-making will become the norm: 'no decision about me without me' [9].

This paper explores shared decision-making for people with epilepsy, through the following five questions:

1. What is shared decision-making?
2. What is the relevance of shared decision-making for people with epilepsy?
3. How can we implement shared decision-making in epilepsy consultations?
4. What tools are available to assist in shared decision-making for people with epilepsy?
5. What are the benefits of shared decision-making for people with epilepsy?

2. Key questions

2.1. What is shared decision-making?

Shared decision-making is an approach where clinicians and patients make decisions *together* using the best available evidence [10,11]. It promotes active two-way participatory collaboration between the clinician and patient. Clinicians are experts in disease, treatment options, probabilities, and prognosis, whereas patients are experts in their preferences, values, attitudes to risk, and social circumstances.

Shared decision-making is applicable to clinical situations where more than one reasonable option exists for that person—a position of *clinical equipoise*. The correct option for a particular individual may

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Table 1
Examples of clinical scenarios in epilepsy amenable to shared decision-making.

Anna is a 29-year-old woman with genetic generalized epilepsy. She has been seizure-free for one year since taking sodium valproate. Previously, she took lamotrigine but was having daily myoclonic seizures and generalized tonic–clonic seizures every month. She now wants to start a family and has come to discuss treatment options.
John is a 48-year-old man with structural focal epilepsy due to right-sided hippocampal sclerosis. Despite trying four different antiepileptic drugs, he continues to experience focal dyscognitive seizures around three times a month, causing a great deal of disruption to his life. He wants to know whether epilepsy surgery would be an option for him.

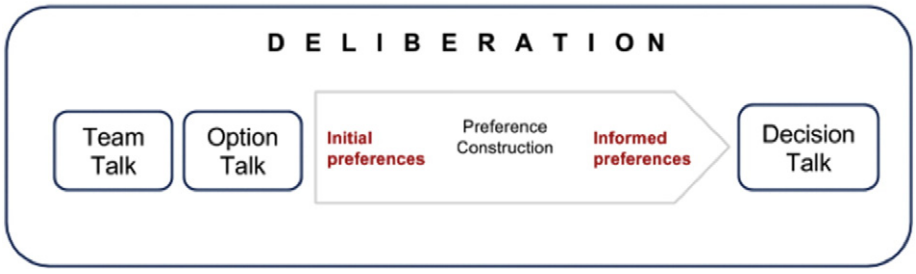

Fig. 1. The talk model for shared decision-making [10,12].

depend on their personal preference, lifestyle, social circumstances, and cultural and religious beliefs.

Shared decision-making enables *patient-centered* care — care that is responsive to individual personal preferences, needs, and values and assures that patient values guide all clinical decisions. In some ways, shared decision-making can be thought of as the "pinnacle of patient-centered care" [7].

A shared decision-making approach is similar to another patient-centered care method, motivational interviewing. Shared decision supports the *decision-making* process, whereas motivational interviewing guides *behavior change* [12]. At the heart of both methods is the ethical principle of self-determination [13]. Shared decision-making can be thought of as a 'middle ground' between a completely paternalistic approach and a completely autonomous approach.

2.2. What is the relevance of shared decision-making for people with epilepsy?

Shared decision-making is relevant to all aspects of clinical medicine. It is especially relevant to long-term conditions, such as epilepsy. Table 1 illustrates two relatively common clinical scenarios in the epilepsy clinic where there are several acceptable management options (clinical equipoise). The best option for Anna might be to continue to take sodium valproate (perhaps forgoing her plans for pregnancy), to switch to levetiracetam, or to revert to lamotrigine; John might want to undergo surgery (with all its perceived risks and benefits), or he might be happier to try another medication. Shared decision-making would help in each scenario to ensure that each individual makes the best decision for them. Of course, there are many more examples involving clinical equipoise (or near equipoise) in the epilepsy clinic where shared decision-making could be useful and effective.

2.3. How can we implement shared decision-making in epilepsy consultations?

A useful model for structuring a shared decision-making clinical encounter is as follows: *team* talk, *option* talk, and *decision* talk (see also Fig. 1) [13,14]. Team talk involves letting the patient know that they will be supported to consider and compare alternatives, option talk involves providing more detailed information about the options, and decision talk involves supporting the decision and assisting the patient to reach a decision (see Table 2 for an example). A more detailed model for shared decision-making, *collaborative deliberation*, is the foundation for the talk model (see Elwyn et al. [15]).

It is important to provide effective *decision support* during option talk and decision talk. This can involve providing facts, figures, and

Table 2
An example of how to structure a clinical epilepsy consultation to facilitate shared decision-making (for a background of the scenario, see Table 1).

Team talk
Clinician: We have three options for your treatment. You can continue to take sodium valproate, switch back to lamotrigine, or try a new drug, levetiracetam. Each option involves a balance between you getting the most effective treatment for your epilepsy and reducing any risks to your baby.
Anna: I know that sodium valproate can be harmful during pregnancy, but my epilepsy is well controlled at the moment and changing drugs has always been a problem in the past.
Clinician: Yes, I agree. I think it is important that we consider the options carefully as we need to help you to make the decision that is right for you and one that you are happy with. I know this might seem difficult—I will support you to do this.
Option talk
Clinician: Have a look at this sheet (Option Grid®) which gives some more information about the options. If it is ok with you, I will finish my paperwork while you read the sheet (see Fig. 3 for the Option Grid®), and feel free to write on it.
Clinician: How did you get on? What is important for you here? Would you like me to go over anything?
Anna: Ok. I think I really do not want to take anything that might harm the baby, but my epilepsy was worse when I was taking lamotrigine. Do you think that levetiracetam is going to be any better at controlling my seizures?
Clinician: There is certainly less chance that levetiracetam would harm your baby when compared to valproate. In terms of the epilepsy, there is every chance that levetiracetam will control your epilepsy at least as well as lamotrigine and probably better — but we cannot be sure until you have tried it.
Decision talk
Anna: Ok. Even though my epilepsy has been at its best for years, I think I would like to try levetiracetam if that is ok as I really want to reduce the risk to the baby as much as possible.
Clinician: Can I just check that you are happy with not being able to drive for six months while changing from valproate to levetiracetam?
Anna: Yes, that is ok — I saw that on the sheet. I am not driving much at the moment as I am working from home most of the time, so it should not be too much of a problem for me.