Recommendations for development of acute seizure action plans (ASAPs) from an expert panel

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Welcome to the Neurelis Medical Affairs podcast series. These podcasts offer an opportunity to learn directly from the authors about recently published articles discussing strategies for the treatment of seizure clusters in patients with epilepsy.

In this episode, we hear from Dr. Patricia Penovich from the Minnesota Epilepsy Group in St. Paul. She discusses recent recommendations on the development of acute seizure action plans, or ASAPs, for people with epilepsy. The recommendations were published in 2021 by Penovich and colleagues in an open-access article titled “Recommendations for development of acute seizure action plans (ASAPs) from an expert panel” in the journal *Epilepsy & Behavior*.

Welcome, Dr. Penovich, thank you for joining us today. Perhaps I can set the stage for our discussion with some context. An estimated 3 million adults and 470,000 children and teens live with epilepsy in the United States. A national survey indicated that although 90 percent of respondents with epilepsy were taking medication to control seizures, only 44 percent had no seizures in the previous year, meaning 56 percent still experienced seizures. A proportion of these patients experience seizure clusters, also called acute repetitive seizures. What is the impact of seizures, and particularly seizure clusters, on a patient’s life?

Penovich: [1:40] So first, we should remember that seizures are most always unpredictable. Groups of seizures, which are termed cluster or acute repetitive seizures, are frightening for the patient, as well as the care persons. They are uncertain about when the seizures may stop, whether there could be a possible injury, as well as what might be the consequences of repeated or prolonged seizures. This cluster of seizures or ARS may frequently lead to transport to the emergency room because the individuals are concerned that status epilepticus may be beginning. As our earlier research uncovered, seizure clusters have several negative impacts on people's lives. These include both financial and health risks for the immediate seizures and potential ER and hospital admissions.

These clusters very often limit participation in daily activities, such as working, taking care of children, participating in hobbies, going to school, or even being independent. They likely have impacts on mood, resulting in increased anxiety and depression, and may hinder relationship with friends and family. The patient and the caregivers report feeling exhausted, stressed, helpless, and scared. Friends and family report that their quality of life is affected. So all of these effects on quality of life are difficult to measure, but they may have significant effects on the patient, family, caregiver, and the community.

Narrator: [3:13] Thank you for that context. Perhaps you can describe the concept of a seizure action plan and how it can help people with epilepsy and their caregivers manage their condition?

Penovich: [3:22] The seizure action plan, or S.A.P. or SAPs, is broadly based, historical, descriptive, and a daily treatment summary for the individual with epilepsy. In our earlier study, the group found that only 30% of adults with epilepsy have an SAP. It shares important information among providers, including the patient's daily medications; the description of the seizure event, including the warning or aura of the seizure; as well as what the patient may look like postictally. It then individualizes the care to that patient. It delineates the plan and by doing so may lead to the education and understanding of their epilepsy and thus empowers the patient in the family. The acute SAP, or ASAP, provides specific details for the acute treatment for the time of recurrent seizures or cluster seizures. It provides an actual roadmap. So in moments of the acute panic at the time, when folks are typically not thinking clearly, they can be directed about what to do.

So it provides rapid recognition of what is going on and guidance for what to do and when to do. It reinforces appropriate and timely care, including when and how to use the rescue medication, if one is prescribed for the patient. It provides clarification around common concerns about when and how to act, including the first aid steps; what and when to use the rescue medication if they have it; and recognition of injury or other serious condition that would prompt them to call 911 for EMS transport. It is likely to increase the comfort with the seizure care that they're giving at home, and it potentially improves the home management of seizures, thus reducing healthcare utilization. So for example, if the seizure is able to be stopped with the use of rescue medication at home, then an EMS transport may well not be necessary.

Narrator: [5:46] Clearly, an ASAP is a valuable tool in many situations. Dr. Penovich, who may use an ASAP and how can it help in the care of someone who is experiencing a seizure?

Penovich: [5:57] Let's be really clear that any person may use the A.S.A.P. or ASAP. The primary users obviously are the patient and the patient's caregiver or family, or other people who are dedicated as a caregiver, as well as additional caregivers that the patient may share the plan with later. Secondary users may include school staff; group home staff; coworkers as well as infrequent caregivers such as relatives or babysitters who may not see them but a few times a year; camp staff; emergency responders; and personnel in a medical facility such as the primary care clinic or the emergency department. It is intended to be used when an emergency occurs and should include simple instructions about when to give basic first aid, when administration of the rescue medication is appropriate,` and when to call 911 for emergency transport. Also, if the patient has gone to the emergency room, it provides the professionals there with documentation about what has already been done at home and what rescue medication has been given.

Narrator: [7:13] Dr. Penovich, you were a co-chair of an expert panel convened to discuss recommendations for the development of ASAPs for people with epilepsy. Those recommendations were published in 2021 in an open-access article in the journal *Epilepsy & Behavior*. Can you tell us a bit about how the expert panel, which was sponsored by Neurelis, went about developing the recommendations?

Penovich: [7:36] Sure. This expert panel was composed of folks who deal with patients with epilepsy from across the country. This included clinical adult and pediatric practitioners who were neurologists, epileptologists, and nurse practitioners. There were PharmDs involved, as well as epilepsy advocates. With our review, we completed a thorough search for existing English literature on SAPs used not only in epilepsy, but in other chronic diseases such as diabetes and asthma. We then used this to inform a discussion of the need for SAPs and ASAPs and opportunities for improvement in epilepsy care. There was clearly an unmet need for guidance for immediate urgent home treatment in epilepsy.

Narrator: [8:29] The recommendation published by you and your colleagues suggests that an ASAP be customized to the individual and developed in collaboration with the patient, caregiver, and neurologist or epileptologist, as well as other relevant healthcare providers including primary care providers. What might the typical process for developing an ASAP look like?

Penovich: [8:50] It is very important to remember that this is a cooperative effort that should be accomplished by a meeting that occurs at the same time with the patient, the caregiver, and the healthcare provider. At this time, they can discuss the goals and strategies that are appropriate for this individual patient, and thus all three groups are aligned. We can use this development process as an opportunity for patient education, which will then most likely lead for a better buy-in and adherence to the protocol. It is very important to evaluate the ASAP regularly, at least once a year, to revise it and modify it as necessary—such as at times when medications have been changed, when the patient has a health change, when there's a change in the seizure pattern. Remember, it's not useful if it's outdated.

The telemedicine appointment may be a very convenient way to update and review these plans when needed, particularly for the patients who live far from the neurologist or epileptologist, or frequently, when there's not an appointment available in office. Another time that may be very important to develop the plan or to revise it is if the patient has been in the hospital. Medications and plans are frequently changed at this time. If the plan is reviewed at the hospital, the patient goes home with an updated plan. It may reduce subsequent visits to the emergency room or another admission to the hospital prior to the patient actually having been able to be seen back at the office.

Narrator: [10:33] We’ve talked about the overall goal of an ASAP and how to create one. Perhaps we can turn to what information it contains. What content does an ASAP require in order to help someone having a seizure?

Penovich: [10:45] We want the plan to be inclusive, but not so long that it ends up being useless. So, a one-page plan, not four pages of intimate detail. To be useful, the ASAP should contain patient specific information, such as who the emergency contact is; the usual signs and symptoms for this patient; what might be atypical for them; what are the first aid instructions; when a rescue medication should be used; the actual instructions for the rescue treatment administration, remembering that pediatric dosing is based on weight; what are the steps to evaluate how the seizure event is progressing; and what are the emergency steps.

Narrator: [11:29] As part of your deliberations, the expert panel created a sample ASAP; and it is included in the published article. Listeners can access the article and sample ASAP through the Neurelis Medical Affairs Resource Center at neurelismedicalaffairs.com or at the *Epilepsy & Behavior* journal website. For people who might want to design their own or adapt another one, can you describe for us in general terms the recommendations of the expert panel on key elements of the ASAP and why they are important?

Penovich: [11:58] It's really important to remember that this is an individualized plan. It's not a template for everybody. It's not the same for everybody. The key elements of the format should be that it's customizable, it's revisable, and it's dated. It should be short and easily digestible. The information should be brief and clear for the widest possible range of caregivers and understandable to all. It should not be written at a PhD thesis level. Remember that the acute stress of the event often occurs with the result being that the caregiver is panicked and may not be thinking clearly.

Step-by-step instruction should be included for all treatments, including the rescue treatment. Graphics and/or a color-coded system such as a traffic light graphic can be very useful in a stressful situation. So green can mean, "Go for a fast action of first aid."

Yellow can mean, “Caution. Check if the patient is meeting rescue criteria and give it.” Red can mean, “High alert. And call 911.” If possible, the document could be included as part of the electronic medical record, and thus be downloadable and printed and easily sent to the patient’s school or other providers.

Narrator: [13:24] Thank you. Dr. Penovich, do you have any final thoughts about ASAPs and their role in caring for patients with epilepsy that you'd like to share with our listeners?

Penovich: [13:31] I think it's important for us to remember that 70% of adults with epilepsy and 55% of children with epilepsy do not have an SAP. Yet, more than 56% of patients have continued seizures each year. All patients with epilepsy should have an SAP, as well as the simple one-page acute seizure action plan. The ASAP is a critical tool for patient safety. There are so many potential benefits. The patient may well become empowered, may have a decreased seizure burden. ER visits and hospitalizations may potentially be decreased, thus decreasing the total cost of care. The patient and the caregiver may have lessened fear and give them confidence and skills for self-management at home. I would really like to encourage the listeners to refer to the sample ASAP available at neurelismedicalaffairs.com. Thank you so much for this opportunity to talk to you about the SAP and the ASAP.

Narrator: [14:35] Thank you, Dr. Penovich, for speaking with us today and sharing your expertise. We very much appreciate it. And thank you to our audience for joining this conversation. For more information on this article or to obtain a copy of the sample ASAP template created by Dr. Penovich and the expert panel, please contact your Neurelis Medical Science Liaison directly, or the Neurelis Medical Affairs team at medinfo@neurelis.com.

This podcast is one of a series. To access the series as well as other resources for your patients with seizure clusters, visit neurelismedicalaffairs.com.