A Plan for Action: How Stronger Patient Communication Can Yield Improved Outcomes in the Treatment of Seizure Clusters

A Q&A with Nancy Santilli, PNP, MN, FAAN

Patients and physicians often think about seizures very differently. In particular, due to some of the limitations of communication between patients and providers, seizure clusters remain poorly understood and managed. That’s according to findings from a new study indicating that the gap in understanding seizure clusters among health care providers and those with epilepsy can negatively affect diagnosis and treatment.¹

A seizure cluster is characterized as a closely grouped series of seizures that can cause serious harm, such as hospitalization and missed school or work. It can also result in disabilities and increased fear and anxiety for patients. Yet, according to study co-author Nancy Santilli, PNP, MN, FAAN, despite the impact that these events can have on patients’ lives, there is a lack of common language to discuss seizure clusters. Ahead, Ms. Santilli shares insights on how physicians and all providers have a unique opportunity to have meaningful conversations with patients with epilepsy, which may have a positive effect on care for seizure clusters.

Can you discuss the gap that exists between providers and patients when it comes to understanding seizure clusters?

Having worked in epilepsy field for a good portion of her life, Ms. Santilli was involved in some of the original efforts to define seizure clusters as phenomena that existed in certain patient populations. “Even at that time there was difficulty in trying to put nomenclature around what we were observing in a way that was meaningful to a healthcare provider, but also translating that to the patient experience,” she notes. Since then, new therapies have come to market that are now used as part of regular care. And yet, according to Ms. Santilli, problems remain when it comes to identifying seizure clusters and understanding their impact on patients. “What we’re finding is that, even 20 years later, there’s still this gap between how a health care provider talks about this phenomenon and the way a patient does.” According to Ms. Santilli, this may translate to a gap in care. “If you have two partners in this health care relationship who cannot communicate effectively so that a provider can determine how to best

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treat or take care of the patient, there can be a significant gap in the desired outcomes.” This communication gap, she says, needs to be closed. “It is important to understand the experiences of the patient with cluster seizures and try to translate their experience to something that’s clinically meaningful.”

Part of the difficulty arises from the experience of cluster seizures, says Ms. Santilli. “A provider takes a clinical approach, asking questions about the length and frequency of events, which makes sense from a medical perspective, while a patient focuses on the impact cluster seizures have on their life,” she notes. “For patients, the experience of cluster seizures can have significant impact if untreated, potentially resulting in a life threatening clinical event.” It could also create issues of further disabilities, result in missed days from school or work, and create fear and anxiety associated with not knowing when the next cluster is going to occur and not having control over them, according to Ms. Santilli.

What are the challenges of accurately identifying/diagnosing seizure clusters and can you offer any tips regarding how providers can better understand the impact of clusters on patients’ lives?

“When we reviewed the literature, we found a gap in the application of a meaningful definition of seizure clusters,” says Ms. Santilli. “Providers have struggled to come up with a common definition that then can be translated into something that’s meaningful to patients. The dialogue between the healthcare provider and consumer is really very important. Otherwise there is difficulty recognizing the event, talking about it, and evaluating it. Without this information, an appropriate treatment plan cannot be instituted,” she explains.

Ms. Santilli notes that while it is important to sit down with patients and ask them whether they have more than one seizure in 24-hour period, it is equally important to probe patients and follow up about the impact cluster seizures are having on their life. “Questions such as, ‘Are you missing time from work?’ and ‘Are you not able to do your normal activities of daily living?’ help providers validate the impact.” There are times when the individual can be significantly impacted by their seizure clusters due to their frequency, which should prompt the need for additional treatment and a seizure action plan.

Therefore, although it may not be common to probe patients about the impact cluster seizures are having on the patient, getting patients to open up about this is critical. “If you don’t ask about the impact, it is hard to have a dialogue since it the way consumers talk about their seizure clusters.”

How can a seizure action plan help patients and providers navigate different situations that may arise in patients with epilepsy?

“One of the recommendations made as part of our study is that every patient should have a seizure action plan so that if seizure clusters were to occur the consumer knows what to do,” says Ms. Santilli. A clearly defined action plan can help the consumer distinguish the difference between seizure clusters and life threatening status epilepticus.

During the conversation with the patient, the provider can gather information and explain seizure clusters so that they can identify potential patterns together, says Ms. Santilli. “If you don’t look for it, you might not see it,” she observes. Dutiful record-keeping may help to identify patterns over time, not just over a week or month, but sometimes over several months. “If you see a pattern emerging, putting together an action plan consisting of rescue treatments and steps to take when the seizure cluster is occurring can be incredibly helpful for patients.”

To gain a better understanding of seizure frequency, asking patients to keep some sort of diary is also helpful. A diary can offer a record of the patient’s day-to-day experience, the details of seizures, and the timeframe in which they occur. According to Ms. Santilli, there are many ways to do this. “Nowadays there are online diaries, calendars, and tracking apps that make it much easier for patients to keep records. However, a simple paper and pencil diary can be really helpful.”

Do you have advice for how to implement seizure action plans in practice?

It is important that staff members can identify warning signs of seizure clusters, according to Ms. Santilli. “If you know that there is a patient who could potentially be at risk or seems to be having a pattern of calling frequently due to seizures or reporting the negative impact seizures

PRACTICAL POINTERS

Healthcare providers do not have a common definition of seizure clusters in the medical literature. This has made identifying the prevalence of seizure clusters difficult and could hinder diagnosis of the phenomenon.

Providers should ask detailed questions to better understand the impact of seizure clusters on patients’ lives and collaborate with patients on developing a seizure action plan to help manage, prepare for, or prevent seizure clusters.
are having on his or her life, that patient’s file should be flagged. The clinician can evaluate these situations, and together with the consumer develop an action plan,” says Ms. Santilli. “When it comes to epilepsy and seizure clusters, everybody in the office should be on alert about the potential for these events.” She observes further that the neurology community should be more action-oriented when it comes to issues such as seizure clusters. “Every patient should have a seizure action plan so that they are educated about how to address single seizures, seizure clusters, and status epilepticus should they occur. Unfortunately, there is still a gap in this area,” she says. “Action plans help to arm patients and their care partners to more effectively manage seizures, by providing the necessary tools to assess and intervene as appropriate with physical care and medication.”

Can you describe the role of caregivers in the delivery of epilepsy action plans?

According to Ms. Santilli, the role of caregivers to patients experiencing seizure clusters depends on the seizure type. “Patients who experience an alteration of consciousness are very dependent on a care partner to recognize that this is an event that requires intervention or action on their part to help either eliminate or reduce the severity the event,” she says.

Caregivers play a significant role in the development of a seizure action plan, since, in many incidences, they are providing the necessary intervention. “The seizure action plan isn’t just for patient. It is for the reference of any individual who serves as a care partner to what constitutes a single seizure or cluster, along with the necessary steps to take should any of them occur, then the appropriate treatment and support can be administered,” says Ms. Santilli.

For patients with uncontrolled seizures who come to the office with a caregiver, Ms. Santilli notes that health care providers need to secure permission to have a conversation with the caregiver and involve them in the development of seizure action plan. “The better informed caregivers are, the more likely the appropriate intervention will be provided during seizure events such as clusters.”

Do you have any take-home points about the importance of not only understanding patterns of seizures but having a dialogue with patients about how to best address them?

Most importantly, Ms. Santilli notes, is to ask the questions: “Has the patient had a series of seizures in a short period of time? Do the seizures seem to cluster at certain periods of time? How many seizures have occurred in a 24-hour period?” The second thing to do, she explains, is to ask patients to keep a record of their seizures. Records will make it easier to identify seizure patterns, such as clusters. “Ask the patient and their care partners to look for patterns, even if they haven’t previously identified any. Both patients and providers need to be more vigilant about looking for seizure patterns that could indicate the patient is having clusters.”

Once you determine the frequency of seizures, it’s important to establish a seizure action plan, says Ms. Santilli. “A seizure action plan allows providers and patients to understand when and how to intervene and may help relieve undue fear and anxiety, as well as avoid missed time from work or other negative consequences,” she notes. And for patients who have a plan in place, Ms. Santilli notes that it should be updated periodically.

It is important for the provider to set the tone and ask the right questions, says Ms. Santilli. “Implementing a seizure action plan is about empowering the patient to self-manage their condition and facilitate better outcomes,” she says.

By deepening their own understanding of seizure clusters and their impact on the lives of patients, providers can strengthen their ability to work with them to develop a meaningful intervention plan for positive treatment outcomes. That’s why, according to Ms. Santilli, every patient who has the potential for seizure clusters should have a seizure action plan. ■

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