Empowering With Rescue Therapy: A Rescue for More than Just Seizures

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The Rescue Therapy in Epilepsy Project Part 2: Insights from People with Epilepsy and Families on Expert-Derived Preferred Practices

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Background: The number and type of therapies available to treat seizure clusters (SCs) or periods of increased seizure activity have risen in recent years. Gaps still exist on defining SCs, when to use them, and educating patients and families. The Epilepsy Foundation developed and published expert-derived consensus on preferred practices for rescue therapies (RTs), 79% of which were agreed upon by a larger group of healthcare professionals (HCPs). This paper describes insights from people with epilepsy (PWE) and families/caregivers (FCGs) on these practices to assess similarities and trends between PWE, FCGs, an expert panel, and HCPs.

Methods: Online survey including expert-derived preferred practices for RT was completed by a convenience sample of 176 PWE/FCGs. Respondents rated agreement with each preferred practice using a 0–8 point Likert scale. Results were examined by relationship to epilepsy, prior use of RTs, and comparison to the expert panel and larger group of HCPs. Results: 41.5% of respondents were PWE and 54.6% were FCGs; 70% represented PWE age 18 and over or those who cared for adults with epilepsy. Levels of agreement were similar to those of HCPs—consensus was obtained on 79% of preferred practices. Differences were noted on which items achieved consensus and strength of consensus for some items. Differences between PWE and FCG, and between those who had and had not previously used a RT were found. A proposed definition of SCs did not reach consensus, but there was strong consensus for individualized seizure action plans and more RT education.

Commentary

Educating people with epilepsy (PWE), caregivers, and healthcare professionals (HCPs) about the need for use of seizure rescue medication is an important task given the morbidity and mortality associated with seizure clusters (SCs) or periods of increased seizure activity. It is thought that roughly 5% of PWE in the United States have periods of increased seizure activity above ones typical seizure pattern, and yet it has been reported that only 20% of this population report use of rescue therapy (RT).\(^1\) Despite this reportedly low utilization of RT, both patients and caregivers acknowledge living in fear that PWE will have a seizure at any time and concede a significant emotional burden.\(^4\) This highlights the question of why RT has not been used more, especially since it has been shown to lower Emergency Department (ED) visits and hospitalizations, injuries, and mortality rate.\(^2\) Now that new formulations of RT are significantly easier to administer, and in the setting of the COVID-19 pandemic, where patients try to avoid emergency room care if possible, the conversation with PWE and their caregivers about RT is more important than ever. While seizure first aid may often be discussed, many providers find themselves approaching the discussion of RT only in the last few minutes of a busy office visit. With limited time, a brief discussion about when to go to the ED may be discussed but detailed seizure action plans (SAP) with specific RT recommendations may be left incomplete unless schools or group homes require it. Additionally, education of when to use RT as well as training in how to use it, are not done consistently.

Given so many inconsistencies in discussions, definitions, training, and education, the Epilepsy Foundation developed and published an expert-derived consensus on preferred practices for rescue therapies (RTs). It focused on: “(1) the need for a common language, (2) when to use or prescribe RTs, (3) assessing the need for RTs, and (4) communication and education about RTs.” The purpose for developing this consensus paper was to enhance RT education and to enable clear communication about gaps and priorities.

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The Shafer et al article reviewed in this commentary addresses insights gained from an online survey administered to PWE, families/caregivers (FCGs), health care professionals (HCPs), and an expert panel. The online survey was derived from expert consensus on preferred practices for RTs. The survey was disseminated through the online newsletter of epilepsy.com and social media channels of the Epilepsy Foundation. Agreement was rated using a 0–8 Likert scale. Consensus of 80% or above was considered in “agreement” with the expert preferred practice. 176 PWE/FCGs responded to the online survey with 41.5% of respondents being PWE and 54.6% being FCGs. Over half of the respondents (54.4%) reported between one seizure per month and daily seizures, whereas only 15.8% had been seizure free in the past 1–2 years. Of the total sample, 67.1% had used a RT in the past, which may not be a representative sample across all provider settings.

The article highlights gaps in communication and targets for improved utilization. For example, PWE/FCGs rated the following items of higher importance than experts or other HCPs: using RTs when a person is able to identify triggers or high-risk situations that may cause a change in seizure frequency or severity (88% PWE/FCGs vs 82% experts and 73% HCP), and assessing a history of prior emergency room visits and hospitalizations for seizures when considering the need for RT (86% PWE/FCGs vs 80.6% experts). The importance of discussing RTs when there was a change in health status or other medical conditions was also rated slightly higher by PWE/FCGs (87.4%) than experts (84.6%), but notably higher than HCPs (76.7%). These items highlight that PWE may recognize certain circumstances or triggers that can lead to seizures or lower their seizure threshold, placing them at a greater risk for breakthrough seizures, and feel these topics are of high importance for further education and discussion. Nevertheless, there is a fine balance between education and enabling a patient with a sense of control and empowerment with the use of RTs, while also educating about safety and appropriate frequency of use of RTs. PWE/FCGs did not agree on the proposed definition of cluster seizures; consensus dropped from 83.9% (experts) to 55.4% (PWE/FCGs). This emphasizes that if PWE/FCGs do not come to an agreement with their HCPs on what defines their individual seizure clusters, they may not understand when to use RT or adhere to a plan that the HCP outlines. There was consensus that a person should be prescribed a RT if a person had “(1) a first seizure longer than 5 minutes, multiple seizures or status epilepticus before treatment, (2) status epilepticus in the past, and (3) cluster seizures in the past.” Additionally, there was a strong agreement for the need for RT education and use of SAPs, regardless of use of RT. These results lend further support for the necessity of individualized assessments and discussions and represent opportunities where a patient or family member could modify self-management practices to improve seizure control if they knew more about RTs. It is also important to stress that education alone is not enough and that there needs to be a shared discussion and understanding to improve overall utilization and patient safety.

In summary, the article showed that there was a strong consensus for individualized seizure action plans and more RT education. A limitation of the study was that the sample contained a large number of people with high seizure frequency/severity who may not represent the full spectrum of PWE. However, despite this limitation, the article highlights a need for more detailed conversations regarding the identification of those who should have a prescribed RT and when to use it. This emphasizes the need for clear communication, consistency, and ease in discussing and documenting SAPs as well as use of RTs. Necessary areas that need to continue to be addressed include gaps in consistent verbiage about what types of seizures constitute a seizure emergency, expectations for when is the ideal time to utilize RT from both the PWE/FCG and HCP perspectives, as well as differences in priorities between PWE/FCG and HCPs, and how to assess the need for RTs and when discussions should be initiated. By working to further investigate and develop education to address these gaps, the ultimate goal would be to help identify behaviors or seizure patterns and better define actions to minimize risk. Development of more clearly defined education and strategies would ideally offer a sense of control and empowerment for PWE/FCGs and lessen fear and emotional burden, ultimately improving quality of care.

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**References**

1. Penovich PE, Buelow J, Steinberg K, Sirven J, Wheless J. Burden of seizure clusters on patients with epilepsy and caregivers. *Neurologist*. 2017;22(6):207-214.
2. Haut SR. Seizure clusters. *Curr Opin Neurol*. 2015;28:143-150.
3. Detyniecki K, O’Bryan J, Chezom T, Rak G, Ma C, Zhang S, et al. Prevalence and predictors of seizure clusters: a prospective observational study of adult patients with epilepsy. *Epilepsy Behav*. 2018;88:349-356.
4. Buchhalter J, Shafer PO, Buelow JM, French JA, Gilchrist B, Hirsch LJ, et al. Preferred practices for rescue treatment of seizure clusters: A consensus-driven, multi-stakeholder approach. *Epilepsy Behav*. 2021;117:107836. https://doi.org/10.1016/j.yebeh.2021.107836.
5. Shafer PO, Santilli N, Buchhalter J, Gilchrist B, Kukla A, French JA, et al. The rescue therapy in epilepsy project Part 2: Insights from people with epilepsy and families on expert-derived preferred practices. *Epilepsy Behav*. 2021 Dec;125:108444. doi:10.1016/j.yebeh.2021.108444.