



CHOC Children's Hospital
Best Evidence and Recommendations

Standardized Epilepsy Education on a Pediatric Neuroscience Unit

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PICO: In pediatric patients with epilepsy, does early standardized education on anti-epileptic medication adherence promote better success in long-term seizure control?

P (Population/Problem): In pediatric patients with epilepsy,

I (Intervention/issue): does early standardized education on anti-epileptic medication adherence

C (Comparison): compared to general medication education

O (Outcome): promote better success in long-term seizure control?

Background:

Epilepsy is one of the most common chronic neurological disorders affecting approximately 7.1 per 100 people in the United States (Paschal, Hawley, Romain & Ablah, 2008). A child is typically diagnosed with epilepsy while in the inpatient setting. These children usually have no past medical history, and it is often his or her first hospitalization. Generally, the length of stay is approximately 1-2 days, and the child is prescribed an anti-epileptic drug (AED) in addition to rescue medication. In the two short days that these families are hospitalized, they not only had to overcome the initial shock of a new diagnosis but are now facing the challenge of managing a chronic illness independently.

One of the most imperative requirements for long term seizure control is medication adherence, which is defined as the patient's treatment behaviors positively corresponding with the healthcare professionals' recommendations (El-Rachidi, LaRochelle, & Morgan, 2017). However, this can be very problematic in the pediatric population. Many factors can influence a patient's success, such as culture, socioeconomic status, and developmental state of the child, medication scheduling, and substance formulation (El-Rachidi et al., 2017).

Strict medication adherence is necessary in epilepsy. Unfortunately, 58% of children who have been newly diagnosed with epilepsy have shown non-adherence to AED within the first six months of their diagnosis (Nieuwlaat et al., 2014). This leads to poor seizure control, which can have detrimental effects on the child's physical and intellectual abilities. Non-adherence also has a direct impact on increased mortality, increased health care costs, and inaccurate medical decisions on the treatment plan (Modi, Guifoly, & Raush, 2013).

Early education at the onset of the child's diagnosis addressing medication non-adherence and providing solutions are critically necessary for long term seizure control (Nieuwlaat et. al, 2014). Unfortunately, there are few studies that identify the most effective healthcare professional delivery mechanism for patient and family education. Epilepsy Monitoring Centers across the world are now starting to develop programs and technology to improve medication compliance. Rather than a basic education, these new programs are innovative in their approach to address the cognitive-behavioral skills that are required in the management of Epilepsy (Wagner, Smith, Ferguson, van Bakergem, & Hrisko, 2011). Specific topics of these skills include: adherence prescribed treatment regimen, interacting with healthcare providers, behavioral techniques, life style changes, and problem focused coping. These programs engaged



participants in active learning by designing colorful workbooks, role playing, and engaging in group activities (Wagner et al., 2011).

The purpose of this project is to identify the best practices for new diagnosis epilepsy teaching. This issue is incredibly important to our neuroscience population. Often families will be re-admitted due to increased seizure activity secondary to medication levels that fall below the therapeutic range. Poor seizure control and frequent hospitalizations can have a profound effect on a child's emotional and intellectual disability. Secondly, while the neuroscience unit's (NSU) nursing staff are experts in educating our families about general epilepsy facts and medication side effects, there is a lack of consistency in how this information is delivered. This could potentially leave families lacking all the information necessary to manage epilepsy on their own. Additionally, our current education does not support the day-to-day cognitive problem-solving skills that these families require to manage their child's chronic illness.

Search Strategies and Databases Reviewed:

- Databases searched for this review included: CINAHL, PubMed, the Cochrane Library, and Wiley Online Library. The key terms included in the search were “pediatric epilepsy”, “medication non-compliance”, “medication non-adherence”, and “education”. Several limiters were used to refine the search, which included articles published in the last 10 years, English-language, and full-text available. This search yielded a total of 28 articles. The inclusion criteria for the studies chosen for this literature review include the following: published in the last 10 years (2007-2017), published in English, a population of pediatric children less than 18 years of age, and a discussion of medication non-adherence. Studies were excluded if they did not meet the aforementioned criteria. Fourteen eligible studies were selected for further analysis and discussion of practice recommendations.
- Additionally, several websites were reviewed including the American Epilepsy Society (AES), American Academy of Pediatrics (AAP), National Guideline Clearinghouse, American Association of Neuroscience Nurses (AANN), and Society of Pediatric Nurses (SPN).

Synthesis of the Evidence:

- Epilepsy education programs for families and children have not been thoroughly studied in the United States. However, according to the Cochrane Review Committee, there is substantial evidence that families want more information than they currently receive and that they want to be educated in a manner that best fits their individualized situation (Nieuwlaat et al., 2014).
- Wagner et al. (2010) developed the COPE (Coping Openly and Personally with Epilepsy) program at the Medical University of South Carolina. This program focused on improving self-management skills teaching tools such as homework assignments, vignettes, and role plays. Although the sample size was small due to lack of participants, a randomized controlled trial did show a positive trend toward improvement in their health knowledge.
- A German program titled FLIP & FLAP created a curriculum which incorporated a mascot, a game, and a colorful workbook. A non-randomized control study of 10 epilepsy centers across the country collected data immediately before the program and then 6 months later. Compared to the control group, which received generalized education for both the patients and families, the intervention (FLIP & FLAP) group showed greater knowledge about epilepsy and improvement on their self-management skills (Jantzen et al., 2009).
- The United Kingdom developed the SMILE (Self-Management in epILEpsy) program which focused on teaching families with poorly controlled epilepsy behavioral techniques for better seizure management. The course materials included program workbook in which the families could work through nine educational modules. A pilot study showed that the program perceived



to have a positive experience (Laybourne et al., 2015).

- A randomized controlled study with a pre-and post-test design was performed in epilepsy clinics of tertiary care hospital. The intervention group received epilepsy-specific education, while the control group received only generalized education. Learning tools were such as pamphlets with pictorial representation were utilized, covering all epilepsy topics taught in the course. Twenty-eight percent of those in the intervention group reported decreased seizure frequency (Dash, Sebastian, Aggarwal, & Tripathi, 2014).

Practice Recommendations:

The evidence illustrated in these studies demonstrates the effectiveness of a standardized education approach to improving medication compliance, therefore improving seizure control. Based on this information, the following practice changes are recommended for the Neuroscience Unit at CHOC Children's Hospital:

- Design and create a patient and family educational workbook.
- Present in-service to all NSU staff nurses to educate about best evidence regarding medication education and behavioral counseling.
- Develop nursing education checklist to be utilized for all new-onset epilepsy patients with the purpose of standardizing all education provided to each family.

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