It's Current

Epilepsy Resources and Updates

Lost in Transition? A Practice Tool for Finding Your Way to Adulthood

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Epilepsy can be a lifelong disease, with seizures beginning in childhood and continuing into adulthood. A need exists for the care of children with epilepsy to be transitioned at the appropriate time to adult epilepsy providers. The majority of child neurology and pediatric epilepsy providers do not have the capacity, resources, or training to see their patients once they become adults. Patients and their families become accustomed to the family-centered style of care that is central to pediatric medicine. The adult care model focuses on independence and self-sufficiency, when at all possible. Further, when referred by their pediatric colleagues, adult providers may feel insufficiently prepared to care for patients with complex pediatric epilepsy syndromes. Common epilepsy syndromes, such as juvenile myoclonic epilepsy (JME), present in the pre-adolescent and adolescent years, with care originating in the pediatrician's office. Unfortunately, more than 25% of young adults with refractory epilepsy never see an adult neurologist or epileptologist, instead receiving all their epilepsy care through a primary care provider (1). Gaps in the transition process may account for many patients becoming "lost" within the healthcare system.

Recently, the topic of transitioning adolescents into adult care has become of great interest. The American Academy of Pediatrics published guidelines for successful transition of an adolescent with and without developmental disabilities (2). "Transition" refers to the complex process of preparing an pre-adolescent or adolescent and his or her family for the adult care model. Usually, the transfer of care occurs without an orderly transition, and this can often fail to meet the needs of the patient and family (1) and be difficult on the accepting adult provider. Very few studies have been performed on how to successfully perform the task of transition, and many healthcare providers do not have a formal process for this transition. Perceived and actual barriers exist in completing this task. This is particularly problematic for children and adolescents with epilepsy who are on complex medication regimens, have protective parents, and are facing the daunting task of independence from them.

Three areas exist that serve to highlight the importance and need for a comprehensive transition of the adolescent patient with epilepsy: First, children with refractory focal or generalized epilepsy often require multiple treatments for their epilepsy. These children often remain refractory to medical treatment. A knowledge of newer treatments and epilepsy surgery by a specialist could greatly benefit these patients. Second, comorbidities that often accompany epilepsy can be addressed by a specialist. Third, a multidisciplinary approach addressing the social and cognitive needs of patients with epilepsy can be performed by neurologists. Often, the epilepsy patients require other special services due to comorbid developmental or mental disabilities, and they continue to have disabilities that remain stable or even worsen with time. Inclusion of all of these components is essential in a proper transition to the adult specialist.

Unfortunately, few epilepsy providers offer such a comprehensive transition. A major barrier identified by the American Academy of Pediatrics was the lack of a transition tool (2). Such tools can serve as a template to provide an efficient, effective transition that addresses the needs of all involved. Therefore, the Practice Management Committee of the American Epilepsy Society (AES) developed a transition tool for adolescent epilepsy patients, with a separate version for those with significant developmental disability. This tool was created by members of the Practice Management Committee (with special expertise in pediatric epilepsy), discussed amongst the entire committee, and then outside comments were elicited from other experts, including Drs. Carol Camfield, Peter Camfield, Shlomo Shinnar, and James Wheless.

The committee designed specific tools for clinicians to use in developing and implementing a process for successful transition of an adolescent epilepsy patient into adult epilepsy care. The process takes years of development, discussion, and implementation with the patient and his or her family. The tool begins with recommendations that start between the ages of 10 to 13 years. Each year, certain items are reinforced while introducing and discussing new topics. The goal of the later portion of the transition is to involve the adult epilepsy provider who will eventually assume sole care of the patient. Overlapping involvement by both the pediatric and adult epilepsy providers is paramount for a successful transition (1). Optimal communication among the different providers and

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the patient care team is essential. The practice tool serves as an outline to assist in accomplishing this goal.

Since the transition for a patient with developmental disabilities is different and can be more complicated, a separate tool was developed. Many with developmental disabilities have refractory epilepsy and require continued close observation and care that the pediatric epilepsy provider has given. Different steps are necessary to complete a proper transition, as full independence may not be possible for these patients. The American Academy of Pediatrics has agreed that all patients with developmental disabilities have a separate process for transition than those without a disability (2). Often, patients with developmental disabilities cannot live independently and require continued assistance of parents or other caregivers for the activities of daily living (ADL). These caregivers will continue to be present during clinic visits with the adult epilepsy provider. Using this specific practice tool with both the pediatric and adult provider allows for more acceptance of having additional care members involved throughout adulthood. For epilepsy patients without disabilities, independence should be encouraged and developed, as stated in the tool. Introducing this concept in the pediatric portion of the patient's care allows for an easier implementation and acceptance by all involved.

Ideally, the tool can serve as a template for both the child and the adult epilepsy provider to ensure compliance while serving as a reminder for the necessary steps. The tool can be given to the providers, patients, and their families for cohesive involvement. It is important to note that the age for each specific task may vary with the patient's level of maturity. The transition practice tool is not meant to be a rigid, inflexible checklist. Staging of the tool into different categories and age ranges allows for a gradual process due to the layers of complexity and barriers that exist in providing optimal care

for these patients. Using the practice tool will ensure that all the areas of care are addressed and updated prior to the final transition to the adult epilepsy care provider. The information listed on the practice tool can assist in summarizing all necessary information communicated to the adult provider prior to final transition. All areas can be addressed and completed prior to the final transition for a more efficient process. The tool can serve as a reminder to involve other supporting services that may be helpful or necessary for the patient and family. Finally, the tool can be used to develop a provider specific checklist that can be used for each patient to guide and ensure proper completion of the transition process.

Optimal care for the patients with epilepsy is the major goal of those who treat these patients. Therefore, it is important that consideration is given to every option and care need. Unfortunately, the adolescent patient can be lost in this transition to adult provider care. Epilepsy care providers can serve as a model for other disciplines and disease states in assuring that our patients and their needs are met, optimally and efficiently, through proper transition of their epilepsy care from pediatric to adult epilepsy care provider. The practice tools developed for transitioning adolescents with epilepsy to adult care providers assists in this process and helps them better navigate the adult healthcare system.

References

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