



Transition from Pediatric to Adult Specialty Care for Adolescents and Young Adults with Refractory Epilepsy: A Quality Improvement Approach^{1,2,3,4,5}

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Received 9 January 2015; revised 26 June 2015; accepted 27 June 2015

Key words:

Transition;
Epilepsy;
Adolescents;
Clinical decision support;
Self-management

Adolescents and young adults with refractory epilepsy are particularly vulnerable to serious medical and psychosocial challenges during transition from pediatric to adult care. Quality improvement methods were used to address the transition process on an academic medical campus. Outcomes achieved were decreased time from referral to first appointment in the adult clinic, $H = 8.2$, $p = 0.004$, $r = 0.43$; and increased social work referrals using decision support, $z = 10.0$, $p = 0.0006$, $OR = 6.13$. As measured by the 13-item Patient Activation Measure, pre–post change in patient activation as an outcome of self-management education was not statistically significant.

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¹ No extramural funding.

² No commercial support.

³ Previous presentations of this work:

¹ August 22, 2012

Nursing Grand Rounds, Children's Hospital Colorado, Aurora, CO.

² October 17 & 19, 2012

Healthcare Transitions Research Consortium Research Conference (HCTRC), and 13th Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult Based Care, Houston, TX.

³ March 1, 2013

Rocky Mountain Interdisciplinary Research and Evidence Based Practice Conference, Denver, CO.

⁴ March 10, 2013

American Association of Neuroscience Nurses 45th Annual Meeting, Charlotte, NC.

⁴ Disclosure of submission to other journals: This manuscript is NOT currently being reviewed by another journal, and there are no other manuscripts with related data currently submitted to other journals. Specifically, I requested that it NOT be published in the abstracts for the HCTRC where it was presented in October 2012 (see above).

⁵ Disclosure of financial interests: I have no relationships with commercial or private corporations or entities that present a financial conflict of interest with the work that is submitted within this article.

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A MAJOR FOCUS of ongoing health care reform efforts is the need to improve care delivery and quality of life for individuals living with a chronic illness (Robert Wood Johnson Foundation, 2014). Epilepsy is a chronic condition characterized by recurrent seizures that commonly begins in childhood and encompasses a spectrum of etiologies, seizure types, co-existing conditions and severity. The Centers for Disease Control (CDC) and the Epilepsy Foundation state that approximately 150,000 new cases of epilepsy will be diagnosed this year and that nearly a half million children under the age of 17 years are currently affected by epilepsy (Centers for Disease Control and Prevention, 2013; Epilepsy Foundation, 2014). Epilepsy across the spectrum: promoting health and understanding, a landmark report by the Institute of Medicine (IOM) focused on epilepsy care, research and awareness reports that the chances of developing epilepsy in a lifetime are one in 26 (England, Liverman, Schultz, & Strawbridge, 2012).

Background Knowledge

The risk of developing epilepsy is higher in children with underlying neurological conditions such as cerebral palsy, congenital brain anomalies and neurodevelopmental disorders. Other neurological conditions such as stroke, neoplasm, meningitis, brain abscess, and trauma also contribute to an increased risk for epilepsy (Centers for Disease Control and Prevention, 2013). Children who develop epilepsy often carry the burden of co-existing conditions. The added complexity of their needs with these comorbidities requires a coordinated, team approach to their care (Bellini et al., 2013; Hamiwka & Wirrell, 2009; Smith et al., 2007; Soria et al., 2011).

The term, refractory (also referred to as intractable, and more recently drug resistant) is used to characterize individuals with epilepsy whose seizures that have not completely remitted despite adequate treatment with two or three first line antiepileptic drugs (AED) used individually or in combination (Berg, 2005; Sinha & Siddiqui, 2011). The minimum number of seizures that define a diagnosis of refractory epilepsy range from one every 2 months to one per year (Cascino, 2008). One early study on this topic, reported that approximately 50% of patients with partial epilepsy (seizures arising from a localized area of the brain) will not become seizure free on medications (Kwan & Brodie, 2000). In a more recent study, the likelihood of remission for refractory epilepsy in adults was only about 14% (Callaghan, Anand, Hesdorffer, Hauser, & French, 2007). Poor adherence to medications early in the diagnosis may play a role in the development of difficult to treat epilepsy (Modi, Rausch, & Glauser, 2014).

Over a decade ago, several leading medical organizations collaborated on a consensus document addressing the topic of transition for children and youth with special health care needs (CYSHCN). "The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood." (American Academy of Pediatrics, American Academy of Family Physicians, & American

College of Physicians-American Society of Internal Medicine, 2002). A subsequent clinical report published in 2011 further outlined the importance of coordination between patient, family and providers to optimize the Adolescents and Young Adults' (AYA) ability to assume adult roles and activities (Cooley et al., 2011).

Families of children with epilepsy are often referred to and establish relationships with tertiary health care systems based on proximity, access, and available specialists. While these settings offer an ideal model of care for infants and children, as AYA gain increasing independence, the pediatric approach is not particularly adept in engaging the patient and family in preparations for managing the transition to adult health care services (Reiss, 2012). Some of the barriers include lack of confidence by both the pediatric epilepsy specialist and family regarding the adult provides knowledge to manage their epilepsy or address co-morbid diagnoses that are commonly seen. Many adolescents have limited knowledge of their disease despite years of clinic visits in the pediatric center (Kirk, 2008). This phenomenon occurs when discussions during these visits are directed primarily to the parent, not the child (Camfield, Camfield, & Pohlman-Eden, 2012).

Adolescents with epilepsy face unique challenges at a crucial developmental juncture, where the need to conform to peer standards can indirectly lead to an increase in seizures; and in turn further impact self-esteem and peer relationships. Common risk taking behaviors like the use of drugs, alcohol, experimenting with sexuality and the risk of pregnancy, make successful adjustment to adult life, including higher education and employment, particularly difficult (Nordli, 2001). Pediatric epilepsy clinics need to support and offer education to promote epilepsy self-management to lay the foundation for successful transition to adult care (England et al., 2012; Patel, 2013; Sawyer & Aroni, 2005).

Proposed models of care to support transition of AYA with chronic illness include transition clinics, development of a transition nurse coordinator role or other newly created delivery models where care is provided by specific individuals in a clinic designed for this purpose, rather than integrated into everyday specialty team functions (Betz, 1998; Betz & Redcay, 2003, 2005; Carrizosa, An, Appleton, Camfield, & Von Moers, 2014; Jurasek, Ray, & Quigley, 2010; Rearick, 2007). Published literature and professional organization statements on the topic of transition to adult care have increased substantially over the last decade. This increased focus coincides with national attention on the patient centered medical home model, care coordination in chronic illness and health care reform (Kelly, Kratz, Bielski, & Reinhart, 2002). The need for solutions has created a sense of crisis around the issue of transition in many tertiary pediatric facilities. The challenges are shared by the AYA, the parent/caregiver, the established pediatric and new adult providers, and a health care system that is being tasked to move from routine patterns of care delivery to creative, streamlined, disease specific models of coordinated care (Reiss, Gibson, & Walker, 2005).

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