



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

Jennifer A. Disabato DNP, CPNP-PC, AC^{a,*}, Paul F. Cook PhD^a, Laura Hutton LCSW^b, Tristen Dinkel BSN, RN, CPN^c, Paul M. Levisohn MD^d

^aUniversity of Colorado College of Nursing, Anschutz Medical Campus, Aurora, CO

^bDepartment of Family Services, Children's Hospital Colorado, Aurora, CO

^cNeurology Clinic, Children's Hospital Colorado, Aurora, CO

^dDivision of Child Neurology, University of Colorado School of Medicine, Anschutz Medical Campus, Children's Hospital Colorado, Aurora, CO

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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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* Corresponding author: Jennifer A. Disabato, DNP, CPNP-PC, AC.

E-mail address: Jennifer.disabato@ucdenver.edu.

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).

Identifying the Problem

Pediatric and adult epilepsy teams located on an academic medical campus in the mountain west recognized the need to improve transition for AYA yet faced inherent and complex system challenges. Providers from both the pediatric and adult tertiary care hospital health systems had frequently interacted as members of the Professional Advisory Board of the local affiliate of the Epilepsy Foundation, a national advocacy group for people with epilepsy. Young adult patients and their families struggling with issues related to adult care transition had contacted the foundation for assistance, leading the advisory board to convene a task force to examine the issue further. Interest expressed by the project lead, a neurology advanced practice nurse (APN) seeking a practice doctorate, coincided with the timing of the task force, and was followed by a meetings with both adult and pediatric teams to further discuss the unique challenges perceived by each group. Many barriers to successful transition were identified, leading to a multifaceted planned program of change to begin addressing the complex process and system issues beginning in early 2010.

The adult clinic group identified a lack of preparation for AYA patients in transitioning to the level of independence expected in the adult care setting. Lack of knowledge on the part of the AYA regarding disease self-management was concerning because the Health Information Privacy and Portability Act (HIPAA) insures privacy of medical information for individuals 18 years and older, unless express permission is granted by the patient ([U. S. Department of Health and Human Services, 1996](#)). Adult providers noted that there was increased anxiety expressed by both AYA and parents, as the parents were effectively eliminated from discussions about their adult child's health status in the new and unfamiliar adult clinic setting.

Other challenges were the unreliable transition of medical records from the pediatric to the adult setting and the lack of a clear and succinct summary of the patient's epilepsy diagnostic and treatment history. For example, adult providers voiced a need for a summary of prior epilepsy management that included: types of seizures, a history of antiepileptic drugs (AED) used including adverse drug events or side effects, other treatments and outcomes, recent imaging and electrophysiological studies, and overall level of neurological, cognitive and social functioning.

At the time the Quality Improvement Project (QIP) was initiated, the average length of time to secure an appointment in the adult setting was between 6 and 12 months. Early efforts were focused on identifying the needs of the adult team with the hope that more AYA would secure care in the clinic in a timely fashion. One positive development was the adult facility's decision to adopt the same electronic medical record (EMR) system that was fully functioning in the pediatric setting. This enhanced the potential for electronic sharing of information that would support any changes as a result of the QIP.

Intended Improvement

The overall aim of the project was to improve the transition of adolescents and young adults with refractory epilepsy from the pediatric to adult neurology clinic. Although all patients seen in the pediatric neurology clinic would benefit from program improvements, the primary outcome of time from referral to the first adult clinic appointment was measured only for the subset of AYA who transitioned to the adult neurology clinic on the same university medical center campus. It became apparent to the project team that if pediatric providers felt confident that a referral to the adult clinic could occur in a reasonable time frame, and adult providers had sufficient health and medical history information necessary to provide safe and effective care, the likelihood of a serious gap in care would be minimized and patients/families would be more receptive to the transition. This became the starting place for the teams' work on transition. The group however, readily acknowledged that there was a distinction between "transfer of care" and a "comprehensive transition plan of care", as outlined in the original 2002 consensus document ([American Academy of Pediatrics et al., 2002](#)).

Improving transition can be viewed from the perspective of the patient, caregivers/family, pediatric and adult providers, and other health care team members; and from the lens of administrative processes in a health care system ([Reiss et al., 2005](#)). Both pediatric and adult institutional processes were reviewed to understand existing limitations and identify feasible potential improvements. Champions for the project from several disciplines emerged as various aspects were investigated, explained and discussed. Members of the pediatric epilepsy care team (MD, PNP, PA) two epilepsy team nurses, the neurology social worker, the lead RN in the adult clinic, and individuals from other pediatric center departments (process improvement, clinical decision support, EMR) all participated in the project work-group at various times. The project lead provided routine updates on the groups' activities in the monthly epilepsy care team monthly meeting.

Study Question

The QIP was evaluated based on the primary question; *will process improvements in the pediatric epilepsy clinic decrease the time to transition to adult neurology care on campus for AYA with refractory epilepsy?* Additional questions were: (1) Will the addition of patient self-management education by the clinic nurses increase patient activation in epilepsy self-care? (2) Will the implementation of a Best Practice Advisory (BPA) guideline tool in the EMR increase communication between providers and social workers in planning and providing resources for transition? (3) Will the pediatric epilepsy team experience increased satisfaction, knowledge and comfort related to transition care?

Methods

Ethical Issues

This project was granted an exemption as non-human subjects research and approved as a QIP by the local Institutional Review Board. Online surveys did not include

Internet Service Provider addresses and could not be tracked individually. Follow up surveys as part of the intervention were conducted via email, mobile phone or telephone, and based on the patient's preference. The project lead was the only individual with access to the password protected online survey account where data from patients and providers were kept. All data were de-identified prior to converting Excel spreadsheets to SPSS for data analysis.

Setting and Participants

The pediatric neurology clinic where the QIP took place is organized around nursing care teams for various neurological conditions. A nurse from the epilepsy team manages clinic intake and patient education during visits. Each exam room is equipped with a computer so access to department specific documents for patient care and teaching is readily available. The facility has a fully implemented electronic medical record (EMR) system. The epilepsy provider team is made up of physicians, nurse practitioners and physician assistants. Patients and families are followed by the same provider over time. The pediatric neurology clinic team includes a dedicated social worker and providers who are familiar with other specialty services within the facility to which they can refer epilepsy patients, including rehabilitation services.

The adult neurology clinic providers are staff physicians with residents and fellows rotating through the academic training program. A Physician Assistant (PA) joined the team toward the end of the project. A registered nurse specializing in epilepsy manages intake and initial triage of appointments, assists in the clinic, and provides telephone follow up as needed. There was no assigned social worker although one is accessible to address psychosocial crisis situations.

Planning the Intervention

In the fall of 2010, after meeting with both the adult and pediatric epilepsy team members, the APN project lead developed a brief online survey sent to adult neurology providers and clinic nurses (combined $n = 18$). The survey was developed after an extensive review of current literature identifying barriers to transition and discussions with both adult and pediatric epilepsy providers. Survey recipients included the team from the adult neurology clinic involved in the project, but also other adult neurologists in the region identified through the local Epilepsy Foundation database. The goal of the survey was to identify challenges faced in caring for newly transitioned young adults. The results of this survey served as a basis for choosing topics for self-management modules that the project lead and epilepsy RNs developed for the clinic RNs to review with patients nearing transition out of the pediatric neurology setting. Eleven adult epilepsy physicians (68%) and one RN (50%) responded to the survey. The survey presented a list of 13 items, asking the respondents to choose what they considered the five most essential tasks for the AYA in preparation for transitioning to adult care. The majority of the respondents chose the items that related to managing medications and preparation for

adult care appointments. Other highly ranked items included the AYA knowing their seizure type and epilepsy diagnosis; and to be able to identify important lifestyle choices that impact epilepsy. These latter two items were determined to be less amenable to a short clinic teaching intervention, so two self-management education (SME) topics focusing on managing medications and preparing for adult appointments, were chosen as content for the patient teaching modules.

The survey also provided an opportunity for providers to rank specific system challenges in assuming care of AYA. The most highly ranked process challenge was obtaining timely and useful historical medical record information to support the provision of safe and effective care. Addressing this issue was especially pertinent for this population of complex patients with a history of frequent health care system encounters.

Addressing the Transfer of Medical Information

To address the need for improvements in transfer of records between the pediatric and adult settings, a commonly used cause and effect tool called a "fishbone" diagram was utilized to establish the patient, staff and system inputs (Institute for Healthcare Improvement, 2014). Several simultaneous plan-do-study-act (PDSA) cycles were implemented. One series of PDSA cycles focused on the development of a new process for completing Release of Information (ROI) Forms to send to Health Information Management (HIM). This began with the project lead 'walking the path' of the form to understand where delays were occurring. The outcome was the placement of an accurately pre-filled ROI form accessible on the department Web page that could be completed with the patient's biographic information and correct address for the receiving clinic, printed in the clinic visit and faxed or sent to HIM on the same date.

Another series of PDSA cycles focused on the development of an Epilepsy Transition Summary Letter template in the EMR that populated specific fields from the patient's health record and included the key disease specific information requested by the adult team. As a result of team discussions, letter revisions, timing studies, and review of feedback forms from participating nurses and providers, the process evolved to the nursing team initiating the letter, and the provider completing it. A document outlining the new process, the location of the letter template in the EMR, and specific directions for faxing patient referrals to the adult clinic was posted on the department Web page for easy access by the team.

Development of Self-Management Education Teaching Modules

Once the record transfer issues had been addressed, the focus shifted to the development of educational modules for use by the epilepsy nursing team as part of a clinic teaching intervention for identified AYA. Two self-management modules were developed based on feedback from the adult provider survey as to gaps in knowledge they observed in

their young adult patients. The 10-slide teaching modules were on the topics of Medication Management and Managing Appointments in Adult Care. The criteria for presentation of these modules at the end of the visit for AYA patients were; (1) age 16 years or more (2) cognitively able to participate in an educational intervention, and (3) being seen in the main campus neurology clinic in a follow up visit.

Patients and caregivers were informed of the self-management education modules during clinic intake by the nurse and both were encouraged to consider allowing the AYA to see the provider independently for the initial part of the visit, as a way to begin acting as their own health historian, an expectation in the adult care setting. Patients were given the option of choosing one or both educational modules to review, and caregivers present at the visit were invited to participate. After review of the module(s), a one-page takeaway summary of the information in the module was given to the patient for later review and reference. The clinic nurses completed a checklist for each patient who underwent the educational intervention as a way to communicate with the project lead regarding the module(s) chosen by the patient, the length of time to complete, whether or not the patient chose to see the provider alone, and patient contact information for telephone follow up.

Addressing Gaps in Provider Communication with Social Work

A challenge in the existing process for referrals from the epilepsy provider group (MD, NP, and PA) to the neurology social worker (SW) was identified. The former practice was email or phone call messages from the providers to the social worker requesting a call to the patient and family to discuss transition to adult care. The email or phone contact to the SW usually occurred after a clinic or telephone encounter with the patient or family where the need to transfer to adult care was raised by the provider. This system was identified as lacking the necessary detail to make the most efficient use of the social worker's time and expertise. For example, the social worker reported that phone calls often appeared to catch the parent or patient unaware that the provider was considering transition, which shifted the consultation to a discussion of why and when transition was appropriate, rather than time spent discussing important issues related to legal changes that occur at age 18 years including medical power of attorney, guardianship, vocational, social supports and self-care readiness. The project lead worked with the lead social worker to identify the specific information needed to enhance interactions with the patient and families. The final outcome was the development of a decision support tool in the electronic medical record (EMR) called a Best Practice Advisory (BPA), linking to a specific Social Work Transition to Adult Care order.

The advisory was a "pop-up" advisory box in the EMR indicating that the patient was nearing the age of adult care transition, and to consider placing a social work order for

transition discussion and support. The BPA was triggered when the pediatric provider opened an encounter for any patient age 16 years and older with an epilepsy diagnosis code being seen in a follow up visit. The order included embedded "smart text" with drop down menu choices for the provider to describe their request for support, and how the patient and family responded to the transition discussion. This allowed the social worker to be aware of the patient and families unique needs.

The initial advisory was modified after 8 weeks to pop up during Order Entry rather than upon initial opening of the chart. This was requested by providers to better match clinic visit work flow so that the appearance of the BPA was reminder when they were reviewing, placing and discussing other orders with the patient and family. If the provider determined that the timing of beginning transition discussion and support was not appropriate, the advisory and associated order could be deferred in the EMR with a single click, and would trigger again for consideration in subsequent follow up visits.

Provider and Team Satisfaction

To establish an understanding of current strengths and areas of opportunity for the entire pediatric epilepsy team, the project lead developed a brief online survey to assess satisfaction of both the providers and other team members (nurses, medical assistants, neuropsychologists, and social workers) knowledge/skills and comfort related to the current transition practices. The 10 item survey included six items related to individual satisfaction with knowledge and skills rated on a five point scale (unsatisfied to very satisfied), and four items related to comfort (rarely if ever, to always). The survey was sent to the pediatric neurology department early in the QIP and repeated a year later. The purpose was to assess whether the addition of the new tools to support patients and the epilepsy team with transition to adult care changed their overall satisfaction with the process. The survey also included space for comments, which were useful to the project lead in understanding unique or more obscure issues related to transition to adult care for this group.

Measures for Evaluation

Primary Outcome: Time to Transition

The primary outcome measure, time from referral to first appointment in the adult setting, was calculated in days from pediatric clinic referral to adult clinic appointment date. The denominator was the original adult clinic appointment date irrespective if the patient cancelled or rescheduled. The adult epilepsy clinic nurse coordinator sent a list of AYA patients referred to the adult program from the pediatric center and their scheduled visit dates to the project lead at the end of each quarter. A chart review confirmed the visit date when the referral from the pediatric center was made, and both dates were entered into an Excel spreadsheet. Adolescents and young adults who had not been seen in pediatric neurology for more than 3 years, or

those who were referred to adult neurology by the Special Primary Care Clinic in the pediatric facility were excluded from the denominator.

Patient Activation

Improvement or change in the AYA's ability to self-manage their healthcare was measured using an established tool, the Patient Activation Measure (PAM) before and after the clinic educational intervention. The 13-item Patient Activation Measure is a reliable and valid tool used in adult populations to assess knowledge, skills and confidence in chronic disease self-management with the aim of supporting patient autonomy using motivational interviewing strategies (Hibbard, Mahoney, Stockard, & Tusler, 2005). Permission was obtained from the authors to use the tool and change the terms 'health condition' in the original scale to 'epilepsy', and to convert the PAM into an online survey format for this project. During clinic intake, patients were asked to complete the survey after current concerns, health status and medications were reviewed by the RN but prior to the provider seeing the patient. Four to 6 weeks later, a follow up phone call directly to the patient took place. The purpose of the call was to answer any questions the patient had related to the clinic teaching intervention. Within 2 weeks of this phone call, a follow-up PAM survey was sent by US postal mail or email link to the 32 patients who had completed the survey during clinic intake.

Social Work Referrals

Orders placed for transition social work consultation and support after the BPA was activated were measured and tracked using a standard reporting feature in the EMR. This was compared with data collected by the social workers for transitions consult requests by phone or email prior to the BPA. Using the EMR reporting tool, the number of orders placed could be compared with the number of visits that met the established criteria (16 years and older, epilepsy diagnosis code and follow up visit type). A change in the percentage of patients who were recipients of social work support for transition was reported in four adjacent 8 week (40 clinic days) time periods.

Pediatric Epilepsy Team Satisfaction

The pre and post team satisfaction survey was anonymous and included six items related to transition knowledge/skill and four related to comfort, rated on a five point scale (low to high). The survey was sent to all pediatric neurology providers, nurses and social workers before and after the interventions. The purpose of the survey was to assess change in epilepsy team satisfaction with transition knowledge and comfort, and compare it with the other sub-specialty teams in the department. It was not designed to measure change for a given individual. Surveys remained open for approximately 1 month for both pre and post measures with email reminders sent twice after the initial request.

Analysis Plan

Evaluation of the primary outcome of time from referral to appointment was achieved using median number of days per quarter over nine quarters displayed in a box and whiskers plot. Evaluation of the change in patient activation after the SME module teaching intervention in the clinic and follow up phone call was analyzed using pre–post dependent t-test in the Statistical Package for Social Sciences software, v.20 (SPSS). The variables of patient age, module chosen, and decision to see the provider independently for a portion of the visit were intended to be analyzed using Pearson correlation coefficients to determine if there were relationships between the variables and change in PAM scores. However, post PAM data accrual was low with only 14 patients completing both pre and post surveys. One-way analysis of variance (ANOVA) was chosen for the 28 fully completed pre-PAM scores. Four of the 32 pre-PAM surveys were incomplete and not included. Change in the number of social work consults achieved through the use of the Best Practice Advisory for transition support was evaluated using descriptive statistics comparing pre-advisory, first advisory design, and revised advisory design outcomes in four adjacent and equal time periods. For the pre–post analysis of the provider and team satisfaction, numbers were assigned to the responses (1–5) and uploaded from the survey tool to SPSS where means could be compared between these two partially independent, small samples.

Results

Will time to transition to adult neurology care be decreased?

The process changes coincided with a steady decrease in time to first appointment in the adult clinic, with the median number of days decreasing from 206 in 2010 to 62 in 2011, remaining stable at 63 for the first quarter of 2012 (Figure 1). The non-parametric Kruskal–Wallis test used for statistical analysis, $H = 8.2$, $p = 0.004$, $r = 0.43$, showed a statistically significant decrease in time to transition to the University adult epilepsy clinic.

Will Self-Management Education Improve Patient Activation in Self-Care?

Patients participating in the self-management education intervention ($n = 32$) were equally distributed between male (16) and female (16), ages ranging from 15.2 to 25.2 with a mean age of 18.5 for the males and 18.0 for the females. Race and ethnicity data were not obtained. Patient Activation before and after the teaching module intervention in the clinic, and a follow up phone call showed no change in the 44% of patients who completed both pre and post PAM surveys.

Will Social Work Consultation Referrals to Support Transition Care Increase?

The number of social work referrals was evaluated in four 40 clinic day blocks over an eight month period for a total of

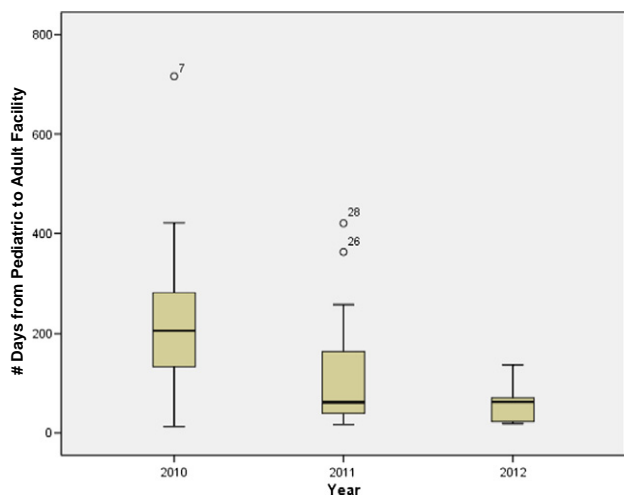


Figure 1 Improvement in time to transition from pediatric to adult facility over nine quarters, displayed by year. CHCO = Children’s Hospital of Colorado; UCH = University of Colorado Hospital; Q1 = first quarter of year. Patients 7, 26 and 28 length of time to transition were outliers as shown.

four time points during the project (Figure 2). At baseline, the number of referrals was 5.8% of patients 16 years and older who were referred to the social worker for transition planning. Referrals increased to 27.5 % in the last time point, representing a 21.7 % increase over an 8 month period, $z = 10.0$, (OR + 6.13, $p = .0006$).

Will the Pediatric Epilepsy Team Have Increased Satisfaction with Transition Knowledge, Skills and Comfort?

Team satisfaction measured in mid-2011 and early 2012 showed improvement in mean scores for the six-knowledge/skill items from 2.75 to 3.08 however, this change was not statistically significant. One knowledge item on the topic of answering patients’ questions about what needs to be in place for transition approached statistical significance, $p = 0.06$. In the four comfort items, the mean scores decreased slightly but not significantly from 4.04 to 3.93. The survey allowed

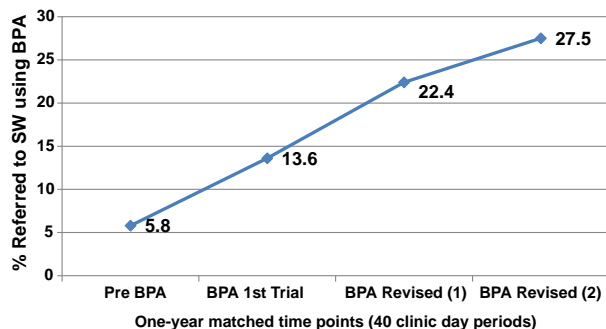


Figure 2 Change in percent of AYA referred for social-work consultation, pre-/post-best practice alert/order. BPA = best practice alert; AYA = adolescent and young adult.

for comments and although not quantifiable, they included concerns about the lack of adult neurologists available to take complex patients and the lack of patient and family follow through with transition processes and agency referrals. These comments can inform future process improvements and provided context for the unique challenges the team identified in caring for transitioning AYA.

System Process Change Outcomes

Process improvements that occurred as a result of the project included the establishment of an Epilepsy Transition to Adult Care letter template and accessible ROI forms to streamline requests for records transfer. In the group of patients who transitioned to adult care in the adjacent University adult neurology clinic, the percentage of patients who had the newly created transition summary letter sent in advance increased from 38 to 78% from 2011 to 2012. While this increase was not statistically significant (OR = 5.68, $p = 0.11$), it was clinically significant to both teams.

Discussion

Young adults with epilepsy are vulnerable on many fronts, including safety risks related to bodily injury during a seizure, the potential for vehicular or workplace injuries, consequences of drug and alcohol experimentation while on AED, risks of unplanned pregnancy, and difficulty with peer socialization (Chiron & An, 2014; Devinsky, 2014; Nashef, Capovilla, Camfield, Camfield, & Nabbout, 2014). Although the number of patients with epilepsy who transitioned between the pediatric and adult neurology clinic in the nine quarters was relatively small (n=32) these patients represent significant utilization of health care resources because of the nature of this chronic illness, often presenting in early childhood and requiring lifelong specialty care and follow up.

This QIP led to improved communication between the pediatric and adult clinics through the initiation of a transition summary letter and processes to improve timely access to records. The project also improved internal pediatric team communication through the use of an EMR tool and pre-developed text to enhance the utility of the social work transition consultation order. Unexpected benefits of the new social work referral process included more frequent discussions with patients and families about the criteria and processes for guardianship and medical durable power of attorney; as well as changes in the level of independence required for success in the adult clinic setting, needs for important medical information to be accessible, and many other safety concerns related to living with epilepsy.

The improvements in referrals may not be fully explained by the QIP interventions. For example, a new physician’s assistant (PA) joined the adult neurology team during the last quarter of the study. The addition of a PA provided the ability to open slots for new patients. In addition, some adult providers began to accept a few Medicaid patients when they had not in the past. However, increased awareness of both

pediatric and adult provider concerns about transitioning patients, and improvements in communication between the two facilities as a result of this QIP, were felt to have indirectly contributed to these adult clinic process changes.

Using a developmental approach to self-management education, specifically, brief and relevant teaching modules that included options to view smart phone applications for medication tracking, was considered an important factor for the nurses engaging AYA patients in epilepsy self-management. Clinical relevance and recall of the teaching intervention were high, based on anecdotal patient feedback during follow up phone calls. All patients spoken to directly remembered the discussion and/or reviewing the educational module while in clinic. For example, one patient had questions about how to be prepared if they had a seizure out in public and were not with family members. Another requested contact information for the local Epilepsy Foundation when informed of the availability of resources to assist in speaking with a potential employer to explain their disease. Nurses and providers reported that participating in this QIP led them to a greater awareness of the challenges of transition and to focus more attention on the needs and responses of the AYA patient.

Limitations

The significant improvement in time to transition as a primary outcome of this project cannot be directly compared to other published models for transition (Carrizosa et al., 2014; Jurasek et al., 2010), as the focus of this project was a recognized need for improvement in a single local subspecialty clinic. The QIP did not focus on families, parents, or other caregivers who may have played a significant role in the life of an AYA. A fear of 'letting go', coupled with frustration in securing appropriate adult specialty care, are common issues for these important individuals in the AYA's life (Reiss et al., 2005).

The primary outcome measure looked specifically at the on campus partner organization and did not measure the total number of patients who transitioned. This QIP did not address the more challenging population of significantly cognitively impaired AYA who receive care from multiple settings, require guardianship, and will never live independently. These patients are often seen in multiple pediatric clinics and were felt to be beyond the scope of this project. The non-matched survey methodology used for the provider and team satisfaction survey and small sample size limited the utility of this measure and the conclusions that can be inferred from the results.

Interpretation

The results of the pre-post PAM measure showed an equal number of patients with change in activation in a positive or negative direction and several patients with no change. These findings may be explained by a heightened level of awareness in the AYA regarding the skills needed to manage medications and adult care as a result of the

intervention. The initial survey was done early in a clinic visit and followed by discussion during the visit, teaching at the end of the visit and a follow up phone call. For some patients, the focus on their ability to truly manage their own care may have led to a decrease in confidence to do so when measured 8–10 weeks hence. The teams' perspective was that the PAM was not an effective measurement tool in adolescents, although may be useful in helping the team move from provider directed care to an approach that encourages patient autonomy and ultimately activation toward disease self-management in this population; which is consistent with the overarching aim of the tool (Hibbard et al., 2005).

Conclusion

Improvements in health care outcomes in complex systems with multiple overlapping processes are challenging to measure and even more challenging to achieve. In addition, there are difficult issues that arise when comorbidities further complicate chronic illness management. Choosing meaningful measures and target outcomes for improving care in these populations is challenging at best. Transitioning from pediatric to adult care is one of these overlapping processes. In the AYA patient with refractory epilepsy, the need for coordinated team-based approaches is essential. In large urban academic medical centers where pediatric and adult specialty care groups manage the most complex cases, quality improvement strategies can address the needs of transitioning AYA.

In this instance, the QIP brought pediatric and adult neurology teams together to address transition between settings. The decreased level of frustration for pediatric providers around unacceptably long wait times in the adult epilepsy clinic was discussed in team meetings. In turn, the adult providers verbalized that they were more prepared to see these complex patients equipped with a succinct summary of epilepsy diagnostic and treatment history. Patients and families benefited from early contact and intervention with the team social worker. There was evidence that this connection was meaningful and improved as a result of the QIP. Clinic RNs now have teaching tools that are feasible to integrate clinic visit education.

The findings of this QIP may be useful to care teams from other pediatric chronic illness populations working to improve processes and create tools to enhance team communication both within teams and across systems. Advanced practice nurses, who are often program development leaders on teams that manage chronic illness care, can consider the outcomes of this QIP as they design transition interventions and programs to support and improve transition for AYA from pediatric to adult specialty care. National best practices for transition to adult care serve as a standard by which pediatric specialty care teams can model evidence-based interventions to enhance the quality of life for emerging young adults (Betz et al., 2014).

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