Outcomes of a Quality Improvement Project Supporting Transition from Pediatric to Adult Neurology Care Using Tools Developed in the Electronic Medical Record (EMR)

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Background: Pediatric health care teams working with Adolescents and Young Adults (AYA) with neurological disorders benefit from streamlined, proactive, team based approaches to initiating transition to adult neurology care. Quality Improvement (QI) activities in a pediatric neurology department on an urban academic medical campus established sustainable tools to support transition preparation for successful transfer to adult neurology care.

Methods: Plan-Do-Study-Act cycle QI methodology was chosen to expand tools that had been developed and successfully implemented with a subset of epilepsy patients in a 2011-2012 pilot phase. Best Practices outlined by the Center for Health Care Transition Improvement (www.gottransition.org) served as the foundation for the project. Tools expanded to all neurology patients included an Electronic Medical Record (EMR) Best Practice Advisory (BPA) for placement of a focused social work consultation order to initiate transition planning, and expanding the number of diagnosis specific transition summary letter templates. New tools included transition to adult care guidelines and a modified transition readiness assessment flowsheet in the EMR. A Redcap transition database was developed and is being integrated with EMR reports to track steps, beginning with the BPA, through the first adult neurology appointment.

Results: EMR reports tracked quarterly utilization of the BPA initiated social work order and use of the transition summary letter templates through expansion to all neurology patients. Statistical process analysis is pending final data through Q2 2014. Preliminary data shows a steady number of social work consultations for eligible patients, with Q1 2014 rates similar to Q4 2013. The use of the transition summary letter templates increased in the first two quarters of 2014 compared with all of 2013, with newly developed templates accounting for 15% of the letters. Full data analysis through SPSS using the Redcap database integrated with EMR reports is pending.

Conclusion: QI strategies provide a framework for successful team processes and reduce institutional barriers to transition planning and transfer of AYA to adult neurology care. Tools built into the EMR are accessible, efficient, and allow the retrieval of data points to identify
barriers and measure success over time. Ongoing work will focus on refinement of data analysis and establishing a departmental benchmark for use of the tools.

Access to Coordinated, Family-Centered, Community-Based Care for Children with Special Healthcare Needs
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Background: The Maternal Child Health Bureau identified six indicators essential in achieving coordinated, family-centered, community-based care for children with special healthcare needs (CSHCN). Current studies examine only one indicator and focus on individual conditions limiting understanding of overall quality of care.

Purpose: Using data from the 2009-10 National Survey of CSHCN (n=34,393), we examined indicators by child’s specific condition(s) including: physical (PC), mental (MC), developmental (DC), physical and mental (PMC), physical and developmental (PDC), mental and developmental (MDC) and physical, mental and developmental (PMDC). Indicators include: partnering in decision making, adequate insurance, and access to medical home, early/continuous screening, community services and healthcare transition (HCT). Bivariate and multivariate analyses determined the association between groups and indicators.

Results: The majority of the sample had a PC (48%), MC (17%), or PMC (21%) with the remaining 15% split between DC, PDC, MDC, and PMDC. CSHCN received medical home and HCT services least often. Children with DC, alone or with another condition, were significantly less likely to receive each indicator (p<.0001) even after controlling for demographic and family-related characteristics. Compared to children with PC, those with: PMDC had the lowest odds of having a medical home (61% decreased odds(Do)), adequate insurance (34% DO) and community services (67% DO); MDC had the lowest odds of partnering in decision making (51% DO); DC had the lowest odds of receiving HCT (66% DO; p<.0001).

Conclusion: Children with DC receive quality healthcare and community-based services half as often as other CSHCN. This disparity must be addressed by researchers, providers and policymakers.

JUST TRAC It!: Assessing a Mobile-Health (mhealth) Intervention for Youth with Chronic Health Conditions and/or Disabilities (CHC/Ds) to Encourage Engagement and Readiness Behaviors for Transition
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**Background:** A developmentally-appropriate approach is required for youth with CHC/Ds to prepare youth and their families for self-management expected in the adult health care system. A major component of healthcare reform centers on the use of technology to empower youth in their healthcare decisions.

**Objective:** The purpose of this study was to determine whether using a mobile-health (mhealth) intervention, promoted as Just TRAC It! would improve engagement, self-management and transition readiness. The project leveraged the recent phenomenon that most youth own cell phones, and the various existing functions could be used for entering health information. The study sought to determine if encouraging youth 14-18 years of age with a CHC/Ds, to use the functions on their own personal phones was a feasible activity and to determine if having this easily retrievable personal data in their phones would be used when they were required to make health decisions and manage health care. The recommendation was “When you come to the clinic, turn your phone on”, as a counter to the usual mantra, “Turn your phone off”.

**Methodology:** This pilot study used a qualitative approach through a cross-sectional study of 30 youth participants between 14-18 years of age. Prior to a subspecialty clinical visit (rheumatology, neurology) youth were invited to participate. After consenting, research students trained youth to input personal health information into their phone’s existing functions (Notes, Contacts and Calendar content). Youth were then asked to complete a one-month and four-month follow-up online survey that evaluated the usefulness (measured by usability, impact on health care visit, and knowledge translation).

**Results:** While the youth indicated they only used 22% of the apps once during the follow-up period, 71% of participants indicated that they will “Always” or “Sometimes” use ‘TRAC it’ to bring question(s) to their medical visits. Fewer youth (47%) indicated they would use the phone to maintain appointments. One youth commented that the work of loading the information into her phone improved her health literacy.

**Conclusion:** Just TRAC it! is well received by youth, free and easy to implement. This intervention can be linked to the self-management skills required for readiness to transfer to adult health care services.

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**Diabetes Care Responsibility among Emerging Adults with Type 1 Diabetes**

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**Background:** The transition to adulthood is a critical time for youth with type 1 diabetes who are expected to assume primary responsibility for diabetes care in contrast to adolescents who share responsibility with their parents. Because little is known about these youths’ responsibility, this study described primary diabetes care responsibility (daily, non-daily and financial) about 1 year after the senior year in high school.

**Methods:** As part of a larger longitudinal study, this report is of 162 emerging adults with diabetes who were enrolled as high school seniors and completed a questionnaire approximately 1 year later. Participants were asked questions on their responsibility for 4 daily (e.g. calculating insulin dose, deciding what to eat at home and when not, and deciding when
and how much to exercise); 8 non-daily (e.g. keeping track of and refilling supplies, making health care appointments, and deciding to tell others about diabetes); and 3 financial (e.g. paying for prescriptions and health care appointments) diabetes care tasks. A score for percent of youths’ primary responsibilities was calculated by counting the number of responses indicating that the youth alone performed or made decisions about a task and then dividing by the total number of items.

**Results:** These youth were primarily responsible for 91% (SD = 15%) of daily; 42% (SD = 33%) of non-daily; and 15% (SD = 34%) of financial diabetes care.

**Conclusions:** Health care professionals are encouraged to work with parents and youth on co-managing non-daily diabetes care for which youth are only moderately responsible. With today’s technology, youth and parents can maintain contact about such tasks as tracking supplies and making health care appointments. Anticipatory guidance is advocated around youth learning about financial aspects because eventually these youth will be on their own.

Study funding: R01NR009810.

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**Transition Readiness, Asthma Morbidity and Asthma Health Related Quality of Life**

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**Introduction/Rationale:** Asthma rates have increased worldwide, but one of the the greatest increases in incidence, morbidity, and mortality have been seen in African American emerging adults living in inner-cities. It is during this period of life that youth transition from pediatric to adult health care. Health care transitions should be purposeful and planned and should support the developing capacity of youth for self-reliance, personal responsibility, autonomy and independence. However, current evidence suggests that this aspect of care is widely neglected or inadequately addressed especially among African Americans. A failure to adequately address health care transitions may affect morbidity and asthma health related quality of life (AHRQOL). Asthma morbidity has been found to be related to AHRQOL, but no studies have examined the relationship between these variables and transition readiness. This study’s primary goal was to describe transition readiness, asthma morbidity, and AHRQOL among African American emerging adults (ages 18-24 years).

**Methods:** This study used a cross sectional design. Forty African American emerging adults age 18-24 years that sought care for asthma related health concerns at a large, inner city, academic emergency department (ED) responded to an online survey while receiving care.

**Results:** Fifty-Seven percent of participants were male. Asthma morbidity was measured by symptom days, nights awakened due to symptoms and use of a rescue medicine for symptoms over the past 7 days. Over a 7-day period, on the average, participants reported 4.11 days of asthma symptoms; 3.82 night-time awakenings due to symptoms, and used their rescue medications 3.60 times. Forty three percent reported 2 or more ED visits within the past 12
months. Also the results indicated a direct relationship between transition readiness score and quality of life score \( r = 0.38, p = 0.02 \). No significant correlation was found between symptoms and transition readiness.

**Conclusion:** Overall findings from our preliminary work suggest that asthma morbidity is high among the study population in that many of the participants experience asthma symptoms most days of a given week. Participants also frequently sought care in the emergency department, and most report beginning skills in transition readiness. Our findings also indicated that asthma had some effects on participant’s quality of life. A higher transition readiness score was associated with higher asthma health related quality of life score.

**Using PDSA Cycles as a Quality improvement Tool to Implement a Systemwide Transition Checklist**

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**Background:** An interdisciplinary transition committee made multiple contributions to standardizing transition information across our pediatric health system. The committee worked closely with our Information Service teams to implement a self-management checklist for transitioning patients into the electronic medical record (EMR). This longitudinal, dynamic document is accessible to all care team providers throughout the health system, including both primary and specialty care. Plan Do Study Act (PDSA) cycles were implemented in five specialty clinics to test access, ease of use and to reveal further improvement opportunities.

**Methods:** A checklist was developed by the transition committee based on models in the literature and was built into our EMR. Pilot clinics were identified and teams established to initiate the checklist with the family during an outpatient clinic visit. Each team used the EMR-embedded checklist on several patients, then described the experience and made recommendations for improvements using a standard template designed by the team. The results were compiled and analyzed at monthly interdisciplinary transition committee meetings.

**Results:** The pilot clinics found the checklist easy to access within the EMR, and it took only a few minutes to review and document updates with the family. All the pilot clinics reported the checklist helped advance the transition process by helping staff prepare, helping the team determine where to focus with the patient/family, and by enabling involvement of the parents in preparation for transition. Each of the clinics that piloted the checklist revealed barriers to be addressed, as well as key recommendations for improvement.

**Conclusion:** PDSA cycles were completed by five pilot clinics. Overall, the pilot clinics had positive responses and valuable recommendations for improvement. The next steps include expanding the use of the improved transition checklist to other outpatient clinics and addressing the barriers when used by a larger number of clinics.
Measuring Important Concepts for Youth in Transition: OK 1.9.15
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Background: There are a paucity of instrument measuring concepts of importance for adolescents’ and young adults (AYA) transitioning to adult healthcare. Two such concepts have been self-efficacy and self-management. These concepts are central to the Ecological Model of Adaptation Outcomes in Spina Bifida and the Individual and Family Self-Management Theory, two frameworks guiding an interdisciplinary team of behavioral scientists exploring transition.

Methods: This presentation reports: (a) analysis of data from cross-sectional studies of AYA (n=50; n=120; n=32) and parents (n=102) used to evaluate the self-efficacy measure (Communication and Problem-Solving Self-Efficacy Scale—CPSES) ) (b), the psychometric background of the Interview version of the Adolescent Self-Management and Independence Scales (AMIS II), and (c) structure of the newly developed self-report AMIS II-Questionnaire (Sawin, Brei, Holmbeck, Pasulka, 2013). The CPSES is a 10-item instrument measuring the AYA’s (or parent’s) perception on how confident the AYA is in communicating with parents, peers, and health care providers in everyday and difficult situations and how confident the AYA is with communication and problem solving skills overall (0=“not confident at all” to 100=“very confident”). The AMIS II measures how often the AYA performs 17 self-management behaviors on their own without help from others. The AMIS II questionnaire converts the original 17 interview items to 31 self-report items.

Results: Exploratory factor analysis on the first sample and a confirmatory factor analysis (CFA) using structural equations modeling using the 2nd and 3rd samples confirmed a single factor self-efficacy measure. CFA also supported two subscales of the AMIS II (Condition and Independent Living). Internal reliability for each measure ranged from α=0.79-0.90) and construct validity provided additional support for the measures.

Conclusion: There is preliminary evidence to support the validity and reliably of these patient reported outcome measures.

Adaptive Challenges for Adolescent with Sickle Cell Disease and Their Parents
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Background: Adolescents with sickle cell disease face unique challenges in self-managing complex symptoms and an unpredictable disease during a developmental period critical for future health outcomes. These challenges are poorly understood and warrant attention. The purpose of this study was to explore and describe the adaptive challenges adolescents with SCD and their parents face, and the adaptive work they engage in to self-manage the disease.

Methods: A qualitative descriptive focus group design using semi-structured interviews was used. Two adolescent and two parent/caregiver focus groups with a total of 29 participants were recruited from a major SCD center. Inclusion criteria were diagnosis of SCD (Hg SS) and
age 11-18 years for adolescents and daily interaction with adolescents for parents/caregivers. Data analysis included content analysis. Codes and categories were organized using the Adaptive Leadership Framework.

**Results:** Participants included adolescents (N=14, 78.6% males, mean age14.4 years old, & 64.3% African American) and parents/caregivers (N=15, 80% parents, mean age 44 years, 73.4% female, 80% African American. Taking charge for managing care was an adaptive challenge for the Adolescents and transitioning responsibility of care to the adolescent was an adaptive challenge for the parent/caregiver. Adolescents used several adaptive strategies including pushing back, stepping up with time, and establishing a circle of trust. Adaptive strategies used by parents included vigilant watch over vs. lean back, do for vs. do with, and shield vs. engage in open dialogue.

**Conclusions:** Transition of responsibility of care from the parent/ caregiver to the adolescent imposes adaptive challenges for both. Providers, adolescents, and parents/caregivers need to arrive at a shared understanding of the challenges to increase the adaptive capacity of the adolescent to self-manage the disease. Future research should explore these challenges and test interventions targeted at improving adaptive strategies.

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**Congruence of Transition Perspectives Between Adolescents with PHIV and their Guardians: An Exploratory Qualitative Study**

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**Background:** Youth with perinatally acquired HIV infection (PHIV) are now routinely living into young adulthood requiring the transition to adult infectious disease care. Transition to adult care can be challenging due to different models of care and HIV-related stigma. Recent research has underscored the importance of evaluating the congruence of adolescent and guardian perspectives about transition to adult care settings. However, no research explores the ways in which transition perspectives of youth with PHIV converge or diverge from those of their caregivers.

**Methods:** In-person recorded interviews focused on transition planning/involvement in transition decisions were conducted with 18 adolescents with PHIV (mean age 17.3 years) and their guardians (mean age 58.1 years). Guardians included five biological parents, seven adoptive parents, and six grandparents/other relatives. Participants were recruited from a southeastern US pediatric infectious disease clinic. Transcribed responses were coded as congruent or divergent by two independent reviewers (92% interrater agreement). Additional qualitative data were coded for emergent themes.

**Results:** Adolescents and guardians held congruent views that the transition process had not started with the majority of adolescents seeming unaware of transition. However, fewer dyads agreed upon the level of adolescent and guardian involvement in transition decisions (11 and 9 dyads, respectively). For example, one adolescent remarked, “My mom’s not really involved [in transition decisions]”, but her mother stated, “I’m there 100%, probably 110%.” Few pairs
mentioned the same parties and only two dyads agreed the adolescent would be involved when asked broadly about who would be involved in the transition process.

**Conclusions:** Findings suggest that providers should assess congruence of adolescent and guardian perspectives with special attention to expectations for level of involvement in transition-related decisions. Future research should explore associations between congruence of transition perspectives and measures of transition success such as behavioral (e.g., appointment attendance) and serological markers (e.g., viral load).

**Transition Readiness among Teens – Differences by Chronic Condition**
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**Background:** Emphasis on transition readiness thus far has been either disease-specific or aggregated across multiple chronic conditions. Identifying what differences exist in transition readiness by chronic condition is essential for understanding whether resources need to be applied systemically across medical systems, or whether special emphasis should be placed within specific populations. It was hypothesized that differences would be observed by group, with developmental/behavioral diagnosis group demonstrating poorer readiness than chronic medical conditions, and typical youth displaying the highest levels of readiness.

**Methods:** Youth ages 13 to 22 with IQ scores above 85 were recruited from a large free-standing children’s hospital. Clinics represented include type 1 diabetes (n = 34), turner syndrome (n = 33), spina bifida (n = 21), autism spectrum disorder (n = 28), and adolescent medicine (n = 35); participants from adolescent medicine were screened to ensure that they did not have a chronic condition. For these analyses, demographics (age, gender, race, maternal education), health literacy, and the sum score of the Transition Readiness Assessment Questionnaire (TRAQ) were included.

**Results:** There were no differences in health literacy across groups; therefore, it was excluded from subsequent analyses. After accounting for the demographic effects, significant differences in transition readiness were found by group (F (5, 138) =31.25, p < .01). Follow-up analyses indicated that there were no significant differences between youth without chronic conditions and youth with type 1 diabetes (p = .10). All other groups had significantly lower transition readiness scores compared to youth without chronic conditions (p ≤ .01) and significantly differed by condition.

**Conclusions:** While youth without chronic conditions and youth with type 1 diabetes showed higher transition readiness than other subgroups, all groups would benefit from enhanced transition preparation. Specific interventions for specific subpopulations may also be indicated.