

## Abstracts

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We present a collection of abstracts from the 2013 Annual Healthcare Transition Research Consortium in Houston, Texas. The HCTRC is an organization of volunteer adolescent/emerging adult patients with chronic conditions, parents and health providers/researchers with the purpose to advance an evidence-based research agenda on health care transition and self-management. Abstracts are submitted by an international group of members, and accepted for the conference by committee members of the Transition Research Consortium. Of those accepted for the conference, the editors chose six abstracts with relevance for the *Journal of Pediatric Rehabilitation Medicine*. We hope they demonstrate the variety of work ongoing in transition, from developing models of care to factors associated with successful transition.

### **Bone health in adult survivors of pediatric-onset cerebral palsy**

Deborah Thorpe, PT, PhD, Heidi Kecskemethy, RD, CSP, CDT (A.I. DuPont Hospital for Children), Richard Grossberg, MD (Case Western Reserve University School of Medicine), Kevin Sheridan, MD (Gillette Children's Specialty Care), Richard Stevenson, MD (University of Virginia), Brent Henderson, BS, Sebastian Hildago, BS (The University of North Carolina at Chapel Hill), Beth Nikolova, BS (Gillette Children's Specialty Care), Richard Henderson, MD, PhD (The University of North Carolina at Chapel Hill).

**PURPOSE:** The aim of this study was to describe bone health in adults with pediatric-onset cerebral palsy (CP) across mobility levels.

**METHODS:** A cross sectional study of 263 adults with CP ages 18–71 years, who had not received bisphosphonate therapy. Retrospective Dual X-ray Absorptiometry (DXA) scans of left and right distal femurs (R = 238, L = 250) using Hologic QDR 4500W densitometers were each divided into three regions and analyzed using Hologic v8.25 software. Multiple regression analysis determined associations between

bone mineral density (BMD) and Gross Motor Function Classification System (GMFCS) Level, age, sex, body mass index (BMI), and fracture history.

**RESULTS:** Participants were 55% male and 84% Caucasian at GMFCS Levels I–V. The more mobile, the higher the mean BMI (SD) [29.5(8.7) kg/m<sup>2</sup>] and mean BMD (SD) [1.19 (0.15) gm/cm<sup>3</sup>]. Thirty-two percent had a history of prior fracture and of those, 62% of the fractures were sustained by adults in GMFCS Levels IV and V. However, the most functional adults in GMFCS Level I had the highest fracture rate. For Region 1; age, GMFCS level, weight, and prior fracture history explained 58% of the variance in BMD. For Region 2; age, GMFCS level, and weight explained 58% of the variance in BMD. For Region 3; age, GMFCS level and weight explained 61% of the variance in BMD.

**CONCLUSIONS:** Results suggest that adults with CP who ambulated, with higher BMIs, had better bone health. However, adults who ambulated also had the highest fracture rate? Future studies should address longitudinal reporting of bone health in persons with CP to determine specific variables which predict bone health and fracture risk over time, and to determine the most efficacious interventions for increasing or maintaining bone health.

### **Transfer Clinics: Supporting Youth with Special Health Care Needs in the Move from Pediatric to Adult Health Care**

Khush Amaria, PhD, C. Psych, Miriam Kaufman, BSN, MD, FRCPC, Geraldine Cullen-Dean, RN, MN and Megan Henze, OT Reg. (Ont)  
The Hospital for Sick Children

**PURPOSE:** Transfer of care of adolescent patients from pediatric to adult health care is associated with challenges and potential risks for patients and families. The Good 2 Go Transition Program at The Hospital for Sick Children supports the use of adolescent-oriented Transfer Clinics to decrease these risks and influence

positive transition outcomes. Key features of the Transfer Clinic include developing a designated clinic appointment for patients at their ultimate or penultimate appointment in the paediatric system. The focus of these clinics include the development of a MyHealth Passport, discussion of differences between paediatric and adult health care systems and meeting an adult-health care provider. Since 2007, 16 Transfer Clinics were facilitated by the Good 2 Go Transition Program. **METHODS:** This study examined the impact of the Transfer Clinic on adolescent patient's beliefs *at time of transfer* and *after transfer* into the adult health care system. A total of 134 adolescent patients completed a survey following their experience in the Transfer Clinic in the last 5 years. A subset of patients ( $n = 103$ ) consented to completing a follow-up survey approximately one year after their transfer to adult care occurred.

**RESULTS:** Satisfaction ratings for attending a Transfer Clinic were generally positive at the time of discharge. The impact of attending a Transfer Clinic on feeling prepared, patient's perceptions and knowledge, and subsequent engagement in the adult care system was also positive. Over 95% of patients contacted for a post-transfer survey had attended an appointment in the adult system and over 90% of patients reported their health as the same or better since transfer. The effect of time from transfer (1 to 5 years) was examined. **CONCLUSION:** Lessons learned from the implementation of a Transfer Clinic in paediatric hospital setting will be discussed, including identification of specific tools that were helpful in preparing for adult health care (e.g., meeting new adult health care provider, completing a MyHealth Passport). Transfer Clinics can be an effective tool to support the transfer of patients with special health care needs from speciality paediatric to adult health care settings.

#### **A co-creative, youth-driven approach to exploring the patient journey of young adults with chronic health conditions (CHCs) transitioning to adult care**

Mary Paone, Sandy Whitehouse, Kyla Brophy, Dewey Evans and Erin McFee

**PURPOSE:** Youth with CHCs face significant challenges adapting from pediatric to adult care, namely differences in clinical environments, amount of allied health support, and differing expectations. Understand-

ing the young adult (YA) patient's experience provides information for clinical process redesign. This study engaged students to explore the transition of YA patients by mapping their journey.

**METHODS:** Qualitative descriptive methodology using semi-structured interviews and co-creative processes were used to explore the patient journey of four youth (ages 18–22) with CHCs following their transition. The Nursing and Design student dyad was randomly matched with a YA patient. Nursing students analyzed the interviews for common themes, barriers and issues. Design students created drawings reflecting their interpretation of the YA journey. Through an iterative co-creative process, the student dyad created a visual map of the YA's transition. A final reflective meeting included the YA to ensure accuracy of interpretation, learning and overall experience.

**RESULTS:** Substantive learning occurred amongst participants including high levels of empathy, respect and understanding. Themes that emerged to guide clinical education and resources; ensuring youth voice in health care decision-making, early initiation and ongoing dialogue of transition preparation and planning, and the importance of the young adult and family roles and responsibilities to ensure successful transitions.

**CONCLUSION:** This youth-driven project reinforced the need for patient-centered care, early integration of transition interventions and the importance of exploring the youth's experience.

#### **Perspectives on Systems of Support for Transitioning Youth with Special Health Care Needs**

Megumi Okumura, MD, Mara Sanders, NP and Roberta Rehm, PhD  
UCSF

**PURPOSE:** Youth and young adults with special health care needs (YSHCN) experience challenges during health care transitions. Therefore we wished to investigate mechanisms of healthcare support used by YSHCN during the transition to adult care.

**METHODS:** We conducted in-depth semi-structured interviews with YSHCN aged 16–25, their family members and providers in San Francisco. We focused our interviews on support mechanisms both within and outside of the health care system. We performed a multi-step qualitative analysis process, which included open coding with secondary-level coding for important themes.

**RESULTS:** Forty-one interviews were conducted. A distinctive category, which emerged was the presence of, or need for, a health care ‘advocate’. The health care advocate was described as an individual who assisted the YSHCN with the health care transition, particularly to overcome a specific barrier that the youth encountered. This ‘advocate’ was often someone who was knowledgeable about either the health care system in general, or the patient’s specific medical condition or disability. The ‘advocate’ role was served by a variety of players, not all of whom were health care providers.

**CONCLUSIONS:** Youth require additional support outside of standard disease treatment models. Community agencies and programs can be well poised to help these youth through the transitioning period.

#### **The Child Health Belief Model: Conceptualizing How Cognitive Factors Influence Transition Readiness**

N. Fenton, K. Javalkar, S. Cohen, A. Phillips, and M. Ferris

**PURPOSE:** The aim of this study was to examine if the child health belief model (CHBM) is an empirically supported way to conceptualize transition readiness. The factors of this model include: perceived severity, benefits, barriers, self-efficacy, susceptibility, and family support.

**METHODS:** Patients 13 to 21 years old with a diagnosis of chronic kidney disease stage  $\geq 2$  or inflammatory bowel disease were approached to participate. Participants completed 5 scales which included: The Beliefs About Medication Scale<sup>1</sup>, The Adolescent Medication Barriers Scale<sup>2</sup>, The Brief Measure of Illness Self-Efficacy<sup>3</sup>, The Social Support Questionnaire-Family Version<sup>4</sup>, and the TR<sub>x</sub>ANSITION scale<sup>5</sup>. Fifty-eight participants were recruited: 50% CKD, 46% male, 62% private insurance, 38% public insurance, 56% Caucasian, and 31% African American. The average age of the sample was 16.92 ( $\pm 1.93$ ).

**RESULTS:** Results indicate that the CHBM was a statistically significant way to conceptualize transition readiness when disease type was controlled for ( $R^2 = 20.6$ ;  $F(7, 50) = 3.11$ ,  $p = 0.008$ ).

**CONCLUSION:** The CHBM is an empirically supported way to understand transition readiness. These findings suggest that the cognitions adolescents have about their illness may be critical factors in understanding the transition process.

#### **Transition of Primary Care for YSHCN in Staff Model HMO**

Ann Behrmann, MD (atbehrma@wisc.edu) and Mala Mathur, MD, MPH (mmathur@ghcscw.com)

**BACKGROUND:** Group Health Cooperative of South Central Wisconsin (GHC-SCW) is a 70,000+ member non profit staff model HMO affiliated with U. of Wisconsin Hospital. GHC was an early adopter of EMR (2002) and medical home implementation (2004). In June 2012 two pediatricians began a QI project to create workflows for primary care transition. This project focused on medical issues of transition in a primary care setting. Partners included the WI State Medical Director for CYSHCN, the coordinator of the Southern Regional Center and the National Got Transition Collaborative.

**METHODS:** Our QI project included 1) Adapting transition checklists for GHC-SCW patients and for families, 2) Creating EMR smart texts for transition 3) Developing two handouts – one for teens and one for parents regarding healthcare transition including changes to MyChart access. 4) Initiating workflow to distribute to YSHCN informational packets of community and state resources.

In our pilot project transition checklists were distributed to all adolescents during a 9-month period in our practice. We collected the completed questionnaires from 92 young adults ages 14–22 (25% being YSCHN) and 63 families.

**RESULTS:** We were surprised that 99% of all youth surveyed, including 96% of YSCHN, answered that they understood their healthcare needs and issues.

Our checklist results also suggest that close to half (45%) of all youth surveyed did not carry their healthcare information with them.

**DISCUSSION:** Authors noted a discrepancy between youth knowledge of their disease processes/medications and the checklist results. We understand the importance of measuring this knowledge in subsequent transition work. Patient education materials are crucial to support verbal patient education. Families need more education about transition and accurate information about state laws.

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**CONCLUSION:** This pilot engendered positive feedback from families, youth and colleagues. Our next challenge will be spreading this program organization wide.

Engaging administrators early, allocating time on structural processes and workflows are important be-

fore pilot begins. Establishing measurable outcomes initially, tracked through EMR data, is also important.