Health Care Transition
Research Consortium

17TH ANNUAL HEALTH CARE TRANSITION RESEARCH CONSORTIUM RESEARCH SYMPOSIUM

October 22, 2025

SCHEDULE

8:00 AM - OPENING REMARKS

Cecily L. Betz, PhD, RN, FAAN; Megumi J. Okumura, MD, MAS
HCTRC Research Symposium Co-Chairs

Albert C. Hergenroeder, MD
Baylor College of Medicine, Texas Children's Hospital

8:20 AM - KEYNOTE PRESENTATION:

What Evidence is Needed for Health Care Transition Best Practices?
Maria E. Diaz-Gonzalez de Ferris, MD, MPH, PhD
AnneLoes van Staa PhD, MA, MD RN
David Lee Wood, MD, MPH

9:20 AM - PLATFORM SESSION 1: ADOLESCENTS/EMERGING ADULTS/SELF-MANAGEMENT

Moderator: *Jason Woodward, MD, MS*

Platform #1: Inpatient Experience of Emerging Adults: A Qualitative Study
Nicole Oakman MD; Bethany Corbin MD; Amal Syed BSA PA: Luke Coffman BS; Hannah Schneider BA; Maria Valentina Harmjanz MD MPH; Ashley Jenkins MD MSc

Platform #2: The Provision of Optimal Medical Care for Adults with Chronic Health Conditions Originating in Childhood
Catherine A. Harwood, MSSW; Lailea Noel, PhD

Platform #3: Adaptation and Evaluation of an Intervention to Promote Autonomy and Competence in Adolescents with Sickle Cell Disease
Blanca Sanchez-Fournier, BA; Jordyn Babla, BS; Titilope Fasipe, MD, PhD; Beth H. Garland, PhD; Mary Majumder, JD, PhD; Albert C. Hergenroeder, MD; Constance M Wiemann, PhD

10:00 AM - BREAK

10:15 AM - POSTER SESSION 1: 21 POSTERS

11:30 AM - LUNCH

12:00 PM - BREAKOUT SESSIONS

Breakout Session #1: Specialty-Care Process Improvement Initiative to Support Youth and Young Adults with Childhood-Onset Disability During the Transition from Pediatric to Adult Care
Tori Bahr, MD; Rhonda Cady, PhD, RN

Breakout Session #2: Bridge to Adulthood: Defining and Achieving Metrics
Carlie Stein Somerville, MD; Betsy Hopson, PhD

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Breakout Session #3: Putting Healthcare Transition in Context: The Role of Social Workers in Interdisciplinary Transition Teams
Caren Steinway, MSW, MPH; Angela Berger, MSW; Terri Hickam, MSW, CCM; Reny Partain, MSW, MPH; Stephanie Pratt, MSW; Susan Shanske, MSW; Symme Trachtenberg, MSW

Breakout Session #4: Self-Advocates are the Key to Successful Transition Programming
SymmeTrachtenberg, MSW; Alyia D'Ambrosio, Lead REACH Advisor (Young Adult with chronic health issues)

12:45 PM - PLATFORM SESSION 2: CONTINUOUS QUALITY IMPROVEMENT/PROGRAM DEVELOPMENT/MODELS OF CARE

Moderator: *Thomas Davis, MD*

Platform #1: Developing a Pilot Program: Assisted Blood Draws for Patients with Intellectual and Developmental Disability in Adult Care
Erini Pappas, MD; Michelle Feil, MSN, RN; Lisa Sator, PT, DPT, WCS, CLT; Ethan Kannel, MBA; Mollie Illenberger, MSN, RN, CEN; Dava Szalda, MD MSHP

Platform #2: Bridging Gaps in Emergency Care: A Clinical Pathway to Improve Healthcare Transition for Medically Complex Adults
Erin Benekos DNP, APRN, FNP-C; Shelby Shelton MPH, CCRC; Rammy R Assaf, MD; Courtney Malave, MSW, LCSW; Reny Partain, MPH, LCSW; Wendy Gray, PhD; Mayumi Kaneko, MSN, APRN, FNP-BC; Laura Sarff, DNP, RN, MBA, CPHQ, NEA-BC; Kate Bayhan, DNP, RN, CCRN; Alexandra Roche, MD

Platform #3: The Brigham Transition Care Team: Two Years of a Model for Accepting Complex Pediatric Young Adult Patients into an Adult Health Care System
Niraj Sharma, MD; Margaret Threadgill, MD, MBA

Platform #4: Impact of a Structured Transition Program Including the Assistance of a Virtual Transition Visit
Tara Shores, BSN, RN, CBC; Toby Rockefeller, MD, FSCAI; Brian Birnbaum, MD, FACC, FAAP

1:45 PM - POSTER SESSION 2: 22 POSTERS

3:00 PM - CALL TO ACTION: ADVANCING HEALTH CARE TRANSITION RESEARCH AND PRACTICE FOR INDIVIDUALS WITH RARE DISEASES

Maria E. Diaz-Gonzalez de Ferris, MD, MPH, PhD

3:30 PM - PLATFORM SESSION 3: CONTINUOUS QUALITY IMPROVEMENT/PROGRAM DEVELOPMENT/MODELS OF CARE/ HEALTH CARE TRANSITION OUTCOMES AND READINESS

Moderator: Parag Shah, MD

SCHEDULE

Platform #1: Leveraging Lessons Learned: The Transition Learning Collaborative
Susan Shanske, MSW; Kristina Taylor, BSN, RN; Lindsey McMahon, MPH; Ahmet Uluer, DO, MPH

Platform #2: A Review of Medicaid Managed Care Contracts to Inform Plans for Advancing a System of Services for CYSHCN and their Families
Annie Schmidt, MPH; Samhita Ilango, MSPH; Peggy McManus, MHS; Patience White, MD, MA

Platform #3: Value-added? Assessing Transition Readiness in Youth and Young Adults with Spina Bifida
Megan Gallagher, MPH; Rhonda Cady, PhD, RN

Platform #4: Adult in Age but Pediatric in Size: A Single Center Retrospective Study of the Care of Small-sized Adult-aged Patients
Erica Onwuegbuchu MD, MS; Erin Tully MD; Adam Greenberg MSN, CRNP; Christine Chamberlain BSN, RN, CPN; Richard Chung MD; Dava Szalda MD

4:30 PM - WRAP-UP

Cecily L. Betz, PhD, RN, FAAN; Megumi J. Okumura, MD, MAS
HCTRC Research Symposium Co-Chairs

AGENDA

7:15AM - REGISTRATION/BREAKFAST

8:00 AM - OPENING REMARKS

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Moderator: *Jason Woodward, MD, MS*

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Platform #2: The Provision of Optimal Medical Care for Adults with Chronic Health Conditions Originating in Childhood
Catherine A. Harwood, MSSW; Lailea Noel, PhD

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Platform #3: Adaptation and Evaluation of an Intervention to Promote Autonomy and Competence in Adolescents with Sickle Cell Disease
Blanca Sanchez-Fournier, BA; Jordyn Babla, BS; Titilope Fasipe, MD, PhD; Beth H. Garland, PhD; Mary Majumder, JD, PhD; Albert C. Hergenroeder, MD; Constance M Wiemann, PhD

10:00 AM - BREAK

10:15 AM - POSTER SESSION 1

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Poster #1: Self-management in the Context of Psychosocial Health: A Qualitative Descriptive Study of Adolescents with Chronic Conditions
Katherine Melton, PhD, RN; Kira Fried, BS; Mimi Stotsky, PhD; Jean Connor, PhD, RN, CPNP, FAAN; Greg Sawicki, MD, MPH

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Poster #2: Using a Transition Mastery Score to Assess Program Effectiveness and Patient Readiness to Transition to an Adult Model of Health Care
Stephanie Pratt MSW, LMSW; Joy Fullbright MD; Tara Shores BSN, RN, CBC; Ashley Sherman MA;Nikita Raje MD, Msc, FACAAI, FAAAAI

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Poster #3: Understanding Adolescent Young Adult Health Care Transition Learning Priorities Through Annual Goal Selection
Stephanie Pratt MSW, LMSW; Nikita Raje MD, MSc, FACAAI, FAAAAI; Neeti Redy; UMKC; Joy Fullbright MD

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Poster #4: Pediatric to Adult Transition Care for Youth With Special Healthcare Needs (YSCHN): An Online Training for Care Providers
Romila Santra, MA; Niraj Sharma, MD, MPH

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Poster #5: Quantifying Success: Evaluating Transfer Metrics in a Specialty Transition Clinic
Wendy Gray, PhD; Erin Benekos, DNP, FNP-C; Mayumi Kaneko, RN; Courtney Malave, LCSW; Parasto Dorriz, MPH; Sandra Hollist; Reny Partain, LCSW, MPH; Alexandra Roche, MD; Michael Weiss, DO

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Poster #6: Prevalence and Trends in Pediatric-Onset Chronic Conditions in the United States, 1999-2018
Lauren E. Wisk, PhD; Niraj Sharma, MD, MPH

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Poster #7 The Needs of Patients and Families with Mucopolysaccharidosis (MPS) During the Transition from Pediatric to Adult Health Care
Autumn Cabral, BS; Susan Shanske, MSW; Kristin McKay; Kim Stephens, DBA; Julie B. Eisengart, PhD; Joseph Muenzer, MD, PhD; Wendy Gray, PhD; Ahmet Uluer, DO, MPH

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Poster #8 Transition to Adult Care in Adolescents with Sickle Cell Disease: Are We Meeting the Mark?
Oluwaseun Olaiya, DO, FAAP; Ajibike Lapite, MD, MPHTM; Kezia Asiedu; Duc T Nguyen, DO; Titilope Fasipe, MD, PhD; Venee N. Tubman; MD, MMSc

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Poster #9: Satisfaction with care among adults with DD and caregivers receiving integrated or usual care
Daniel Gilmore PhD, RDN; Deitsch, OTD, OTR/L; Deondray Radford, BS; Emily Johnson, MD; Lauren Wang, MD; Corey Keeton, MD; Aurora Rivendale, MD; Susan M. Havercamp, PhD; Lindy L. Weaver, PhD, OTR/L; Ingrid Adams, PhD, RDN, LD; Brittany Hand, PhD, OTR/L

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Poster #10: Smart Phrase Impact on Weight Loss Discussion for Adults with Concurrent Down Syndrome and Obesity
Michelle Cornacchia, MD; Julie Marchioni; Kevin Lynch; Mark Kapran; Ara Khoylyan

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Poster #11: TRAQ Stars: Improving Transitions of Care for Adolescents with Diabetes, A Quality Improvement Initiative
Joshua S. Mercer, MD, MBA; Alice Basin, MD; Aashna Shah, BA; Camille DiCarlo, BE, MS; Jordan Poythress, BSN, RN, CDCES, CPN; Rebecca Sadun, MD, PhD; Alexandria Wiersma, MD; Emily Sterrett, MD, MS; Robert W. Benjamin, MD; Ruchi Doshi, MD, MPH

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Poster #12: Small Programs, Big Institutions: Increasing Peer Support Program Engagement for Adolescent and Young Adult Patients Living with Chronic Conditions, A Continuous Quality Improvement Initiative
Joshua S. Mercer, MD, MBA; Ruchi Doshi, MD, MPH; Yu-Lin A. Lee, MD; Dana Clifton, MD; LaKaya Craig, MS; Jon Wolseth, PhD

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Poster #13: New Spina Bifida Health Care Transition Toolkit

Patience White, MD, MA; Hadley Wood, MD; Nkem Chineme, MPH; Jamie Jones, MPH; Peggy McManus, MHS; Ellen Fremion, MD

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Poster #14: Outpatient Care of Young Adults in Pediatric Hospitals

Laura Hart, MD, MPH, FAAP, FACP; Sara Wagner, BS; Kristin Jensen, MD, MPH

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Poster #15: Impact of a pediatric-adult health care transition program, including perspectives from transferred patients and caregivers

Yeka Nmadu, MD; Rossy Guzman Rodriguez, MD; Meskerem Nemomsaa, MD; Jennifer Brailsford, PhD; Chanda L. Jone, BA; Lindsey B. Hollingsworth, PA-C; Matthew Garber, MD; Rita Nathawad, MD

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Poster #16: New Health Care Transition Toolkit Series for Youth with Intellectual and Developmental Disabilities

Jane St. John; Marie Clark; Rachel Shandler, Patience White, MD, MA; Peggy McManus, MHS

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Laura Payne MPH RN CPN AE-C; Meghan Camacho BA; Suzanne Ngo MD; William C. Anderson III MD

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Poster #18: PREPARE for Autistic Adults: Resident Physicians' Experiences with an Adult Autism Training Program

Alison Deitsch OTD, OTR/L; Daniel Gilmore PhD; PREPARE Autistic Advisory Board; Lisa Juckett, PhD, OTR/L; Christopher Hanks, MD; Susan M. Havercamp, PhD; Daniel Coury, MD; Brittany N. Hand PhD, OTR/L

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Poster #19: Transition from Pediatric to Adult Care from the Perspective of Parents of Young People with a Pediatric Rheumatic Disease in Switzerland: A Qualitative Study as Part of the Contextual Analysis of the HEROES (Rheumatology Transition for Young People in Switzerland) Study

Matter Marlis, RN; Tarr Natalie, PhD; Daly Mary-Louise, RN; Wörner Andreas, MD; Daikeler Thomas, MD; Staudacher Sandra, PhD; Berben Lut, PhD, RN

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Jihye Lee, PhD, RN; Tyra Gridwood, PhD, RN; Cecily L. Betz, PhD, RN, FAAN

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Poster #21: Transition Documentation: Developing Standards and Visual Prompts to Support Triage of Transition-Aged Patients Presenting to the Pediatric Emergency Department

Adam Greenberg MSN, CRNP; Elizabeth Lolly, BS; David Junod, BS; Joseph Zorc MD, MSCE; Dava Szalda MD, MSHP; Richard Chung MD, FAAP, FSAHM

11:30 AM - LUNCH

12:00 PM - BREAKOUT SESSIONS

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SymmeTrachtenberg, MSW; Alyia D'Ambrosio, Lead REACH Advisor (Young Adult with chronic health issues)

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Moderator: *Thomas Davis, MD*

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Erini Pappas, MD; Michelle Feil, MSN, RN; Lisa Sator, PT, DPT, WCS, CLT; Ethan Kannel, MBA; Mollie Illenberger, MSN, RN, CEN; Dava Szalda, MD MSHP

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Erin Benekos DNP, APRN, FNP-C; Shelby Shelton MPH, CCRC; Rammy R Assaf, MD; Courtney Malave, MSW, LCSW; Reny Partain, MPH, LCSW; Wendy Gray, PhD; Mayumi Kaneko, MSN, APRN, FNP-BC; Laura Sarff, DNP, RN, MBA, CPHQ, NEA-BC; Kate Bayhan, DNP, RN, CCRN; Alexandra Roche, MD

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Tara Shores, BSN, RN, CBC; Toby Rockefeller, MD, FSCAI; Brian Birnbaum, MD, FACC, FAAP

1:45 PM - POSTER SESSION 2

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Nancy C. Cheak-Zamora, PhD; Servando Rodriguez Barajas, MS, LPC

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Stephanie Pratt, MSW; Angela Berger, MSW; Terri Hickam, MSW, CCM; Reny Partain, MSW, MPH; Susan Shanske, MSW; Caren Steinway, MSW, MPH; Symme Trachtenberg, MSW

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Kylie Cullinan, MD; Emily Bufkin, MD; Rishi Shah, MBA, CHA; Lauren Tardo, MD

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Alberta Kaichian, MSW, LCSW, CCTP, C-DBT; Isabela Garcia, LLM; Bertha S. Hayden, Esq.; Rachel Cuevas; Dr. Debra Lotstein, MD, MPH, FAAP, FAAHPM; Courtney Porter, MPH, CPHQ

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Victoria Koenigsberger, BA; Ali Yalcindag, MD; Meghan Geary, MD; Madeleine Ward, MD

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Craig DiPietro, RNCC, BSN, AMB-BC, Jennifer Disabato, DNP; Kimberly Ndahayo, DNP, FNP-C; Chelsey Stillman, MPAS, PA-C; Brittany Croop, FNP-C; Naveed Chaudhry, MD; Jordan Gallegos, MD

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Barbara Hepp, BSN, RN, CPN, CCCTM; Shelly Heinrichs, LCSW; Juan Ramos, BS, FHN; Shianne Goering, MHA; Jennifer A. Disabato, DNP, CPNP-PC,AC; William C Anderson, III, MD

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Poster #8: A Novel Scoring System for Transition of Care of Pediatric Rheumatology Patients
Kyla Blasingame, MD; David McDonald, MD; Karissa Chesky, BS; Jimin Kim, BS; Charles Lee, BS; Constance M. Wiemann, PhD; Blanca Sanchez-Fournier, BA; Miriah Gillispie-Taylor, MD; Tiphanie P. Vogel, MD, PhD

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Rhonda J. Horick, DSW, MSW, BSN; Jason Woodward, MD, MS; Diane Burns; A Nicole White, PhD, MBA; Allie Bushong

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Poster #10: Failure to Launch: Investigating Transfer to an Adult Multidisciplinary Clinic
Madeline Booth MS; Ashley McCool MHA; Rishi Shah FACHE; Emily Bufkin MD

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Poster #11: Evaluating Youth and Parent/Caregiver reports on Healthcare Transition Readiness in Egypt: Validation of the Arabic STARx and STARx-P Questionnaires
Peter Said, MD; Yara Abumohsen, MS; Pierina Parraga; Stephen R. Hooper, PhD; Maria E. Diaz-Gonzalez de Ferris, MD, MPH, PhD; Afaf ElAdl, MD; Guido Filler, MD

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Poster #12: Strategic Partnership Analysis to Identify Opportunities for Health Care Transition Education and System-Level Change
Tori Bahr, MD; Wendy Berghorst, RN; Rhonda Cady, PhD; Megan Gallagher, MPH; JP Mahoehney, MPH, RN; Peggy McManus, MHS; Patience White, MD

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Poster #13: Developing an Interdisciplinary Transition Clinic for Adult Patients with Congenital Heart Disease
Khadija Shah, ScM; Samantha J. Klaver, PhD; Sara R. Ford, MD; Suzanne McLaughlin, MD; Toi Spates, MD; Barbara Jandasek, PhD; Marisa Wayciulis, BS; Janet Anderson, EdD

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Chelsea Ghena, DNP, APRN, CPNP-PC; Carolyn Reynolds, MSN, APRN; Camille Reay

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Lela Kanter, DNP, FNP-C; Rebecca Robert, PhD, CPNP-PC; Barbara Speller-Brown,DNP, MSN, PNP-BC

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Poster #16: How the Timing of Pediatric-to-Adult Healthcare Transfers Differs By Specialty in a Population of Commercially Insured People With Disabilities
Megumi J. Okumura MD, MAS; Lauren Wisk PhD; Anushree Agarwal MD; Nancy Morden MD; Ellen Meara PhD; Nancy Beaulieu PhD; Christina Fu PhD; David Cutler PhD; Mary Beth Landrum PhD; Alyna T. Chien MD, MS

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Poster #17: ATLAS: Developing Institutional Programs to Support Adolescent and Young Adult Patients Living with Chronic Conditions
Joshua S. Mercer, MD, MBA; Ruchi Doshi, MD, MPH; Yu-Lin A. Lee, MD; Dana Clifton, MD; LaKaya Craig, MS; Jon Wolseth, PhD

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Poster #18: Transition Practices and Barriers in Spina Bifida Care: A Survey of SBA Clinical Care Partners
Betsy Hopson, PhD; Rhonda Cady, PhD; Kathy Huen, MD, MPH; Judy Thibadeau, RN, MN; Ellen Fremion, MD, FACP, FAAP

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Poster #19: The Quest for Health Information Resources by Young Adults with Disabilities: Building Theory
Beth Rossen, BA, BAAN, RN, MSc, PhD

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Poster #20 Medication Dosing Challenges for XLH patients in the Transition Age.
Maria Díaz Gonzáles de Ferris, MD, PhD, MPH; Guido Filler, MD, PhD

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Poster #21: Bridging the Gap between Care Team Education and Clinical Practice: Development of a Health Care Transition Curriculum
Tanika Middleton, BSN, RN, CCM; Ashley McCool, MHA

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Poster #22: Developing Patient Family Electronic Learning (e-learning) Education for Health Care Transition through System-wide Collaboration
Noemi Manriquez, BA; Ashley McCool, MHA

3:00 PM - CALL TO ACTION: ADVANCING HEALTH CARE TRANSITION RESEARCH AND PRACTICE FOR INDIVIDUALS WITH RARE DISEASES

Maria E. Diaz-Gonzalez de Ferris, MD, MPH, PhD

3:30 PM - PLATFORM SESSION 3: CONTINUOUS QUALITY IMPROVEMENT/PROGRAM DEVELOPMENT/MODELS OF CARE/ HEALTH CARE TRANSITION OUTCOMES AND READINESS, PARAG SHAH, MD)

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4:30 PM - WRAP-UP

Cecily L. Betz, PhD, RN, FAAN; Megumi J. Okumura, MD, MAS
HCTRC Research Symposium Co-Chairs

PLATFORM #1

Inpatient Experience of Emerging Adults: A Qualitative Study

Nicole Oakman MD; Bethany Corbin MD; Amal Syed BSA PA: Luke Coffman BS; Hannah Schneider BA; Maria Valentina Harmjanz MD MPH; Ashley Jenkins MD MSc

BACKGROUND

Emerging adults, defined as 18 to 25-year-olds, are a population with shifting healthcare needs. Existing research on the emerging adult inpatient experience is limited to survey-based studies, which indicate that this population reports worse experiences than younger and older patients. This project uses a phenomenological qualitative approach, characterizing emerging adults' perceptions of inpatient healthcare experiences

METHODS

We conducted a multi-institutional, semi-structured interview study of patients aged 18-25, hospitalized at 2 academic adult hospitals. Interview questions explore inpatient hospital experiences, with open-ended questions referencing many aspects of care. De-identified interviews were recorded and transcribed. We developed a code book using a combined inductive and deductive thematic analysis. Two independent coders identified and obtained 100% consensus on all codes and themes.

RESULTS

Nine interviews were conducted from 6-2023 to 4-2024. Mean participant age was 22.6 years, with 55% identifying as Black, 33% White, and 11% as other; 11% identified as Hispanic. Analysis of the interviews created 68 codes. Five themes were identified through thematic analysis:

1. Emerging adults' perception of respect for their autonomy directly correlates with satisfaction of care.
2. Providers need to recognize the impact of acute/chronic illnesses and hospitalizations on emerging adults' lifestyle and societal responsibilities.
3. Emerging adults' perceptions of healthcare provider's attitudes towards them impacts their perception of quality of care.
4. Emerging adults' previous experiences during childhood or prior hospitalizations impacts their perception of current hospitalization encounters.
5. The navigation and current processes of medical systems leads to frustrations for emerging adults in their inpatient experiences.

CONCLUSIONS

Emerging adults have unique experiences and healthcare concerns. Improvement in patient autonomy, communication, and recognition of life disruptions may increase satisfaction. Previous pediatric hospitalizations have large impacts on future inpatient experiences. This work creates a foundation to advocate for future interventions and research to improve the experience of emerging adults in adult hospitals."

CONTACT: Nicole Oakman, MD
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PLATFORM #2

The Provision of Optimal Medical Care for Adults with Chronic Health Conditions Originating in Childhood

Catherine A. Harwood, MSSW; Lailea Noel, PhD

BACKGROUND

The number of adults with chronic health conditions originating in childhood (ACHCOC) is steadily increasing. There is well established information on pediatric care for this population. Though, not enough literature examines the pediatric-to-adult healthcare transition from the perspective of adult providers. This research will reveal common traits related to how adult providers tailor patient-centered care to this population. Ultimately, if more is known about how and why adult providers care for adults with complex childhood-onset conditions, the care needed for ACHCOC can be expanded. The primary research question for this project is, "What additional considerations are necessary when adult providers are delivering care to adults with chronic health conditions originating in childhood from the perspective of the adult providers?" The aim was to describe and evaluate how these providers approach caring for adults who have transitioned from pediatrics.

METHODS

Semi-structured qualitative interviews (N=12) were conducted with healthcare providers (i.e. MD, DO, PA, or APRN) who work with ACHCOC in the United States. Participants were recruited via convenience, snowball, and purposive sampling. Interviews covered participants' motivation for caring for members of this population, views of optimal care, and ideas for advancing care. Virtual interviews lasted 30-60 minutes and were transcribed and coded thematically using NVivo software

RESULTS

Preliminary findings showed key themes, including the importance of involving family, the value of interdisciplinary teams, the necessity of considering individual developmental needs, creativity with funding, and the need for more mental health services.

CONCLUSIONS

The data suggest that in addition to seamless medical care, prudent attention to additional considerations is critical when caring for this vulnerable population. Findings suggest that implementing these considerations through an interdisciplinary approach would be advantageous during the transition process. Adult providers facilitate the provision of optimal medical care for these adult patients.

CONTACT: Catherine A. Harwood, MSSW
caharwood@utexas.edu

PLATFORM #3

Adaptation and Evaluation of an Intervention to Promote Autonomy and Competence in Adolescents with Sickle Cell Disease

Blanca Sanchez-Fournier, BA; Jordyn Babla, BS; Titilope Fasipe, MD, PhD; Beth H. Garland, PhD; Mary Majumder, JD, PhD; Albert C. Hergenroeder, MD; Constance M Wiemann, PhD

BACKGROUND

Adolescents and young adults with special health care needs (AYASHCN) need time alone with pediatric providers to develop self-management skills, yet only 44% of AYASHCN have met with providers without caregivers. A successful multi-level (provider, AYASHCN, caregiver) Intervention designed to Promote Autonomy and Competence in 17-to-18-year-old Transition-Aged Youth (IPACT) was recently adapted for 14-to-17-year-olds with sickle cell disease (SCD). This study describes the adaptation and pilot evaluation.

METHODS

Adaptation occurred through consultation with SCD providers and patient/caregiver focus groups and advisors. The provider (n=6) intervention focused on skills to interview adolescents alone and support self-management. The parallel adolescent/caregiver intervention (n=15 dyads) used a Motivational Interviewing-influenced approach to support time alone with providers, communication between adolescent and caregivers, and adolescent self-advocacy. Outcome measures included participant satisfaction; percent of visits adolescents were interviewed alone; adolescent self-efficacy and perceived importance to meet with providers alone; competence in healthcare self-management; and autonomy and support for health care autonomy from caregivers/providers. Data will be analyzed using paired and independent sample t-tests.

RESULTS

To date, 11 of 15 dyads have completed the two-session intervention. Preliminary results include: over 90% of participants reported high satisfaction with sessions, over 80% would recommend them to a friend, and all agreed the intervention should become standard-of-care. Participant perceived importance of meeting with providers alone increased from baseline to post-intervention. Reports of adolescents meeting with their provider alone increased from 33% at baseline to 100% post-intervention. Adolescents valued being prepared for clinic visits and learning self-management and self-advocacy skills. Caregivers appreciated the suggestions for teen preparation, the focus on independence, and strengthened communication. Provider outcomes will also be reported.

CONCLUSIONS

The intervention was well received by participants. These findings set the stage for taking this intervention to scale for all adolescent sickle cell patients, making the intervention a standard component of clinic visits."

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POSTER #1

Self-management in the Context of Psychosocial Health: A Qualitative Descriptive Study of Adolescents with Chronic Conditions

Katherine Melton, PhD, RN; Kira Fried, BS; Mimi Stotsky, PhD; Jean Connor, PhD, RN, CPNP, FAAN; Greg Sawicki, MD, MPH

BACKGROUND

Adolescents with chronic conditions are at risk for poor health outcomes related to unsuccessful self-management. However, the influence of peers and other psychosocial factors on self-management is poorly understood.

METHODS

We recruited adolescents (12-17 years) with ≥1 chronic health condition from a single children's hospital. We conducted semi-structured video or phone interviews which were transcribed and independently coded by 2 researchers. An iterative codebook guided content analysis and coders meet weekly to resolve discrepancies

RESULTS

24 adolescents with a range of chronic conditions participated (see Table 1). The overarching theme: Self-management in the Context of Psychosocial Health was characterized by six subthemes. 1) Multidimensional Support Needs: Comprehensive support from peers, family, and school is needed to support psychosocial health and self-management. 2) Excluded, Targeted, and Misunderstood: Across conditions adolescents reported negative peer interactions and health-related bullying which affected how they viewed their diagnosis and treatments. 3) Fitting in Versus Standing Out: Participants expressed a desire to fit in and feel "normal". 4) To Share or not to Share: Regardless of diagnosis, participants describing controlling how much peers knew about their health. 5) Taking Care of Myself: Participants expressed generally high levels of confidence in their self-management abilities; a supportive best friend often served as a key self-management facilitator. 6) "They know what you're going through": For those who had the opportunity, peer support from other chronically ill teens had a positive impact on coping and psychosocial health. Participants were generally open to trying peer support.

CONCLUSIONS

Peer relationships served both as a self-management facilitator (i.e., a supportive best friend giving medication reminders) and as a barrier (health- related bullying leading to illness concealment at school). Similarities in the data across chronic conditions supports a disease-agnostic approach to future self-management interventions, such as peer support.

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POSTER #2

Using a Transition Mastery Score to Assess Program Effectiveness and Patient Readiness to Transition to an Adult Model of Health Care

Stephanie Pratt MSW, LMSW; Joy Fullbright MD; Tara Shores BSN, RN, CBC; Ashley Sherman MA; Nikita Raje MD, Msc, FACAAI, FAAAAI

BACKGROUND

The Transition to Adulthood Program at Children's Mercy Kansas City is available hospital wide to eligible patients. Adolescent Young Adults (AYA) 15 years and older complete an annual Transition Readiness Assessment (TRA) to evaluate how ready a patient is to transfer to an adult model of health care. AYA/caregivers answer questions on a Lickert scale: someone else will have to do this, I want to learn this, I am learning how to do this, Yes, I can do this, and N/A.

METHODS

The transition mastery score was developed to effectively assess the progression of AYA/caregivers' knowledge throughout the program. TRA responses were scored 0-3, based on assessment responses. A percentage score was created to account for variable denominators. AYA/caregiver mastery score percentages were reviewed from TRAs completed 6.1.2019-6.30.2024. Mastery scores were reviewed over time and based on anticipated level of independence of AYA at time of transfer.

RESULTS

There was a sample size of 10729 observations by 10459 unique patients. Spearman correlations were used to look at the relationship between age and mastery score. There was a correlation showing a positive relationship indicating that as patient age increases so does the mastery score. Mastery scores were reviewed for each level of anticipated independence and analysis showed groups were significantly different from each other. Median scores were used to evaluate the difference between levels of independence. AYA capable of being independent had a median score of 88, needing some support was 70.5, and needing full support was 48. Mastery scores at the time of transfer had a median score of 93.

CONCLUSIONS

Review of the transition mastery score allows us to evaluate our approach to health care transition. It also highlights the varying needs based on their anticipated level of independence. Further evaluation of the educational platform and resources available for those needing full support is indicated.

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POSTER #3

Understanding Adolescent Young Adult Health Care Transition Learning Priorities Through Annual Goal Selection

Stephanie Pratt MSW, LMSW; Nikita Raje MD, MSc, FACAAI, FAAAAI;
Neeti Redy; UMKC; Joy Fullbright MD

BACKGROUND

Health care transition is the process of moving from a pediatric model to an adult model of health care. Children's Mercy Kansas City has implemented a whole-hospital approach to health care transition. The programs unique method of allowing Adolescent Young Adults (AYA) and caregivers to choose the goals for their health care transition supports a plan that prepares AYA in managing their own health care and tailors care towards the desires and needs of the AYA/caregiver.

METHODS

The Transition Readiness Assessment (TRA) is administered annually based on the AYA age and anticipated level of independence at the time of healthcare transition. At conclusion of the TRA AYA select their transition goal for the upcoming year. AYA are able to choose more than one transition goal if desired. AYA and caregivers choose between standard and complex care goals. An education platform was created to support the knowledge progression of the AYA/caregiver.

RESULTS

During the time frame analyzed 11,174 surveys were completed by 8,764 patients selecting 17,875 transition goals. In those capable of being independent and anticipated to need some level of support knowing their medical history/condition and creating a three-sentence summary were the top goals selected for those aged 15-17 and 17-18 years old. While caregivers of AYA requiring full support identified legal as the top learning goal for these age groups. Finding an adult provider moved up to the top of the list across all levels of independence as AYA aged and was the top goal chosen in those aged 19-20 and 21-22 years old.

CONCLUSIONS

Allowing patients and families to choose their own goals has enabled us to evaluate what their learning priorities are. We can disseminate educational materials focused on the goals of the highest priorities to AYA/families and ensure competencies are met to support successful integration in adult care.

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POSTER #4

Pediatric to Adult Transition Care for Youth With Special Healthcare Needs (YSCHN): An Online Training for Care Providers

Romila Santra, MA; Niraj Sharma, MD, MPH

BACKGROUND

This newly developed web-based curriculum aims to teach medical professionals and trainees to better facilitate pediatric to adult care transition for youth with special healthcare needs (YSHCN). Nearly 1 in 5 children in the United States have chronic conditions of childhood origin and of this population, about 1.2 million turn 18 each year - a statistic that rises as YSCHN live longer. Smooth care transitions facilitate continuity of care, patient satisfaction, and outcomes.

Barriers to effective transitions include lack of clinical transition programs and difficulty finding adult providers comfortable with YSCHN. Numerous surveys indicate this discomfort stems from insufficient education about childhood-onset diseases and principles of transition care.

Currently, there exists no formal online training concerning transition care. To address this gap, we have developed a self-guided online training for pediatric and adult providers serving YSCHN.

METHODS

This training broadly covers tenets of YSCHN care through six interactive, online modules: Introduction to Transition, Adherence, Decision-Making, Health Equity, Social Determinants of Health, and Solutions. Each takes 5-10 minutes to complete. Conditions including intellectual/developmental disability, cystic fibrosis and sickle cell anemia are longitudinally integrated to illustrate key principles. For example, the concept of shared decision-making is introduced through intellectually disabled young adults with healthcare proxies or legal guardians. Sections leverage patient and caregiver interview clips to teach via first-hand experiences. These modules are developed on Articulate 360, utilizing interactive graphics and self-check quizzes.

RESULTS

This training is in progress, with anticipated completion July 2025. Future work will (1) pilot this training with pediatric and internal medicine residents, (2) collect feedback through interviews and questionnaires, (3) evaluate knowledge acquisition and retention, change in clinical behavior, and satisfaction.

CONCLUSIONS

This novel online curriculum utilizes patient-centered teaching to equip providers with essential knowledge on YSCHN transition care.

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POSTER #5

Quantifying Success: Evaluating Transfer Metrics in a Specialty Transition Clinic

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BACKGROUND

Attending an adult provider appointment is one measure of transition success, but it only marks the endpoint of a broader process. Little has been published on transfer metrics in medically complex youth. We present data on transfer metrics from our specialty transition clinic.

METHODS

Our clinic, a referral-based consultation service for medically complex youth, provides customized transition care guided by the Six Core Elements. To evaluate transfer success, we reviewed the literature to identify appropriate metrics. We identified and tracked metrics related to clinic accessibility, transition readiness, care coordination, and continuity of care.

RESULTS

From mid-2023 to April 2025, our clinic transferred 46 medically complex patients to adult care. Sixty-six patients are currently “in process” and 17 were lost to follow-up. Time from referral to first outreach and first appointment was 71 and 96 days, respectively (clinic accessibility). All patients had their transition readiness assessed (transition readiness), but only 10 had multiple assessments (Mean improvement = 13 percentage points). All patients had a transfer checklist, and 98% had an adult PCP (care coordination). All attended an adult provider appointment, with 61% seeing their new provider within six months of their last pediatric visit (continuity of care).

CONCLUSIONS

Our clinic effectively transfers medically complex patients to adult care. However, few patients had multiple transition readiness assessments, suggesting many providers are not discussing transition earlier, relying on our clinic as the “first and final stop” for transition services. Delays in linkage reflect internal referral processing challenges rather than clinic availability. With an established tracking system, we aim to improve timely linkage to care. Transfer success extends beyond adult provider appointment confirmation. Clinic accessibility, transition readiness, care coordination, and continuity of care offer a broader understanding of successful transfer and where transition programs can focus future efforts."

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POSTER #6

Prevalence and Trends in Pediatric-Onset Chronic Conditions in the United States, 1999-2018

Lauren E. Wisk, PhD; Niraj Sharma, MD, MPH

BACKGROUND

We sought to provide an updated estimate of the current prevalence and recent trends (over the past two decades) in pediatric-onset conditions among a nationally- representative sample of youth to identify opportunities for prevention and intervention.

METHODS

We performed a secondary data analysis of nationally-representative data on 236,412 participants (ages 5-25 years) from the 1999-2018 National Health Interview Survey. Chronic conditions (CCs) and functional limitations (FLs) were self-reported by the participant or a qualified proxy-respondent. We employed multivariate linear probability models to estimate annual average increase in CC/FL prevalence and differences in prevalence across sociodemographic characteristics.

RESULTS

The prevalence of children (5-17 years) with a CC/FL has risen from 22.57% in 1999/2000 to 30.21% in 2017/8 – an adjusted annual increase of 0.24 percentage points per year (p<.0001) or about 130,000 additional children per year. The prevalence of young adults (18-25 years) with a CC/FL has risen similarly (adjusted annual increase of 0.33 percentage points per year, p<.0001). Asthma and mental/behavioral health conditions were some of the leading CC and FL (respectively) contributors to this increase for both age groups. We estimate that approximately 1.2 million youth with a CC or FL currently turn 18 each year.

CONCLUSIONS

The US is currently seeing an unprecedented number of youth with pediatric-onset conditions. It is incumbent for the US health system to seek ways to treat these patients in pediatric settings and eventually matriculate them into adult care.

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POSTER #7

The Needs of Patients and Families with Mucopolysaccharidosis (MPS) During the Transition from Pediatric to Adult Health Care

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BACKGROUND

The mucopolysaccharidoses (MPS) are a group of rare genetic disorders characterized by progressive multisystem disease. With recent improvements in medical care, people with MPS are increasingly surviving into adulthood. A smooth transition from pediatric to adult-based medical care is therefore crucial to maintain overall well-being. However, to our knowledge, little research has assessed the needs of people with MPS and their families during the transition from pediatric to adult care in the US.

METHODS

With input from community focus groups and a survey methodologist, we designed an online survey to ask patients and caregivers about their experiences regarding the transition from pediatric to adult care. Using a mixed methods approach, we analyzed eligible responses from 23 participants across the US who have or care for someone with MPS I (57%), II (26%), III (9%), and IV (4%). 9 participants were patients, ages 19.6-31.1 years, and 14 were caregivers, ages 26.6-62.7 years. 11 (48%) fully transferred to adult care.

RESULTS

While 54.6% of participants worried that adult-based care would be lower in quality compared to pediatric care, 50% felt glad the transfer to adult care occurred. 47.6% reported difficulty finding adult-based providers and experienced minimal understanding of MPS among adult practitioners (42.8%), lack of appropriate-sized medical equipment (33.3%), and minimal coordination between pediatric and adult care teams (28.6%). Most patients (55.6%) felt their abilities were underestimated. Caregivers reported increased anxiety (83.3%), hopelessness (33.3%), muscle pain (25%), and headaches (16.7%) during the transition process.

CONCLUSIONS

Patients and families with MPS need early preparation, care coordination, appropriate-sized medical equipment, and resources for informational and emotional support during the transition to adult care. While families worry about the transfer to adult care, increasing awareness and resources for support can help ease concerns, make the transition smoother, and improve outcomes for patients and caregivers."

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POSTER #8

Transition to Adult Care in Adolescents with Sickle Cell Disease: Are We Meeting the Mark?

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BACKGROUND

Adolescents with sickle cell disease (SCD) report lack of confidence in management of their own health as a barrier to transition to adult care. Transition readiness tools (TRT) increase confidence, but their impact on transition rates remains unknown. We aimed to assess the use of TRTs and to define the association between the use of TRTs and successful completion of an appointment with adult hematology, as well as the association with use of acute care during the transition period

METHODS

We conducted a single-institution retrospective study of adolescents with SCD who transitioned from pediatric to adult hematology from 2017-2023. We defined the transition period as the time between the last pediatric and first adult visit. We collected demographic data and measured TRT use, the duration of the transition period, and Emergency Department (ED) usage during the transition period.

RESULTS

A total of 138 patients met inclusion criteria. The median age at transition was 19.6 years (IQR: 18.5, 20.9). The distribution of genotypes, gender, and race were similar to our overall clinic cohort. Eighty-four patients (60.9%) had a documented adult hematology visit and 86 (62.3%) utilized the TRT. TRT use was associated with increased likelihood of establishing with an adult hematologist (OR = 2.99, p = 0.01). Median time to first adult visit was similar between TRT users and non-users; 245 days (IQR 48.0, 448.0) versus 263 days (IQR 96.0, 473.0), p=0.96. The median rate of ED visits/year during the transition was 0.62 (IQR 0.35, 1.19) and 0.89 (IQR 0.38, 1.81) in those with versus without TRT use.

CONCLUSIONS

TRT use was associated with higher likelihood of having an adult hematology visit, though it did not shorten the transition period or reduce intervening ED use. Studies to optimize TRT implementation and to assess the impact of TRTs on transition outcomes are needed.

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POSTER #9

Satisfaction with care among adults with DD and caregivers receiving integrated or usual care

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BACKGROUND

Adults with developmental disabilities (DD) frequently experience low satisfaction with community healthcare and unmet healthcare needs. Integrated care (IC), where primary care and mental health services are co-located, is one care delivery model that may promote satisfaction with care and reduce unmet needs among adults with DD that has not yet been evaluated. Our objective was to evaluate satisfaction with care, unmet healthcare needs, and healthcare utilization among adults with DD receiving IC relative to those receiving usual care.

METHODS

Participants included adults with DD and caregivers of adults with DD. N=50 adults with DD (N=33 IC) completed self-reports, and N=61 caregivers provided proxy-reports (N=31 IC). Participants completed an online survey measuring satisfaction with care, unmet healthcare needs, and healthcare utilization. Follow-up interviews were completed with N=14 adults with DD (N=11 IC) and N=17 caregivers (N=8 IC). Participants were compensated with a $15 Amazon eGift code for completing the survey, and a $25 gift code for completing an interview. Quantitative survey data were analyzed with descriptive statistics and were compared between groups using Fisher's Exact tests, and qualitative interview data were analyzed with thematic analysis.

RESULTS

A total of 138 patients met inclusion criteria. The median age at transition was 19.6 years (IQR: 18.5, 20.9). The distribution of genotypes, gender, and race were similar to our overall clinic cohort. Eighty-four patients (60.9%) had a documented adult hematology visit and 86 (62.3%) utilized the TRT. TRT use was associated with increased likelihood of establishing with an adult hematologist (OR = 2.99, p = 0.01). Median time to first adult visit was similar between TRT users and non-users; 245 days (IQR 48.0, 448.0) versus 263 days (IQR 96.0, 473.0), p=0.96. The median rate of ED visits/year during the transition was 0.62 (IQR 0.35, 1.19) and 0.89 (IQR 0.38, 1.81) in those with versus without TRT use.

CONCLUSIONS

Adults with DD receiving integrated and usual care had high satisfaction with care. Future studies are needed in different healthcare contexts to better understand how IC is associated with satisfaction with care for this population.

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POSTER #10

Smart Phrase Impact on Weight Loss Discussion for Adults with Concurrent Down Syndrome and Obesity

Michelle Cornacchia, MD; Julie Marchioni; Kevin Lynch; Mark Kapran; Ara Khoylyan

BACKGROUND

Increase weight loss discussion in adult patients with Down Syndrome and obesity in Dr. Cornacchia’s Comprehensive Care Clinic, Geisinger Medical Center by 50% by August 1st, 2024 using a new smart phrase based on GLOBAL Down Syndrome Guidelines.

METHODS

The patients in this study were adult patients with Down Syndrome and obesity (BMI > 30) in Dr. Cornacchia’s Comprehensive Care Clinic, Geisinger Medical Center. The data obtained in this study could potentially be extrapolated to larger populations of patients with Down Syndrome and obesity.

INTERVENTION

Adult patients with concurrent Down Syndrome and obesity seen in a Geisinger Medical Center Comprehensive Care Clinic between December 2023 and March 2024 were included in the study. Patient charts were reviewed, monitoring for prevalence of discussions with patients about dietary modifications, physical activity, or other weight loss interventions, such as medications

RESULTS

A smart phrase prompting the weight loss discussions was developed and implemented between April 2024 and July 2024. The frequency of discussion about weight loss strategies during the outpatient visits was tracked pre- and post-intervention. Results were subsequently compared for evaluation.

CONCLUSIONS

There was a 71% increase in the prevalence of weight loss discussions between providers and adults with concurrent Down Syndrome and obesity with integration of the smart phrase, which exceeded our target of greater than 50%.

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POSTER #11

TRAQ Stars: Improving Transitions of Care for Adolescents with Diabetes, A Quality Improvement Initiative

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BACKGROUND

Adolescents with chronic conditions face many challenges during the pediatric-to-adult healthcare transition (HCT). Individuals who received inadequate HCT may experience poorer clinical outcomes and health-related quality of life than those who undergo a structured process. The Transition Readiness Assessment Questionnaire (TRAQ) is a validated self-assessment tool that measures youths' healthcare self-management and advocacy skills. We aimed to use the TRAQ to establish a formal HCT process in a pediatric endocrine clinic.

METHODS

Using quality improvement (QI) methodology via plan-do-study-act (PDSA) cycles, we created and implemented a structured process for administering and reviewing the TRAQ (process measure) with patients and caregivers to integrate HCT into standard clinical practice (outcome measure). This initiative took place at an academic pediatric diabetes clinic which serves >200 patients over >450 clinical encounters annually. We included patients > 16 years with a diagnosis of diabetes (both Type 1 and 2) and 1+ in-person clinic visits in 2024. Over six PDSA cycles, the most effective interventions included utilizing the electronic medical record (EMR) to ensure automatic and more frequent TRAQ assignments, making completion status more visible for diabetes teams on the EMR, and providing education on HCT during diabetes business meetings. Balancing measures included appointment length and team satisfaction.

RESULTS

TRAQ completion increased from 28% to 61% over 12 months (Figure 1), while the average rate of review of completed TRAQs increased from 0% to 32%. There were no changes to balancing measures.

CONCLUSIONS

We increased administration and review of the TRAQ that has been sustained over 60% and 30%, respectively, during the intervention period. Establishing successful TRAQ administration is a part of a framework to incorporate HCT into standard clinical care for both patients with diabetes. Next steps include sustaining TRAQ utilization over time and expanding the target populations to include other chronic conditions."

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POSTER #12

Small Programs, Big Institutions: Increasing Peer Support Program Engagement for Adolescent and Young Adult Patients Living with Chronic Conditions, A Continuous Quality Improvement Initiative

Joshua S. Mercer, MD, MBA; Ruchi Doshi, MD, MPH; Yu-Lin A. Lee, MD; Dana Clifton, MD; LaKaya Craig, MS; Jon Wolseth, PhD

BACKGROUND

Adolescent and young adults (AYA) with chronic conditions experience increased rates of mental health disorders, lower educational and vocational attainment, and poorer health-related quality of life. Peer support and mentorship programs may improve condition self-management, decrease social isolation, and support the pediatric-to-adult healthcare transition. Program enrollment relies on provider and institutional awareness to identify eligible patients which can be difficult given clinic staff turnover and the cyclical nature of residency. Our goal was to increase referrals to Adolescents Transitioning to Leadership and Success (ATLAS), a local, academic peer support program, through a quality improvement (QI) initiative, utilizing referrals (process measure) as a measurable proxy for program engagement (outcome measure).

METHODS

This initiative took place at Duke University Hospital in 2024. To increase ATLAS referrals, interventions were targeted to increase provider (faculty and trainee) knowledge of the program. For PDSA-1, information about ATLAS and the referral process was presented at provider meetings. For PDSA-2, quarterly emails were sent to providers, and provider and patient-focused flyers and dot phrases were disseminated. Referral numbers, referring providers, and referring department or clinic were recorded.

RESULTS

Prior to our interventions, the mean referrals/quarter between 2020-2023 was 11.6, with yearly totals of 34 (2020), 57 (2021), 51 (2022), and 43 (2023). In 2024, ATLAS referrals increased to 87, representing a 102% increase in yearly referrals from 2023. In PDSA-1, there was a mean 19.5 referrals/quarter. In PDSA-2, there was a mean increase to 26 referrals/quarter. The number of providers making referrals increased from 24 (2023) to 42 (2024).

CONCLUSIONS

Targeted interventions towards providers regarding ATLAS led to a substantial increase in referrals. Next steps include sustaining program awareness longitudinally for faculty and staff and increasing interprofessional team members engagement to ensure that ATLAS is accessed by those who would benefit most."

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POSTER #13

New Spina Bifida Health Care Transition Toolkit

Patience White, MD, MA; Hadley Wood, MD; Nkem Chineme, MPH; Jamie Jones, MPH; Peggy McManus, MHS; Ellen Fremion, MD

BACKGROUND

Every year more than 1,500 children are born with spina bifida (SB), and the 30-year survival rate is nearly 90%. These children face ongoing medical and surgical care needs related to their motor and sensory deficits and comorbidities, including neurocognitive, orthopedic, respiratory, gastrointestinal, urologic, growth, and mental health conditions. The transition to adult care is often complex and requires gradual and developmentally appropriate collaboration and coordination to support adult functioning, independence, and safe transfer into adult care.

METHODS

The SB health care transition (HCT) Toolkit was developed by a 17-member multidisciplinary expert group of subspecialist and primary care pediatric and adult clinicians, and individuals with lived expertise. Three sections of focus were identified: Planning for Transition, Transition to Care, and Integration and Post-Transition Care in the Adult Clinic.

RESULTS

The Toolkit was a collaborative effort between the American Academy of Pediatrics (AAP), Centers for Disease Control and Prevention (CDC), Got Transition, and the Spina Bifida Association (SBA). It is available in over 40 languages, with easy-to-use resources. It was reviewed by several non-author experts, including AAFP and AAPM&R. Relevant AAP committees/councils/sections reviewed the Toolkit, and CDC provided clearance.

CONCLUSIONS

This comprehensive digital Toolkit is the first dedicated HCT resource for persons with SB, focusing on both pediatric and adult healthcare. It highlights SBA care guidelines to support SB care in adult practices where clinicians may be unfamiliar with the condition. It also includes a customizable and fillable Medical Care Plan tool that can be updated based on the changing needs of the patient and serving as a care plan, transfer, and emergency information resource.

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POSTER #14

Outpatient Care of Young Adults in Pediatric Hospitals

Laura Hart, MD, MPH, FAAP, FACP; Sara Wagner, BS; Kristin Jensen, MD, MPH

BACKGROUND

Nearly 30% of young adults have a chronic condition (YACC), such as asthma, congenital heart disease, and intellectual and developmental disabilities. YACC experience poor health outcomes compared to both younger and older age groups with chronic conditions. Current policy and guidelines encourage YACC to continue to receive care with pediatric providers until they are prepared to transfer to adult care. However, it is unclear how many adults continue to receive care in pediatric settings

METHODS

Using data from PEDSnet (a pediatric learning health system and clinical research network of 10 pediatric hospitals within PCORnet, the National Patient Centered Clinical Research Network), we identified all patients ages ≥15years with at least 2 outpatient visits in the year 2018. We excluded those seen at urgent care and all obstetric visits. Results were stratified by age and by hospital to understand variation by hospital.

RESULTS

There were 208,192 eligible adolescents ages 15-17yr seen across PEDSnet, compared to 108, 887 adults ages 18 and up (n= 54, 783 for ages 18 to 21yr, n = 13,430 for ages 22 to 26yr, and n= 40,674 for ages 27yr+). Overall, adults ages 18yr and up accounted for 3.6% of all outpatient visits, with a range of 1.0% to 7.1% across the hospitals. At 4 of the 10 hospitals, adults ages 27yr and up made 2-3% of outpatient visits.

CONCLUSIONS

The large drop-off in the number of adults seen compared to older teens suggest that many YACC exit pediatric care around the age of 18yr, even as guidelines recommend considering a move to adult care at an older age. Nonetheless, adults ages 18yr and up account for a considerable proportion of outpatient visits at pediatric hospitals, with significant variation across hospitals. Data informs access and workforce planning in the care of YACC in the outpatient setting."

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POSTER #15

Impact of a pediatric-adult health care transition program, including perspectives from transferred patients and caregivers

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BACKGROUND

Health Care Transition (HCT) supports youth moving from pediatric, parent-led care to adult, patient-centered care. Adolescents with special health care needs are at higher risk for gaps in care and reduced engagement. The Jacksonville Health and Transition Services (JaxHATS) program serves patients aged 13–23 years in Northeast Florida to address these challenges. Despite structured support, securing adult care remains a challenge. To improve continuity, our SMART aim is to increase the percentage of patients with a scheduled adult primary care provider (PCP) at their final JaxHATS visit to 75% by June 2026.

METHODS

We used the Institute for Healthcare Improvement model. Our main metric was the proportion of patients with an identified adult PCP by age 22.5. Interventions included a flow sheet to track transitions and interviews with patients and caregivers to explore barriers and facilitators. Data were plotted yearly on control charts, and interview responses were analyzed inductively to assess the transition experience.

RESULTS

Only 21% of patients had adult PCP visits scheduled by their final JaxHATS visit. Patients were counseled 69% of the time and identified a PCP 40% of the time. While processes are improving, no special cause variation has been observed. Patient narratives revealed transition barriers, including difficulty finding accessible PCPs and building relationships with new providers. Illustrative quotes include, “even though they made it easy, it's still scary, because you get used to having his doctor” and “I was surprised how/why it's so difficult for us to find a doctor's office that will take a new adult patient.”
Conclusion: While discussions were frequent, identifying and scheduling with adult PCPs remained difficult. One barrier was the inability to schedule a new PCP while still in JaxHATS. We expect special cause variation this year and plan to add completed PCP visits to our metrics.

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POSTER #16

New Health Care Transition Toolkit Series for Youth with Intellectual and Developmental Disabilities

Jane St. John; Marie Clark; Rachel Shandler, Patience White, MD, MA; Peggy McManus, MHS

BACKGROUND

Only 14% of youth with I/DD receive HCT preparation. Studies confirm lack of accessible HCT tools for this population. Using the Charting the Lifecourse (CtLC) framework, 6 HCT Toolkits were produced by UMKC for the Center for Transition to Adult Health Care for Youth with Disabilities, led by Family Voices, along with SPAN and Got Transition.

METHODS

UMKC worked with Got Transition initially around important aspects of HCT and then worked with SPAN and their Youth Advisory Group to co-create each kit. UMKC then revised and finalized. To ensure cognitive accessibility, an EZ-reader format and a side-by-side guide were designed for youth, including stopping points and prompts to practice new HCT information. A separate 15-member Youth and Family Product Review Group piloted each "finished" toolkit with other youth and families and then participated in monthly calls on what they liked or didn't. UMKC made needed changes and shared the final product before posting publicly.

RESULTS

The 6-part HCT Toolkit Series include: Understanding HCT, Knowing About Your Health Care, Leading Day-to-Day Health Care Routines, Understanding Your Legal Rights in Health Care Settings, Leading Your Health Care Visits and Interactions, and Planning for Moving to Adult Health Care. Feedback underscored the value of co-creation, with youth and families feeling their input improved the kits. Many appreciated the repetition in content, making new concepts easier to grasp. Also, the kits sparked important conversations on topics they hadn't thought much about before. A Toolkit Feedback Evaluation Survey is planned to ask about increases in understanding and ability to participate in one's own care.

CONCLUSIONS

These new HCT Toolkits were designed with and for youth with I/DD. They represent a major addition to the CtLC Library under the healthy living life domain and also available at www.movingtoadulthealthcare.org

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POSTER #17

Expanding Patient Enrollment and Nursing Engagement in an Asthma-Focused Pediatric-to-Adult Transition Program

Laura Payne MPH RN CPN AE-C; Meghan Camacho BA; Suzanne Ngo MD; William C. Anderson III MD

BACKGROUND

The Asthma Self-Care, Education, and Transition (ASCEnT) Program at Children's Hospital Colorado provides transition preparation for adolescent and young adult patients with asthma being cared for in Pulmonology or Allergy. Demand for transition preparation exceeded capacity of a single nurse care coordinator, prompting new strategies to address transition education, with a specific focus on younger adolescents and patients at network of care locations.

METHODS

Educational messages were distributed via Epic MyChart for patients 14 years of age and older with at least two prior follow up appointments with Allergy or Pulmonology and a diagnosis of asthma. MyChart messages introduced the ASCEnT program and provided age-specific transition preparation goals. Nurses in network of care locations were recruited to be nurse transition champions. Nurse champion responsibilities included introducing ASCEnT during clinic visits and providing medication management education based on Transition Readiness Assessment Questionnaire responses.

RESULTS

From 07/2024 through 04/2025, 97 patients aged 14 to 16 were sent MyChart messages, leading to engagement with 77 patients, a 175% increase in this age group compared to the year prior.Approximately 20% of patients did not open the MyChart message. Five nurse transition champions were recruited at four sites starting in 02/2025.The nurse champions engaged ten additional patients in the transition process as of 04/2025.

CONCLUSIONS

Engagement of young adolescents in transition preparation is key as early intervention can help streamline transfer later. MyChart messaging provides a relatively low burden method to introduce transition education and increase participation. A team-based approach with multiple transition champions across several clinics ensures patients receive transition care regardless of patient location.

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POSTER #18

PREPARE for Autistic Adults: Resident Physicians’ Experiences with an Adult Autism Training Program

Alison Deitsch OTD, OTR/L; Daniel Gilmore PhD; PREPARE Autistic Advisory Board; Lisa Juckett, PhD, OTR/L; Christopher Hanks, MD; Susan M. Havercamp, PhD; Daniel Coury, MD; Brittany N. Hand PhD, OTR/L

BACKGROUND

Autistic adults experience disproportionately high rates of physical and mental health conditions, along with significant unmet healthcare needs. A major contributing factor is the lack of physician training in providing care for autistic adults, which perpetuates healthcare disparities and leaves many providers feeling ill-equipped. To address this gap, we developed a novel physician training program—Promoting Residents’ Excellence in Patient-centered cARE (PREPARE) for Autistic Adults—to enhance resident physician’s’ readiness to deliver patient-centered care to this population. Our research team conducted a qualitative study examining how PREPARE influenced resident physicians’ knowledge, attitudes, and self-efficacy in caring for autistic adults. This research is a part of a broader mixed-methods evaluation.

METHODS

Participants (N = 29) were recruited from three Ohio State University residency programs and enrolled in the PREPARE pilot program. Following program completion, participants (N = 18) completed a semi-structured interview exploring their experiences and perceived impact of the training. Participants were compensated with up to $250 and 5 hours of conference credit. Interviews were analyzed using an inductive, phenomenological approach. The PI reviewed interview transcripts and developed a preliminary codebook. Three researchers independently coded interviews until 90% agreement was met across codes.

RESULTS

Three primary themes emerged. First, active learning increases efficacy. Participants reported that interactive components—such as standardized patient encounters—enhanced understanding and content retention. Second, I feel like I’ve really grown as a practitioner. Residents described greater competence and confidence in caring for autistic adults post-training. Third, insights from others increased efficacy. Engagement with facilitators and peers enriched participants’ learning through collaborative dialogue.

CONCLUSIONS

Preliminary findings suggest that the PREPARE program improves residents’ knowledge, confidence, and capability in providing care for autistic adults. These results indicate PREPARE is a potential approach to enhance providers’ readiness and ability to care for this population.

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POSTER #19

Transition from Pediatric to Adult Care from the Perspective of Parents of Young People with a Pediatric Rheumatic Disease in Switzerland: A Qualitative Study as Part of the Contextual Analysis of the HEROES (Rheumatology Transition for Young People in Switzerland) Study

Marlis Matter, RN; Natalie Tarr, PhD; Mary-Louise Daly, RN; Andreas Wörner, MD; Thomas Daikeler, MD; Sandra Staudacher, PhD; Lut Berben, PhD, RN

BACKGROUND

In Switzerland up to half of the 3000 children and adolescents diagnosed with a pediatric rheumatic disease (PRD) need continuous medical care into adulthood. Parents often play a vital and supportive role in the transition of their children from pediatric to adult care. The transition phase requires, among other things, a complex reorganization of family roles, such as the transfer of responsibility for self-management and healthcare from parents to adolescents and young adults (AYA). Despite their central role, the perspective of parents is still under-researched. The aim of this study is to explore the experiences and needs of parents of AYA with a PRD in relation to current practices and future models of the transition process in Switzerland.

METHODS

Based on qualitative research, following a rapid ethnography methodology, the project utilizes various methods: semi-structured interviews with parents, observational sequences in rheumatology consultations, and informal conversations with different stakeholders in two pediatric rheumatology centers and their adult counterpart. Data analysis follows Braun and Clarke’s six phased reflexive thematic analysis.

RESULTS

Eight interviews were conducted with a parent of an AYA with a PRD and aged between 16 and 24. AYA are at different phases of the transition process – before, during, or after transition to adult medicine. These interviews were complemented by 10 observation sessions. An initial analysis showed that parents are heavily involved in supporting their children in their disease- and self-management and in achieving autonomy and independence. Parents experience high psychosocial and emotional stress and express a desire for open and structured communication.

CONCLUSIONS

Parents need support in dealing with their AYA’ disease-related challenges and want comprehensive information and active involvement in their care - throughout the entire transition process. Healthcare professionals are required to meet these needs through proactive, structured communication and participatory collaboration.

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POSTER #20

Their Voices Need to be Heard: Young Adults with Chronic Conditions' Retrospective Perspectives of Their Health Care Transitions

Jihye Lee, PhD, RN; Tyra Gridwood, PhD, RN; Cecily L. Betz, PhD, RN, FAAN

BACKGROUND

As more youth with chronic conditions transition from pediatric- to adult-focused care, there is a critical need for healthcare transition practices and policies to evolve to fulfill unmet needs. To accomplish this, we sought to understand healthcare transition experiences and gaps in services provided from pediatric care to meaningfully include the perspectives of the perspectives of young adults with diverse chronic conditions who had already transferred to adult-focused care.

METHODS

We utilized an online RedCAP survey to collect descriptive, retrospective data of healthcare transition experiences from 45 young adults (aged 18+ years) with chronic conditions. Descriptive statistics were used to assess survey responses.

RESULTS

Most respondents were aged 20–25 years (46.7%), female sex (75.6%), and White race (77.8%). Respondents reported considerable unmet needs related to referrals to adult providers, challenges in navigating referrals to other adult systems of care, including those related to education, employment and community living. Overall, these findings suggest that while some transition services were provided, comprehensive support—particularly in areas such as finding adult providers, future planning, and managing healthcare needs—was lacking for most respondents

CONCLUSIONS

We found substantial gaps between recommended healthcare transition best practices and actual services provided to this at-risk population. Our novel findings indicate a critical need for more comprehensive, psychologically supportive, and developmentally appropriate healthcare transition planning for youth with chronic conditions. Healthcare transition planning should align with established healthcare transition guidelines and incorporate patient-centered care, such as providing services to address unmet insurance and socioeconomic needs, of youth and young adults with diverse chronic conditions.

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POSTER #21

Transition Documentation: Developing Standards and Visual Prompts to Support Triage of Transition-Aged Patients Presenting to the Pediatric Emergency Department

Adam Greenberg MSN, CRNP; Elizabeth Lolly, BS; David Junod, BS; Joseph Zorc MD, MSCE; Dava Szalda MD, MSHP; Richard Chung MD, FAAP, FSAHM

BACKGROUND

Updated documentation of transition status is an important task embedded within the Six Core Elements of Healthcare Transition and keeps patients/family and clinicians aligned throughout the process. However, consistent documentation within the electronic medical record (EMR) can be challenging, particularly for medically complex patients receiving care from multiple providers. This issue becomes more challenging for patients who have only party transferred their specialty care to adult providers and present to the pediatric emergency department (ED). Critical information to guide admission planning may not be easily accessible, leading to inappropriate admissions, delayed transfers, and increased patient/family and clinician stress. To address this, we created an EMR-based tool to support standardized transition documentation and visualization at the point-of-care.

METHODS

To create this tool, we collaborated with ED stakeholders and EMR developers. There was consensus that, at minimum, each specialty would document within a "smartform" whether transition planning started or was complete. The smartform allows data to be discretely stored and reported. For visualization, users would see a color-coded transition status in the same location within the EMR for any patients ≥ 18.

RESULTS

To date, twenty-four departments/programs have adopted the smartform. ED stakeholders report that the status indicator has facilitated the appropriate triage of transition-aged patients. With stakeholder feedback, the smartform was amended to include an indication why some specialty care remains in pediatrics. The next iteration may include the preferred admission service for patients straddling care between pediatric and adult medical systems.

CONCLUSIONS

Initial feedback from ED stakeholders indicates that the smartform is a feasible way to communicate transfer status. Plans for ongoing expansion and tracking of its use are underway. Future data collection will aim to quantify the effect on transition-related process improvements including building concordance across divisions for timeline for transfer of patients and effect on patient outcomes.

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BREAKOUT SESSION #1

Specialty-Care Process Improvement Initiative to Support Youth and Young Adults with Childhood-Onset Disability During the Transition from Pediatric to Adult Care

Tori Bahr, MD; Rhonda Cady, PhD, RN

Evidence supports early and planned pediatric to adult healthcare transition (HCT) for youth and young adults (YAYs) with childhood-onset disability. Community Health Needs Assessments for Gillette Children's, a Minnesota-based pediatric specialty-only health system serving YAY with childhood-onset disability, indicated YAY are not receiving HCT support. This reflects National Survey of Child Health findings, with only 30% of Minnesota youth with complex health conditions receiving HCT preparation.

Organizational leadership prioritized development of standardized HCT program. In 2023, a multidisciplinary team of clinicians, lived experience partners and process specialists/researchers assembled. Grounded in patient and family-centered care and The Six Core Elements of HCT™, we utilized Flow Maps and Key Driver Diagrams to understand barriers and opportunities at the clinician (training, workflow), organizational (medical record modifications, executive leadership support, metrics collection), patient/youth (self-management skill acquisition, finding adult providers), and system level (reimbursement, adult provider availability). We translated evidence and co-developed standardized tools (transition readiness assessments, HCT electronic medical record order set, clinician/YAY/family HCT resources) and processes (HCT policy, clinician/YAY/family education) for the Pediatric to Adult Healthcare Transition (PAHTI) program. Process and outcome measures that evaluate progress toward adoption and sustainability were identified.

Clinicians in Gillette's Spina Bifida Clinic received training on PAHTI tools and processes for two 1-hour sessions and completed the HCT Feedback Survey, indicating HCT tools and processes would facilitate better teamwork. Since November 2024 implementation, 24/29 eligible YAY initiated HCT planning, average age 19.7 years, 65% male and 85% with government insurance

Upcoming PAHTI implementations include Down Syndrome (4/2025) and Complex Care (7/2025) clinics. We will recount strategies, tools, processes, and lessons learned for building a resilient HCT infrastructure, and plans for scaling the program for organization-wide implementation continues into 2026.

Intended session audience is persons interested in translating HCT evidence into sustainable programs for YAY with childhood-onset disabilities.

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BREAKOUT SESSION #2

Bridge to Adulthood: Defining and Achieving Metrics

Carlie Stein Somerville, MD; Betsy Hopson, PhD

Goals:

1. Recognize urgency and value of Transition Programs: Participants will understand the clinical, financial, and operational consequences of inadequate healthcare transitions—and the value proposition of structured programs.
2. Identify Key Metrics for Stakeholder Engagement: Participants will learn which data points (e.g., ED utilization, care gaps, patient retention, satisfaction scores) most effectively influence buy-in from hospital administration and payers.
3. Explore Multidisciplinary Collaboration Models:
    i. Participants will gain insight into how various specialties (e.g., pediatrics, internal medicine, behavioral health, social work, care coordination) contribute to a successful transition framework.
4. Share Real-World Outcomes and Benchmarking Data:
    i. Participants will review successful case studies or pilot data showing measurable improvements in patient outcomes, cost savings, and satisfaction from existing transition programs.
5. Develop a Plan for Metrics-Driven Program Design: Participants will leave with a practical understanding of how to apply shared metrics to design or enhance a transition program tailored to their institution's needs.
6. Foster Ongoing Collaboration and Resource Sharing:

Participants will build connections to support continued exchange of strategies, tools, and data as they advance transition initiatives in their own settings"

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BREAKOUT SESSION #3

Putting Healthcare Transition in Context: The Role of Social Workers in Interdisciplinary Transition Teams

Caren Steinway, MSW, MPH; Angela Berger, MSW; Terri Hickam, MSW, CCM; Reny Partain, MSW, MPH; Stephanie Pratt, MSW; Susan Shanske, MSW; Symme Trachtenberg, MSW

Goals: Interdisciplinary teams are most effective when the roles and responsibilities of all members are clearly defined, utilizing the unique expertise of each to collaborate. The goal of this session is to convene interdisciplinary team members in identifying and describing the unique roles of various professionals in the transition process. Session participants will reflect on their HCT roles and responsibilities and on the roles and responsibilities of other transition team members. Next, using the social work role as an example, we will discuss a mechanism that may help others more clearly define transition roles. The session will discuss a process used to review literature on existing social work core competencies in transition and initial insights into consensus building exercises with transition experts to hone and refine these competencies.

Social work provides a unique opportunity by which to explore transition roles. Social workers are trained across micro, mezzo, and macro practice areas that include human development, biopsychosocial assessment, system navigation and advocacy. Further, social workers can assess and address coping, behavioral needs, and emotional concerns. Defining the role of social workers as part of interdisciplinary teams creates a more robust system of transition support, a concept that can be applied to other professions and perspectives.

To conclude, participants will be invited to participate in a formal Delphi study, where they will use their expertise in transition-related service delivery to further consensus building on core competencies for social workers involved in the transition of adolescents from pediatric to adult healthcare.

Take-home messages include:
1) the value of engaging interdisciplinary team members
2) defining team member roles to optimize their perspective and training
3) specific skill sets of social workers in HCT as a model.

Intended Audience: Interdisciplinary team clinicians, especially social workers; patients/families; researchers and anyone involved in HCT efforts.

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BREAKOUT SESSION #4

Self-Advocates are the Key to Successful Transition Programming

SymmeTrachtenberg, MSW; Alyia D'Ambrosio, Lead REACH Advisor (Young Adult with chronic health issues)

Goals/Take Home Messages: Find ways to include the voice of youth in HCT programming and educational events for youth and caregivers; Learn the many roles of YSHCN in HCT

REACH: Rapport, Empowerment, Advocacy through Connections and Health is a program for youth with special healthcare needs (YSHCN). Created in 2003, by YSHCN, REACH supports YSHCN and their caregivers to navigate transition to adulthood medical, community and financial services. REACH Advisors, who are Self-Advocates, provide peer support, resources, and guidance. The Social Work Lead and REACH Advisors mentor diagnostically specific hospital-based programs plan, develop, and host REACH events. Psychoeducational workshops focus on self-care, self- health management, self-advocacy, educational and/or vocational planning and social-emotional well-being. Examples include REACH for College, Work, Sickle Cell, Spina Bifida, Trisomy 21, as well as In-Patient groups and social media/podcasts. Consultation is provided to the Hospital transition to adulthood administrative and clinical leadership.

REACH workshop participants provide pre workshop content requests. Post REACH event evaluations utilize Redcap to capture workshop effectiveness and content relevance. Youth and caregivers always value the concrete community and financial resources offered and often request more time for peer socialization.

REACH Social Work leadership has benchmarked self-advocacy programs to understand the roles, responsibilities, and funding for self-advocates. A brief review of the literature found there are limited publications exploring the role of self-advocates in HCT. An in-depth review of the literature focused on the role of self-advocates informing the practice of health care transition with the goal of future publication is planned.

Intended Audience: All attendees

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PLATFORM PRESENTATION #1

Developing a Pilot Program: Assisted Blood Draws for Patients with Intellectual and Developmental Disability in Adult Care

Erini Pappas, MD; Michelle Feil, MSN, RN; Lisa Sator, PT, DPT, WCS, CLT;
Ethan Kannel, MBA; Mollie Illenberger, MSN, RN, CEN; Dava Szalda, MD MSHP

BACKGROUND

Adults with Intellectual Developmental Disabilities (IDD) require routine labs. Obtaining labs may be challenging due to differences in communication, unfamiliarity with new environments, discomfort associated with needle sticks, long wait times, and loud waiting areas creating overstimulation.

METHODS

Patients with diagnoses of IDD , who had previously failed traditional blood draws, were selected for this pilot program. Representatives from the primary care team, phlebotomy team, patient and family relations team collaborated to develop a protocol for patients to have labs drawn in an outpatient setting. This protocol included:

1. Referral by primary care
2. Outreach by nurse to introduce service
3. Lab appointment at the end of the day, in a quiet location of the lab
4. Anxiolytic ordered to home pharmacy with directions to take 30 minutes prior to appointment
5. RN navigator meets patient/family at arrival and direct wheelchair transportation to phlebotomy, with no time in waiting room
6. Phlebotomy with an experienced provider
7. Transport back to car via wheelchair

RESULTS

The pilot is currently ongoing, and full numbers will be reported at time of conference. To date, participants successfully had their ordered laboratory tests drawn. Benefits reported by the families included better timing of labs and increased patient comfort. Areas for improvement identified by family included titration of anxiolytic medications to optimize patient comfort. Staff noted structural factors like having an even larger room with a more soundproof door to minimize distractions.

CONCLUSIONS

Facilitated lab draws for patients with IDD is feasible even in a busy academic lab. The success of this pilot program is represented by successful blood draws and patient and family comfort and satisfaction. Moving forward, growth opportunities include training additional staff and consideration of additional structural factors. We also plan to use this data to advocate for a child-life specialist hired by adult medicine.

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PLATFORM PRESENTATION #2

Bridging Gaps in Emergency Care: A Clinical Pathway to Improve Healthcare Transition for Medically Complex Adults

Erin Benekos DNP, APRN, FNP-C; Shelby Shelton MPH, CCRC; Rammy R Assaf, MD; Courtney Malave, MSW, LCSW; Reny Partain Rady MPH, LCSW; Wendy Gray, PhD; Mayumi Kaneko, MSN, APRN, FNP-BC; Laura Sarff, DNP, RN, MBA, CPHQ, NEA-BC; Kate Bayhan, DNP, RN, CCRN; Alexandra Roche, MD

BACKGROUND

Transition from pediatric to adult healthcare remains a challenge for medically complex young adults. Pediatric emergency departments (PEDs) often serve as points of re-entry into pediatric systems, perpetuating fragmented care and delaying transition to adult services. Integrating transition-focused interventions within the PED is complex due to competing demands but represents a critical opportunity to improve care continuity. This quality improvement project evaluated the feasibility and utility of implementing a clinical pathway (CPW) within the PED to support transition services for medically complex adults.

METHODS

This project included adult patients (≥18 years) presenting to a PED at a stand-alone pediatric hospital. A structured CPW was developed to standardize screening, identify medically complex patients eligible for the consultative transition clinic, offer transition resources, or connect patients with external adult providers when specialty consultation was needed.

RESULTS

A total of 118 adults were screened over 10 weeks, identifying 115 unique patients. CPW utilization reached 100% by Week 9 and was maintained through project completion. Of those screened, 85 (73.9%) were excluded due to absence of a chronic condition (50.4%) or presence of a single chronic condition (16.5%). Patients meeting criteria for medical complexity (n=27, 23.5%) were referred to a transition clinic. Among those referred, 100% had ongoing pediatric subspecialty oversight and 96.3% lacked a documented transition readiness assessment. Many (40.7%) required inpatient admission after their index ED visit. Once referred, 33% completed a transition clinic visit by project conclusion.

CONCLUSIONS

Medically complex adults frequently return to the PED due to continued dependence on pediatric specialists and insufficient transition planning. While the PED is designed for emergency management, it also represents a critical gateway to comprehensive transition planning. By optimizing clinical pathways and intentionally prioritizing transition services, healthcare systems can reduce the burden on PEDs, improve care continuity, and lower healthcare utilization costs."

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PLATFORM PRESENTATION #3

The Brigham Transition Care Team: Two Years of a Model for Accepting Complex Pediatric Young Adult Patients into an Adult Health Care System

Niraj Sharma, MD; Margaret Threadgill, MD, MBA

BACKGROUND

The transition from pediatric to adult health care systems is fraught with barriers which often lead to "bounce-backs" to the pediatric system, transition postponement, increased ED utilization and inpatient hospitalizations, and decreased patient and provider satisfaction. Even when a transition has been prepared excellently by pediatrics, if the adult "accepting" side is not optimized to accept these patients, the above barriers and poor outcomes remain looming large. We present data from the first two years of the Brigham Transition Care Team (TCT), which was developed to improve the acceptance of patients into the adult health care system.

METHODS

Within one large urban adult quaternary-care health system, the TCT (two Medicine-Pediatrics physicians and one care coordinator) and virtual transition process (VTP) were developed. VTP includes: coordination with referring pediatric providers, virtual appointments with young adults with medical/social complexity and their families, addressing insurance issues, identifying an accepting PCP and communicating the transition plan, and ongoing availability/follow-up with all stakeholders. Measures included subjective patient/provider experience, time to complete the transition process, and referral to an adult complex care program.

RESULTS

Over 24 months, 185 young adults (53% male, average age of 23.1 years) were referred to the TCT. 41.6% required insurance change. 13.2% were referred to the complex care program, 80 completed transition to their new adult PCP, with an average turnaround time of 18.2 weeks. All stakeholders endorsed positive experience and increased confidence in the transition process.

CONCLUSIONS

Optimizing an adult healthcare system to accept complex transition patients is integral to successful transition. Having a formal acceptance process for these patients improves patient/provider experience and confidence in the adult system and increases value for the quaternary-care adult health system. Next steps will include increased marketing, collecting additional qualitative, primary diagnoses and language spoken to determine inequities and barriers.

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PLATFORM PRESENTATION #4

Impact of a Structured Transition Program Including the Assistance of a Virtual Transition Visit

Tara Shores, BSN, RN, CBC; Toby Rockefeller, MD, FSCAI; Brian Birnbaum, MD, FACC, FAAP

BACKGROUND

Young adult patients are lost to follow-up as they age out of pediatric care. Increasing numbers of patients born with CHD survive into adulthood, the need for structured transition programs from pediatric to adult care becomes critical. Young adult patients feel unprepared and anxious about transition, often delaying care until symptomatic. Young adult patients feel unprepared, nervous or don't know what to expect as they age out of pediatric care. Our heart center began closer collaboration with two local experienced ACHD programs and created a unique virtual transition clinic for handoff.

METHODS

Process involves yearly structured transition education starting at age 15. Between ages 18-22, transition order is placed by referring provider to ACHD team. Process includes chart review, patient contact, and scheduling virtual appointment with both pediatric and adult ACHD teams. Virtual appointment covers cardiac anatomy, surgical history, medications, insurance, and other specialty considerations. First appointment with new provider is scheduled during this session, with option for an ACHD team member to attend. ACHD Health Passport is provided, and the ACHD team is notified once the patient attends adult cardiology appointment.

RESULTS

Since the program's inception, 420 patients have been referred for transfer. 252 have completed the transition, 61 active patients with referrals sent and appointments scheduled or awaiting, 45 in queue for scheduling, and 53 unreachable/inactive insurance issues with letter sent. 105 virtual visits conducted. Feedback from patients and families has been overwhelmingly positive, highlighting the program's role in improving patient satisfaction and closing gaps in care.

CONCLUSIONS

Structured virtual transition clinic has successfully facilitated transition from pediatric to adult CHD care, resulting in improved patient satisfaction and continuity of care. A feedback survey has been launched on transition process. The program's success has led to its adoption by other areas of our hospital and other hospitals.

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POSTER #1

Disparities in healthcare transition services between autistic, special healthcare needs, and typically developed adolescents: Who are we leaving behind?

Nancy C. Cheak-Zamora, PhD; Servando Rodriguez Barajas, MS, LPC

BACKGROUND

The transition from pediatric to adult healthcare systems, known as healthcare transition (HCT), represents a critical milestone for adolescents. This period can pose substantial challenges for populations with unique needs, such as autistic adolescents (A-ASD) and adolescents with other special healthcare needs (A-OSHCN). HCT services are needed to assist in the smooth transition from pediatric to adult care. This study examined the receipt of HCT service across groups to identify potential disparities in access to care.

METHODS

We used the 2021-22 National Survey for Children's Health to analyze the differences in HCT received within adolescents aged 12-17 across three condition groups- A-ASD, A-OSHCN, and adolescents with typical developmental (A-TD). HCT services were assessed using validated measures, including two composite and three subscales. The subscales measured provider guidance, quality of clinic visits, and continuity of care. The composite subscales included a cumulative score, including 8 HCT items, and a cutoff score assessing the total score and subscale scores (5-criteria assessment).Adjusted and unadjusted analyses were used.

RESULTS

There were significant disparities in the HCT services received across groups. A-OSCH consistently demonstrated higher likelihoods of receiving HCT services ($p < .001$) compared to A-ASD and A-TD. A-ASD received higher quality clinic visits compared to A-TD ($p< .001$). A-ASD did not significantly differ from A-TD on any other HCT measures. Additional analyses are being conducted to assess associations between individual, family, and system-related variables and HCT outcomes for each group.

CONCLUSIONS

The findings underscore the urgent need for targeted policy initiatives and clinical practice improvements designed to ensure that all adolescents receive comprehensive support for successfully navigating the transition to adult care. Additionally, comprehensive measures of HCT service receipt should be implemented to reflect the needs of various adolescent groups accurately.

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POSTER #2

Core Competencies for Healthcare Transition Social Workers

Stephanie Pratt, MSW; Angela Berger, MSW; Terri Hickam, MSW, CCM; Reny Partain, MSW, MPH; Susan Shanske, MSW; Caren Steinway, MSW, MPH; Symme Trachtenberg, MSW

BACKGROUND

Healthcare transition (HCT) comes with a myriad of psychosocial stressors and complex, systemic challenges. Social workers are trained to help individuals navigate these changes at the micro, mezzo, and macro levels, but their role on interdisciplinary transition teams has not been well defined. Previous research found that 95% of formal transition programs include a social worker. The goal of this study is to further understand the role social workers play on HCT teams and to define the core competencies that social workers must possess to deliver transition services.

METHODS

A comprehensive review of peer-reviewed literature on social work competencies in HCT was completed by a master’s level medical librarian. Search terms included: “social work competencies” and “healthcare transition” or “adolescent health”. A second search used additional keywords “interventions”, “skills”, and “care coordination”. Databases searched included PubMed, PsycINFO, CINAHL, Social Work Abstracts, and ERIC.A group of seven subject matter experts on social work and HCT established inclusion criteria and reviewed articles to identify themes and core competencies.

RESULTS

A total of 10 articles were found in the first search. Subject matter experts found 7 met the inclusion criteria. The second search yielded an additional 18 articles, of which 8 met inclusion criteria. The articles ranged in publication date from 2010 to 2024. The primary themes identified were developmental framework, resource facilitation, patient/family/provider relationships, interdisciplinary teams and collaboration, and social work education and training. Individual social work competencies were identified for each theme.

DISCUSSION

There is limited published literature exploring the role of social work in HCT. Articles that do exist support a broad set of core competencies across multiple themes. The next steps include conducting a Delphi study to build multidisciplinary consensus on social work HCT competencies.

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POSTER #3

Development of a Multidisciplinary Care Center in a County Health System

Kylie Cullinan, MD; Emily Bufkin, MD; Rishi Shah, MBA, CHA; Lauren Tardo, MD

BACKGROUND

People with disabilities face increased barriers to accessing health care compared to their non-disabled peers. This is particularly consequential for emerging adults with pediatric-acquired chronic conditions, who face additional challenges such as changes in insurance, transitioning to an adult model of care, and often needing to identify a new care team. Parkland Hospital, a public hospital system in Dallas, Texas, created a novel clinic—the Developmental & Cognitive Clinic (DCC)—to deliver comprehensive, multidisciplinary care through several disease-specific programs. The Neuromuscular Clinic (Muscular Dystrophy/Spinal Muscular Atrophy) was launched in December 2022, followed by the Cerebral Palsy Clinic (October 2023), the Spina Bifida Clinic (March 2024), and the Genetic Epilepsy Clinic (April 2024). Clinicians at DCC include specialists in neurology, physical medicine & rehabilitation, cardiology, urology, internal medicine & pediatrics, and neurosurgery, with staffing varying by clinic. Support staff include a dietitian, registered nurse, and social worker.

METHODS

Using electronic medical records from the Parkland Hospital, patient demographics, referral patterns, and encounter data were analyzed to characterize the population and clinical volume from October 2023 to April 2025.

RESULTS

Fifty-five percent of patients seen in DCC were between 18 and 25 years old. Seventy-three percent of patients were on public insurance (6% Medicare, 67% Medicaid), 16% had a county-sponsored health plan, 9% had private insurance, and 1% were self-pay. The clinic received an average of 19 referrals per month over the past year—a 50% increase over 1.5 years. Clinical volume quadrupled during this period, increasing from an average of 15 patients per month (October–December 2023) to 57 patients per month (February–April 2025).

CONCLUSIONS

A multi-specialty clinic provides a centralized care model for an underserved population: young adults with pediatric-acquired chronic conditions. The growth of this clinic demonstrates both the feasibility of and the need for innovation in existing care models.

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POSTER #4

Navigating Health and Legal Transitions: Accessible Support for Families from Decision-Making to Conservatorship

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BACKGROUND

Health care transitions for individuals with significant cognitive or developmental disabilities often require legal interventions to ensure continuity of care and decision-making after the individual turns 18. Families with limited legal knowledge, language barriers, or access to legal representation face additional challenges. The Center for Healthy Adolescent Transition (CHAT) aimed to develop support for caregivers to determine the appropriate interventions and address challenges related to pursuing legal interventions.

METHODS

An educational workshop, Alternatives to Conservatorship: A Variety of Choices to Support Decision-Making, was developed by CHAT Programs Social Worker to provide families with information about the available options to support decision-making. CHAT also partnered with a local non-profit legal services organization to address challenges through a court-connected workshop that guides caregivers through the conservatorship process. The conservatorship workshop, a single-day event, includes eligibility pre-screening, legal education, and form completion assistance. Families are first encouraged to attend the Alternatives to Conservatorship workshop, available in both English and Spanish. If these alternatives are deemed unsuitable, families are then invited to attend the conservatorship workshop.

RESULTS

To date, 42 Spanish-speaking and 68 English-speaking caregivers have attended the educational workshops. A total of 67 families participated in ten Bet Tzedek workshops, with 64 completing and filing or preparing conservatorship forms for court submission. Bilingual support and hands-on assistance were identified as key contributors to success.

CONCLUSIONS

This interdisciplinary workshop model effectively reduces legal barriers for caregivers during health care transitions by integrating legal and social services in a culturally sensitive, streamlined format. Partnerships between legal nonprofits and health systems offer scalable solutions for addressing complex legal needs. Integration of bilingual legal services within a pediatric health care setting empowers caregivers to overcome legal obstacles and secure essential protections for their youth.

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POSTER #5

Preliminary Outcomes from a Pilot Health Care Transition Program for Young Adults with Childhood-Onset Rheumatic Conditions in Rhode Island

Victoria Koenigsberger, BA; Ali Yalcindag, MD; Meghan Geary, MD; Madeleine Ward, MD

BACKGROUND

Young adults with childhood-onset rheumatic conditions encounter challenges and barriers to care when transitioning to an adult rheumatologist. This study aimed to pilot the first program in Rhode Island to systematically transition patients from pediatric to adult rheumatology using aspects of the Six Core Elements of Health Care Transition (HCT) from Got Transition.

METHODS

One research assistant, two primary care physicians, one pediatric rheumatologist, 10 adult rheumatologists, and three rheumatology practice managers facilitated the program. Patients 18 years or older with confirmed rheumatic disease, deemed stable to transition by the pediatric rheumatologist were eligible. The program consisted of four visits, three months apart: two appointments with pediatric rheumatology, with half of time devoted to transition readiness education; a final in-person pediatric visit, with the adult rheumatologist on video for a warm handoff; and an appointment with adult rheumatology. Patient-reported transition readiness was assessed at each visit using the Transition Readiness Assessment (TRA) from Got Transition.

RESULTS

64 patients age 18 or older had appointments with the Pediatric Rheumatology Clinic from 5/1/24-1/31/25. 13 were eligible, determined by diagnosis and disease stability, and eight entered the pilot. Mean enrollment age was 19.5 years (range: 18-23). All participants completed a baseline TRA. Mean patient scores for initial self-perceived importance of transition to an adult doctor and confidence in transitioning were 8.13 and 7.13, respectively (out of 0 [not] to 10 [very]). Thus far, two participants successfully transitioned to adult rheumatology.

CONCLUSIONS

While initial stages of our first rheumatology transition pathway have proven feasible, with notable success in warm handoff video visits with adult rheumatologists, challenges include time and clinical infrastructure. Next steps involve finalizing remaining adult appointments and assessing impact of this program on patients with multi-modal data - qualitative and quantitative surveys.

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POSTER #6

The Epilepsy Transition Clinic (ETC): A Warm Handoff Bridging Pediatric to Adult Neurology

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BACKGROUND

Pediatric patients with complex epilepsy face barriers to achieving successful transition to adult care, including prolonged gaps from time of referral to first adult appointment. Advanced practice providers (APPs) in pediatric and adult neurology clinics on an academic medical campus partnered with epileptologists to design a three-visit warm-handoff Epilepsy Transition Clinic (ETC) pathway across settings to assure a safe transfer.

METHODS

Criteria to attend ETC include a previously failed transfer, ketogenic diet, neurostimulation device implantation and/or epilepsy surgery. Pediatric neurology providers refer patients to one of two pathways. Patients are scheduled into a pre-set ETC template with their epilepsy MD or APP. For the MD pathway, the adult epilepsy MD attends a joint visit at the pediatric center; with an adult APP joining by telehealth to become familiar with the patient and build the medical record. For the APP pathway, the adult neurology APP joins the pediatric APP appointment.The patient is scheduled with the same adult APP in two weeks; and the adult neurologist within 2 months. This ensures a comprehensive exchange of care history and transition goals/concerns.

RESULTS

From January 2024 through March 2025, 56 patients attended the initial visit in pediatric neurology; 35 (63%) in the MD-MD, and 21 (37%) in the APP-APP pathway. For all patients, 53 (95%) were successfully established in adult epilepsy care, with 35 (63%) attending all 3 visits. Adult neurology visits two and three were attended by 43 (77%), and 46 (82%), respectively. A patient/family satisfaction survey is being distributed, and findings will be included in the presentation.

CONCLUSIONS

The ETC has increased trust between providers, patients, and families. The initial 1.5 years of data are informing future directions including exploration of billing options, adding more MDs and APPs to increase utilization, and adding state benefits counseling access for ETC patients."

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POSTER #7

Engaging Patients/Families Who are Resistant to Adult Care Transitions

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BACKGROUND

Patients and caregivers can be resistant to transition to adult care, evidenced by lack of response to communication attempts and no shows at scheduled first adult clinic visits. The Improving Pediatric to Adult Care Transition (ImPACT) Navigation Hub (INH) at Children's Hospital Colorado provides transition support to young adults and families through provider referrals. Resistance to transition was addressed by the INH in consultation with the hospital legal team.

METHODS

The interdisciplinary INH team engages with families by introducing their role in transition, establishing preferred methods of communication, and verifying the families' transition goals. Resistance is defined by failure to engage with the INH or referring team in transition planning. After six attempts (3 each by referring team and the INH) to contact the family, a collaborative decision between the INH and care team determines if a transition resistance or care termination letter is sent. The latter notifies the patient/caregiver of their responsibility to secure adult care. A lack of response to the letter(s) is documented in Epic, and the primary care provider (PCP) is informed.

RESULTS

Over 3.5 years, 13 of the 209 INH patient referrals were sent certified letters; 3 for transition resistance and 10 for termination of care. Two of 13 received both letters. Nine of 13 (69%) re-engaged in transition communications with their clinic team and the INH and had successful transition preparation and eventual transfer to adult care.

CONCLUSIONS

Addressing transition resistance is a patient safety measure. The INH approach to patients who are resistant to transition provides impetus for the patient/caregiver to re-engage in the pediatric center for transition education and support. This process eliminates assumptions of ongoing care in pediatrics and includes the PCP for continuity.

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POSTER #8

A Novel Scoring System for Transition of Care of Pediatric Rheumatology Patients

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BACKGROUND

Success of transition from pediatric to adult care depends on many factors. Various scores for transition readiness have been developed, but few patient-level transition success scores exist. We created a novel transition success score for pediatric rheumatology patients.

METHODS

Pediatric rheumatologists and adolescent health experts were consulted. Four components were included in the score: attending the first adult appointment in the time frame designated by the pediatric rheumatologist (component 1), refilling medications within 3 months of the first adult appointment (component 2), attending a second adult appointment (component 3), and no rheumatology-related emergency department visits in the first year after transition (component 4). Scores were determined via electronic medical record (EMR) review; each component was weighted as one-quarter of the total transition success score. The few patients who transitioned off medications were scored successfully for component 2.

RESULTS

From 2017-2024, we identified 357 patients who transitioned from pediatric to adult rheumatology using direct provider notification and EMR review. Of those, 199 were able to be scored, i.e. had details accessible via EMR plus >1 year since the final pediatric appointment. 73 (37%) patients scored 100 and 77 (39%) scored 75. Only 3 patients (1.5%) scored 0. By component, 114 patients (57%) met component 1, 151 (76%) met component 2, 160 (80%) met component 3, and 166 (83%) met component 4.

CONCLUSIONS

We developed a transition success score within our rheumatology transition program. Although 150/199 patients (75%) fulfilled 3 or 4 out of 4 components of successful transition, we were unable to document a second adult rheumatology appointment for a surprising 20%. Our next steps include correlating components of our transition program, including demographics, transition planning, self-reported transition readiness, and receipt of a transition summary letter, with the transition success score to better understand what factors predict successful transition.

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POSTER #9

Spina Bifida Transition Coach- A Pilot Intervention

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BACKGROUND

Transitioning to adulthood presents challenges for adolescents and young adults (AYA) living with spina bifida (SB) including developmental changes, healthcare services and support. These changes may lead to complications including unmet healthcare needs, autonomy development, decreased levels of community participation and potential decline in quality of life.This research aims to transform the journey by developing an evidence-based intervention that will enhance self-management, self-advocacy, and community inclusion. Through a partnership between the Spina Bifida Coalition (SBC) and the Cincinnati Children's Hospital Spina Bifida Center (C-SBC) supported by the Rubinstein Foundation and UC CCTST funding to bridge the identified gaps, we propose an intervention utilizing a Spina Bifida Transition Coach (SB-TC). The SB-TC will offer a personalized intervention empowering the AYA to improve their self-management, self-advocacy, and community inclusion skills as they transition.

METHODS

This mixed-methods study utilizes a systemic literature review with a pilot intervention to create and refine the SB-TC model. The review identifies effective health coaching /patient navigator strategies, informing the development of a customized, evidence-based SB-TC role. Stakeholder collaboration is important and an Advisory Council consisting of caregivers, AYA, and healthcare professionals collaborate to ensure a training curriculum addressing real-world challenges faced by AYA. Fifteen AYA will work with the SB-TC focusing on personalized goal setting, coaching, and self-management skills.

RESULTS

Ongoing assessments will evaluate participant engagement, SMART goal progression, and transition readiness while gathering satisfaction feedback from AYA, caregivers, healthcare professionals and community stakeholders. Quantitative assessments of participants working with the SB-TC will measure knowledge, independence, and self-management skills pre and post intervention to determine effectiveness.

CONCLUSIONS

Developing a culturally competent and patient-focused transition model that will bridge the gaps AYA face as they transition. This model will work to remove barriers, enhance facilitators, and build a more inclusive healthcare system that will support AYA.

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POSTER #10

Failure to Launch: Investigating Transfer to an Adult Multidisciplinary Clinic

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BACKGROUND

Young adults with special health care needs (YASCHN) and their families identify limited availability of adult clinicians and difficulty locating adult clinicians with specialized knowledge about pediatric-onset chronic diseases as barriers to successful health care transition. As a response to these barriers, Parkland Health launched the multidisciplinary Developmental and Cognitive Clinic (DCC) to support the successful transfer and integration of YASHCN into the Parkland adult care system. Patients with muscular dystrophy are one of the qualifying diagnoses served by DCC. However, DCC's neuromuscular clinic appointments are underutilized despite committed resources. This project aimed to increase the number of patients referred and integrated into the Neuromuscular division of DCC and to increase the transition readiness of transferring patients.

METHODS

A root cause analysis (RCA) was performed by interviewing clinic staff and administrators to identify barriers to transitioning from Children's Health Neuromuscular Clinic to DCC. A process map was constructed for the referral process. A fishbone diagram identified common themes regarding unsuccessful transfer to adult care at DCC. A key driver diagram illustrated the potential intervention points to address the barriers shown in the fishbone diagram.

RESULTS

The RCA revealed the following most reported themes: lack of standardized transition education, a delayed start to transition conversations at Children's, and lack of communication between Children's Health and DCC care teams.

CONCLUSIONS

Developing a standardized Neuromuscular Adolescent Clinic transition policy/practice and utilizing the Transition Readiness Assessment Questionnaire (TRAQ) will facilitate transition conversations and encourage a return to the six core elements. These conversations will allow for the integration of education about DCC. The TRAQ was implemented in January 2025. Additional opportunities include patient education and building relationships between the pediatric and adult care teams."

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POSTER #11

Evaluating Youth and Parent/Caregiver reports on Healthcare Transition Readiness in Egypt: Validation of the Arabic STARx and STARx-P Questionnaires

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BACKGROUND

Healthcare transition (HCT) tools such as the STARx (youth version) and STARx-P (parent/caregiver version) Questionnaires assess readiness with chronic conditions by self-report or their caregiver's proxy-report. This study evaluates the feasibility, acceptability, and psychometric performance of the Arabic STARx and STARx-P Questionnaires in an Egyptian clinical population.

METHODS

We enrolled 107 adolescent-caregiver dyads from Zagazig, Egypt. Youths (mean age 13.3 ± 1.2 years; 60% male) had kidney disease (24%), thalassemia (33%), or diabetes (43%). All participants completed the Arabic STARx or STARx-P Questionnaire using a paper-based format. Exploratory factor analysis (EFA) and Cronbach's alpha were used to assess reliability and structure. Bivariate and regression analyses examined associations between scores and demographic predictors.

RESULTS

Youth reported significantly higher total HCT readiness scores than caregivers ($p < 0.001$), particularly in disease knowledge and self-management domains. Caregivers scored higher in provider communication ($p < 0.001$). The final youth version included 16 items across three domains; internal consistency was acceptable ($\alpha = 0.707–0.744$). Similar reliability was observed in caregiver responses ($\alpha = 0.632–0.786$). Regression analysis showed that caregiver scores positively predicted youth self-management and provider communication scores ($p < 0.001$). Four caregivers with low literacy required assistance. Participant feedback confirmed strong cultural and linguistic alignment of the tools, though some items reflected structural healthcare limitations (e.g., clinic policies requiring caregiver presence).

CONCLUSIONS

The Arabic version of the STARx and STARx-P Questionnaires are feasible, reliable, and culturally appropriate for assessing HCT readiness in Egyptian youth with chronic conditions. Youth-caregiver score discrepancies underscore the importance of dyadic assessment in HCT planning. Findings support the broader inclusion of Arabic in validated STARx tools and call for culturally tailored interventions to enhance youth autonomy and caregiver engagement in HCT.

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POSTER #12

Strategic Partnership Analysis to Identify Opportunities for Health Care Transition Education and System-Level Change

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BACKGROUND

Nealy 37% of Minnesota (MN) youth, ages 12-17, have a special health care need (YSHCN), and 7 out of 10 of MN YSHCN are not receiving health care transition (HCT) preparation support from their health care providers. MN's Title V Program for CYSHCN provided multi-year funding support to Gillette Children's Hospital, with consultation from Got Transition, to address these gaps. Initial work revealed individual practices and clinics often face organizational or system-level challenges that limit HCT implementation in MN. Strategic partnership analysis was initiated to identify opportunities for HCT education, quality improvement, and systems change.

METHODS

Structured, 30-minute interviews were conducted with leaders from advocacy (Family Voices MN, PACER), professional (MN Chapter AAP, MN Medical Association, MN Association of Community Health Centers) and state agencies (MN Medicaid, MN Health Care Home, MN Rare Disease Advisory Council). Questions focused on past/current HCT initiatives, potential partnership opportunities, and advice about expanding HCT knowledge

RESULTS

Advocacy organizations noted they often work in silos. Suggested opportunities include partnerships to increase educational opportunities and peer mentorship and advising families to add HCT into their youth's transition individualized education plan. Professional organizations noted many competing priorities. Suggested opportunities include options for HCT provider education (newsletters, webinars and lunch and learn), convening pediatric and adult medicine organizations and joining strategic planning meetings. Some state agencies noted HCT is not a priority. Suggested opportunities ranged from incorporating HCT in MN's preventive visit guidance, Sickle Cell Disease HCT payment pilot, incentives for adult providers and connecting with primary care stakeholder groups.

CONCLUSIONS

This strategic partnership analysis underscored the limited attention to HCT in Minnesota. Findings will assist the MN HCT planning group identify potential program development and partnerships for specific education, QI, and policy options.

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POSTER #13

Developing an Interdisciplinary Transition Clinic for Adult Patients with Congenital Heart Disease

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BACKGROUND

Advances in pediatric cardiology care have significantly improved survival rates among children with congenital heart disease (CHD), resulting in a growing number of adults with CHD (ACHD). Regrettably, many of these individuals encounter difficulty maintaining appropriate cardiac follow-up as they transfer into adult care settings. Transition clinics have emerged to support continuity of care, though best practices for their design remain unclear, and implementation varies widely across institutions. This project describes the development and implementation of an interdisciplinary Cardiology Transition Clinic at a large academic medical center, highlighting successes, challenges, and implications for similar models of care.

METHODS

The development of our institution's Transition Clinic stemmed from careful collaboration between several departments, including the Divisions of Adult and Pediatric Cardiology, Department of Psychology. and Social Work. Alongside a series of planning meetings, literature reviews were completed to gain insight into current clinical models of transition and examine publicly available transition readiness measures.

RESULTS

Ultimately, a monthly Transition Clinic, in which patients are seen by both an ACHD cardiologist and a pediatric psychologist on the same day, was developed and implemented. In addition, standardized intake forms to be completed by all patients were integrated to assess transition readiness, psychosocial needs, and potential barriers. Clear communication between the clinicians, social work, and medical staff is maintained throughout the service to ensure a smooth transition and transfer process.

CONCLUSIONS

This integrated Cardiology Transition Clinic model of care offers a structured, multidisciplinary approach to assessing readiness and addressing barriers within the transfer to adult care. This model of care and its successes contribute to the growing body of knowledge on effective transitional care practices to develop standardized, evidence-based approaches to navigating this critical stage in patient care across institutions.

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POSTER #14

You and I Health Club: A Virtual Healthcare Transition Education Platform Pilot

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BACKGROUND

Much of the current literature on teen to adult health care transition (HCT) focuses on a specific disease process or clinic - leaving a gap in understanding at the system level. Within our own system, education and resource connecting is also provided at the clinic level leaving many clinicians overwhelmed with the gathering and maintenance of materials. A virtual health club was designed to centralize HCT related education, skill building, and resource-connecting at the system level.

METHODS

The Got Transition® Readiness Assessment (RA) was used as a template for building an educational program to cover general HCT topics - ensuring there are resources available for each question on the RA. Educational materials were divided into 3 levels to reflect the beginning, middle, and end of the HCT journey. Within each level material is delivered via flashcards and interactive activities to engage youth and families in the learning process.

RESULTS

A public-facing website was created to house all HCT related education and resources, providing a single location for anyone on the care team to reference. This will empower youth and families to interact with the materials independent of clinic visits and work at their own pace, making the material more digestible and less overwhelming. To compliment the website materials, physical flashcards and activities will be provided to increase accessibility of information.

CONCLUSIONS

The website and materials will be piloted this year in 2 subspecialty clinics (Diabetes and Spina Bifida). We hope the public nature of this website will allow equitable access to HCT education and resources to families across our system and communities.This will also allow adult providers to continue supporting youth in this journey, by proving access to HCT resources to all providers, regardless of setting."

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POSTER #15

Improved Communication and Follow-up with Recent Graduates of a Pediatric Sickle Cell Adolescent Transition Program

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BACKGROUND

Adolescents and young adults with sickle disease experience higher rates of morbidity and mortality than their peers. While the National Alliance to Advance Adolescent Health has released a widely endorsed framework, the Six Core Elements of Healthcare Transition, to support adolescents' and young adults' with special healthcare needs transition to adult care, only a small fraction of this population receives structured support as they navigate the adult healthcare system. The goal of this evidence-based project was to improve the implementation of the Sickle Cell Adolescent Transition (SCAT) program, a healthcare transition program, by using REDCap software to streamline communication with program graduates during Element 6: Transition Completion, through automated text message surveys and reminders.

METHODS

The sample included 94 graduates who graduated between 2014 and 2024 from the SCAT program. A mixed-method, one-group, post-only design was employed to collect quantitative data from SCAT program graduates and qualitative data from program staff through focused interviews on lessons learned from implementation.

RESULTS

Ninety-one SCAT graduates received text message surveys and automated reminders. Twelve percent provided survey responses, which included progress on the American Society of Hematology's key quality indicators for SCD. Staff members (N=4) reported an increased ease and efficiency in obtaining and using feedback from graduates. However, they noted current staffing as a potential barrier to future implementation.

CONCLUSIONS

This project improved the SCAT program's implementation of Element 6: Transition Completion by aligning its post-transition follow-up survey to nationally recognized quality care indicators for SCD and leveraging REDCap's text message capabilities to facilitate more efficient and sustainable data collection and analysis. The strengths of this project lie in the lessons learned from implementing a practice change involving multiple technologies and departments across a large hospital system and the creation of concrete tools and resources for healthcare transition."

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POSTER #16

How the Timing of Pediatric-to-Adult Healthcare Transfers Differs By Specialty in a Population of Commercially Insured People With Disabilities

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BACKGROUND

The timing of the transfer from pediatric to adult health care is variable and inconsistent. Recommendations to transfer vary from ages 18-26. This study examines the ages at which outpatient pediatric-to-adult primary care and specialist healthcare transfer occur for a population of AYA-D in the commercial population.

METHODS

This cross-sectional study uses five years of claims data (2012-2016) from a national commercial insurer representing 76,500 person-years of outpatient healthcare use among AYA-D aged 13-26. Outpatient visits were characterized according to the type physicians billing for care—23 different types of pediatric-focused physicians (e.g., general pediatricians, pediatric cardiology) and 20 different types of physicians without pediatric-focused training (e.g., internal medicine, endocrinology). The timing of the pediatric-to-adult transfer was assessed by noting the age band at which the proportion of total outpatient visits was greater for physicians without pediatric-focused training.

RESULTS

Table 1 describes the demographic profile of AYA-D with disabilities, with 70% having 1 disabling condition. The midpoint age at for primary care pediatric-to-adult transition occurred was at age 19, the majority of visits were being provided by Family Medicine and Internal Medicine (Figure 1). Many adolescents were already being seen by non-pediatric providers at age 13 (Figure 2).The ages at which specialist pediatric-to-adult transfers varied by specialist type—the transfer occurred prior to ages 13-14 for 9 specialty types (e.g., allergy/immunology), before ages 17-18 for 3 specialty types (e.g., neurology), and after ages 17-18 for 5 specialty types (e.g., gastroenterology). Pediatric-focused care continued through ages 25-26 for 19 pediatric-focused specialty types.

CONCLUSIONS & ACTION STEPS

Adolescents and young adults with disabilities may particularly benefit from seamless pediatric-to-adult healthcare transitions, and this study illustrates the timing of transfers occurring at a myriad of ages prior to adolescence and into late young adulthood. Healthcare providers need to prepare patients for pediatric-to-adult healthcare transfer to occur at any age.

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POSTER #17

ATLAS: Developing Institutional Programs to Support Adolescent and Young Adult Patients Living with Chronic Conditions

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BACKGROUND

Adolescents and young adults (AYAs) with chronic conditions live into adulthood at increased rates, creating a need for education and support surrounding pediatric-to-adult healthcare transitions (HCTs). Adolescents Transitioning to Leadership and Success (ATLAS) at Duke Children's Hospital uses a positive youth development (PYD) framework that centers peer and near-peer support between teens living with chronic conditions and mentors who also live with chronic conditions. ATLAS focuses on self-management and life skills development, so that transitioning to adult healthcare is placed within the context of transitioning to young adulthood.

METHODS

ATLAS was founded in 2009 and offers four programs. Patient recruitment is performed by provider referrals for qualifying patients and through self-referrals. Leadership and LEAP (Leadership, Experience, Advocacy, and Progress) are peer support programs for teens and young adults, respectively.Fit is a health and wellness program for ages 18-30 with intellectual or developmental disabilities. Finally, Bobby's Coaches is for AYAs with a cancer diagnosis.

RESULTS

Since 2013, there have been 507 patient referrals to ATLAS placed by 159 providers. ATLAS meetings have had 346 participants (average of 38 per year) and 154 mentors (average of 12 per year). There are currently 62 active participants, and 7 previous participants serving as mentors. A previous ATLAS participant/mentor stated that "ATLAS is the intersection between peer mentorship and self-empowerment, helping to build skills to thrive in the world for the rest of our lives." Family feedback has cited the importance of ATLAS in their child's successful health transition.

CONCLUSIONS

Since their introduction, ATLAS programs have been a critical support tool for AYAs undergoing HCTs at Duke. Their success highlights the value of peer support programs with a PYD framework at medical institutions. The next step is to increase awareness of program benefits so that similar programs can be implemented at other institutions.

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POSTER #18

Transition Practices and Barriers in Spina Bifida Care: A Survey of SBA Clinical Care Partners

Betsy Hopson, PhD; Rhonda Cady, PhD; Kathy Huen, MD, MPH; Judy Thibadeau, RN, MN;Ellen Fremion, MD, FACP, FAAP

BACKGROUND

Transition from pediatric to adult healthcare for individuals with spina bifida (SB) remains a critical challenge. Although transition guidelines exist, implementation varies, and limited data describe provider experiences and perceived barriers. This study assessed current transition practices and identified key challenges and facilitators among Spina Bifida Association (SBA) Clinical Care Partners.

METHODS

This study is part of a larger mixed methods project exploring SB transition practices and reports findings from the quantitative phase. A 47-item survey was developed by the SBA Transition Working Group and distributed to 30 SBA Clinical Care Partners in March and April 2025. The survey assessed transition workflows, tools, strategies, and perceived barriers. Descriptive statistics analyzed responses.

RESULTS

Fourteen clinicians completed the survey (47% response rate), including physicians (n=5), neuropsychologists (n=2), advanced practice providers (n=2), nurses (n=2), and therapists/others (n=3). Most practiced in children's hospitals (70%), with 79% serving youth ages 16–24 and 43% also following adults. All respondents saw more than 100 patients annually. While 66% reported transferring over half of their patients, processes varied and only 42% had a method to confirm successful transfer to adult care. TRAQ-SB was the most frequently used assessment tool (67%), and common strategies to improve readiness included goal-setting (75%) and educational materials (75%). Major barriers included insurance limitations, geographic constraints, and identifying adult providers. Respondents cited early planning, youth and family education, and access to SB specialists as predictors of success. Most described families as ""receptive but cautious" (92%). The most requested SBA support was a centralized registry of adult providers.

CONCLUSIONS

Despite strong provider engagement in transition, wide variability in practices and persistent systemic barriers remain. Findings underscore the need for standardized workflows, early transition planning, and national tools such as a centralized provider registry to support successful transitions for individuals with SB and will inform focus groups with SB clinicians during summer 2025.

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POSTER #19

The Quest for Health Information Resources by Young Adults with Disabilities: Building Theory

Beth Rossen, BA, BAAN, RN, MSc, PhD

BACKGROUND

This constructivist grounded theory study aims to understand experiences of health information-seeking processes of young adults with lifelong physical disabilities during transition from pediatric to adult healthcare. Its additional purpose is building a theoretical framework comprised of processes and sub-processes. Previous research linked lifestyle health behaviors and health information-seeking, finding that during the transition from pediatric to adult healthcare, this population's lifestyle health behaviors put them at risk for secondary health conditions. The issue is exacerbated because, during this transition, these young adults move from comprehensive, coordinated pediatric services to less coordinated adult services inadequately addressing interrelated physical, psychological, and emotional problems accompanying physical disability. Research demonstrated a paucity of health information and resources available during this transition. It underscored little attention was directed at health information-seeking by this population.

My study addresses gaps in knowledge about health information-seeking processes of this population as they transition from pediatric to adult healthcare. Using Charmaz's constructivist grounded theory methodology,

METHODS

I conducted ten in-depth, semi-structured interviews and three in-depth theoretical sampling interviews with young adults with lifelong physical disabilities transitioning from pediatric to adult healthcare to learn about their health information-seeking experiences and to develop a theoretical framework.

RESULTS

My iterative data analysis revealed four categories and associated sub-categories related to the interplay concerning personhood and environment constituting the building blocks for a middle-range theory. The resulting theoretical framework embodies the core construct of the quest for health information resources by young adults with lifelong physical disabilities during their transition from pediatric to adult healthcare and four categories and associated sub-categories.

CONCLUSIONS

Contributions of my findings to knowledge and theory, and implications for clinical and public health practices, education for healthcare professionals, and policy emphasizing public health policy seeking to mitigate health disparities of these young adults compared to their peers without disabilities, are discussed.

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POSTER #20

Medication Dosing Challenges for XLH patients in the Transition Age.

Maria Díaz Gonzáles de Ferris, MD, PhD, MPH; Guido Filler, MD, PhD

BACKGROUND

Burosumab dosing in patients with X-linked hypophosphatemic rickets (XLH) during the transition from adolescence to adulthood embodies unrecognized complexities not addressed in current protocols. All patients under 18 years of age, typically receive Burosumab at 0.8-2.0 mg/kg every two weeks (q2w), with a maximum dose of 90 mg. After age 18 years, guidelines recommend 1.0 mg/kg every four weeks (q4w), also capped at 90 mg. This change in both cumulative monthly dose and dosing interval may disrupt pharmacokinetic and pharmacodynamic (PK/PD) stability during a physiologically dynamic period and does not account for physiological differences by sex.

METHODS

Sex-specific changes in body composition, including increasing fat mass and variable extracellular fluid volume (ECV) occur into late adolescence and early adulthood. While linear growth is typically complete by age 17 in females, it may continue beyond age 18 in males. Given that Burosumab distributes primarily within ECV rather than total body mass, physiologic and not purely chronological age should guide dosing. Additionally, FGF23 levels are unreliable for monitoring treatment, due to the lack of assays measuring unbound FGF23. Hence, clinical PD monitoring using tubular maximum phosphate reabsorption normalized for glomerular filtration rate (TmP/GFR) is recommended, with a target of 3.0-4.0 mg/dL (1.0-1.3 mmol/L).

RESULTS

Proposed physiologically-guided approach to Burosumab dosing during the transition age in XLH, integrating growth status, dosing taper (25% reduction every 3 months once stable), and clinical PD monitoring via TmP/GFR (target: 3.0–4.0 mg/dL).

CONCLUSIONS

We propose an ECV-normalized dosing strategy, supported by TmP/GFR-based monitoring, to guide individualized adjustments during the transition age (Figure 1). While reimbursement policies often enforce age 18 cutoffs, future protocols should integrate assessment of growth velocity, epiphyseal status, and physiologic markers to support precision medicine approaches in XLH treatment.

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POSTER #21

Bridging the Gap between Care Team Education and Clinical Practice: Development of a Health Care Transition Curriculum

Tanika Middleton, BSN, RN, CCM; Ashley McCool, MHA

BACKGROUND

As system-wide health care transition (HCT) services and programs were being implemented, care team members at Children's Health identified a gap between knowledge of HCT, including available tools/resources, and integrating HCT into patient care workflows. Through a partnership between the system-wide centralized transition infrastructure department and the Nursing Professional Governance Ambulatory Clinical Practice Council (CPC), an opportunity to update an existing HCT computer-based training course (CBT) with a more comprehensive training offering was identified.

METHODS

A multidisciplinary workgroup was established that included the system-wide transition council and members of the Ambulatory CPC. All workgroup members provide transition services in various specialty areas. Design sessions with the workgroup were facilitated by the internal training department to identify topics and content to be covered in the offering. Topics and content were further developed and finalized after a series of reviews from the workgroup members. Quick Reference Guides (QRG's) for each course were created to highlight workflow implementation and resources to care team members.

RESULTS

To encompass the breadth and depth of identified topics and content, the offering was designed as a curriculum of three courses with a pre and post survey for learners. The curriculum was awarded continued education credits for certain disciplines.The curriculum was made available for care team members to self-assign and complete. Based upon discipline and role in HCT, care team members that have not completed the curriculum will have it assigned.

CONCLUSIONS

Development of a system-wide HCT curriculum guided by care team members utilizing a collaborative and consensus-based approach can be time and resource intensive. The prioritization of care team member HCT education supports the streamlining of processes/workflows, while developing knowledge and confidence in providing HCT focused care in clinical practice.

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POSTER #22

Developing Patient Family Electronic Learning (e-learning) Education for Health Care Transition through System-wide Collaboration

Noemi Manriquez, BA; Ashley McCool, MHA

BACKGROUND

Got Transition's Six Core Elements of Health Care Transition, identify providing education and resources to patient families as recommended steps in the Health Care Transition process in element three (Transition Readiness) and element four (Transition Planning). Within our pediatric health care system, transition champions and care team members requested the development of transition focused e-learnings for patient families to access as a supplement to transition discussions and planning in clinic and printed education materials.

METHODS

Our centralized infrastructure transition department asked for volunteers from our system-wide multidisciplinary transition council of representatives from different specialties to form a work group to identify topics for patient education e-learnings and develop scripts and content for each e-learning. After scripts were finalized by the workgroup, review for appropriate health literacy levels was completed by our patient education department and, when approved, translated into Spanish. Scripts were provided to the internal instructional designer to develop the e-learnings.

RESULTS

This work resulted in eight e-learnings in English and Spanish covering a variety of transition topics for both patients and families. Engagement and interaction is required by viewers in each e-learning. Each e-learning has an optional survey asking learners for feedback on content and experience. E-learnings are available on our external website and can be accessed through a QR code on an educational one pager.

CONCLUSIONS

A collaborative approach guided by clinical care team members supports the development of system-wide transition patient education. E-learnings are one method of disseminating transition patient education. Consistency in education and messaging across a large pediatric health care system impacts culture and clinical practice of health care while supporting patient experience.

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PLATFORM PRESENTATION #1

Leveraging Lessons Learned: The Transition Learning Collaborative

Susan Shanske, MSW; Kristina Taylor, BSN, RN; Lindsey McMahon, MPH; Ahmet Uluer, DO, MPH

BACKGROUND

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PLATFORM PRESENTATION #2

A Review of Medicaid Managed Care Contracts to Inform Plans for Advancing a System of Services for CYSHCN and their Families

Annie Schmidt, MPH; Samhita Ilango, MSPH; Peggy McManus, MHS; Patience White, MD, MA

BACKGROUND

Medicaid covers almost half of children and youth with special health care needs (CYSHCN) in the US, and the vast majority are served by Medicaid managed care organizations (MCOs). The purpose of this study was to inform state Title V programs in considering potential areas of collaboration with Medicaid to improve systems of care for CYSHCN and their families. Title V programs and Medicaid agencies have a long history of working together and are required to collaborate to ensure that CYSHCN are provided needed preventive care, treatment, and follow-up.

METHODS

We reviewed 16 general and 3 specialty MCO contracts to search for policy and program provisions related to family engagement in the design, provision, and oversight of care to CYSHCN, and accountability for a system of services for CYSHCN and their families We abstracted relevant provisions and organized them into themes, and we identified examples of distinctive provisions.

RESULTS

The most common family engagement provisions were definitions of family-centered care, representation on advisory councils/quality improvement (QI) committees, and care management and treatment planning. One distinctive strategy was a requirement that MCOs assign CYSHCN to providers who provide family-centered care and provide pediatric-to-adult health care transition (HCT) services (e.g., HCT assessment tool, HCT policy, and discussion of legal changes at age 18). The most common system of services accountability provisions were related to performance measurement and QI for CYSHCN and/or special needs populations and reference to specific standards, policies, and procedures. One distinctive strategy was a requirement that a specialty MCO provide targeted HCT planning and a dedicated HCT specialist to support complex transitions to adulthood.

CONCLUSIONS

A report summarizing our findings offers provisions and distinctive examples of state strategies that could lead to collaborative efforts between Medicaid and Title V, building on the long history of interagency partnerships.

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PLATFORM PRESENTATION #3

Value-added? Assessing Transition Readiness in Youth and Young Adults with Spina Bifida

Megan Gallagher, MPH; Rhonda Cady, PhD, RN

BACKGROUND

Research indicates adolescents and young adults (AYAs) with Spina Bifida (SB) are vulnerable to poor health outcomes during pediatric to adult healthcare transition (HCT). Developing self-management skills is key to successful HCT and evidence supports assessing self-management readiness. Gillette Children's, a Minnesota pediatric specialty-only health system serving AYA with childhood-onset disability, initiated standardized HCT processes incorporating the Six Core Elements. The Transition Readiness Assessment Questionnaire - Spina Bifida (TRAQ-SB) (Fig 1) assesses shunt, bowel, bladder, and skin self-management skill using a scale of 1-5, 1 being "No, I do not know" and 5 being "Yes, I always do this."

METHODS

TRAQ-SB was completed by AYA (and/or parent), aged 15-25 and seen in Gillette Children's Pediatric or Adult SB Coordinated Clinic. TRAQ-SB reviewed by physical medicine and rehabilitation providers. Medical records abstracted post-visit to understand how the TRAQ-SB informed the providers care plan. Mean TRAQ-SB score was calculated following developer recommendations. Analysis compared TRAQ-SB scores of respondents <18 years and 18+ years.

RESULTS

47 AYA completed the TRAQ-SB; mean/median age 19, with 22 AYA <18 years and 29 AYA >= 18 years. TRAQ-SB mean/median scores were lower in youth <18 years but difference was not statistically significant (Fig 2). The distribution of self-management skewed towards readiness for both age groups (Fig 3). Provider documented action triggered by TRAQ-SB responses was variable and not associated with lower TRAQ-SB score. 9/22 (41%) AYA <18 years received self-management education or referral (social work, neuropsychology, driver education) while 4/31 (13%) AYA >=18 years received only self-management education.

CONCLUSIONS

The variable findings compelled the question, "Is readiness assessment a value add to AYA and clinicians?" We will conduct focus groups with clinicians, AYAs, and parents of AYA during Summer 2025 to answer this question. Findings will inform modifications to readiness assessment tools and processes."

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PLATFORM PRESENTATION #4

Adult in Age but Pediatric in Size: A Single Center Retrospective Study of the Care of Small-sized Adult-aged Patients

Erica Onwuegbuchu MD, MS; Erin Tully MD; Adam Greenberg MSN, CRNP, Christine Chamberlain BSN, RN, CPN; Richard Chung MD; Dava Szalda MD

BACKGROUND

In the United States, fewer than half of youth with special healthcare needs receive adequate transitional care as they approach adulthood. Patients who are adult age, but pediatric size experience unique challenges during transition to adult-centered care. At our institution, our transition policy makes an exception for transfer to adult care, particularly inpatient care, for adult patients who are of pediatric size (defined as < 35kg). This decision was made because of perceived difficulties with medication dosing and reliable provision of appropriately sized equipment for such patients in adult systems. This study aims to define this cohort of patients at our large free standing children's hospital.

METHODS

This was a retrospective chart review of adolescents and young adults (≥ 15 years) who are less than 35 kg. We describe demographics and other patient characteristics including medical complexity (defined as patients with > 2 chronic health conditions and/or functional limitations), technology dependence (as defined by respiratory or GI support such as positive pressure ventilation or G-tubes), health care utilization within the last year, and most common diagnoses. Finally, we classify where our 18+ patients are in the transition process based on number of adult providers and engagement with our transition program (ACTT).

RESULTS

Patients were stratified into two age groups, 15-17 years (N=188) and > 18 years (N=112), to understand the current size and potential growth of this patient population. Most patients were female (53%, 62%) and White (51%, 67%). Most patients were medically complex in both groups (63%, 82%), with chronic health conditions (77%, 94%) and many also with technology dependence (48%, 63%). Common diagnoses included cerebral palsy, intellectual and developmental disorders, feeding disorders and genetic syndromes. Over the last year, patients had significant health care utilization including an inpatient stay (25%, 28%), CHOP PCP use (19%,29%) or CHOP subspecialty care use (90%, 82%) within the past year.Finally, the majority of 18+ patients were not yet established at our institutional transition clinic or seeing any adult providers.

CONCLUSIONS

In our study, we found a larger cohort of patients than anticipated not yet ready for transition. These patients are often a medically complex population with significant health care utilization. As patients age into adulthood, it will be important to consider barriers to transition such as small size which might preclude full transition to adult care. Additionally, we should think about building new models of care in adult centers and use of existing transition medicine programs to interface with these patients and their teams. This project highlights the need to think critically about a potentially growing population who are chronologically adult but remain pediatric size."

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