A Family-Centered Research Agenda for Improving Health Care Transitions for Children with Special Health Care Needs

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Today’s Speakers

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Association of Maternal and Child Health Programs
Ask Questions!

We look forward to a lively discussion with our audience. Submit your questions through the Q&A.
National Health Systems Research Agenda for CYSHCN

• Developed as a major part of CYSHCNet’s initial 5-year Cooperative Agreement with the Maternal and Child Health Bureau, Health Resources and Services Administration

• Rationale:
  • Number of CYSHCN is increasing, as is research on how to improve systems of care
  • Outcomes are not improving, and research is not always well coordinated
  • Needs of families are not always explicitly included in research priorities
  • Core Outcomes (MCHB) and System Standards (AMCHP/NASHP) are well articulated
  • Research needs to be aligned with outcomes, and efforts need to be coordinated
Development of National Research Agenda

• Began in 2018 with multistakeholder priority-setting process: RAND Appropriateness Method (RAM) and published in 2020 (Coller et al., Pediatrics, March 2020)

• Additional stakeholder input to include more/diverse families, provider groups

• Six major areas identified, with research questions prioritized within each area:
  o Transitions of Care
  o Caregiving at Home/Caregiving Processes
  o Principles of Care
  o Child Healthcare
  o Family Health
  o Financing
Improving Health Care Transitions for Children and Youth with Special Health Care Needs

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ABSTRACT

Health care transitions (HCT) from pediatric to adult health care remain a challenge for children and youth with special health care needs (CYSHCN), their families and their clinicians. While the American Academy of Pediatrics has emphasized the need to improve HCT, there has been limited research and implementation of a quality improvement (QI) model to improve HCT for CYSHCN. Our study sought to develop a 3-year QI project focused on providing guidance and tools to improve HCT for CYSHCN. The QI project focused on improving HCT for CYSHCN by addressing the following objectives: improve communication, knowledge, and skills among clinicians and families; facilitate transitions during adolescence and young adulthood; and improve the quality of care for CYSHCN. The QI project was conducted in partnership with pediatric and primary care providers. The study utilized a mixed-methods approach, including qualitative and quantitative data collection and analysis. The study findings indicate that the QI project was successful in improving HCT for CYSHCN. The study also identified areas for improvement and opportunities for future research.

KEYWORDS: Transitions from Pediatric to Adult Health Care; Research Evidence; Stakeholder Engagement; Policy Implications

WHAT’S NEW

We add to the literature key areas for future transitions research based on a RAND process of stakeholder engagement. Health care providers appropriately resources for youthful-aged adults and families. 1. There have been guidelines from numerous professional organizations; most recently the American Academy of Pediatrics and American Academy of Family Physicians and American College of Physicians (AAP/ACFAMPCP) in the 2019 Clinical Report. This guideline includes a literature review, a framework illustrated in the Four Components approach, and clinical recommendations in infrastructure, education, payment, and research. 2. Several clinical models have been investigated, but these studies have relied on single target rather than comprehensive approaches using available informatics. These approaches have improved with some clinical models. Unfortunately, these interventions lacked descriptions of the theoretical target mechanisms for the desired outcomes, so there is a

SUMMARY OF EXISTING KNOWLEDGE ON HEALTH CARE TRANSITIONS FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

1. Facilitate health care transitions (HCT) experienced by CYSHCN are well-studied and include: patient-level barriers (insufficient preparation, poor self-management skills, chronicity barriers), clinician-level barriers (lack of time in practice, lack of familiarity with transition) and system-level barriers (lack of infrastructure resources on the adult health care system, including case coordination or developmental).
Background

- The transition and transfer from pediatric to adult care is a vulnerable time for adolescents and young adults with special health care needs.

- Adolescents experience lower continuity of care and higher morbidity:
  - High attrition rates post-transfer
  - Higher Hba1c

- Well-developed research describes numerous barriers experienced on patient, provider, system, and policy levels:
  - Developmental concerns for young adults
  - Provider access and knowledge
  - System barriers to knowledge transfer and follow up
  - Insurance and reimbursement practices that do not support health care transition (HCT)
Background

• To address barriers to HCT, multiple academic societies, such as the American Academy of Pediatrics, American College of Physicians, Adolescent Medicine, and subspeciality groups have advocated for improving the transition process.

• Health systems have been working on trying to improve this “transition process” to improve quality of care delivery to these adolescents and young adults.

• Unfortunately, there is not a clear evidence on how to ensure optimal HCT outcomes.
Stakeholder Questions

“What are the best models to accomplish youth-adult transition planning? How might this translate to other transitions (e.g., to new providers, new settings, new schools, etc)?”

“How do gaps in insurance and community supports during early adulthood effect CYSHCN health outcomes, and how can they be reduced?”
The Gap: “Fixing” HCT

• Barriers to HCT are complex and the way to address barriers to HCT requires a multi-modal approach with input from patients and families.

• No single “magic bullet” that addresses all the barriers identified.

• There continues to be significant research gaps in HCT that we address in the paper.
Recommendations

- Understanding the optimal development and implementation of HCT service models
- Defining the process and outcome measures that capture adequacy of transition-related activities
- Evaluating fiscal policies that incentivize the processes of transition readiness development, transfer to adult health care services, and continuity of care within an adult health care setting
Addressing the Gap: Include Patients and Families

• Most studies do not engage families or youth in the research process

• Disconnect between family/youth goals and provider goals for HCT serves as a source of continuing failure to improve HCT

• Aligning the goals of families, youth, and providers provides opportunities to advance the field by defining appropriate process and outcome measures and generating creative solutions
Addressing the Gap: Look Beyond Healthcare

• Many interventions focus on clinic-based interventions, and yet young adults and their families don’t live their lives in the clinics

• Strategies that work with community engagement, schools, and outside programs that fulfill needs of youth (e.g., vocational attainment) will likely allow youth to grow and develop their health care management skills

• Working with community programs will also facilitate additional barriers to healthcare, and bring cultural and social competencies
Addressing the Gap: Rigor and Real World

• Greater use of randomized controlled trials and quasi-experimental methods that would help evaluate measurement and outcomes are needed.

• Currently much of the research has been driven by single academic center pilots but do not use theoretically driven models or evaluations that allow for greater generalizability.

• Using implementation science strategies to see what “works” is critical to change health systems nationally.
Addressing the Gap: Addressing Policy

• Funding and funding strategies are key to implement sustainable transition programs

• Projects describing cost effectiveness and strategic funding strategies have not been performed

• State and federal demonstration projects would help advance how best to fund incentives and programs to ensure high quality HCT
Conclusion

• Funding agencies are now increasingly prioritizing HCT research
  • National Institute of Mental Health
  • National Institute of Child Health and Human Development
  • Patient-Centered Outcomes Research Institute

• Robust development of transition measures and key outcomes are still needed

• Theory-driven interventions that are disease agnostic and rigorously tested are critical to changing the way we go about the HCT process
Faculty disclosures

Ifeyinwa Osunkwo reports consultancy for Novartis, GBT, Cyclerion, Cheisi, Acceleron, Emmaus, Agios and FORMA Therapeutics; Speakers’ bureau for Novartis, and GBT; Advisory board participation for Novartis, GBT, Acceleron, Cyclerion, Cheisi and FORMA Therapeutics; Grants from HRSA, PCORI, NC DPH and CDC; DSMB membership for Micella Biopharma; Editor-In Chief for Hematology News, Editorial Board of The Hematologist.
[SCD] Transition is Complex; The TRIAD Approach is Critical

- Medical Issues
- Psychology Issues
- Social Issues
- Community Based Organization (CBO)
- Medical (Ped/Adult)
- Patient with SCD

1. Care Standardization
   - Consistency
   - Pathways
   - Communication
   - SCD Action Plan

2. Provider Education
   - Understanding Patient Pain
   - Building Partnerships
   - Comfort and Confidence

3. Community Engagement
   - Education
   - Partnering with Schools, Healthcare, Employers

4. Patient-Provider Relationship
   - Improved Communication
   - Skilled Listening
   - Patient Navigation/Peer Mentor

5. Patient Education and Resources
   - Understanding Self-Care
   - Support Resources
   - Networks of Care
ST3P-UP Sickle Cell Trevor Thompson Transition Project

• A PCORI-sponsored $9.8m prospective, double arm, unblinded, cluster randomized study of a structured education-based transition program +/- virtual peer mentoring

• 14 sites (peds + adult program + community-based organizations)

  • **Standard arm**
    - Structured transition process
    - Implementation using quality improvement (QI)
      • Change across pediatric and adult clinics and CBO

Jan 05, 1968 - Nov 10, 2016
ST3P-UP Study Design Informed by TRIAD

Standardize Process of Transition Planning and Education
- Use www.gottransition.org model
- QI Model for Improvement, implement practice change
- QI Coach to oversee work with each site
- **Transition Coordinator = Transition Quarterback**
- Work in a TRIAD along with CBO
- Every patient in practice benefits

Addition of peer mentors will improve outcomes
- Acute Care Reliance = Acute care utilization / All healthcare encounters
- **Quality of Life Self Efficacy**
- Remaining in adult care for 1 year or more (regular visits)
- Process and Outcomes (QI, patient engagement, etc)
Transition QI Collaborative (SMART) Aim Statement

Sickle cell disease (SCD) is a complex chronic disease that results in significant morbidity, mortality, and poor quality of life for teens and young adults.

A successful transition from pediatric care to adult care has great impact on the health and lives of these patients.

We aim to improve the health of teens and young adults with SCD by implementing an evidence-based transition program in pediatric and adult SCD programs.

We will accomplish this by December 30, 2021, using the Model for Improvement and the Got Transition Six Core Elements.
SCD Transition QI Measures – Patient Centered

**Outcome Measures**

**Standardized Transition Readiness Assessment [TIP-RFT]**
- Standardized assessment
- Helps identify gaps in readiness
- Focus intervention and support
- Update annually
- Goal 75%

**Provide Detailed Transition Specific Medical Summary**
- Address medical & psychosocial factors
- Personal info relevant to care
- Update, share with patient, caregiver, adult provider
- Goal 100%

**Individualized Emergency Care Plan / Disease Management Pan**
- Plan for managing SCD plus Pain
- Acute care Emergency Department / Hospital
- Plan for home pain management
- Update regularly (annually)
- Goal 75%

**Process Measure**

**SCD Transition Process Measurement Tool [6CE]**
- Transition Policy
- Tracking/Monitoring
- Readiness and Orientation
- Planning/Integration
- Transfer/Initial visit
- Transfer Completion /Ongoing care
- Goal 90%
## QI Process Measurement Tool (PMT) Peds & Adult

### Health Care Transition Process Measurement Tool for Transitioning Youth to Adult Health Care Providers

<table>
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<tr>
<th>Implementation Requirement</th>
<th>Yes/No</th>
<th>Possible</th>
<th>Actual</th>
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### Health Care Transition Process Measurement Tool for Integrating Young Adult to Adult Health Care Providers

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### Notes
- Each row should be expanded with specific details and verifications.
- Ensure all required fields are filled.
- Use consistent formatting throughout.
- Include any additional notes or comments where necessary.
### Emergency Care Plan Tool - Home & Acute Care

**CAROLINAS HEALTHCARE SYSTEM**

**SCD Pain Action Plan**

#### Pain Under Control (VAS 6 - 3)
- No pain or minimal pain
- Mild Pain to Uncomfortable

- Can all activities without pain. Hardly notices pain at all. Feels low level of pain when pays attention. Pain then but may ignore most of the time.

**GREEN ZONE**

- Prevent Symptoms/Alerting Trigger:
  - 1) Take long-acting medications every day
  - 2) Good practice: grief, anger, and. Providing support and Medicine. How Much to Take
  - 3) Medication. How Much to Take

- Gastrointestinal rotation strategies (Deep breathing and fall asleep)
- Other instructions

**PAIN UNCOMFORTABLE (VAS 4 - 6)**
- Not feeling well. Distressful to Distressing
- Always have pain but can still do normal activities. Can work through the pain but may need to stop some time to do other activities.

**YELLOW ZONE**

- Immediate Alert: Continue all activities from the Green Zone
- Pain Medication: How Much to Take

- Continue off of IV pain medications for 3-4 hours then initiate Green Zone Pain

**PAIN UNMANAGEABLE (VAS 7 - 10)**
- Uncomfortable. Severe, Intense, or 

**RED ZONE**

- Fever: 103°F or higher
- Chest pain
- Shortness of breath
- Sudden weight gain
- Rash

- Call to the nearest Emergency Department before 911. If pain is not in the Green Zone and not at risk, see numbers below.

**Danger Get Help Immediately! Call 911 if refusing to answer.**

**Patient Signature:**

**Date/Time:**

**Primary Care Provider:**

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Self vs Validated Score for Process Measurement Tool Score

PMT Score at Baseline

PMT Score at 24 mo
We Did It😊😊😊!! PMT Scores over 24 months

13/14 (92.9%) Pediatric clinics and 10/14 (71.4%) Adult clinics achieved PMT goal of >90% by 24 mo
Pediatric Patients with a Current Readiness Assessment (Collective Data)

Pediatric Patients with a Current ECP (Collective Data)

Adult Patients with a Current Self-Care Assessment (Collective Data)

Adult Patients with a Current ECP (Collective Data)
Lessons Learned

Transition from pediatric to adult care is a major concern for persons living with sickle cell disease.

A standardized transition program can and should be implemented in both pediatric and adult clinics using QI. When using a PMT tool, information received must be validated for accuracy and consistency.

All 14 participating pediatric and adult sites showed significant progress over two years of implementing a structured HCT process aligned with the Six Core Elements.

Community partnerships are a critical part of the transition process as life happens outside the medical system.

The Transition Coordinator is the most vital “glue” for success.
Transition is more than a doctor's appointment. How are we researching what happens outside the clinic, or after the transition discussion is had?

Remember social determinants - existing research fails to address WHY transition may not occur or be sustained.

Cultural components - What does “transition” and "family" look like?

Often transition doesn’t occur because patients cannot be safely cared for on the adult side.

Especially during COVID, “youth” may stay or return to where they have natural supports in place.

Families and caregivers are more than “parents of CYSHCN.”

It takes a village - stop the blame game!

Youth and families can plan and prepare, but there must be something on the other side to support them.
The Truth About Transition…

- 5 Primary Care Physicians in 6 Years
  - Changes in insurance
  - Not responsive to needs
  - I’m not a science experiment

- Moving to a new state as a “transition expert,”…Nobody’s interested

- How do we educate and incentivize adult providers to take on medically complex ADULTS as patients?
  - Begin by infusing within education and training

- Involve ADULTS with disabilities and medical complexities to inform the discussion of what is on the other side of the bridge within the adult health care system.
Ask Questions!

We look forward to a lively discussion with our audience. Submit your questions through the Q&A.
We pursue a system that works for children with special health care needs.

Join us: lpfch.org/CSHCN

Read the Latest Research
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Apply for a Grant
Submit your idea for system improvement