



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 HCT literature has expanded, gaps remain in how to improve health outcomes during transitions. HCTs broadly encompass three key domain areas: transition planning, transfer to adult health care clinicians or an adult model of care, and integration into an adult care/model of care.

The CYSHCN national research agenda development process, described in a previous article, prioritized several key research areas to address deficiencies in the HCT process. The highest priority questions identified were “*What are the best models to accomplish youth-adult transition planning? How might this translate to other transitions (eg, to new clinicians, new settings, new schools, etc.)?*” and “*How do gaps in insurance and community supports during early adulthood affect CYSHCN health outcomes, and how can they be reduced?*”. Based upon

these priorities, we describe the current state of transition research and recommendations for future investigation.

Recommendations: The authors recommend 3 primary areas of investigation: 1) Understanding the optimal development and implementation of HCT service models in partnership with youth and families to improve transition readiness and transfer 2) Defining the process and outcome measures that capture adequacy of transition-related activities and 3) 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. This article explores approaches within each research domain.

KEYWORDS: Transition from Pediatric to Adult Health Care; research agenda; stakeholder engagement; families; patients

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WHAT'S NEW

We add to the literature key areas for future transition research based on a RAM process of stakeholder engagement.

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

1. Barriers to health care transitions (HCT) experienced by CYSHCN are well studied and include patient-level barriers (insufficient preparedness, poor self-management skills), clinician-level barriers (lack of time in practice, lack of familiarity of disease) and system-level barriers (lack of

infrastructure resources on the adult health care system including care coordination or developmentally appropriate resources for youth/young adults and families).

2. There has been guidance from numerous professional organizations, most recently the American Academy of Pediatrics/American Academy of Family Practitioners and American College of Physicians (AAP/AAFP/ACP) in the 2018 Clinical Report.¹ This guideline includes a literature review, a framework called the Six Core Element approach, and clinical recommendations in infrastructure, education, payment and research.
3. Several clinical models have been investigated, but these studies are limited to single targets rather than

comprehensive approaches using available frameworks. Disease-specific outcomes have improved with some clinical models. Unfortunately, these interventions lacked descriptions of the theoretical target/mechanism for the desired outcomes as there is a lack of implementation sciences approach to investigation.²

4. Few studies have investigated how funding incentives for quality improvement can best promote HCT activities in practice.

BACKGROUND

Children and youth with special health care needs (CYSHCN) face challenges when attaining disease self-management skills as they age into being an “adult” health care consumer. These challenges have been associated with poor health outcomes, with numerous studies demonstrating loss to health care follow up and increased morbidity and mortality during the transition and transfer period.^{3–6} For over 30 years, clinicians have documented the need to support youth and families in this process.^{7–9} The process of moving from pediatric to adult care is referred to as “health care transitions” or HCT. The goal of HCT is to improve the ability of the youth to manage their health and health care to maintain their optimal health and wellbeing. The HCT process includes a planned, proactive preparation of youth to transition from dependence on families to having developmentally appropriate self-management skills. Through this process, the youth gains self-management skills, finds and transfers care to adult clinicians and ultimately, is integrated into an adult health care system. The goal of HCT includes ensuring high-quality care through utilizing the quadruple aim approach: maximizing a positive youth/young adult and family/guardian experience, improving overall health outcomes, improving health care utilization and reducing health care costs, and ensuring that patients, clinicians and families can take joy and meaning in the efforts to improve the transition process for CYSHCN.¹⁰

While medical society consensus statements can guide the HCT process, operationalizing this in practice has been problematic. Despite existing transition planning recommendations, services have been deficient, with only 17% of adolescents with special health care needs receiving recommended transition planning.^{11,12} Numerous articles have documented the multitude of barriers to the transition process that CYSHCN encounter, and these barriers are complex.¹³ Barriers to transition have been found on the patient level (insufficient preparedness, poor self-management skills, developmental and social maturity), clinician level (lack of time in practice, lack of familiarity of disease, poor communication between providers) and system level (lack of disease-specific resources, lack of infrastructure support such as care coordination especially in the adult health care system, and lack of developmentally appropriate resources for young adults).^{14–18} Researchers have published

ecologic frameworks explaining transition and transfer failure and potential transition targets,^{19–21} but these targets have not been extensively tested within service programs. In addition, studies have lacked rigorous study designs (e.g. randomized control trials or quasi-experimental designs). As systems of care delivery vary across institutions and regions, strong study designs and implementation sciences approaches to understanding best practices are required for any future investigations.

Despite recent efforts to develop and evaluate HCT programs, those involved in delivering HCT services are still requesting additional information on the most effective transition models.^{2,22,23} Most published research has been focused on transition readiness and transfer of care, particularly with disease-specific outcomes. Examples of existing HCT research activities include mechanisms to improve adherence to health care monitoring, improving specific measurable disease outcomes such as Hb1c control, improving quality of life, improving health care involvement by the patient, improved disease self-efficacy (literacy, management) and life-readiness skills and cost.² These interventions have had mixed results. Current research gaps prevent stakeholders from developing the “ideal” transition and transfer program. Therefore, prioritizing research that is meaningful to parents, patients and clinicians is critical to advancing the field and improving clinical care.²⁴ This paper expands upon initial priorities in research and health-care for CSHCN on HCT developed by CYSHCN, discusses our current understanding from the literature, offers examples of critical research questions, and identifies possible approaches to answering these questions.

RESEARCH AGENDA DEVELOPMENT

Initial development by CYSHCN of the national research agenda for CYSHCN took place iteratively through a multi-stakeholder development process during 2017-8. [intro paper]. Stakeholders prioritized several key domains in transition research that were deficient in current practice for CYSHCN. These domains include models of care, insurance, community supports, impact on families, workforce, evaluation and measurement/outcomes.²⁵ In the area of transition, the highest priority research questions were “*What are the best models to accomplish youth-adult transition planning? How might this translate to other transitions (eg, to new providers, new settings, new schools, etc)?*” and “*How do gaps in insurance and community supports during early adulthood affect CYSHCN health outcomes, and how can they be reduced?*”. We summarize research gaps which directly address the two RAM research priorities and layout general recommendations to address these research gaps.

SUMMARY OF KNOWLEDGE GAPS IN HCT FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

1. Rigorous HCT trials have not yet evaluated what service models are most effective across differing health care systems.

2. Few studies address the medical and social complexity of young adults with SHCN, which may also reveal the crucial factors/components that improve outcomes.
3. While HCT frameworks/approaches exist, there are few implementation studies in patients with different levels of medical and social complexities.
4. Demonstration projects are needed to better understand what financing structures incentivize HCT planning, transfer and integration into adult care that also hold both the pediatric and adult systems accountable for the HCT outcomes.
5. Further developments of tools/instruments that can measure successful outcomes using the quadruple aim approach are needed.
6. Future research needs to systematically address medical and social complexity, both in the pediatric and adult medical and community systems.

WHAT IS KNOWN AND CURRENT KNOWLEDGE GAPS FOCUSED ON THE FINDINGS FROM THE RAM PROCESS

OVERARCHING RESEARCH QUESTION #1 (RQ1)
“What are the best models to accomplish youth-adult transition planning? How might this translate to other transitions (eg, to new providers, new settings, new schools, etc)?”

Identifying the “best service model” has been difficult to determine due to the heterogeneity of current studies (eg different settings, measures and target populations). Numerous papers have been written on recommendations for what entails an ideal transition process and program.²⁶ Studies of HCT interventions, however, have largely been limited to cohort studies rather than clinical trials. Few studies have provided comparison groups in evaluating the actual impact of specific transition models on transition outcomes.²⁷ Even fewer have had youth and family input in their studies.²⁸ Several systematic reviews have described condition-specific outcomes that transition programs have tried to improve.²² Components of these intervention programs included but were not limited to enhanced case management, development of instructional materials, self-education programs, mentoring/navigation services, electronic medical record transition builds and changes in clinical service structure to ensure successful HCT.² Overall, the reviews indicate that a structured approach significantly improves transition outcomes in public health, patient satisfaction and utilization of care.^{2,22} However, a “one size fits all” approach to HCT is unlikely to be successful. Therefore, taking an implementation science approach, which focuses on the systematic uptake of interventions into routine practice, to determine best practices

and process targets/change agents in HCT across different settings is necessary.²⁹

Service models also need to address how to study the increasing level of medical and social complexity that the young adults with SHCN have.³⁰ For example, HCT educational programs to help with autonomy or disease self-management may look different for someone with intellectual or physical disabilities, regardless of their underlying pattern of conditions.³¹ Currently, most research funding targets specific disease outcomes rather than the total needs of an individual, creating a gap in knowledge about solutions that cut across conditions. In addition, social constructs, such as family mental health, poverty, and family trauma/adverse childhood events, need to be addressed in any HCT service model. Knowing how to adapt service models to meet the complex social needs of families and account for underlying medical complexity is critical for generating evidence-based best practices. Having sufficient follow-up time to evaluate the overall impact of these service models and having funding that goes beyond the traditional 3-5 year range of typical grants are needed to ensure that the field can evaluate long term outcomes.

OVERARCHING RESEARCH QUESTION #2 (RQ2)
“How do gaps in insurance and community supports during early adulthood affect CYSHCN health outcomes, and how can they be reduced?”

Insurance is a critical component of ensuring health care continuity in the United States health care system. Due to changes in services and changes in the funding structure of those services and insurance at age of maturity, transition-age youth often face challenges in retaining continuous health care coverage, though this has improved with the Affordable Care Act.³² In the United States, changes and gaps in insurance and underinsurance, especially with those covered under public plans, can lead to problems with continuity of care.³³ To address RQ2, studies should investigate how systems can mitigate healthcare discontinuity due to changes in insurance from payer to payer and changes from private to public insurance plans. Changes in healthcare equity arise when young adults are covered by public insurance plans, as many providers refuse to take public insurance. Recommendations of new payment structures to facilitate HCT in practice have been generated by Got Transition.³⁴ Studies evaluating these structures (eg, Title V reimbursement, value based payment approaches and improved incentive structures) are needed to evaluate whether clinician incentives can maintain access to care for complex care patients as they transfer and integrate into adult health care. More importantly, demonstration projects that would incentivize clinicians to accept public insurance such as Medicaid, are critical to ensure continuity of care and decrease subsequent morbidity in medically vulnerable young adults. Lastly, developing ways to ensure payer accountability for transition outcomes would likely promote evidence-based HCT processes.

KEY ADDITIONAL RESEARCH GAPS THAT NEED TO BE ADDRESSED IN ORDER TO SUPPORT RQ1 AND RQ2

There are 4 additional gaps in knowledge (family involvement, community supports, measurement/outcomes and workforce) that should be addressed to fully answer the previously highlighted research questions.

ENSURING THE INPUT FROM YOUTH AND FAMILIES IN TRANSITION RESEARCH

While not explicitly noted in both RQ1 and RQ2, acquiring direct family and youth/young adult input in both generating HCT research studies and in interpreting research findings is critical to meet the quadruple aim. Research findings that include actual family, youth, young adult voices/input are represented only in a few qualitative studies³⁵ and findings that have emerged from analyses using the National Survey of Child Health.³⁶ The lack of communication between youth/young adults/families and researchers is apparent from studies that describe a disconnect from the priorities of youth, young adults and families from the clinicians who are developing HCT programs.^{15,37,38} Without addressing this gap between the needs of researchers and youth, young adults and families, the healthcare community will continue to struggle with developing effective programs for CYSHCN. Families, youth and young adults should be equally engaged and financially compensated for their expertise in all aspects of future HCT research as has been outlined by the Patient Centered Outcomes Research Institute (PCORI) and foundations.^{39,40}

DEVELOPING HCT COMMUNITY SUPPORTS AND RESOURCES OUTSIDE THE HEALTH CARE SYSTEM

For most CYSHCN, school, work, and life are often prioritized over health care needs. Unfortunately, studies have not focused on HCT processes that address home and community living. The focus of the vast majority of HCT interventions remains in medical settings. Many CYSHCN rely on schools (through the individualized education plan process and vocational planning) and community-based supports for their day-to-day needs. A major source of chronic illness/disability support is subsequently lost after age of transfer. Some HCT studies and interventions have focused on career development and life skills learning,⁴¹ but the HCT field lacks research that can guide programs to effectively assist CYSHCN to maximize educational and employment attainment, in context of their health.⁴² Ideally, future studies will enhance physical and psychological wellness and prevent social isolation due to illness/disability and the subsequent morbidity that is related to social isolation.⁴³

GAPS IN MEASUREMENT AND OUTCOMES

Understanding the effectiveness of HCT programs requires measurement of appropriate HCT processes and outcomes.⁴⁴ Perhaps the most obvious deficits in the transition literature are instruments that can reliably measure transition readiness activities/processes that predict successful transition outcomes and there is

no agreement on the parameters for a successful transition outcome. Current instruments that measure HCT readiness, such as the Transition Readiness Assessment Questionnaire (TRAQ), Self-Management and Transition Readiness Assessment (StarX) have been used broadly in intervention studies, but they do not have external validation to enable them to predict “successful” outcomes. The Patient Activation Measure (PAM) has shown promise in predicting patient engagement in their health resulting in lower costs but has not been broadly applied in HCT studies.^{45–47} Having an instrument with high sensitivity and predictive capability for HCT success would be invaluable to clinicians to develop HCT models of care. Studies have defined HCT success over a range of outcomes such as having fulfilled transfer visits to an adult clinician, “good” biometric data in specific disease states, attaining employment or school enrollment or higher quality of life measures. Variability in reported prioritized outcomes between clinicians and families make it difficult for researchers to define a “successful transition” in research studies.²⁴ Families prioritize quality of life outside of the hospital as a key outcome, while most disease specialty societies focus on a biological outcome such as HbA1c. Finally, lack of longitudinal datasets to study developed measures also hampers researchers’ ability to measure transition outcomes.

WORKFORCE AND INFRASTRUCTURE DEVELOPMENT

Developing high-quality HCT programs requires a workforce and system structure that can make HCT successful. The literature has many examples of barriers to HCT promotion and care. Provider barriers are found along the entire spectrum of the health care workforce, from nurses, physicians, social workers, family navigators, and ancillary service providers.^{17,48} Studies are needed that evaluate both the model of care and level of provider training in HCT and how the combination relates to the provision of high quality HCT health care delivery between pediatric and adult systems. Promoting studies that investigate how to best support both pediatric and adult providers in HCT is critical to developing best practices in the workforce.

SUMMARY OF RECOMMENDATIONS FOR FUTURE RESEARCH

1. Using implementation sciences methods, develop and rigorously evaluate HCT models of care (eg, RCTs or quasi-experimental designs).
2. Ensure that families and patients work with researchers to co-create new evidence-based HCT research
3. Develop process and outcome measures that reliably measure and predict transition success
4. Develop and evaluate fiscal and policy models that would support successful HCT.

RECOMMENDATIONS FOR FUTURE RESEARCH

Below are three recommended study areas to help address the deficits noted in the previous section.⁴

Models of care: Studying the patient in context to the family and community to answer “What are the best HCT service models to accomplish youth-adult transition planning, transfer and integration into adult care?”

The HCT research literature has largely focused on patient compliance with medications or clinic visits. Therefore, we recommend a community based participatory research approach to developing and enhancing HCT models to meet the needs of families and youth in their communities. Individual interventions could be disease-specific, community-specific or function specific. Models should be tested broadly across numerous health conditions and differing settings using robust study methods. Research approaches might:

1. Evaluate the application of a structured HCT approach to service models, using current guidelines and frameworks. Use implementation science or quality improvement methods (RE-AIM,⁴⁹ IHI QI methodology⁵⁰) as part of the study design. For example, a study utilizing youth and family leaders and /or community-based organizations as navigators and/or care coordinators to aid in the transition process in comparison to using social workers or community health workers in this role may be promising. Evaluation of clinician education programs/workforce capacity and HCT-focused Medical Home service models are also needed.¹
2. Rather than conducting a pre-post evaluation design, ensure that future studies of model systems use traditional randomized control trial or advanced quasi-experimental designs.
3. Have researchers and families/CYSHCN co-create and evaluate an intervention that ensures transition planning, transfer and integration into adult care. This engagement would ensure that the intervention covers all three aspects of transition and meets the needs of families in their community. Interventions with family and community involvement may lead to studies such as designing ways to improve supported decision making in families and ways to support extended caregivers (parents, relatives, community resources) and improve community engagement, schooling and employment.
4. Include HCT outcomes that reflect the needs of CYSHCN and their families. For example, transition programs that facilitate work force entry or educational needs in context to the demands of disease management or family-level interventions that train parents to help reinforce disease self-management skills and build resiliency.

TRANSITION OF CARE OUTCOMES AND MEASURES

Developing measures and instruments that can reliably predict core transition outcomes is critical for evaluating

any HCT program and policy. Multiple tools may be required to measure transition processes and outcomes. As mentioned above, youth and family-centered health care metrics need to be included. To advance the field in this area, two main research activities in HCT are proposed:

1. Studies to compare existing and new core process and outcome measures to develop a standardized set of transition quality measures that can be utilized for future clinical trials in HCT. These measures need to be generated in a way that accounts for the differences that clinicians, patients and parents may have in defining key HCT processes and outcomes. Therefore, different instruments may be required for each group.
2. Need for longitudinal cohort studies and datasets to develop long term measures and data about transition-age youth
 - a. Extend the age range of child-focused surveys such as the National Survey of Children's Health to age 26 or older, to generate important data on the health and healthcare of transition-age youth.
 - b. Measure experiences of youth and parents and clinicians separately as satisfaction and ideal outcomes may differ between these groups
 - c. Evaluate what processes can both aggravate and alleviate health disparities during the HCT process

INSURANCE AND GOVERNMENT POLICIES TO SUPPORT TRANSITIONS

Very few studies exist that evaluate how funding mechanisms and financial incentives can promote HCT. Studies that evaluate continuity of care and accountability within health care systems are critical to ensuring that long-term evidence-based supports are actualized and sustained. Studies that look at proactive ways state and federal government programs can assist in the transition process are critical to ensuring that process of care is funded and can be maintained. More importantly, understanding the fiscal impact of transition models is needed to ensure that more comprehensive and standardized transition activities are funded and maintained. Three potential study approaches are below:

1. Study the effect of local incentives to pay for the initial transfer visit to an adult provider, or additional incentives for communication around the transfer, on HCT planning and successful transfer with a medical summary and emergency care plan to an adult health-care clinician.
2. Evaluate the effect of health plan/insurance-based case management (eg, state title V programs) on HCT outcomes.
3. Determine what fiscal processes and programs can improve health equity across HCT. For example, can health plans, through incentives or case management, promote health equity across the level of disability and socioeconomic status?

CONCLUSIONS

Several key areas of research outlined in this paper would advance the field of health care transitions for CYSHCN, as guided by literature review and the RAM process. This research would focus on patient and family transitions of care in the context of their social and community environment, and uncover knowledge about adequate services and payment structures and incentives to promote continuity of care and the need for family/youth and young adult-centered models of care across the lifespan. Through increased work in these areas, the lives of all transition-aged youth/young adults and families, regardless of disease condition or functional and intellectual status will be improved.

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