

Issue Brief

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A Triple Aim Approach to Transition from Pediatric to Adult Health Care for Youth with Special Health Care Needs

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Abstract

It is a triumph of modern medicine that over 90% of children with chronic illness now survive into adulthood. This also presents a new set of challenges, as adult health care systems struggle to find capacity to accommodate complex and vulnerable young adults with a variety of childhood onset chronic conditions. The number of these patients is growing; they are expected to live longer, and they account for a significant proportion of health care utilization and spending in their age group.

These individuals face multiple challenges: developing into adults; living with chronic illness; and the difficulties associated with the transition between complex health systems. Emerging research suggests that young people fall through the cracks during the time of transition, with costly hospitalizations and, in some cases, devastating long-lasting health consequences. There appears to be a substantial opportunity to advance transition care in all three domains of the Institute for Healthcare Improvement's Triple Aim framework: to improve clinical outcomes, improve patient, family and provider experiences and decrease per capita health care spending.

In this Issue Brief, we describe key unmet needs regarding a) developing chronic disease self-management; b) enhancing capacity of the adult health care system to care for young adults with special health care needs; and c) reducing lapses in care during the transition period. Based on these unmet needs, we make recommendations for improving health care during transition that incorporate relevant high-value strategies for health care delivery. We also describe current challenges to improving care during the transition period, and suggest priorities for future research.

Background

The majority of children with chronic illness now survive into adulthood, and recent surveys indicate that 18% of young adults have a special health care need.¹ This is due in large part to advances in modern medicine such as increased survival of extremely premature infants,² expanded surgical options for patients with congenital heart defects,^{3,4} and improved treatment of genetic disorders such as cystic fibrosis⁵ and sickle cell disease.⁶ However, such successes have created new challenges for patients and the health care system.

As adolescents and young adults with serious chronic illness live longer, they are expected to move from pediatrics to adult-oriented health care, a process that can be hazardous for this vulnerable group. Consensus statements on the importance of providing high-quality transition care from the American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians and numerous other specialty organizations are now more than a decade old.^{7,8} However, transition continues to be inadequately addressed, with 60% of young

people not receiving attention to core transition issues.⁹ The transition period is also associated with negative and costly health outcomes. Examples of well-described health deteriorations during the transfer period include poor glycemic control in those with Type I

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diabetes,¹⁰ increased sickle cell crises,¹¹ loss of transplanted organs¹² and even death.¹³ In addition to the tragic consequences for these young individuals and

their families, such health crises are expensive. Health care utilization and spending for children, adolescents and young adults with childhood onset chronic illness is substantial, concentrated among a relatively small proportion of patients, and on the rise.¹⁴⁻¹⁶ For example, a large analysis of utilization patterns in children's hospitals showed that just 3% of patients accounted for 22% of inpatient charges. Furthermore, odds of re-hospitalizations were greater among adolescents and young adults when compared to younger children.¹⁶ Health care transition is becoming an increasing contributor to the crisis in US health care spending. New strategies are needed for providing high-quality, economically sustainable health care during the transition period.

High-Value Care Principles Applicable to Transition

The Institute for Healthcare Improvement has popularized a "Triple Aim"¹⁷ framework, which is a useful conceptual approach for improving transition care. The framework focuses on enhancing a patient's experience of care,

improving the health of the population, and reducing per capita cost of health care. High-value health care combines Triple Aim concepts to maximize health outcomes achieved per dollar spent while maintaining a patient-centered focus.¹⁸

There is limited evidence on how to provide high-value transition care. This is due in large part to the relatively small amount of published data regarding longitudinal cost of care for adolescents and young adults during the transition period. However, several general principles of high-value health care have particular relevance:

- **Team-based coordinated care.** All team members are valued and empowered to use their full set of skills and expertise (i.e., work at the top of their license), and there is clear accountability for various aspects of care.¹⁹⁻²¹
- **Population segmentation.** Health care interventions are tailored to individual patient and family needs. Patients are stratified based on factors such as medical complexity and ability for self-management. Segmentation is a patient- and family-centered approach to care^{17,21,22} and increases efficiency. Services are directed to those who will benefit most.
- **Technology support tools.** Telemedicine is defined as "the use of technologies to remotely diagnose, monitor, and treat patients."²³ Telehealth is defined as "the application of technologies to help patients manage their own illnesses through improved self-care and access to education and support systems."²³ Both have the potential to improve care quality and reduce

cost. However, such tools must be thoughtfully applied to ensure they address true needs in an efficient manner.

Unmet Needs in Transition Care

One of the major challenges in addressing transition care for adolescents and young adults with chronic illness is the heterogeneity of childhood onset diseases and relatively low prevalence of specific conditions. However, many of the challenges reported by these young people, their families and medical providers during transition are common across diseases. Three categories of unmet needs are particularly salient around the time of transition and transcend many medical conditions:

- The need to improve chronic disease self-management
- The need to enhance capacity of the adult health care system to care for young adults with special health care needs
- The need to reduce lapses in care during the transition period

These common challenges create an opportunity for identifying strategies to improve transition care across disease states. The recommendations described in the next section apply high-value care principles to address common unmet needs.

Recommendations in Transition Care

Recommendation 1: Develop chronic disease self-management skills

Successful transition to adult-oriented medical care is contingent upon having strong disease self-management skills such as problem solving, decision-making, forming partnerships with health care providers and taking action.²⁴ These skills can build self-efficacy for chronic disease management, which has been linked to improved health status and reduced health care utilization.^{25,26} Specific strategies to improve chronic disease self-management are summarized in Table 1.

Table 1. Strategies for developing chronic disease self-management skills

- Identify who is likely to be primarily responsible for disease self-management in the future (i.e. patient vs. family) and gradually transfer medical management from parent to young adult, when relevant*
- Provide health coaching to develop self-efficacy and self-advocacy skills
- Address mental health co-morbidities negatively associated with treatment adherence by routinely screening for and treating anxiety and depression
- Provide support for coping with chronic illness by linking young adults and family members to peer support and mentorship

* Parents who have long been directing their child’s health care needs may have difficulty relinquishing control over health care decisions. For other young adults, such as those with cognitive impairment, parents may need to retain their role managing their child’s health. Thus, the ability to direct self-management strategies toward either a young person or parents/other caregivers may be particularly helpful.

All three high-value principles are relevant to maximizing value in this domain. Health coaching may be conducted by trained lay people. Population segmentation would allow for targeted interventions to address self-management and mental health concerns in those who are most likely to benefit.

Thoughtfully applied technology can assist with screening and segmentation, increase access to services, and provide innovative means to support self-management. On-line or mobile programs may be particularly appealing to young people. The potential impact of improving self-management in young people is immense, as these skills may be used for many years into the future.

Recommendation 2: Identify and support the receiving care team

Significant differences in practice, knowledge and culture exist between pediatric and adult providers. Identifying, engaging and educating providers who will assume responsibility for a patient's care may alleviate anxiety associated with transition for patients, families and health care professionals alike. Facilitating communication between the present and the future care team can minimize lapses in care, resulting in improved health outcomes and experiences for patients. Key strategies for improving team-based care through the transition are summarized in Table 2.

Table 2. Strategies for identifying and supporting the receiving care team through transition and beyond

- Begin identifying an appropriate receiving team well in advance of transfer
- Facilitate communication between pediatric and adult care providers
- Offer a simple means of consultation between receiving clinical teams and experts in childhood onset conditions (e.g. telemedicine consults)
- Provide disease-specific educational support for rare childhood conditions
- Ensure adequate care coordination for medically complex patients

Population segmentation and thoughtful technology applications are relevant in this domain as well. Segmentation can be used to identify adolescents and young adults who require the greatest amount of support through the transition. Telemedicine offers a low-cost means to link families and community providers to subspecialists with expertise in rare childhood onset conditions.

Recommendation 3: Provide guidance to patients and families as they move between health care systems

During transition, young adults and adolescents are required to move between two complex health care environments, a task that may be difficult even for highly engaged patients. Furthermore, transition is a time of heightened vulnerability requiring structured planning and coordination to avoid lapses in care. Transition to adulthood brings about many changes in addition to health care (e.g. school graduation, separation from parents, gaining independence)

and coincides with a multitude of medical service and provider changes (health insurance, ancillary services, suppliers of durable medical equipment). Key strategies for successfully navigating through the transition are summarized in Table 3.

Table 3. Strategies for navigating through the transition

- Create clear and transparent institutional and/or organizational policies and procedures for transition
- Set clear expectations with patients and families with regard to transition
- Designate a stable point-of-contact through transition
- Ensure patients are prepared for transfer using a structured checklist of items to be addressed (e.g., up-to-date medical summary including a care plan, establishing and learning to use a personal health record, identifying new providers)
- Anticipate age-related medical insurance and service changes

A collaborative, team-based approach is essential to provide services in an effective and efficient manner. Trained lay-person navigators can serve as the point-of-contact and oversee transition preparation. Technology can assist with generating documents, sharing information, and creating a personal health record (PHR). A succinct and up-to-date PHR is an important tool to ensure that necessary information remains with the patient, when needed, at the point of care.

Conclusions

All too often, transition to adult care for adolescents and young adults with chronic illnesses is plagued by inadequate preparation for transfer, inability to find the right receiving providers and inadvertent lapses in care. Addressing these challenges calls for a structured approach to transition, which involves setting clear expectations for the changes to come, providing continuity during the time of transition, and establishing accountability for a safe landing in the adult medical system. In contrast to the current practice of pushing patients out of pediatrics, this approach creates a pull system designed to bring prepared patients forward into adult-oriented care. Transition care must be accomplished in a cost-conscious manner in order to be feasible and sustainable for already overburdened health systems. To summarize, recommendations include:

- Develop chronic disease-self management skills
- Identify and support the receiving care team
- Provide guidance and support to patients and families as they move between systems

As these and other recommendations are applied to transition care, careful evaluation will allow timely identification of lapses in care and inform further development of high-value transition health care policies. High priorities for future

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research include evaluating the effectiveness and cost impact of transition programs as well as discerning patterns of health care costs and health outcomes through the transition period. Such evaluation is vital to improve transition in a manner that addresses all three elements of the triple aim: improving the health of the transition population, improving experience of care, and reducing health care costs.

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