Transition Care: Future Directions in Education, Health Policy, and Outcomes Research

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ABSTRACT

All youth must transition from pediatric to adult-centered medical care. This process is especially difficult for youth with special health care needs. Many youth do not receive the age-appropriate medical care they need and are at risk during this vulnerable time. Previous research has identified barriers that may prevent effective transition, and protocols have been developed to improve the process. Health outcomes related to successful transition have yet to be fully defined.

Health care transition can also be influenced by education of providers, but there are gaps in medical education at the undergraduate, graduate, and postgraduate levels. Current changes in federal health policy allow improved health care coverage, provide some new financial incentives, and test new structures for transitional care, including the evolution of accountable care organizations (ACO). Future work must test how these systems changes will affect quality of care. Finally, transition protocols exist in various medical subspecialties; however, national survey results show no improvement in transition readiness, and there are no consistent measures of what constitutes transition success.

In order to advance the field of transition, research must be done to integrate transition curricula at the undergraduate, graduate, and postgraduate levels; to provide advance financial incentives and pilot the ACO model in centers providing care to youth during transition; to define outcome measures of importance to transition; and to study the effectiveness of current transition tools on improving these outcomes.

KEYWORDS: health care financing; health policy; medical education; outcomes research; transition; youth with special health care needs

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WHAT'S NEW

Directions for future efforts in health care transition ought to do the following: integrate transition curricula at all levels of medical education; ensure that essential health benefits and future financial incentives include transition; include transition in accountable care organization pilots; define transition outcomes measures; and study the effectiveness of current transition tools.

THE TRANSITION FROM pediatric- to adult-focused health care for adolescents with chronic conditions is a growing phenomenon. It is estimated that about 10 million youth aged 0 to 17 years in the United States have special health care needs. The proportion of children with special needs increases with age; about 9% of children under age 6 have special health needs, but this proportion almost doubles, to about 17%, for those aged 12 to 17 years.[1] Today, 90% of children with chronic conditions survive into adulthood, and in the United States alone, 500,000 youth with special health care needs (YSHCN) reach age 18 each year.[2] This large number of YSHCN is a result of advances in treatments, pharmacology, surgical techniques, medical technology, and health care delivery systems that have been made over the last 3 decades.[3] Unfortunately, upon reaching adulthood, many of these patients do not receive age-appropriate medical care.[4] The goal of a successful transition is for a young adult to successfully establish care in a new adult medical home from which a new continuity relationship can be established.

It is broadly acknowledged that the process of preparing YSHCN for the eventual move to adult-focused health systems should start in early adolescence and should involve individualized planning and ongoing skills development.[1] A recent consensus statement of the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) suggests that this process should be initiated by age 12. A major goal of transition preparation should be to improve self-management skills in anticipation of eventual transfer of care. YSHCN that receive care from some medical specialists, such as internal medicine–pediatrics (med-peds) and family medicine, may not require the actual transfer of their primary care to another provider. However, even such medical practices should implement policies to encourage YSHCN to learn self-management skills and take on more developmentally appropriate responsibility as they get older. Although some systems advocate a particular age as the appropriate time for transfer, it is increasingly clear that developmental readiness, regardless of age, is a better indicator for the timing of transfer.

The transition to adult care is often disorganized as result of barriers, including emotional and cognitive developmental challenges, lack of individual and family-centered social supports, difficulties in communication and coordination of care between pediatric and adult health care systems, and gaps in health insurance at the age of transition.[5] Programs are being established to address many of these barriers,[6] but additional work needs to be done.

The process of moving from pediatric to adult care can be influenced by early education of patients, families, caregivers, and health care providers. In addition, health care policies must be developed and promoted which support the unique needs of this population. As with any quality improvement effort, valid measurement strategies must be developed to guide transformation of care delivery. Key questions for this field include how to define successful transition, how to develop health utilization and patient-related outcome measures for transition, and ultimately whether successful transition improves young adult health outcomes.[7]

This article reviews the current state of transition care and proposes recommendations for future directions in transition care provider education, health care policy and clinical work, and outcomes research.

MEDICAL EDUCATION AND TRANSITION

In joint consensus statements, the AAP, AAFP, and ACP have twice set goals that “all physicians who provide primary or subspecialty care to young people with special health care needs 1) understand the rationale for transition from child-oriented to adult-oriented health care; 2) have the knowledge and skills to facilitate that process; and 3) know if, how, and when transfer of care is indicated.”[1,6] Despite the increasing number of YSHCN, there remains inconsistent training in transition issues at all levels: undergraduate medical education (UME), graduate medical education (GME), and maintenance of certification (MOC) (Table 1). Multiple groups, from the federal government to professional societies, have called for increased training for all providers in the transition to adulthood.[1,8]

Data from focus groups demonstrate that although training in chronic disease is important to providers, patients, and families, it is not adequately addressed during residency.[9] Recent graduates of pediatric residency programs cite gaps in training regarding chronic disease management.[10] Further, 33% of programs did not provide any education about the transition from pediatric to adult care.[11] Although the Accreditation Council for Graduate Medical Education Next Accreditation System (NAS) Common Program Requirements refers to competencies in “transition,” this is regarding the transfer of patients from different levels of care and team handoffs, not specifically YSHCN.[12]

Internists are much more likely than pediatricians to report training as a factor limiting their ability to care for young adults with childhood-onset chronic disease, particularly patients with neurodevelopmental disorders.[13,14] Internists report a lack of training in congenital and childhood-onset conditions as a major barrier in their willingness to accept youth with chronic disease into their practices.[15] One study of physicians in practice showed that 96% of pediatricians reported treating a patient with cystic fibrosis in residency, while only 78% of internists reported similar experience in their residency training. Within this cohort, 38% of pediatricians felt comfortable being the primary care physician for a patient with cystic fibrosis, while only 15% of internists felt the same. By comparison, 91% of internists felt comfortable being the primary care physician for a patient with hypertension.[16] Med-peds trainees report comfort caring for YSHCN, with 86% of med-peds residents reporting good or excellent preparation to care for YSHCN.[17] However, to date, there are fewer than 400 graduates of med-peds residency programs annually, so med-peds cannot be the only solution to the problem of complex care for young adults.[18]

There are specific recommendations that should be implemented at each level of medical training to teach about transition (Table 2). YSHCN and their families should be included to develop content and as faculty to utilize their expertise and support authentic youth engagement. The Institute of Medicine has recommended increased training of all levels of health providers in adolescent medicine, including the transition to adulthood.[19] At the UME level, curricula must be adjusted to recognize that individuals with particular diseases not only survive into adulthood but also face additional challenges as they grow older. As part of their education in health policy and health care systems, medical students should be taught about care handoffs, disease management, and other points around transitioning to adulthood. These skills should be included in the content and testing for the United States Medical Licensing Examination. Teaching these concepts to medical students while they are undifferentiated in their choice of specialty will prepare them to care for YSHCN regardless of their future field.

Within GME, there should be a natural shift toward learning to provide care for these long-term survivors. Each specialty should include requirements for training with YSHCN that are based on the competencies. For example, within the medical knowledge competency, an orthopedic surgery resident should learn about long-term management of patients with spina bifida. A pediatrics resident should gain exposure to chronic disease management within the ambulatory care setting as part of the