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Health Care Transitions for Adolescents and Young Adults With Special Health Care Needs: Where Are We Now?

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Abstract

Eventually, all adolescents must “graduate” from pediatric-oriented to adult-oriented health care. This transition, most often occurring during young adulthood, is especially important for adolescents with special health care needs and involves not only primary care physicians, but also both pediatric and adult subspecialists. Several studies support the benefit of transitional programs for adolescents and young adults with special health care needs. Additionally, the American Academy of Pediatrics named transitional care as one of its top priorities. However, transitional programs have yet to become an established norm among hospitals and providers, specifically outside of children’s hospitals. This topic synopsis aims to draw attention to this important issue, review the rationale behind current recommendations and report the current status of transitional programs in North America. Moreover, the steps that individual clinicians, practices and health systems may take to plan for successful health care transitions are discussed. (*J Patient Cent Res Rev.* 2017;4:90-95.)

Keywords

health care transition; pediatrics; adult care; adolescents; special health care needs; childhood-onset chronic disease

What Is a Health Care Transition?

As defined by the Society for Adolescent Medicine¹ and reiterated recently by Fair and colleagues,² a health care transition is “the movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.” It is a “complex and dynamic phenomenon”³ that involves the skills, coordination and education of patients, families, clinicians and caregivers.⁴ Ultimately, each adolescent’s health care transition journey is unique,³ predicted in part by various demographic, personal and ecological factors, in addition to the degree and specific features of disability.^{4,5}

Why Are Health Care Transitions Important?

In 1993, the Society for Adolescent Medicine “sounded the alarm” that high-quality health care transitions should be promoted.¹ In 2002, Reiss and Gibson reported the need for systems change as well as personal/local education and activation to ensure effective transitions.³ That same year, a joint commission policy statement was issued by the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP)/Society of Internal Medicine regarding health care transition for young adults with special health care needs.⁶ For purposes of this review, we will generally center on a special needs population that was the focus of the consensus statement and described as “adolescents and young adults with severe medical conditions and disabilities that limit their ability to function and result in complicating social, emotional or behavioral sequelae.”⁶

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The joint commission's stated goal at that time was to ensure that by 2010 "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."⁶ The AAP annual leadership forum made transitioning youth with special health care needs to adult health care one of its top 10 priorities, and in 2011, the AAP, AAFP and ACP released an updated report that provided more specific guidance and further promoted health care transition for youth.⁷

Although transition is aimed to take place during young adulthood (ie, 18–21 years of age), it is recommended that transition planning begin around age 12 for all children and even earlier for children with special needs.^{6,8} Although pediatricians and pediatric subspecialists provide exceptional care to the pediatric patient, they are not trained in routine care of the adult patient. Certainly not all children with special needs (those with family medicine or internal medicine/pediatric physicians and advanced practice providers) will need to transition their primary care clinician or medical home. However, even these patients are likely to encounter transition barriers to new adult specialists and facilities.⁵ Although many children's hospitals have transitional programs, they are not always effective; and a number of institutions, including even large pediatric practices, may not have transitional programs.⁹⁻¹¹

Between age 12 and 18, there are yearly actions recommended — from simply discussing the clinic policy on transition to formulating a longitudinal plan with achievable goals — which ultimately lead to a well-organized transition plan in place prior to the youth turning 18 years old.⁷ This plan may be verbal if the patient has no chronic health conditions, or, particularly applicable for those with complex or special health care needs, it may be in the form of a written document that clearly identifies all providers involved in the transition of care, including primary care providers and both adult and pediatric subspecialists. The 2011 joint commission statement identified essential information needed by the receiving physician to ensure a smooth transition. Essential information includes the youth's baseline functional, neurologic and cognitive status

(including any formal testing results), condition-specific emergency treatment plans and contacts, assessment of the patient's understanding of his or her condition, treatments and prognosis, procreation potential status and any genetic information.⁷

In turn, the receiving primary provider, whether internal medicine or family medicine, must be prepared to receive the adolescent or young adult patient. Responsibilities include identifying the legal health decision-maker and clearly discussing clinic policies with the patient and/or family, including Health Insurance Portability and Accountability Act (HIPAA) regulations, particularly if the patient has become his or her own health care agent. The adult provider also should promote open communication with pediatric or adult subspecialty providers to prevent omissions or redundancies in care.⁷

What Is the Status of Transitional Programs?

Several reviews have identified worse health care outcomes among adolescents and young adults with special health care needs who did not transition appropriately.¹²⁻¹⁵ Other studies have evaluated the benefits of adequate health care transitions for these individuals. Benefits often associated with adequate transitions include reduced medical complications, improved patient-reported outcomes, greater adherence to care, positive patient experience and lower cost of health care. A study conducted by Annunziato et al demonstrated improved medication adherence in liver transplant patients who participated in a transitional program from 2007 to 2012.¹⁶

A few studies also demonstrated positive health, educational and vocational outcomes in youth with chronic illness, and higher levels of satisfaction and independence in patients with cystic fibrosis compared to peers without a transitional program.^{17,18} For example, successful transitional programs have been reported for patients with juvenile arthritis, type 1 diabetes and sickle cell disease.¹⁹⁻²¹

A recent Canadian study of 104,497 adolescents found that, at least in the short term, patterns of health care use and costs during transition did not differ appreciably from those prior to transfer.²² Additionally, McManus et al demonstrated that use of quality improvement techniques could affect systematic clinical transitions

among adolescents in large pediatric practices in the district of Columbia.¹⁰

Nonetheless, formal transitional programs have had mixed success.²³ A recent Cochrane review found limited quality studies that evaluated the effectiveness of specific interventions to improve adolescent transition from pediatric to adult health services, specifically for those with chronic conditions, and was unable to draw firm conclusions.²⁴ Ultimately, “the field lacks a consistent and accepted way of measuring transition success,”²⁵ at least from a research standpoint.

Oswald and colleagues proposed the following clinical definition of successful transition: having the usual source of health care; having a provider who does not treat only children, adolescents and young adults; having insurance that meets the patient’s needs; at least one preventive health visit in the past 12 months; satisfaction with health care services; and no delayed or foregone needed health service in the past 12 months.¹³

Certainly, “health care transition planning is not occurring as a standard of care.”¹¹ It is our own experience that many adult providers are reluctant to receive young adults with special needs due to case complexity, length of office visits and perceptions about expectations regarding their own comfort and expertise. Indeed, similar transition issues were expressed by internal and family medicine providers responding to surveys.^{26,27}

Why Have Health Care Transitions Not Become an Efficient Standard of Care?

This is a fair question, particularly in the era of integrated medical organizations and electronic medical records. Even within the same institution with a common information system, successful transition from pediatric to adult specialty services may be limited for a large number of individuals.²⁸ Several potential barriers to widespread implementation have been identified, particularly among receiving adult providers. These barriers include deficits in education and/or experience.

A nationwide survey conducted by Okumura et al demonstrated a significant lack of comfort in providing primary care for young adults with special care needs (specifically cystic fibrosis and sickle cell disease), with

only 15%–38% of respondents feeling comfortable being the primary care provider.²⁹ Other barriers to providing adult primary care to youth with special needs is lack of training in congenital and childhood illnesses, lack of time and lack of reimbursement for time to coordinate care.^{11,13,21,26,30} No doubt, low volumes of transitioning special needs young adults in most medical practices (and each patient’s unique set of issues) contribute to providers’ perception or actuality of failing to keep current with proper treatment of these individuals.

In addition to the logistic, bureaucratic, medical information and communication challenges in transitioning to adult health services, there are also medical, intellectual, behavioral and emotional issues among adolescents that must be acknowledged.^{5,11,31} This includes the loss of relationships with previous clinicians and staff (pediatric providers may have difficulty letting go as well),³ and the increased emphasis on autonomy and responsibility of the patient, which the adolescent may not be developmentally capable of assuming.^{31,32}

A survey of 183 parents and guardians of youth with autism spectrum disorders revealed that only 60% received transition services, despite high rates of insured status and access to health care.³³ The greatest impediments in this population included reported lack of information regarding the transition process and difficulty finding an adult primary care clinician with sufficient knowledge of autism spectrum disorder.³³ A convenience sample survey of 155 transitioning patients with various childhood chronic diseases and 104 parents reported that significant gaps in transition education existed regarding a variety of health-related and future vocational issues.³² This report also cited lack of adult specialist providers as a barrier to transition.³²

Perhaps most illustrative were detailed stories of patients’ and parents’ experience with the transition process. Three such examples illustrated significant time delays, emotional and practical issues of being made to leave one group of providers for another, the simultaneous occurrence of educational, vocational, transportation and insurance changes, and diminution of parental input at medical visits.³⁴ Patients and family/guardian caregivers themselves may present additional

barriers. Their level of health literacy, adherence to plans, and a variety of cultural, environmental, demographic and systemic variables may affect health care transition preparation and success.¹¹ Indeed, as Hergenroeder et al noted: “It is important to distinguish between health care transition eligibility and readiness.”¹¹

Finally, the patient’s school system is vitally important in health care transitions. Data suggests that transition planning occurs for a majority of students, but that the students themselves may have limited opportunity to lead planning sessions; other contributors, such as vocational agencies, may be limited.³⁵ Anecdotally, school systems appear to vary in their quality of contribution toward health care transition, and communication with the medical home is often lacking.

Where Do We Go From Here in Our Own Practices?

It is clear that a smooth, seamless health care transition from pediatric to adult primary care providers is desired for all youth but is particularly important for youth with special health care needs. Pediatricians, internists, family physicians and subspecialists all have unique roles within the medical home model, and open, ongoing communication among these providers is essential to providing continuous care. The transition may be conducted between individual providers through an established care transition plan within a group or system. Transition also may occur through a dedicated clinic serving as a bridge between adult and pediatric primary care, which may ease the transition to adult providers who otherwise may be uncomfortable with the intricacies of transitional planning and care of youth with special health care needs, particularly if not a regular part of their clinical practice.

It is important that formal “hand-offs” occur between pediatric and adult medical homes and specialists.⁵ Eager and willing acceptance of transitioning patients by adult-oriented providers is essential. One potential decision point is whether pediatric subspecialists should assume the role of choosing and partnering with adult care specialists or whether that should be the responsibility of the primary care clinician. We favor the latter, as primary care consists of the individuals who receive specialist reports, refer for future specialist care

and, in many cases, are in a better position to ensure the receiving specialist is covered by the patient’s health insurance.

With a longer life expectancy for children with congenital and other chronic health care conditions,^{31,36} adult medicine provider training will likely need to evolve to include pediatric illnesses among adult patients. Another potential solution involves pediatric subspecialists continuing to care for young adults in certain situations of pediatric diseases that extend into adulthood.⁵

It is most important to ensure that one’s own medical practice has a transition policy and a transition registry or database.⁹ Preferably there is a general health care transition plan for the entire practice and a specific one for each transitioning individual. Start early, no later than between the ages of 12 and 14.⁹ Such plans should include more patient-centered outcomes like quality of life.² Guidelines and resources are available for state-level, community-level and practice-level assistance in transition care (and for areas of future research).^{8,25,37,38}

Fifteen years ago, Reiss and Gibson listed factors associated with apparently successful transitions based on the results of a series of focus groups involving youth and young adult patients, families and caregivers.³ This list is useful yet today as a starting point for health care transition plans and includes: 1) patient, family and medical providers having a future focus; 2) early start to transition; 3) fostering as much personal and medical independence by the patient as is possible; 4) including future planning for insurance, equipment and navigation skills in addition to future providers; 5) the transitioning patient vocalizing the desire to “function in the adult medical world;” 6) ensuring service reimbursement is not interrupted; 7) pediatric clinicians continuing to provide some care into adulthood; and 8) the patient continuing to receive services from the same health care system.³

Parents, family and guardians should continue to be included in transition planning. They are critical and often the main determinants of transition success or failure. It is important to remember — and have sensitivity regarding — the significant stress experienced by family caregivers of patients with disabilities, particularly at a time of transition.³⁹ Additionally, due to the variability

in the comprehensiveness of transition information given to parents of special needs adolescents, medical homes may need to supplement a family's knowledge base regarding certain critical nonmedical issues. For example, in the state of Wisconsin, parental guardianship is not assumed when the patient reaches age 18, and proactive legal consultation is necessary.⁴⁰

Conclusions

For practical assistance, several sources cited herein have useful checklists to guide patients, families and medical homes in the transition process.^{8,9,31,38} Moreover, we encourage their use. The article by Hergenroeder et al may be consulted for a robust discussion of current issues in transition beyond the scope of this brief review.¹¹ The "Got Transition" project is especially recommended as a standard-of-care source for further information.³⁸

By staying cognizant of specialized needs, using the available tools and, perhaps most importantly, maintaining a willingness to deviate from daily clinical routine, all caregivers can do their part to improve health care transitions for youth with physical and intellectual disabilities.

Patient-Friendly Recap

- A health care transition occurs when an adolescent or young adult changes from pediatric to adult care.
- Health care transitions in youth with physical and mental disabilities can prove challenging and be unsuccessful if not properly planned by patient (when possible), family and clinicians.
- The authors comment on the current lack of standardized transition planning in those with special health care needs and detail the essential components of adequate transition, emphasizing an early start to planning as well as continued involvement of all parties connected to the patient's care.

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Conflicts of Interest

None.

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