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Current Issues in Transitioning from Pediatric to Adult-Based Care for Youth with Chronic Health Care Needs

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Chronic disease in 6- to 21-year-olds affects approximately 1 in 5 US families.[1] Advances in medicine have improved the outcome for children with chronic illnesses; in the US, 90% of children and youth with special health care needs of a physical nature will enter adulthood, numbering one-half million annually. An estimated additional 600 000 16- to 17-year-olds in the US have serious mental illness.[2] In this review, we will include chronic physical, mental, and behavioral illnesses as special health care needs and will combine children, adolescents, and young adults under the umbrella term, youth and young adults with special health care needs (YYASHCN).[3,4]

A 2002 Consensus Statement[3] identified multiple deficiencies in health care transition, including: (1) YYASHCN are not prepared for health care transition; (2) pediatric health care providers are not prepared to assist in transition readiness for YYASHCN and their families; (3) inadequate communication between the subspecialty and medical home providers; and (4) an adult health care system not adequately prepared to receive young adults with special health care needs. Despite increased attention to the importance of health care transition from pediatric to adult-based care, progress in addressing these barriers has been slow. Increased morbidity and mortality have been reported in the post-transition period if the transition is poorly managed, and those with complex conditions and neurocognitive disabilities tend to do worse.[5] The goal of this article is to briefly describe the broad issues of health care transition from pediatric to adult-based care and opportunities for improvement.

Health Care Transition Planning Is Not Occurring as a Standard of Care

In 2009 the term "core transition outcome" was coined to describe key elements in successful health care transition planning for YYASHCN, to include having discussions with a health care provider about future adult health care needs, such as finding an adult provider and securing health insurance, and encouraging young adults to take more responsibility for their care.[6] Forty-one percent of parents of YYASHCN reported that this core outcome was met with no reported discernable improvement between 2005 and 2010.[7] Similarly, transitioning youth report they did not receive health care transition counseling[8] and did not know enough about the transition in advance.[9] In one study, 39% of adolescents with congenital heart disease and 51% of their parents had adequate knowledge of their disease.[10] Impoverished and ethnic minority youth are less likely to report receiving transition preparation,[7] which can contribute to health disparities.

Across many disease conditions, improvement is needed in methods to facilitate transition readiness in pediatric care and in the readiness of adult health care systems to provide care for YYASHCN.[11] There is little evidence to inform what structures and processes facilitate successful transition to adult-based care. Having the patient meet the adult provider before the actual transition to adult care improves success.[5,8] Most studies evaluating transitional care have been for patients with diabetes mellitus with existing evidence supporting the use of educational programs for transition-age patients, transition coordinators, joint pediatric and adult clinics, specific young adult clinics, after hours phone support, and enhanced follow-up after transition.[8,12] Given the associations between oral and systemic health, this applies to dental care as well, especially for YYASHCN who are at risk for poor dental health compared with peers without special health care needs.[13,14] Thus, there are individual patient, family, medical practice, hospital, and system level opportunities for improvement that could contribute to better health care transition.[15]

Preparing Youth and Families for Transition

Adolescence is a period of profound cognitive, emotional, and physical maturation that can be altered by a chronic illness.[4] The interface between adolescent development and a chronic illness should be addressed in health care transition planning while recognizing that young adults are developmentally different than both younger children and older adults. Many YYASHCN and their families have built a trusting relationship with their pediatrician and are ambivalent about transferring to adult-based care.[8] It is also difficult for pediatricians to let go.[4] This relationship exists with pediatric dentists as well, many of whom are

YYASHCN	Youth and young adults with special health care needs

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providing care for patients in their 40s.[13] Planning should start years before the expected transfer.[16]

It is important to distinguish between health care transition eligibility and readiness. Many systems of care approach health care transition based on eligibility, often using age (eg, 18 years), insurance criteria, high school graduation, or becoming pregnant as criteria for transition. However, these criteria may be unrelated to health care transition readiness and their use could exacerbate existing health disparities. Health care transition readiness can be facilitated by early planning, including a written health care transition plan by age 14 years, and acquiring a set of core competencies composed of the essential knowledge and skills needed to self-manage.[16-18] Operational definitions of health care transition readiness have begun to be established and imply being able to navigate the adult health care system. Having basic disease management knowledge and skills is a starting point yet is different from understanding the disease process.[19] Youth with HIV have identified the need for increased continuity of care, assistance with logistics, improved communication between providers and caregivers, and individualized management of their transition process.[20]

Families and YYASHCN need to initiate conversations about health care transition planning at an early age, even before formal transition planning occurs.[21] Families should be encouraged to accept the transfer of health care management and decision-making to transition-ready youth or their trusted health surrogate, as the parents will not be able to play this role indefinitely. Activities that facilitate planning include facilitated networking with families who have children with similar illnesses and using formal and information organizations, such as Family Voices.[22]

There is a need to improve family and patient-centered care.[23] Although families are legally spokespersons for children until the age of majority, health care decisions often are made without involvement of the youth through an "assent to consent" process. In many cases, no discussion occurs nor is the youth given the opportunity to practice informed decision-making via the assent to consent process. As YYASHCN mature, these skills should be taught. Most families are neither trained nor encouraged to transfer knowledge and skills, first as a teacher, then as mentor to the youth. Lack of disease-specific knowledge among YYASHCN is associated with parent education level.[24] The range of support required by the youth, with or without special health care needs, will depend on the young person's health status and cognitive level. Once the youth reaches age 18 years, the decision-maker can range from the patient him/herself, the parent/caregiver as temporary or partial health care surrogate/power of attorney in specific health areas, to full-time support via different levels of guardianship. Only one-half of primary care providers routinely invite the parents out of the room to discuss confidential issues with adolescents.[25] Yet this time is essential for YYASHCN to develop confidence as self-advocates. There is a shared responsibility between pediatric health care providers and families to prepare for the difference between pediatric and adult-based care and to delineate the roles of the youth, family and providers.[8] In fact, a family history collection and clinical decision support tool was noted to have positive effects on patient care, including increases in quality, personalization of care, and patient engagement in primary care.[26] Increasing awareness among the YYASHCN's family that health care transition to adult-based care is a desirable outcome is to be encouraged.[4]

Training Pediatric Health Care Providers and Preparing Pediatric Systems of Care to Plan for Health Care Transition

Pediatric providers and pediatric systems of care need to be better prepared to facilitate health care transition[4,27] and be willing to adopt health care transition as part of their practice. In part, this is related to the competencies of pediatricians that extend through age 21 years: just as adult physicians may not be trained in some pediatric diseases, pediatricians are not trained in many adult diseases. Likewise, in spite of many YYASHCN being seen by pediatric dentists, they are not equipped to provide adult-centered care such as dentures, permanent crowns, and implants.[13] A patient's desire to be more responsible for their health care, by gaining a sense of control over their health, should precede transfer of care from the pediatric provider. Specific skills include scheduling appointments, talking to their doctor alone, and "wanting to be taken more seriously" by their physicians. Encouraging the patient to form a partnership with the pediatric provider and to exercise shared decision making for medical care will require a shift for many physicians. Youth report that health care transition planning was facilitated when they were viewed as a partner in the discussion.[28] Pediatric providers and their practices could improve in a core group of knowledge, skills, and practices regarding health care transition planning, and enhance the sense of partnership with the patient, including being more receptive to their needs.[27,29] These include inviting the parent out of the room and encouraging patients to ask questions about and be involved in decisions about their medical care. In addition, the use of new or interactive (nonprint) media with patient information designed for youth and young adults has been associated with improving patient's knowledge, self-care, and transition readiness, and reducing dropout rates after health care transition to adult-based care.[8] Transition-age teens have voiced a desire for support groups with other teens, a preference for using text messaging for communication, and a desire for an online health management program.[19]

To present transition as a normative event, a written transition policy should be discussed with patients and families, opening the door for families to be asked about their expectations of transition.[8] Lists of contact information for adult providers whom the pediatric provider endorses and to whom the patient could be referred could facilitate the identification of a specific provider that the youth can contact.[8] If possible, the name and contact information of a