

Original Contribution

Transitioning from pediatric to adult health care with familial hypercholesterolemia: Listening to young adult and parent voices

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Familial hypercholesterolemia; Transition to adult care; Young adult; Chronic disorder; Cardiovascular health

BACKGROUND: Young adults with familial hypercholesterolemia (FH) are at a critical period for establishing behaviors to promote future cardiovascular health.

OBJECTIVE: To examine challenges transitioning to adult care for young adults with FH and parents of FH-affected young adults in the context of 2 developmental tasks, transitioning from childhood to early adulthood and assuming responsibility for self-management of a chronic disorder.

METHODS: Semistructured, qualitative interviews were conducted with 12 young adults with FH and 12 parents of affected young adults from a pediatric subspecialty preventive cardiology program in a north-eastern academic medical center. Analyses were conducted using a modified grounded theory framework.

RESULTS: Respondents identified 5 challenges: (1) recognizing oneself as a decision maker, (2) navigating emerging independence, (3) prioritizing treatment for a chronic disorder with limited signs and symptoms, (4) managing social implications of FH, and (5) finding credible resources for guidance. Both young adults and parents proposed similar recommendations for addressing these challenges, including the need for family and peer involvement to establish and maintain diet and exercise routines and to provide medication reminders. Systems-level recommendations included early engagement of adolescents in shared decision-making with health care team; providing credible, educational resources regarding FH; and using blood tests to track treatment efficacy.

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CONCLUSION: Young adults with FH transitioning to adult care may benefit from explicit interventions to address challenges to establishing healthy lifestyle behaviors and medication adherence as they move toward being responsible for their medical care. Further research should explore the efficacy of recommended interventions.

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Introduction

Adolescents and young adults (hereafter, “young adults”), between the ages of 17 to 21 years, are at a critical period for establishing patterns of behavior to promote cardiovascular health.¹⁻⁴ The number of healthy lifestyle choices made by young adults—including exercising, adhering to healthy dietary patterns, being at a healthy weight, and not smoking—is strongly associated with maintaining a low risk for heart disease well into middle age.^{2,5-7} It is at just this time that young adults transition to adult medical care and must learn to independently navigate the health care system while simultaneously managing the routine developmental milestones of early adulthood.⁸⁻¹¹ Moreover, health care professionals face uncertainty regarding how to best facilitate this transition in the general pediatric population.¹²⁻¹⁴

Chronic disorders such as type 1 diabetes or congenital heart disease further complicate the transition to adulthood.¹⁵⁻¹⁸ For young adults with chronic disorders, research has documented prolonged gaps between leaving pediatric subspecialty care and entering care with an adult provider.^{19,20} Factors impeding timely health care transitioning at the patient level include lack of knowledge about one’s disorder, competing life priorities such as work or school, and the desire for continued parental involvement.²¹ Systems-level barriers to continuous access to care include a lack of specific adult provider referrals and insufficient information transfer between pediatric and adult providers.^{19,22} Surveys of subspecialty providers have also documented a lack of training regarding managing transitions.^{23,24}

Young adults with lipid disorders provide a salient example of how a chronic disease adds to the challenges of the health care transition. Heterozygous familial hypercholesterolemia (FH) is a genetic lipid disorder characterized by abnormally high lipid levels and an increased risk of premature cardiovascular disease (CVD) events later in life,^{25,26} with 25% of affected, untreated women and 50% of men having a CVD event by age 50.^{25,26} Early intervention to lower cholesterol levels—including establishing healthy diet and exercise patterns and taking medication—may decrease this risk.^{1-4,27} When transitioning to adulthood, young adults with FH must continue these healthy patterns of behavior as they assume responsibility for management of their disorder.¹⁶⁻¹⁸

Despite the serious consequences of untreated or poorly managed FH and the importance of early adulthood as a

critical period for establishing preventive cardiovascular behaviors, there is a lack of age-specific resources for young adults with FH during the health care transition.^{8,28} In fact, most of the literature on transition age youth in the general population focuses primarily on the logistics of the transfer to adult medical care, such as selecting a new physician and navigating the health care system. However, transfer to an adult model of care is but one of many issues in the large transition to early adulthood for youth with FH, including the realities of understanding and implementing healthy patterns of behavior within the context of an FH-specific treatment plan.^{8,28}

Further confounding this lack of resources are conflicting recommendations in pediatric and adult guidelines for treating high cholesterol in this age population.²⁹ A recent analysis²⁹ of the National Health and Nutrition Examination Survey, conducted by Gooding et al, reported that almost 500,000 young people aged 17 to 21 years in the United States have an low-density lipoprotein cholesterol (LDL-C) level that would qualify for pharmacologic treatment under pediatric guidelines (ie, 2011 National Heart, Lung, and Blood Institute Integrated Guidelines for Cardiovascular Health and Risk Reduction in Children and Adolescents³⁰) but not under a set of adult guidelines (ie, 2013 American College of Cardiology and American Heart Association Guideline on the Treatment of Blood Cholesterol to Reduce Atherosclerotic Cardiovascular Risk in Adults³¹). Although most young adults with FH have an LDL-C ≥ 190 mg/dL and would thus qualify for lipid-lowering therapy under either guidelines, some patients with heterozygous FH have LDL-C levels in the more moderately elevated range (~ 160 – 190 mg/dL) accompanied by a family history of early CVD and would meet criteria for statins under the pediatric but not the adult guidelines. Whether practicing adult providers recommend continuing lipid-lowering therapy or stopping it for these young people is unknown. The discrepancy in guidelines could create uncertainty and confusion for patients with more moderate lipid elevations as they move from pediatric to adult subspecialty care.²⁹

This research was designed to illuminate the perspectives of young adults with FH and parents of affected young adults during the transition to adult care. A series of semistructured, qualitative interviews was conducted to gain insight into the experiences, transitioning needs, and recommendations of these individuals.

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