Transition and Transfer From Pediatric to Adult Care of Young Adults With Complex Congenital Heart Disease

Alison Knauth Meadows, MD, PhD, Valerie Bosco, MS, RN, FNP-C,
Elizabeth Tong, MS, RN, CPNP, Susan Fernandes, MHP, PA-C,
and Arwa Saidi, MB, BCh

Corresponding author
Alison Knauth Meadows, MD, PhD
Departments of Pediatrics and Radiology, University of California, San Francisco, 350 Parnassus Avenue, Suite 307, San Francisco, CA 94143-0336, USA.
E-mail: alison.meadows@ucsf.edu

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Many children with complex congenital heart disease are now surviving childhood with the potential to live meaningful and productive adult lives. The process of transitioning or preparing patients and families for transfer from pediatric to adult care is challenging and rarely implemented properly. An inadequate transition process results in delayed and inappropriate care, improper timing of transfer, and undue emotional and financial stress on the patients, their families, and the health care system. At worst, patients are lost to appropriate follow-up. This article discusses the general principles of transition and transfer for young adults with chronic illness, highlights the needs of young adults with congenital heart disease, discusses the barriers to transition, and proposes goals and key elements of a formal transition program.

Introduction

Many children afflicted with complex childhood illnesses that historically caused early death are now surviving childhood with the potential to lead meaningful and productive adult lives. Although most of these patients eventually transfer their care from a pediatric to an adult health care environment, the process of transitioning or preparing patients and families for this transfer comes with many obstacles. As a result, transition is neither easy to orchestrate nor simple to carry out. At its worst, and as frequently happens now, patients are lost to appropriate follow-up. To avoid these hazards, physicians managing these young patients must recognize the importance of the transition process, an educational and experiential process that prepares patients to take responsibility for their own health care. The process ends when the young patients "graduate" (or transfer) to an appropriate adult health care setting, one that can address their evolving adult needs and can continue to do so for the rest of their lives. Carried out correctly, the process is challenging but rewarding for these young people and provides them with the opportunity to maximize their future physical and psychosocial well-being.

The transition needs of adolescents with congenital heart disease (CHD) are growing. Because of advances in pediatric cardiovascular surgery, percutaneous interventions, intensive care, and medical management, many children with CHD survive into adulthood. As a result, the number of adults with CHD in the United States is rising exponentially and now exceeds 1 million. At least 50% of these patients have complex CHD, but less than 30% are seen by appropriate specialized care, and, unfortunately, few specialists are trained in the complexity of their care. In addition, they often present with complex comorbidities and psychosocial challenges [1–3]. Adolescents with CHD thus constitute a growing population to whom a well-planned and well-executed transition process can be valuable.

This article discusses the general principles of transition and transfer for young adults with chronic childhood illness, highlights the needs of young adults with complex CHD, provides an overview of the barriers to transition, and discusses the goals and key elements of a formal transition program.

Definition of Transition and Transfer

Transition of care, as referred to in this article, is the process by which adolescents and young adults with chronic childhood illnesses are prepared to take charge of their lives and their health in adulthood. It is an educational process that ideally begins before children reach adolescence and continues until they are capable of taking full responsibility for their care [4•].

Transfer defines an event or series of events through which adolescents and young adults with chronic physical and medical conditions move their care from a pediatric to an adult health care environment. In the absence of appropriate adult resources, transfer should be deferred; however, assuming appropriate adult care is available, transfer is likely to be beneficial to patients. Although a pediatric care model is ideal for young children, as it focuses on growth and development and directs education toward the parents or guardians, it is no longer appropriate for adult patients. In contrast, the adult care model uses a visit dynamic that is a partnership with education directed toward the patient, thus encouraging independence, responsibility, and self-reliance [4•].

The goals of a formal transition program are to prepare young adults for transfer of care. It provides uninterrupted health care that is patient centered, age and developmentally appropriate, flexible, and comprehensive. It also educates young people about their medical conditions and promotes skills in communication, decision making, self-care, and self-advocacy [5–9]. As such, such a program fosters greater personal and medical independence and a greater sense of control over their health, health care decisions, and psychosocial environment. The ultimate goal of a transition program is to optimize the quality of life and future potential of young patients [10].

Brief History of Transition

Health care transition for young people with chronic health conditions has long been recommended [10–12]. In the United States, multiple invitational conferences and task forces have identified the problems faced by the growing population of adults with chronic childhood illnesses and their need for formal transition programs. In 2003, the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians presented a consensus statement on health care transition for young adults with special health care needs [13]. This was subsequently endorsed by the Society for Adolescent Medicine in its 2003 position paper [5]. Similarly, in the United Kingdom, the transition of young adults with chronic childhood illnesses to the adult health care system was explicitly addressed by the Royal College of Paediatrics and Child Health in its guidelines on health care for adolescents [6].

Specialty professional organizations have also weighed in on the need for transition programs with practice guidelines and position statements on the transition of young people with chronic health concerns. In particular, the needs of adults with CHD and recommendations for transition and transfer of care have been formalized by expert task forces, including the 32nd Bethesda Conference convened by the American College of Cardiology [14–18], the Canadian Cardiovascular Society Consensus Conference [19–21], and the British Cardiac Society [6,22]. Presently, the American Heart Association has commissioned a committee of pediatric and adult providers to form guidelines for the transition of adolescents with CHD. Perhaps even more compelling is that patient organizations, most notably the Adult Congenital Heart Association, are asking for transition by organizing work groups and promoting the formation of programs across the country.

Barriers to Transfer of Care

Despite recently published guidelines recommending regular follow-up with a specialist in the care of adults with CHD [23•], research suggests that most adults with complex CHD are lost entirely from cardiac care or are cared for by cardiologists without specialized training [24,25]. This is the result of many barriers to smooth transition and transfer, both intrinsic and extrinsic to the physician–patient team. A successful transition program must address these issues [8,11,26,27].

Obstacles that lie outside the patient–physician relationship are often the most obvious. First, there are woefully insufficient numbers of care providers trained in the care of this complex patient population. Second, there are significant financial and insurance barriers to providers' ability to care for these patients.

Less obvious—and often more difficult to address—are barriers that lie within the physician–patient axis. First, the adolescents may impede their own progress [28,29]. Transferring care may be traumatic for adolescents. The challenge of accepting responsibility for their health and lives can be overwhelming, and adolescents may subconsciously see the transfer of care as a danger rather than an opportunity. Moreover, at this time of personal adolescent struggle, they are forced to give up their relationships with trusted and respected pediatric providers and expected to develop new relationships with an unknown group. They are expected to transfer from a pediatric facility within which they feel comfortable to a less coddling adult facility. Finally, the self-image of young people with chronic illness is often infantilized, which promotes dependence. Transfer of care challenges patients to become independent and thus may be resisted.

Similarly, families can be unwitting obstacles to the transfer of their children's care [30,31]. Adult care models usually take an individual rather than a family approach, and although this approach encourages patient self-dependence, the families often feel excluded from this new dynamic. Some parents perceive this as a loss of control rather than a positive step toward greater autonomy and self-sufficiency for their maturing adolescents. In addition, families are often concerned that their children will not be capable of caring for their illness independently, further contributing to the resistance to transfer. Finally, like their adolescent children, they are reluctant to change from the known and trusted pediatric providers and facilities to the unknown adult system. They are often concerned that the quality of care will be impersonal or less skilled. For these reasons, a successful transition program must explicitly acknowledge and address the expected shift in family dynamics and be prepared to assist and counsel families who have difficulty stepping back and letting go of the intimate role they previously had served in their children's care. It must be emphasized that the transfer of care is ultimately a positive step toward reaching full potential.

Pediatric providers can be a barrier to the transition process as well. Too often they are unable to "let go" of the intense and important relationship they have developed with their patients and the families. They also may have sheltered patients from understanding their true prognosis and potential future limitations. In addition, pediatric providers may be skeptical about the knowledge and experience of the adult providers and may communicate this to their young patients in explicit or implicit ways, making them wary of transfer.

Finally, the adult services may pose a significant barrier. A recent study evaluated the concerns of adult providers when accepting patients with chronic childhood illnesses. The providers interviewed were most concerned about their lack of training in treating congenital conditions and in the care of adolescents, the difficulty of meeting patients' psychosocial needs and families' high expectations, the need for superspecialists, the need to face disability and end-of-life issues during youth, and financial pressures limiting visit time [32]. When willing to take on such complex patients, adult providers may unwittingly wish to embark on extensive re-evaluation and prompt changes in management, which can be unsettling to patients and families. Awareness and anticipation of these barriers are critical to facilitating a smooth and successful transition process.

Key Elements of the Transition Process

Regardless of the model of the transition program, there are fundamental principles of transition that have received nearly universal endorsement [6,8,33]. These principles provide a framework for both individual programs and institutions whose goal is to improve the transition experience for young adult patients with chronic health conditions. These principles are well described in the context of a model of care that we developed at our institution. This model incorporates three phases of the transition process: pre-transition, transition, and transfer.

Pre-transition

Although a formal transition curriculum is most appropriately initiated during adolescence, the concept of transition should be introduced much earlier and continued throughout childhood. As children, patients must be counseled that although they may be able to live productive lives, they do not have a normal heart and will require lifelong surveillance. Furthermore, they must be taught that CHD is vastly different from other forms of heart disease, making it imperative that they follow up with providers specializing in adult CHD, particularly in the case of moderate and complex disease.

The transition process is a family process; the family plays a critical role that must be supported and encouraged. In this pre-transition phase, families should expect that their children will become independent and be able to manage their own medical care by young adulthood. Families should be encouraged to help their children reach this goal [8,34,35]. Ideally, using such a strategy of early preparation, the patient and family will enter the transition period with an understanding of the heart disease and the need for lifelong specialized care.

One model for pre-transition counseling uses the transition program advanced practice nurse or physician assistant in this educational role. This practitioner can meet the child during one or more visits in the pediatric cardiology clinic. The same practitioner can provide continuity of care by following the young adult through the formal transition program and ultimately into the adult congenital heart program.

Transition

When patients are developmentally mature enough, they should enter the formal transition program and complete a transition curriculum. This transition curriculum should ensure that the young people understand their diagnosis and medical history. Ideally, they should understand the normal heart (basic anatomy and physiology) and how the heart they were born with differs from a normal heart. They can begin to understand the risks of residual hemodynamic burdens and arrhythmic complications. They should be taught to recognize important and concerning signs and symptoms. The transitioning adolescents should have a good understanding of the rationale for previous therapies and options for future medical, surgical, and catheter-based therapies. Finally, they must be taught to navigate the adult health care system: how to access an adult congenital heart specialist, how often they need follow-up, how to access routine health care, how to access emergency health care, and how to navigate the insurance process.

A standard core educational curriculum (Table 1) is an important component of an organized transition process. This education allows patients to gain control of their health and serve as their own advocates. Completing the goals of this curriculum can be accomplished using a variety of educational modalities and should be tailored to individual patients. The curriculum should be of appropriate breadth and depth but concise enough to be completed before patients move into the adult CHD clinic. This may require two clinic visits for mature, well-adjusted patients with mild disease, mild functional limitations, and a strong support system, or many visits with intense peer support group involvement for young people with learning disabilities, complex disease, significant functional limitations, and no support system. Flexibility is a key to success.

Table 1. Transition curriculum topics

- Residual hemodynamic considerations
  - Hemodynamic issues
  - Symptoms and how to respond
  - Diagnostic tools in follow-up
  - Management options
- Arrhythmia considerations
  - Risks
  - Signs and symptoms
  - Screening tools
  - Diagnostic tools
  - Management options
- Endocarditis considerations
  - Risks, implications, recognition, and response
  - Prevention
- Contraception and pregnancy planning
  - Contraceptive options and risks
  - Risks of pregnancy to mother and fetus
  - Management of pregnancy plan
- Noncardiac surgery considerations
  - Risks
  - Location of surgery
  - Knowledge and skills of surgical and intensive care unit team
- Noncardiac medical problems
  - Access to appropriate care
- Career, vocational, and insurance planning
- Lifestyle issues
  - Marriage and family planning
  - Education
  - Employment
  - Life and health insurance
  - Learning disabilities
  - Anxiety and depression
  - High-risk behaviors
  - Healthy eating
  - Physical fitness
  - Salt and fluid restriction (if warranted)
  - Relative safety of exercise and hobbies
- End-of-life decisions
- Skills training
  - Communication
  - Decision making
  - Creative problem solving
  - Assertiveness
  - Self-care
  - Self-advocacy

An example transition curriculum is outlined below. The curriculum goals can be accomplished in several ways. Much of the curriculum can be addressed at routinely scheduled clinic visits with the participation of physicians, advanced practice nurses or physician assistants, and other support services. In addition, introductory seminars for patients and families, peer support groups, and informational seminars also can address some of the components of the curriculum.

Residual hemodynamic considerations

Most patients with "repaired" CHD have residual hemodynamic burdens. Honest discussions are required regarding these issues, their implications for the future, and the signs and symptoms that should raise concern. Patients should be told about diagnostic testing for appropriate surveillance and potential therapeutic options.

Arrhythmia considerations

Arrhythmias are a common complication experienced by patients with CHD, and patients should be educated about them when relevant. It is important that patients understand the etiology and risks of atrial and ventricular arrhythmias and can recognize the signs and symptoms that should raise concern. Patients should understand the importance of screening tools and diagnostic tests. Finally, arrhythmia management, including medications, radiofrequency catheter ablation, surgical ablation, and device therapies (pacemakers and defibrillators), should be discussed as necessary.

Endocarditis considerations

Few adolescents with CHD understand what endocarditis is and why they are prone to suffer this complication [34]. As a standard part of a transition curriculum, patients should be educated about the prevention and implications of endocarditis.

Contraception and pregnancy planning

It is important to discuss contraception and pregnancy before patients reach adolescence and become sexually active. During these conversations, it must be emphasized that various contraceptive options carry both benefits and risks. Beyond pregnancy planning or prevention, barrier methods for prevention of sexually transmitted diseases should be encouraged. Pregnancy is feasible for many adult patients with CHD. However, before conception, the potential risks to the mother and unborn child should be discussed. Fetal echocardiography and genetic counseling should be offered in selected cases.

Noncardiac surgery considerations

Patients must be advised about the issues regarding noncardiac surgery. Except for the simplest outpatient procedures, noncardiac surgeries in complex patients should be performed in a tertiary hospital in which cardiac anesthesiologists and members of the surgical and critical care teams are comfortable with the care of adults with CHD.

Noncardiac medical problems

Discussions about noncardiac medical problems must be tailored to the individual patient. Patients should be aware of the implications of these issues and know how to access appropriate care.

Career, vocational, and insurance planning

Some adolescents with CHD will develop physical or other limitations and should be advised to pursue education and careers that are sustainable in spite of these limitations. It is important that this part of the process begin before patients reach high school, when academic choices will be made that can limit future options. In addition, most adults with CHD will have difficulties securing health insurance independently. Therefore, obtaining a health plan through an employer may be optimal. Life insurance poses similar obstacles. Early and disciplined self-investment is often desirable.

Lifestyle issues

Because the goal of all medical care is to improve quality of life, a transition curriculum must at some point depart from the medical realm and include discussions about lifestyle and quality of life. In addition to marriage and family planning, education and career choices, and insurance issues as discussed above, several lifestyle issues should be addressed. High-risk behaviors, learning disabilities, and anxiety and depression should be discussed. The importance of healthy eating and physical fitness, the risks of poor nutrition and obesity, and the need for salt and fluid restriction (if warranted) should be addressed.

Skills training

The transition program curriculum should include skills training in communication, decision making, creative problem solving, assertiveness, self-care, self-determination, and self-advocacy. Much of this can be accomplished in informational seminars and peer support groups and reinforced during clinic visits.

Transfer

Timing of transfer

Ideally, transfer of care from the pediatric to adult health care system should occur at the successful completion of a thoughtful transition process. When deciding on the timing of transfer, two important points need to be considered: there should be a policy on timing, and this policy should be flexible.

First, there should be an institutional policy on timing of transition to ensure that transition and transfer actually occur and that they happen in a predictable manner [8]. When patients and families have an explicit target age, they recognize that transition and transfer will occur, appreciate their active involvement in the process, and are prepared for the ultimate transfer of care. Additionally, when transition is the “rule,” young people see the process not as something that they as individuals are forced to go through alone, but rather a natural process that everyone goes through. Finally, a policy on timing ensures that all patients have the opportunity to take full advantage of the transition curriculum.

Second, a transition program must be flexible with respect to timing and should tailor the process to the developmental and psychosocial status of each young person [26,36]. Transition ideally should be completed only after the young patients have accomplished the developmental tasks of adolescence and have demonstrated the ability to manage their health care independently of their families and pediatric providers.

Adolescents have many difficult tasks to accomplish before leaving this stage of development. They must develop a personal sense of identity and adjust to this new physical sense of self, adjust to new intellectual abilities and the increased cognitive demands placed on them at school and in society, develop educational and vocational goals and a plan to meet these goals, establish emotional and psychological independence from their parents and begin to adopt a personal value system, learn to manage their sexuality and begin to develop intimate relationships, and develop increased impulse control and behavioral maturity. It is important to recognize that chronic illness, physical disability, and cognitive limitations can disrupt the usual developmental trajectories. This makes accomplishing such tasks more difficult and the transition process more challenging [9,36].

Furthermore, the sometimes overprotective attitudes of pediatric providers and patient families can diminish self-esteem and hinder the development of self-sufficiency. In general, the adult health care system demands a higher level of personal responsibility and autonomy than the pediatric system. Thus, to be effective health care consumers in the adult health care environment, young people should demonstrate the ability to meet their health care needs independently of their families and pediatric providers before transfer, make their own appointments, meet independently with their health care providers, administer their own medications and other treatments, understand their medical history, and recognize signs of clinical deterioration.

Finally, transfer of care during medical crises or periods of psychosocial disequilibrium should be avoided [8]. All too often, patients are transferred when they become pregnant or after suffering their first “adult” complication. Transfer during these times precludes maximal utilization of the transition curriculum and imposes a tremendous psychological burden on patients.

Adult provider services

Whereas the needs of some patients are relatively straightforward, others have complex medical needs and may require the involvement of a variety of subspecialty consultants in addition to capable primary health care providers willing to coordinate and manage the complex care that they need [6]. Other medical and nonmedical professionals critical to successful transfer include advanced practice nurses or physician assistants, social workers, and those who specialize in vocational and educational issues [8,15,17].

Coordinated transfer process

A coordinated transfer process is the final component of a successful transfer [7,8,37]. A carefully prepared health summary allows seamless transfer of care and provides a blueprint for the new health care team. It should include a complete medical history listing diagnoses and previous interventions, a medication list, laboratory values, and other diagnostic studies, as well as information about the patient's functional status, the tempo of disease progression, and the impact of other comorbidities. Psychosocial concerns, end-of-life preferences, the extent of family involvement, and adherence issues also should be communicated if available. A comprehensive summary avoids having to reinvent the therapeutic wheel and helps to prevent errors from being made or repeated. In addition to the formal medical summary, it is vital that the pediatric providers communicate directly with their counterparts in the adult health care system.

It is important that the adult providers respect the therapeutic plan established by the pediatric providers and communicated to the young patients and their families. As explained previously, immediate re-evaluation and drastic change in management that many new adult providers are tempted to make after care transfer often can be overwhelming to patients and diminish their trust. Regardless, adult providers must also take advantage of the unique opportunity that this transition process provides to take a fresh look at the patients as evolving adults and to reassess therapeutic options in the light of new technological advances. This process can be completed in conjunction with the pediatric providers and after a period of introduction and relationship development in the transition process. In this way, trust is not lost, and the best possible plan for the future is made.

Many transition "tools" have been suggested to aid in a smooth transition and transfer. For example, a central provider (eg, an advanced practice nurse or physician assistant) who can assume responsibility for the entire process is helpful [7,37]. The coordinator can share membership on both the pediatric and adult teams and serve as a liaison between them and as a reassuring presence and advocate for patients and families. In addition, to address the inevitable uncertainty felt by young people and their families about impending transfer, many programs have created a transfer "package" with information about the adult programs [37]. Finally, patients who have already transferred can play a part in welcoming young people who are transferring their care.

Conclusions

As increasing numbers of young people with complex congenital illnesses are surviving into adulthood, there is an urgent need for programs designed to facilitate their smooth movement from pediatric to adult health care environments. This article has identified the important constituents of the transition process and has provided guidelines for the successful transfer of patients to the adult health care environment. We hope that in the near future, transition programs will become the standard of care, making it more likely that patients with complex chronic illness will reach their full potential under appropriate medical surveillance and live meaningful and productive lives.

Disclosure

No potential conflicts of interest relevant to this article were reported.

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