

## AHA SCIENTIFIC STATEMENT

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# Advances in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease: A Practical Approach to Transition Program Design: A Scientific Statement From the American Heart Association

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**ABSTRACT:** It is now expected that most individuals with congenital heart disease will survive to adulthood, including those with complex heart conditions. Maintaining lifelong medical care requires those with congenital heart disease to eventually transfer from pediatric to adult-oriented health care systems. Developing health care transition skills and gaining independence in managing one's own health care is imperative to this process and to ongoing medical and psychosocial success. This scientific statement reviews the recent evidence regarding transition and provides resources, components, and suggestions for development of congenital heart disease transition programs with the goals of improving patient knowledge, self-management, and self-efficacy skills to the level they are capable to eventually integrate smoothly into adult-oriented health care. Specifically, the scientific statement updates 3 sections relevant to transition programming. First, there is a review of specific factors to consider, including social determinants of health, psychosocial well-being, and neurocognitive status. The second section reviews costs of inadequate transition including the public health burden and the impairment in individual quality of life. Finally, the last section discusses considerations and suggestions for transition program design including communication platforms, a family-centered approach, and individual models. Although this scientific statement reviews recent literature surrounding transitions of care for individuals with congenital heart disease there remain significant knowledge gaps. As a field, we have yet to determine ideal timing and methods of transition, and barriers to transition and transfer remain, particularly for the underserved populations. The consequences of poor health care transition are great and garnering outcomes and information through organized, multifaceted, collaborative approaches to transition is critical to improving the lifelong care of individuals with congenital heart disease.

**Key Words:** AHA Scientific Statements ■ transition to adult care ■ adolescent ■ heart defects, congenital ■ self-management ■ social determinants of health

**B**ecause of tremendous advances in diagnostic and surgical techniques, survival of patients with congenital heart disease has improved such that there are now more adults alive with congenital heart disease

than children in developed nations.<sup>1,2</sup> Adolescents and emerging adults of transition age are estimated to comprise 15% to 20% of the overall population with congenital heart disease.<sup>3</sup> Birth prevalence, survival rates, and data

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### Opening Vignette

My daughter was born in the mid-1980s with congenital heart disease. Thankfully, she has always been in excellent care, transferring from a pediatric to an adult congenital cardiologist at age 26. She and I navigated this transition on our own. Although we did successfully transfer medical responsibility, we've realized in hindsight that this could have been a much smoother process.

As a parent, my biggest challenge was ceding control. I felt angst losing any ability I thought I had to protect my daughter from the burden of worry and uncertainty that comes with congenital heart disease. My daughter's challenge was learning to take on medical management and decision-making just as she was navigating the excitement and stress of living independently. As she took over control of her own care, she struggled with wanting to protect me from worry, as I had her.

There are 2 intertwined components of health care transition: transfer of medical care from pediatric to adult health care professionals, and of medical responsibility, from parent to child. Although my daughter's care was transferred without a formal transition process or program, she still experienced transition of medical responsibility, from myself to her. Although we are both comfortable with our roles now, this could have been a smoother and less anxious process, with support and guidance beginning in early adolescence.

Congenital heart disease-specific transition programs will save parents and adolescents/emerging adults the difficulty of figuring out the process on their own. Professional guidance and gradual health care transition, supplemented with information and encouragement from patient family organizations, will definitively make a positive impact on outcomes for those living with congenital heart disease and their families.

—Susan Timmins

extrapolated from Quebec, Canada, estimate 399 000 to 432 000 adolescent and emerging adult patients with congenital heart disease are living in the United States.<sup>3</sup> These patients have unique health care needs and may require care coordination between multiple medical specialists for optimal outcomes.

Health care transition is the process of gaining independence with managing one's own medical care.<sup>4,5</sup> Optimally, the process of transition includes transfer of care, which refers to the actual point in time when a patient's care moves from a pediatric to an adult health care professional or team. Ideally, this process begins in early adolescence but can occur at any time earlier in life and can continue after transfer occurs in emerging adulthood (18–25 years of age). The goal of health care transition is to maximize lifelong functioning through developmentally appropriate health care

services that empower patients as well as their caregivers in the process. Health care transition should be achieved through an organized clinical process with the goals of (1) improving adolescents' knowledge about their congenital heart disease; (2) supporting self-management and self-advocacy skills; (3) learning to navigate a complex medical system; and (4) coordinating integration into adult-centered care, for both primary care and subspecialty care.<sup>6</sup>

In 2011, the American Heart Association produced a scientific statement of best practices in managing transition to adult-centered care for adolescents with congenital heart disease.<sup>7</sup> Since then, efforts have been made to include transition programming as part of pediatric congenital heart disease programs, but there remain significant challenges to successful implementation. This update provides a summary of new research regarding specific considerations in designing and creating successful transition programs for patients with congenital heart disease. By offering perspectives from multiple stakeholders, this update also emphasizes the need for an interdisciplinary team approach to ensure a successful transition process.

## SOCIOECONOMIC, PSYCHOSOCIAL, AND NEUROCOGNITIVE CONSIDERATIONS

Although it is estimated that >1.4 million adults with congenital heart disease are living in the United States, fewer than 30% are currently in subspecialty care.<sup>8</sup> Understanding the potential barriers to successful health care transition is critical to designing transition programming to mitigate these factors, thereby increasing the number of patients who have uninterrupted health care from adolescence through adulthood.

### Social Determinants of Health

Social determinants of health (SDOH) are conditions in the environments in which people live, learn, and work that affect a wide range of health and quality-of-life (QoL) outcomes.<sup>9</sup> For example, systemic inequities leading to racial and ethnic disparities, economic instability, and limited education and employment opportunities all contribute to suboptimal longer-term outcomes, including lapses in congenital heart disease care, resulting in unnecessary morbidity and mortality (Figure). It is not surprising, then, that several studies have shown that SDOH, particularly lower socioeconomic status, contribute to absences in cardiac visits and lapses in care.<sup>10,11</sup> A recent meta-analysis points out that one of the most important interventions for patients with congenital heart disease would be routinely screening for SDOH, with referrals to appropriate services for those who screen positive.<sup>12</sup>

Racial and ethnic disparities in congenital heart disease have persisted for Black and Hispanic patients,

from early in life through adulthood.<sup>13</sup> Black patients with congenital heart disease have higher post-surgical mortality than those who are White,<sup>14</sup> and non-White survivors of congenital heart disease <5 years of age are at significant risk for experiencing a lapse in care as compared to those who are White.<sup>10</sup> These disparities are likely multifactorial and include several systemic inequities (insurance coverage), social determinants (social support, access to appropriate care for adults with congenital heart disease, employment), and implicit bias (conscious or unconscious racism). Many studies have shown that health care professional implicit bias contributes to treatment decisions and treatment adherence, resulting in poorer medical outcomes in the general population.<sup>15</sup> Implicit bias likely impacts all facets of congenital heart disease care, and may result in poor communication with non-English-speaking families and less emphasis on transition and appropriate transfer of care to adult congenital heart disease professionals.

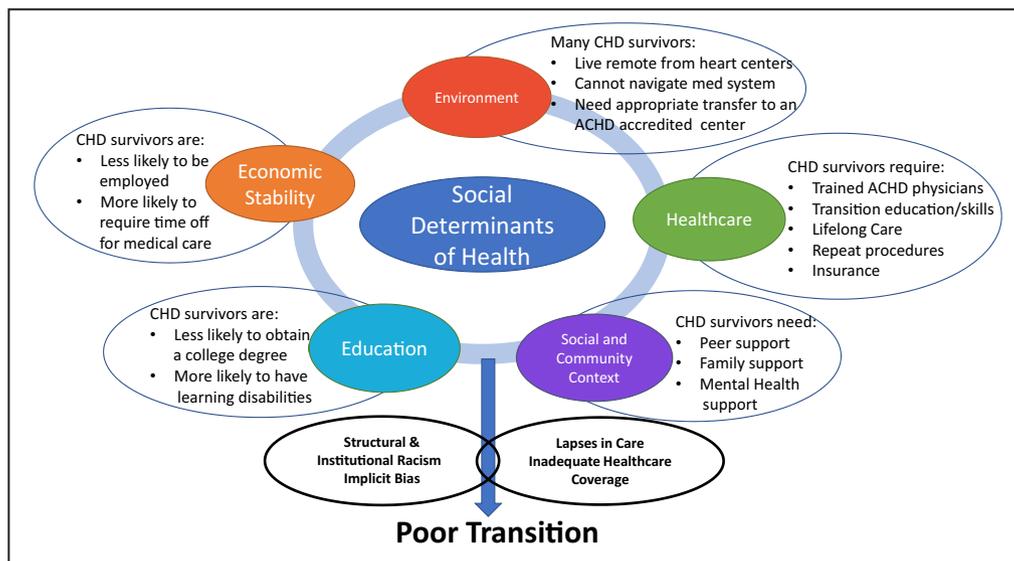
Given that race and ethnicity are social constructs, it is not surprising that several studies have shown that SDOH, particularly lower socioeconomic status, contribute to lapses in care.<sup>10,11</sup> Opportunity costs, including missing work, child care for siblings, and parking/ transportation for appointments, may be prohibitive to clinical care, further exacerbated by needing to travel long distances for appropriate care for adults with congenital heart disease.<sup>11</sup> One study estimated that approximately half of the US population lives over an hour away from a reputable adult congenital heart disease center, and those who are uninsured, Hispanic, or have lower socioeconomic status are most likely to be affected.<sup>16</sup> In recent years, many adult congenital heart disease centers have developed satellite community clinics or developed partnerships with community primary and

specialty care professionals to ease access to services geographically. These challenges drive home the need to adequately prepare minority and lower socioeconomic status patients with transition education and skills beyond the ability and the method of transfer to an adult congenital heart disease center.

Finally, survivors of congenital heart disease, particularly those with complex lesions, are at increased risk for cognitive deficits and emotional distress which can negatively impact educational attainment.<sup>17</sup> Subsequently, cognitive deficits and lower educational achievement can contribute to poorer health literacy and also have implications for employment opportunities. There is recent evidence suggesting that adults with congenital heart disease have high rates of unemployment, particularly among Black individuals.<sup>18,19</sup> Given that education is closely linked with employment, access to insurance, and income, the potential disadvantages experienced by survivors of congenital heart disease must be acknowledged. Establishing programs that screen for the contributions of SDOH and mitigate opportunity costs, provide formal transition education (including skills and training on navigating the medical/insurance systems), and emphasize patient/parent education about the need for maintenance of long-term care, are necessary for minimizing barriers to care during the transition period.

### Psychosocial Well Being of the Patient and Family

Impaired psychosocial functioning can be a barrier for successful transition.<sup>20</sup> During transition to adulthood, adolescents with congenital heart disease may experience several challenges pertaining to identity formation, personality development, resilience, peer



**Figure.** The impact of social determinants of health on health care transition. ACHD indicates adults with congenital heart disease; and CHD, congenital heart disease.

support, and psychological distress. Although these facets may not all be targets or facets of a transition curricula, understanding how psychosocial development plays a role in the transition process to adulthood is important.

Identity formation is a core developmental task and relates to the question: “Who am I and where do I want to go with my life?” Adolescents with congenital heart disease with a strong sense of identity display optimal outcomes in terms of QoL, perceived health, and psychosocial functioning, whereas individuals with a diffused identity score highest on depressive symptoms and loneliness, and lowest on QoL.<sup>21</sup> Extraversion, agreeableness, conscientiousness and emotional stability are personality traits that are positively related to QoL and different dimensions of perceived health.<sup>22</sup>

Peer belonging and peer support are important for young people and important for developing self-management skills.<sup>23</sup> Attention should be given to loneliness, because adolescents with high levels of loneliness experience a higher degree of depression and perceive their health as poorer.<sup>24</sup> Anxiety and depression are more common in persons with congenital heart disease with some studies citing a prevalence as high as 50% of patients with congenital heart disease meeting diagnostic criteria for a lifetime mood or anxiety disorder.<sup>25–27</sup> Longitudinal assessments of anxiety and depression throughout transition are important because anxiety and depression represent potential barriers to self-management as depressed or anxious patients may be reluctant to take responsibility for their health care decision making.<sup>28,29</sup> Information about how and when to access mental health support should be included as part of a transition education curriculum.<sup>30</sup>

Resilience refers to a person’s ability to effectively adapt to stress and adversity. A relevant concept is “sense of coherence,” which represents an individual’s generalized worldview and expresses the extent to which the individual perceives stimuli as comprehensible, manageable, and meaningful.<sup>31</sup> Resilience and sense of coherence focus on capacities for adaptive behaviors, rather than on limitations or maladjustment. As structured interventions can enhance resilience,<sup>32</sup> this represents an opportunity for transition preparation programs to incorporate such interventions as part of a transition curriculum.

Parenting style and parental support is of paramount importance for adolescents with congenital heart disease throughout transition. Parental uncertainty regarding transition is prevalent,<sup>33</sup> and parental anxiety can lead to overprotection, including reluctance to shift greater responsibility for illness management to their adolescent.<sup>34,35</sup> Indeed, parenting styles that are characterized by overprotection, psychological control, punishment, and rejection are associated with the development of heart-focused anxiety, depressive symptoms,

loneliness, worse perceived health, lower QoL, and more risk behaviors.<sup>36–38</sup> Parental support, on the other hand, positively impacts QoL and patient-reported health,<sup>39,40</sup> and negatively impacts depression and loneliness.<sup>40</sup>

Overall, the above-mentioned research indicates that psychological well-being of adolescents and families, as well as parental style and support of independence are significant contributors to successful transitions to adulthood. The question remains, however, how these factors may enhance comprehensive transition programs.

## Neurocognitive Deficits

An individual’s transition goals must reflect their unique neurodevelopmental abilities, strengths and weaknesses. This is particularly relevant to the field of congenital heart disease, in which patients are at elevated risk of neurodevelopmental deficits and disorders in many domains including academic achievement, language and speech, visual perception, fine and gross motor skills, attention, and executive functioning.<sup>41</sup> Both prevalence and severity of neurocognitive deficits increase in accordance with congenital heart disease complexity and the presence of genetic syndromes.<sup>17,41</sup> Unfortunately, transition experiences and outcomes are known to be poorer for youth and young adults with neurodevelopmental disorders.<sup>42</sup>

There are unique challenges when coordinating the transition of youth with neurodevelopmental disabilities from pediatric to adult care. These include: (1) identification of appropriate models of autonomy, (2) provision of appropriate, healthy, and respectful behaviors of health care professionals, (3) proactive incorporation of principles of ethics within transition programs as well as the evaluation of transition initiatives, and (4) responsiveness to the unique needs of youth with neurodevelopmental disabilities.<sup>43</sup> For youth with congenital heart disease, the approach to patient education and self-management skills training should therefore be respectful and flexible. Additional consideration needs to be given to establishing a medical power of attorney for those with severe neurocognitive deficits and a shared decision-making pathway for those with less severe neurocognitive deficits. Ideally, this is discussed and formally documented before transfer.

Whereas most individuals with congenital heart disease will be able to eventually assume full responsibility for their health care oversight, the transition needs of those with cognitive deficits have not been well studied. Patients with more severe neurodevelopmental deficits have traditionally been excluded from transition surveys and interview/intervention research. Effective transition, especially for those with neurodevelopmental disabilities, demands engagement by all key stakeholders including patients, parents/caregivers, pediatric and adult congenital heart disease professionals, and other members of

the health care team such as teachers, social workers, or counselors. Further, shared decision making and coordination within the broader care team is essential to support a proactive, developmental, and family-based approach for youth with intellectual and developmental disabilities.<sup>44</sup>

## THE IMPACT OF TRANSITION

Evidence exists that gaps in recommended care result in higher mortality and morbidity,<sup>45–49</sup> whether in pediatric or adult settings. The transition period has been associated with increasing emergency department utilization and decentralization of care.<sup>50</sup> The Centers for Disease Control and Prevention thus identified the need to develop effective strategies for reducing gaps in congenital heart disease care as a public health goal.<sup>51</sup>

### The Burden of Loss to Follow-Up

The true adolescent/emerging adult population in the United States is difficult to estimate given significant attrition from care during late childhood and early adulthood, making the tasks of identifying the needs of those who are not in care challenging.<sup>52</sup> Health care costs and utilization for this patient population are difficult to estimate given the variability in care patterns, charges across states and health care systems, and reliance on diagnosis codes for estimates. In addition, estimates of health care utilization come mostly from inpatient data, single center studies or weighted national administrative inpatient samples.<sup>53–55</sup> Even in this relatively young population, however, health care utilization is impacted by the high percentage of patients with both cardiac and noncardiac comorbidities.<sup>56</sup>

Health care utilization and costs are strongly related to insurance coverage which can be inconsistent over time and can also vary significantly by age and also by geographic location.<sup>56</sup> Lapses in care occur in 30% to 60% of patients with congenital heart disease and have historically occurred during the transition period, often leading to increased emergency department use and poorer outcomes.<sup>11,49,57</sup> In 1 study, patients experiencing a lapse in care were >2 times more likely to need an urgent or emergency intervention on return to care.<sup>49</sup> In another, patients with complex heart disease managed in adult congenital heart disease care experienced lower mortality.<sup>58</sup> Inadequate insurance coverage likely played a more significant role when individuals living with congenital heart disease were subject to restrictive insurance policies such as preexisting condition exclusions and total lifetime dollar benefit caps.<sup>59,60</sup> The Affordable Care Act, a major overhaul of the US health care system, had several key tenets directly meant to

assist with long-term access to care and survival for pediatric patients born with a chronic disease. The first round of implementation in July 2010 included the expansion of dependent coverage to age 26 years and the elimination of preexisting condition exclusions and lifetime coverage caps. Full implementation was achieved in January 2014 with additional changes including the expansion of state-based Medicaid and limitation of insurance coverage waiting periods to 90 days.<sup>61</sup>

Although changes in the ability to maintain insurance for many patients is encouraging, for transition-aged patients, simply having “insurance coverage” does not necessarily ensure adequate and timely long-term care, nor does it mean access to the type of care and expertise that they require. Additionally, recent data has shown that although full implementation of the Affordable Care Act was associated with improvement in insurance coverage, disparities persisted for transition-aged and Hispanic patients.<sup>62</sup> Further, for many patients with Medicaid or CHIP (Children’s Health Insurance Program) insurance, whose insurance lapses during their 18th or 21st year, options for insurance may be unattainable, as many of their parents do not have insurance (and thus they cannot “stay on their parents’ insurance”) and obtaining their own insurance coverage may be prohibitively expensive. Their ability to obtain employment may also be limited due to their preexisting condition or level of educational attainment, and thus the model of obtaining your health insurance through one’s employer may not be as applicable for congenital heart disease populations. The insurance process can also take time. Therefore, transition preparation needs to emphasize early the importance of trying to maintain insurance via self, family, employment, or government (eg, Medicare, Medicaid, or disability) as well as options for obtaining coverage that will include specialty congenital heart disease care. Social workers and financial counselors can often be very helpful in this process.<sup>62</sup>

### Transition and the Impact on QoL

A goal of transition is to optimize QoL. Uninterrupted health care can potentially minimize hospitalizations and promote physical well-being, thus leading to superior physical and psychosocial QoL. A recent review of the literature showed that transition interventions have beneficial effects on psychosocial outcomes including health-related QoL, disease-related self-management, and transition readiness.<sup>63</sup>

Transition knowledge deficits are common<sup>64,65</sup> and associated with decreased self-efficacy and self-management skills in adolescents and emerging adults with heart disease.<sup>66</sup> Successful transition requires knowledge, perceived self-efficacy, and self-management skills. Self-management behaviors, the patient’s autonomy regarding taking medications, asking questions, and making appointments are primarily related to a person’s self-efficacy, a person’s belief about his or her ability

and capacity to accomplish or execute those behaviors. Uzark and colleagues recently showed that a transition program including transition readiness assessment with improvements in knowledge and self-efficacy at follow-up was associated with improved psychosocial QoL in adolescents and emerging adults with heart disease.<sup>67,68</sup> Consistent with these findings, Valente et al<sup>69</sup> suggested that knowledge related to topics such as exercise, symptoms of problems, birth control options, and pregnancy safety may be uniquely important to the QoL for an adult with congenital heart disease. Furthermore, self-efficacy has been shown to be a predictor of patient-reported outcomes including QoL in adults with congenital heart disease.<sup>70</sup>

Acuna Mora and colleagues<sup>71</sup> found that transition readiness and communication had a significant positive association with patient empowerment, a construct associated with self-efficacy, greater personal control, and self-management or autonomy. A higher level of empowerment may equip adolescents and emerging adults with congenital heart disease with the knowledge and skills to transition to adulthood and facilitate their transfer from pediatric to adult care.<sup>71</sup> Evaluation of perceived self-efficacy is an important component of transition preparation as it is important to development of self-management skills. Self-management skills are low in many adolescents and emerging adults with congenital heart disease and are not associated with QoL<sup>67</sup> as parent-management likely allows QoL to be preserved.

Higher psychosocial maturity and parental fostering of autonomy have both been associated with better perceived mental health status and QoL in emerging adults with congenital heart disease or heart transplant.<sup>72</sup> While and colleagues<sup>73</sup> found that maternal overprotection was a significant predictor of lower health-related QoL pre- and post-transfer and suggest parental preparation for transition should include discussion of the impact of parental overprotection on their child's QoL showed to encourage and help parents to support their child's needs for greater autonomy. An ideal transition program fosters patient independence to maximize productivity and QoL.<sup>74</sup>

## CONSIDERATIONS IN DESIGNING A TRANSITION PROGRAM

Implementation of transition programs can be challenging for health care professionals. With increasing demands of medical documentation, fewer support staff, lack of reimbursement, and a rising volume of patients, finding the time necessary to provide transition-related education is often difficult. Regardless of approach, there are several key principles that should be at the core of health care transition programs for patients with congenital heart

**Table 1. Key Principles and Guidelines for a Congenital Heart Disease–Specific Health Care Transition Program**

1. Emphasize patient self-management, self-advocacy, and engagement, and educate caregivers to encourage patients to move into a primary ownership role with some shared decision making
2. Guide patients in building their medical knowledge and care coordination skills and facilitate caregivers moving into a more supportive role, emphasizing the rationale for transition while acknowledging their fears and concerns
3. Acknowledge individual congenital heart disease subtypes along with the cardiac, noncardiac, and lifestyle (exercise) complexities associated with each congenital heart disease subtype
4. Understand the patient diversity in neurocognitive development, intellectual disabilities, mental health conditions, and comorbidities to provide patient and family psychosocial and educational support from medical care team
5. Emphasize lifelong care, including identifying or knowing how to identify, an adult congenital heart disease specialist before transfer of care
6. Advocate for health equity in transition by recognizing the role of health literacy and social determinants of health for all families in navigating a complex medical system, particularly those with lower socioeconomic status
7. Educate members of pediatric and adult congenital heart disease teams to address the transition needs and provide transition education and skills to all patients with congenital heart disease, particularly those who also have neurodevelopmental deficits

disease (Table 1).<sup>5–7,75</sup> Incorporating transition programs and adapting existing technologies can aide in implementation, but a coordinated effort needs to be undertaken between key stakeholders: patients/families, members of the health care teams, health care organizations, and payers. We present key considerations in transition program design, based on emerging and ongoing research.

## Communication

Optimizing communication is essential for promoting health outcomes among adolescents with congenital heart disease. Adolescents are often accustomed to communication between health care professionals and their parents and may need permission and encouragement to communicate their own questions and concerns. Uzark and colleagues<sup>67</sup> reported that perceived self-efficacy scores improved with receipt of information on how to contact the “heart doctor” and communicate with the health care team.

From a health care professional perspective, communication of information to adolescents and emerging adults can be challenged by lack of physician time and resources, as well as physician comfort and expertise related to knowledge gaps, neurodevelopmental issues, and communication preferences. In a multicenter study, nearly half of teens/emerging adults did not prefer to receive information face-to-face from health care professionals.<sup>68</sup> In general, the internet is one of the main sources of health information used by teens and emerging adults. Unfortunately, web-based sources of information specific to adolescents or emerging adults with congenital heart

disease are limited and not often discoverable through casual web browsing. Text messaging is another mode of communication commonly used by teens/emerging adults with some studies showing this mode as a useful way to collect data and to engage is more meaningful conversation.<sup>76</sup>

In addition to preferred information sources in this age group, neurocognitive impairments, especially in areas of executive functioning, can impact understanding and processing of information. Pike et al<sup>77</sup> found adolescents and emerging adults with congenital heart disease show significant verbal, attention, and working memory deficits compared with healthy controls, but no significant differences were identified between groups for visual memory. These findings suggest that to enhance patient memory/self-care, clinicians should increase use of visual patient education materials. This may include providing information on specific heart defects or surgeries, medications, exercise recommendations, pregnancy risk and contraceptive options, and community resources (eg, counseling). Often these resources also facilitate the patient's communication with others including family members, friends, and other health care professionals, further enhancing outcomes.

Verbal communication between health care professionals and patients and their parents remains an essential component of patient transition education because it builds rapport between patient and physician and typically serves as the initial point of contact for delivering information. In addition, web-based and other visual interventions, especially through smartphone use with text messaging or facilitating access to patient portals, may be a beneficial adjunct to verbal communication, allowing for more time to process and integrate information regarding their congenital heart disease.

### Family-Centered Approach

Parents (and other adult caregivers) are an important source of information for most adolescents with congenital heart disease,<sup>78</sup> and they play an integral role in encouraging patients to increasingly adopt more responsibility for managing their condition. Furthermore, parents also reinforce important health behaviors (eg, physical activity engagement) and provide guidance and support on important developmental milestones (eg, career choice). Therefore, a collaboration among the medical team, parents, and patients is the ideal foundation of a family-centered approach to transition.

Recent literature has highlighted that medical professionals, parents, and adolescent congenital heart disease survivors agree on the importance of parental involvement during transition.<sup>79</sup> Bratt and colleagues<sup>80</sup> identified several themes that emerged from interviews with congenital heart disease families, including parents wanting to have information about transition earlier and to be provided with more education on the process

of transferring care to adult health care professionals. Many parents may have knowledge gaps, including not understanding how health care may change for their child after they turn 18 years of age,<sup>81</sup> thereby making reinforcement of optimal disease self-management difficult. Ideally, parents would receive the same information about congenital heart disease self-management as patients.<sup>79</sup> This would include topics that some adolescents and parents may be less likely to openly discuss, such as birth control, risks of pregnancy, and substance use. To facilitate open dialogue with the medical team, these conversations may occur separately with parents and adolescents, but both parents and adolescents should receive the same information, ideally presented using a neutral, nonjudgmental stance in both oral and written formats. Although parents report wanting this information to be provided by the medical team,<sup>80</sup> both parents and adolescents should also be encouraged to openly discuss the information with each other and ask questions of one another.<sup>3</sup>

Adopting a family-centered approach to transition includes problem-solving potential barriers to families participating in transition programming. Transportation concerns, including traveling long distances to clinic, have been identified as a consideration for program development.<sup>82</sup> Using various modalities, such as telehealth, mobile apps, and websites may reduce the need to travel and possibly enhance participation. For in-person visits, conducting transition appointments immediately before or after the medical visit would also prevent families needing to return. Endorsement of the transition process from pediatric cardiology physicians is vital to emphasize the importance in maintaining continuity of care and ultimate success of the transition program.

A family-centered approach also considers the emotional toll parents experience in relinquishing control to their adolescent,<sup>79</sup> as well as the anxiety adolescents may experience when considering the acquisition of new responsibilities. Medical teams are encouraged to approach families with an empathic mindset. Acknowledging the stress that accompanies change may go far in fostering alliances with parents in the transition process while helping adolescents feel confident in their growing independence. Additionally, medical teams can refer adolescents and their parents to psychologists, social workers, and child life specialists for additional support during transition.

### Formalized Transition Programs

Research from the past decade has included evaluations of transition intervention programs for the congenital heart disease population; outcome measures have included congenital heart disease knowledge, self-management skills, and resilience. Interventions have primarily focused on patient education and have used different models of care. Despite different models

of care, a set of common transition curriculum components and milestones should be considered in the development of any transition program (Tables 2 and 3). Congenital heart disease–specific transition and transfer quality metrics were developed in 2018 for use in internal quality improvement programs.<sup>83</sup> These can be used as the basis for any transition program but should be individualized for the patient and family at the discretion of the health care professional, with consideration given to the individual patient. Regardless of the complexity of the congenital heart disease lesion, all patients should have a baseline level of knowledge of their congenital heart disease and the repairs they have undergone. Although there can be some individualization, the knowledge skills apply to all patients.

## Program Models

Various different models of transitional care have been evaluated. These include:

1. Nurse-led, clinic-based education: A few non-randomized studies have showed improvements in patient knowledge after nurse-led education.<sup>84,85</sup> These studies evaluated structured patient education programs directed at adolescents and adults with congenital heart disease, and showed small but significant increases in patient knowledge, with a better understanding of symptoms warranting evaluation, and of the rationale for follow-up. A clinical trial of a nurse-led 1-hour congenital heart disease patient education intervention led by Mackie and colleagues<sup>86</sup> improved congenital heart disease knowledge and self-management skills, compared with a control group. A follow-up clinical trial by this team focusing on both education and self-management skills over two, 1-hour sessions reduced the time before the first adult congenital heart disease clinic visit.<sup>87</sup>
2. Multidisciplinary transition clinic: Gaydos and colleagues<sup>88</sup> evaluated the impact of a combined knowledge and self-management program delivered within a transition clinic. Compared with historic controls, the transition clinic participants had a significantly lower “lost to follow-up” rate of 26% versus 7%, respectively, with the outcome defined as an absence from care at least 6 months beyond the recommended timeframe. This highlights the opportunity to explain late potential cardiac complications and the rationale for lifelong cardiology follow-up during patient education. Vaikunth and colleagues<sup>89</sup> described a young adult transition clinic, consisting of a social worker, nurse care manager, and adult congenital heart disease physician. Patients were referred by their primary cardiologist. The clinic was offered to 18- to 21-year-old patients and held in the pediatric hospital. A minority of patients seen within this program

transferred to adult service within the time frame of the study, indicating that modification or augmentation of that program was required. Those with severe lesions or an implanted device were more likely to transfer. Flocco and colleagues<sup>90</sup> also evaluated a multidisciplinary clinic and demonstrated improvements in congenital heart disease knowledge and QoL 1 year after enrollment.

3. Comprehensive transition program including multiple visits with a transition coordinator, an information day for adolescents, and parental guidance: Acuna Mora and colleagues<sup>91</sup> have established the STEPSTONES project (Swedish Transition Effects Project Supporting Teenagers with Chronic Medical Conditions), a multifaceted, structured transition program designed to empower adolescents using the method of intervention mapping. This program is being evaluated within a randomized trial being conducted in Sweden.<sup>92</sup>

In summary, a growing body of literature has illustrated the potential for short-term clinic-based interventions to improve patient knowledge. The optimal methods of promoting disease knowledge, self-management skills and resilience are currently unknown, as studies comparing approaches have not been published. Likewise, the impact of transition interventions on QoL or clinical outcomes is not yet established. These are areas requiring further study.

## Transition Measurement Tools

Numerous instruments are available to track adolescent’s transition “readiness” over time.<sup>93</sup> The Transition Readiness Assessment Questionnaire (TRAQ) V4.0 is a 29-item instrument that measures self-management and self-advocacy skills and is responsive to intervention in patients with congenital heart disease.<sup>87,94</sup> However, the TRAQ has some limitations, including a ceiling effect observed with measurement of self-advocacy.<sup>72</sup> The TRANSITION-Q is a 14-item instrument that is also responsive to structured intervention.<sup>95,96</sup> Tools exist to measure congenital heart disease knowledge (eg, Leuven Knowledge Questionnaire and the MyHeart scale) or health literacy (REALM Short Form) can be used over time with individual patients.<sup>86,97,98</sup> Coronary heart disease–specific tools, including assessments of medical knowledge, transition readiness, and template medical summaries, have been developed through collaborations with Got Transition, the American College of Physicians, and the American College of Cardiology. A recent study that focused on transition practices in 96 congenital heart disease centers in Europe showed only 41% offered transition programming while nearly 90% offered structured transfer; however, a recent meta-analysis reported that transition programs were shown to reduce gaps in care compared with usual care (12.7% versus

**Table 2. Key Transition Curriculum Components for Adolescents With Congenital Heart Disease**

Topic	Subtopic
Introduction to transition	What is “transition”? How does it differ from “transfer”?
	Setting timeline expectations for transition and transfer
	Changing patient role (taking charge) and caregiver role (supportive)
	Need for lifelong care
	The medical home—what this means, and the importance of having a primary care physician
	How to find a family physician or general internist and an adult congenital heart disease physician
	Differences between adult versus child-oriented health care settings—“what to expect on the other side”
	Confidentiality, medical record access
Medical knowledge	Discussion of normal heart anatomy—with diagram
	Review of patient’s heart anatomy at birth—with diagram
	Review of catheter and surgical interventions
	Review of current/residual/future hemodynamic challenges
	Anticipated future catheter or surgical interventions, if applicable
	Late potential cardiac complication and noncardiac morbidities
	Explanation of arrhythmias, if applicable
	Review of pacemaker/AICD programming, if applicable
	Review of current medications, if applicable—name, dose, and rationale
	3-Sentence summary of cardiac/medical condition: <ol style="list-style-type: none"> <li>1. My age, diagnosis, and brief medical history (eg, “I am 16, was born with tetralogy of Fallot, and had heart surgery as a baby”)</li> <li>2. My treatment plan (eg, “My pumping chambers are being monitored, and I might need a valve replacement”)</li> <li>3. My concern/question to talk about during this visit (“eg, I’m having a harder time walking up stairs than in the past”)</li> </ol>
	Urgency versus emergency—Symptoms that warrant medical attention
	Create and review portable health summary/passport
	Endocarditis and potential need for antibiotic prophylaxis
Living with congenital heart disease	Potential challenges in scholastic achievement (learning disabilities and ADHD), if applicable
	Educational/vocational interests, and implications for congenital heart disease, if applicable
	Importance of physical activity and appropriate levels for all congenital heart disease types
	Sports restrictions, if applicable
	Birth control, pregnancy, and congenital heart disease risk in offspring (males and females)
	Diet and weight management
	Smoking, vaping, alcohol, and drugs
	Anxiety and depression
	Connecting with others—how and where to find others living with congenital heart disease
	Sibling/friend/parent/partner support
	Insurance planning and avoiding lapses in medical care
	Advanced care directives/medical power of attorney
Approach to requiring noncardiac surgery	
Self-management	What is “self-management” and why does it matter?
	Examples of self-management skills relevant to chronic disease management: <ol style="list-style-type: none"> <li>1. Making appointments</li> <li>2. Taking medications independent of parent/guardian</li> <li>3. Refilling prescriptions</li> <li>4. Attending part of appointments alone</li> <li>5. Calling the doctor about concerning changes in health</li> </ol>
Self-advocacy	What is “self-advocacy” and why does it matter?
	Examples of self-advocacy skills relevant to chronic disease management: <ol style="list-style-type: none"> <li>1. Keeping a calendar of appointments</li> <li>2. Preparing questions before the appointment</li> <li>3. Making sure the questions are answered</li> <li>4. Answering questions of the doctor or nurse</li> <li>5. Making use of community support services as needed</li> </ol>

ADHD indicates attention-deficit/hyperactivity disorder; and AICD, automatic implantable cardioverter-defibrillator.

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**Table 3. Sample Transition Curriculum Tasks for Adolescents With Congenital Heart Disease**

Action	Date started	Date completed	Care coordination	Medical knowledge
Suggested timeframe: Early transition* (12–14 y)				
Set expectations with parent and child regarding transition				
Sees doctor independently for part of visit; prepares 1 question for each medical appointment				
Knows how to access health care professional contact information				
Learns the name of their cardiac diagnosis				
Learns names and roles of team members				
Learns the names of their medications				
Suggested timeframe: Middle transition* (15–17 y)				
Patient is primary source of communication with the doctor during their appointment				
Practices making their own medical appointments				
Learns about their insurance and sets up an insurance contingency if they are at risk for losing insurance once turn 18 y				
Learns about how to fill a prescription				
Can provide a 3-sentence summary of their cardiac history				
Takes medications independently				
Can explain what their medications are for and knows the doses				
Understands medical urgencies and emergencies to be concerned about				
Transition team creates or updates a portable medical summary with youth				
Learns about their insurance options				
Suggested timeframe: Late transition* (18–21 y)				
Patient sees the doctor independently for majority of or entire appointment				
Makes their own medical appointment and coordinates upcoming procedures				
Introduced to an adult congenital heart disease health care professional or learns how to find an adult congenital heart disease professional and Center				
Learns about advanced directives, living wills, and medical power of attorney				
Can explain cardiac diagnosis to another person				
Understands critical need for lifelong care and healthy lifestyle				
Updates their portable medical summary as needed (eg, after medical appointments)				

\*Suggested age ranges can vary based on neurocognitive status and other patient factors.

36.2%).<sup>99</sup> Instituting measures for assessing success allows not only for organizational improvement but will also assess program performance and help develop benchmarks for program comparison. By establishing formal transition and transfer criteria based on metrics of success, programs and centers will be able to compare their efficacy with others across the region/country. This is an important step in establishing transition curriculum as a necessary part of a congenital heart disease center.<sup>100</sup>

### Insurance Reimbursement Models

Finding ways to bill for transition services is of utmost importance for the sustainability of a transition program. One unique solution includes having a nurse practitioner on the team who has a license and can bill for transition services using recommended codes listed on the Got Transition website (includes in-person, virtual, and telephone options).<sup>101</sup> Another

is having a licensed clinical social worker on the team who can conduct health-focused clinical interviews, behavioral observation and clinical decision-making, and evaluate the patient’s responses to disease, illness or injury, outlook, coping strategies, motivation and adherence to medical treatment. This will allow for that person to bill for Health and Behavior CPT codes<sup>102</sup> (applies to services that address psychological, behavioral, emotional, cognitive, and interpersonal factors in the treatment/management of patients diagnosed with physical health problems). Other strategies might be to incorporate components of transition curricula into standard clinic visits, potentially increasing billable time spent with the patient. One may also consider writing a letter to Payers Regarding Recognition of Codes Related to Pediatric-to-Adult Transition Services to see if it assists in the ability to bill for transition services.<sup>103</sup>

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## New Technologies/Advancements for Health Care Transition

With the routine implementation of electronic health records and telehealth platforms, there are new routes of implementing health care transition programming. A limited study in patients with congenital heart disease showed an electronic medical record–based transition planning tool reduced time lapses between the last pediatric visit and the first adult appointment.<sup>104</sup> The electronic health record provides a way to incorporate transition planning tools, checklists, a medical summary/passport, and health care professional recommendations for each individual patient while also ensuring communication between physicians and subspecialty physicians.<sup>105</sup> Because many patients with congenital heart disease often need several subspecialty services, having all practitioners aware of goals and progress toward goals are important.<sup>106</sup> The use of the patient portals and patient communication tools through registry interfaces also allow patients and families to potentially access individual checklists and support materials, depending on the electronic health record platform.<sup>107</sup>

Mobile technology and web-based health apps are promising tools for facilitating transition from pediatric to adult-centered care. A systematic review and meta-analysis of technology-based tools to support teens with chronic disease was published in 2019.<sup>108</sup> Adolescents were receptive to receiving medical information electronically. However, for these technologies to be implemented, there has to be robust engagement of the patient including patient input into design.<sup>109</sup> Additionally, there is evidence that teens have an interest in internet- and mobile-based programs for chronic disease management, regardless of health literacy level.<sup>110,111</sup> This is also true for minority adolescents with chronic diseases which is critically important as minority adolescents, overall, encounter greater transition barriers than their non-minority peers.<sup>111,112</sup> Thus, e-health technology may offer a convenient, familiar, and accessible method for reaching adolescents, particularly for minority populations most at risk for poor transition. A prototype mobile transition application for adolescents and emerging adults with congenital heart disease has been developed with input from adolescents with congenital heart disease and incorporates transition education, skills training, and a mentorship platform and is currently in the usability and testing phase of development.<sup>81</sup>

The COVID-19 pandemic quite rapidly increased the proportion of clinic visits being provided through telehealth. This offers a novel way to implement formal transition programming and education without a separate in-person physician visit. Telehealth allows for multiple team members, including patients and families, to participate in the visit from different locations. However, although telehealth may increase health care accessibility for some, accessibility issues may remain for those with

lower socioeconomic status (eg, unstable internet access and limited data plans), as well as for those families who do not speak primarily English.<sup>113</sup> Ensuring access to stable internet-based services and devices for all patients will be important for delivery of transition programs. Considerations need to be given for state laws regarding the ability of adolescent patients to consent for health care visits as some states require the minor to be of a certain age in order to independently consent for visits.

## CONCLUSIONS

Understanding the concepts behind transition and transfer and implementing solutions are critical to providing optimal care to teens and young adults with congenital heart disease. Accomplishing this goal requires a broad understanding of patient, health care professional, and system barriers in an effort to minimize worsening health disparities for low socioeconomic status and racial and ethnic populations. Programs must also develop a proactive, consistent, and sustainable approach to transition that includes educational curricula, regular reinforcement of concepts, engagement of patients and families, and transition periodic assessments. Determination of the most effective programs and components are still being developed and will require further prospective research. With a coordinated and comprehensive effort, patients with congenital heart disease can maintain congenital heart care with a smooth transition and transfer to adult-oriented care.

## ARTICLE INFORMATION

The American Heart Association makes every effort to avoid any actual or potential conflicts of interest that may arise as a result of an outside relationship or a personal, professional, or business interest of a member of the writing panel. Specifically, all members of the writing group are required to complete and submit a Disclosure Questionnaire showing all such relationships that might be perceived as real or potential conflicts of interest.

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\*Modest.

†Significant.

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