Research Square

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Peer Coaching Adaptive Self-Management Interventions for Young Adults with Congenital Heart Disease (CHASM in ACHD) – A Pilot Randomized Controlled Trial

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Abstract

Background: Adolescents and young adults (AYAs) with congenital heart disease (CHD) are frequently lost to follow-up during transition to adult congenital heart disease (ACHD) care. Successful transition requires navigating developmental changes while simultaneously building self-management abilities. Psychosocial supports are essential, with peer support approaches particularly relevant given the importance of peer relationships during this developmental period.

Methods: AYAs (18–26 years of age) with CHD treated at a single United States academic medical center were randomly assigned (1:1) to a 6-month peer coaching intervention plus disease education, or education only (attention-only control). Peer coaches were young adults with CHD who provided support via phone and text. Questionnaires including the Partners in Health Scale (PIH) and Transition Readiness Assessment Questionnaire (TRAQ) were completed by AYA participants at baseline, 3, and 6 months. Longitudinal follow-up was continued for 18 months after the intervention.

Results: Thirty-one AYAs were randomized (coaching n=16; control n=15). Mean age was 20.5 ± 2.1 years; 64% were female. PIH self-management median scores improved from 76.0 to 86.5 in the intervention group (p=0.001), with no significant change in controls (75.0 to 81.0, p=0.10). TRAQ scores showed non-significant improvements. Successful transition to ACHD care occurred in 44% of the intervention arm vs. 20% of controls (p=0.25), and loss to follow-up occurred in 6% of the intervention arm vs. 27% of controls (p=0.17).

Conclusions: Peer coaching in transition-aged youth with CHD can be safely implemented, positively impacts self-management skills and may improve transition to ACHD care. Larger studies are needed.

1 Introduction

Improved outcomes for patients with congenital heart disease (CHD) have led to increased survival rates and longer life expectancy, creating an expanding population of adults with CHD [1,2]. This has resulted in a critical need to support adolescents and young adults (AYAs) with complex congenital cardiac needs through transition into adulthood [3,5] and to adult congenital heart disease (ACHD) care. The developmental stage of transition from pediatric to adult-oriented healthcare is associated with increased morbidity [4]. During this critical period, young adults must navigate not only typical developmental challenges, but also the complex demands of managing their congenital heart condition independently [6-8].

Peer support interventions are well suited to AYAs and are known to improve activated self-management for individuals with chronic conditions [9,10]. The developmental importance of peer relationships during the transition to adulthood makes peer-based interventions particularly relevant and impactful for this population [11]. However, despite their theoretical appeal and evidence in other chronic conditions, peer support interventions have not been systematically evaluated for youth with CHD [12-15].

To address this critical gap, we conducted CHASM in ACHD (Peer **C**oac**h**ing **A**daptive **S**elf-**M**anagement **In**terventions for Young **A**dults with **C**ongenital **H**eart **D**isease), a randomized controlled trial testing a one-on-one telephone-based peer support intervention versus an attention-only control group in an academic healthcare setting. This study had three primary objectives: first, to evaluate the feasibility and acceptability of the peer coach intervention for AYA with CHD to promote the development of independent self-management skills; second, to determine the efficacy of CHASM in ACHD on primary outcomes (self-management and transition readiness) across 6 months of intervention; and third, to evaluate transfer and continuity of care from pediatric to adult congenital cardiology over the 18 months following the intervention. We hypothesized that the intervention would be well received by participants, would prove feasible and acceptable, and that participants in the intervention group would report greater improvement in primary outcomes and be more likely to transfer to adult congenital cardiology services compared to controls.

2 Materials and Methods

2.1 Design

The study was a pilot, randomized controlled trial (RCT) examining the feasibility, acceptability, and preliminary efficacy of a peer coaching intervention on self-management skills for AYAs with CHD. The study was conducted at a large academic medical center in the Southeastern United States (Duke University Health System) and was approved and overseen by our Institutional Review Board (IRB; Pro00103600).

2.2 Participants

Study participants were between 18 and 26 years of age at the time of enrollment, had a diagnosed congenital heart defect, had access to a personal smartphone, could read and understand English, and lived in the United States. The exclusion criterion was having a condition that interfered with the capacity to provide informed consent or understand, follow, or comply with study procedures, or the need for an English language interpreter. Participants were recruited from pediatric and adult cardiology clinics and were approached by a study team member during clinic visits, through the electronic health record messaging system, or by phone. While participants generally had been considered for transition of cardiology care, not all had been referred to adult congenital cardiology by the time of enrollment. The informed consent process was conducted by a study team member in a confidential manner either in-person or over the phone, using an e-consent form that was emailed to the patient. Participants signed consent prior to completing any study procedures and were then randomized 1:1 to either the study intervention or the attention-only control arm.

2.3 Study Intervention – PiCASO-ACHD

The PiCASO-ACHD (Peer i-Coaching for Activated Self-management Optimization for young Adults with Congenital Heart Disease) intervention is a peer coaching intervention that was originally developed and

tested in a randomized controlled trial with AYAs from nine chronic health conditions[16]. The model is based upon self-determination theory that is delivered by young peer coaches (21–30 years) with a moderate or severe CHD and trained using a tested curriculum that includes motivational interviewing techniques and the benefits of peer relationships through the shared experience of living with CHD [71-19].

2.3.1 Peer Coach Recruitment and Training

Peer coaches were identified by clinic staff (attending physicians, fellows, nurse practitioners) as having exemplary activated self-management skills and, based upon their interpersonal skills, having the potential to be trained as a peer coach. Those young adults who were recommended then participated in a screening process and interview by the study investigators. Eligible candidates were hired as part-time employees, trained using a five-day PiCASO coach training protocol developed by one of the study team members, and supervised semi-monthly by mental health professionals. Training content included a review of the coaching framework including social support and self-determination theories, motivational interviewing techniques, communicating shared lived experience, and information about health behavior change.

2.3.2 PiCASO-ACHD Model

Peer coaching was tailored to the AYA's developmental level and designed to address four key functions of peer support: 1) participation in daily self-management, 2) support for social and emotional issues, 3) linkage to clinical care, and 4) ongoing support [9]. The peer coaches engaged with the AYA for six months, using nondirective approaches, to guide the AYA to address goals around daily self-management, navigation of the health care system, communication with health care providers, and emotional coping.

The peer coaching interactions were conducted by phone, with calls lasting approximately 30 minutes, and texts using the InquisitHealth Mentor 1:1™ Web Based Portal [20]. Peer coaches and AYAs communicated by phone and texts weekly over the first 3 months of the active relationship-building phase (6–12 calls), followed by 3 months of every other week calls in the goal-focused phase (6–12 calls).

2.4 Attention-Only Control

Over 6 months, attention-only control group participants received an electronic newsletter every two weeks with educational content about CHD management and the differences between pediatric and adult health care systems, as well as a monthly phone call from study staff to ensure receipt of the newsletter, to answer questions regarding content, and with the opportunity to link to other resources. If participants reported health concerns, they were directed to contact their healthcare team.

2.5 Outcome Measures

2.5.1 Feasibility and Acceptability

Evaluation of recruitment rates and post-intervention individual interviews were used to assess the feasibility and acceptability of the intervention. Intervention group participants were invited to complete a semi-structured phone interview after completion of coaching. Interviews assessed participant experiences of living with a chronic condition and the impact of the coaching intervention.

2.5.2 Patient-Reported Outcomes

Measures of self-management and transition readiness were collected at baseline, 3, and 6 months post-randomization through the REDCap electronic survey system [21]. Self-management was measured using the Partners in Health Scale (PIH), assessing chronic condition self-management knowledge, partnership in treatment, recognition and management of symptoms, and coping skills [22]. Transition readiness was assessed using the Transition Readiness Assessment Questionnaire (TRAQ), which evaluates the AYA's skills and confidence in managing their healthcare independently [23].

2.5.3 Electronic Health Record Data

Demographics, medical history, functional status, and cardiology follow-up appointment characteristics were collected through electronic health record (EHR) review. Follow up attendance was tracked over 24 months: the 6 month intervention plus 18 months of subsequent follow up. Successful transition was defined as the participant having had a referral, scheduled appointment, or attended visit at ACHD clinic, at this institution or another center during this time period. Loss to follow was defined as a participant who had no scheduled or attended cardiology appointment of any kind. Functional status was classified using the New York Heart Association functional classification [24]. Complexity of congenital heart disease was stratified by simple, moderate, or complex as determined by the ACHD Bethesda complexity classification [25]. Electrophysiology (EP) diagnosis was defined as having an arrhythmia diagnosis in the EHR or having attended an EP appointment. Mental health (depression or anxiety) was defined as a documented diagnosis in the EHR with or without a mental health screening test (GAD-7 or PHQ-9). Hyperlipidemia, hypertension, and diabetes were defined by documented diagnosis in the EHR without the requirement of having documentation of laboratory values, blood pressure, or hemoglobin A1c. Town of residence was determined to be rural or urban based on the most recent North Carolina Department of Health and Human Services Report [26].

2.6 Statistical Analysis

Descriptive statistics were calculated for demographic and clinical characteristics. For continuous variables, means and standard deviations were reported given the small sample size. For categorical variables, frequencies and percentages were calculated. Within-group changes from baseline to 6 months on the PIH and TRAQ were assessed using paired t-tests. Between-group comparisons were performed using two-sample t tests. Categorical follow up outcomes were compared between arms

using Fisher's exact test. Significance was set at $p<0.05$. All statistical analyses were carried out using Jamovi 2.6 (Jamovi Project, Sydney, Australia) [27].

3 Results

3.1 Sample Characteristics

Participant flow is summarized in Figure 1. For this pilot study, the study team identified and approached 48 eligible participants and 31 (65%) completed the consent process and were enrolled in the study. Participants were randomized 1:1 to either the coaching arm (n=16) or control arm (n=15), with all participants successfully completing the program.

Patient demographics and clinical characteristics at time of randomization are provided in Table 1. The mean age at enrollment was 20.5 years (SD=2.1) and 64% of the participants were female. Baseline demographic distribution was similar for both groups.

Table 1: Participant demographics at time of randomization

	Total (n=31)	Coaching (n=16)	Control (n=15)
Age, in years			
Mean ± SD	20.5 ± 2.1	20.6 ± 2.2	20.3 ± 2.1
Biological Sex			
Female	20 (65%)	11 (69%)	9 (60%)
Race			
White	23 (74%)	12 (75%)	11 (73%)
Black/African American	5 (16%)	2 (12%)	3 (20%)
Other/Multiracial†	3 (10%)	2 (12%)	1 (7%)
Ethnicity			
Hispanic or Latinx	4 (13%)	3 (18%)	1 (6%)
CHD Lesion Complexity*			
Simple	14 (45%)	7 (44%)	8 (50%)
Moderate	11 (35%)	7 (44%)	4 (27%)
Complex	6 (19%)	2 (12%)	4 (27%)
NYHA Functional Class			
Class I	28 (90%)	15 (94%)	13 (87%)
Class II or higher	3 (10%)	1 (6%)	2 (13%)
Comorbid Conditions			
Anxiety	7 (23%)	3 (19%)	4 (27%)
Depression	7 (23%)	4 (25%)	3 (20%)
Hypertension	5 (16%)	2 (12%)	3 (20%)
EP Condition	13 (42%)	7 (44%)	6 (40%)

*Condition definition based on Adult Congenital Heart Disease Bethesda complexity classification [26].
†Includes Native American/Alaskan Native (n=2) and Other race (n=1). CHD, congenital heart disease; NYHA, New York Heart Association; EP, electrophysiology.

3.2 Feasibility and Acceptability

At 3-month follow-up, 12 coaching participants (75%) and 9 control group participants (60%) completed surveys. At 6-month follow-up, 10 coaching participants (62%) and 9 control group participants (60%) completed surveys. After completing the coaching intervention, nine participants completed the post-

intervention phone interview (56%) (Figure1). Participants reported high acceptability of the intervention, highlighting the accessibility of the phone and text communication format and the quality of the coaching relationship. Participants valued the ability to communicate flexibly: *"I liked how we were able to message our coach. I personally really liked the phone calls."* The coaching relationship was described as comfortable and goal-oriented: *"When I was working with my coach she was very helpful…we talked about things that I wanted to improve on whether it had been my health or my overall lifestyle,"* and *"I remember not what was said, but how she made me feel."* Participants also described meaningful gains in self-management confidence and condition knowledge: *"She did help me a lot with getting to learn a little bit more about me and about my condition, but also how to just like live with my condition without feeling so limited."*

A distinct and prominent theme across participant interviews was the unique value of connecting with a coach who had lived experience with CHD. Participants consistently described this shared experience as something unavailable elsewhere in their lives: *"What made the experience unique was that that other person had been through something similar. And there are very few people in my life who have had similar experiences,"* and *"you're not alone."* This sense of connection extended even when the specific cardiac diagnosis differed between coach and participant: *"I never talked to anyone with a heart issue…it wasn't the same issue as mine, but I felt that was really cool."* Participants also emphasized the relational ease that came from proximity in age and shared life context: *"We were able to relate because we were so close in age…I felt comfortable talking to her because I knew she could relate to some of what I was saying."*

3.3 Patient-Reported Measures

PIH self-management median scores improved significantly in the intervention group from 76.0 at baseline to 86.5 at 6 months (p=0.001), with no significant change in the control group (75.0 to 81.0, p=0.10). The between-group comparison approached, but did not reach, significance (p=0.06).

TRAQ scores were similar at baseline between arms. The intervention group improved 0.5 points over 6 months (3.9 to 4.3, p=0.12) and the control group improved 0.2 points (4.3 to 4.5, p=0.37). The between-group comparison was non-significant (p=0.47)

3.4 Transition of Care and Continuity

Successful transition to ACHD care occurred in 44% (7/16) of the intervention arm compared to 20% (3/15) of controls, (p=0.25). Loss to follow-up occurred in 6% (1/16) of the intervention arm compared to 27% (4/15) of controls (p=0.17). About half of the participants, 50% (8/16) of the intervention arm and 53% (8/15) of the controls continued with pediatric cardiology follow-up at the close of the longitudinal observation period. Although neither between group difference reached statistical significance in this small pilot study, the direction of effect favored the intervention for both outcomes.

3.5 Healthcare Utilization

Only one patient (in the control group) was uninsured. There was no significant difference in the number of participants diagnosed with hypertension, hyperlipidemia, or diabetes in either group. Between the coaching and control cohorts, participants who held a diagnosis of depression (17.6% vs. 25%) or anxiety (17.6% vs. 25%) were similar. Similar percentages of individuals were scheduled for follow-up appointments for mental health needs (11.8% vs. 12.5%). No emergency room visits were found for mental health concerns in either cohort. Both cohorts had a similar number of emergency room visits for cardiology concerns (5.9% vs. 6.3%) during the 18 months of follow-up.

4 Discussion

This pilot study demonstrates that a peer coaching intervention can be successfully implemented for young adults with congenital heart disease and results in measurable improvements in self-management skills. This was seen despite a control arm that received considerable disease- and transition-based educational materials; the latter were provided to increase enrollment and ensure that all participants benefitted from participating in the protocol. The intervention demonstrated feasibility with successful recruitment and retention rates despite the challenges posed by the COVID-19 pandemic and the unexpected tragic death of a primary investigator (JE). Post-intervention qualitative interviews revealed high acceptability among participants, with positive feedback regarding the peer relationship and support received.

Of clinical significance was the difference in medical retention and successful transition seen between the two groups. Loss to follow up occurred in only 6% of the intervention arm compared to about a third of controls. Successful transition to ACHD care occurred in 44% of the intervention arm versus 20% of controls. Although neither difference reached statistical significance in this small pilot, the magnitudes are notable given that gaps of care during the transition years are a well-documented driver of morbidity in AYAs with CHD [3-5]. An intervention that nearly halves loss to follow up, if reflected in larger studies, would represent a meaningful clinical advance for a population whose attrition during the window of transition has been difficult to address.

These transition outcomes were paralleled with within arm improvements in self-management. PIH scores improved substantially in the intervention arm (median +11.5) but not in controls (+8), and the between-group comparison favored the intervention without reaching significance. This is consistent with participants in the coaching intervention group developing greater skill in managing their chronic condition, partnering with their healthcare team, and recognizing and coping with their CHD symptoms. Transition readiness on the TRAQ scale trended in the same direction, but also failed to reach statistical significance.

Several factors likely contributed to the success of this intervention. First, the use of peer coaches with CHD created a connection based on a shared experience, which allows for the medium of information communication to differ from the typical transfer of information from healthcare provider to patient. Second, the comprehensive training program based on self-determination theory and motivational

interviewing provided coaches with evidence-based skills for supporting behavior change [16]. Third, the flexible, individualized approach allowed the intervention to be tailored to each participant's needs.

The findings support the need for larger studies to definitively establish the efficacy of peer coaching for AYA with CHD. Additionally, future research should identify and potentially target those patients who benefit most from peer coaching interventions. Cost-effectiveness analysis will be important to determine whether peer coaching can also help to reduce healthcare expenditures given the findings of improved self-management scores and appointment adherence. The use of a telephone and text-based delivery model additionally serves as a scalable and accessible format for peer coaching, reaching AYAs regardless of geographic location, a particular advantage for AYAs navigating the transition to adult care.

4.1 Limitations

Several limitations should be noted. First, this pilot study recruited a small sample size, thus limiting statistical power to detect differences in most outcomes. Second, the study was conducted during the COVID-19 pandemic, which may have affected recruitment, delivery of the intervention, and its adoption. Third, while the aim was for the attention-only control group to closely replicate the experience of a standard AYA CHD population, the distribution of educational and follow up contacts by study team members likely extended beyond the usual standard of care and may have attenuated some of the potential treatment effect. This was also from a single large referral center, which may limit generalizability to broader populations. Finally, curtailing data collection at 18 months follow-up may have introduced biases for measuring appropriate follow-up, particularly in patients with milder forms of CHD, who would otherwise not need to be evaluated earlier.

5 Conclusions

Peer coaching in transition-aged AYA with CHD can be safely implemented, improves self-management skills, and may result in more successful patient transitions and reduced loss to follow-up compared to providing appropriate educational materials. The findings of this pilot study provide support for the feasibility, acceptability, and efficacy of utilizing peer coaches for AYA with CHD. Future research and larger trials should focus on identifying patients who most benefit from this structured intervention. The development of a sustainable implementation model will allow for self-replenishment, as participants are taught the tools to eventually become peer coaches themselves and help future generations of AYA with CHD.

Declarations

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Availability of Data and Materials: The data that support the findings of this study are available from the Corresponding Author upon reasonable request.

Ethics Approval: This study was approved by the Duke University Health System Institutional Review Board (IRB; Pro00103600) and conducted in accordance with the Declaration of Helsinki. All participants provided informed consent prior to enrollment.

Competing Interests: The authors declare no conflicts of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

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Figures

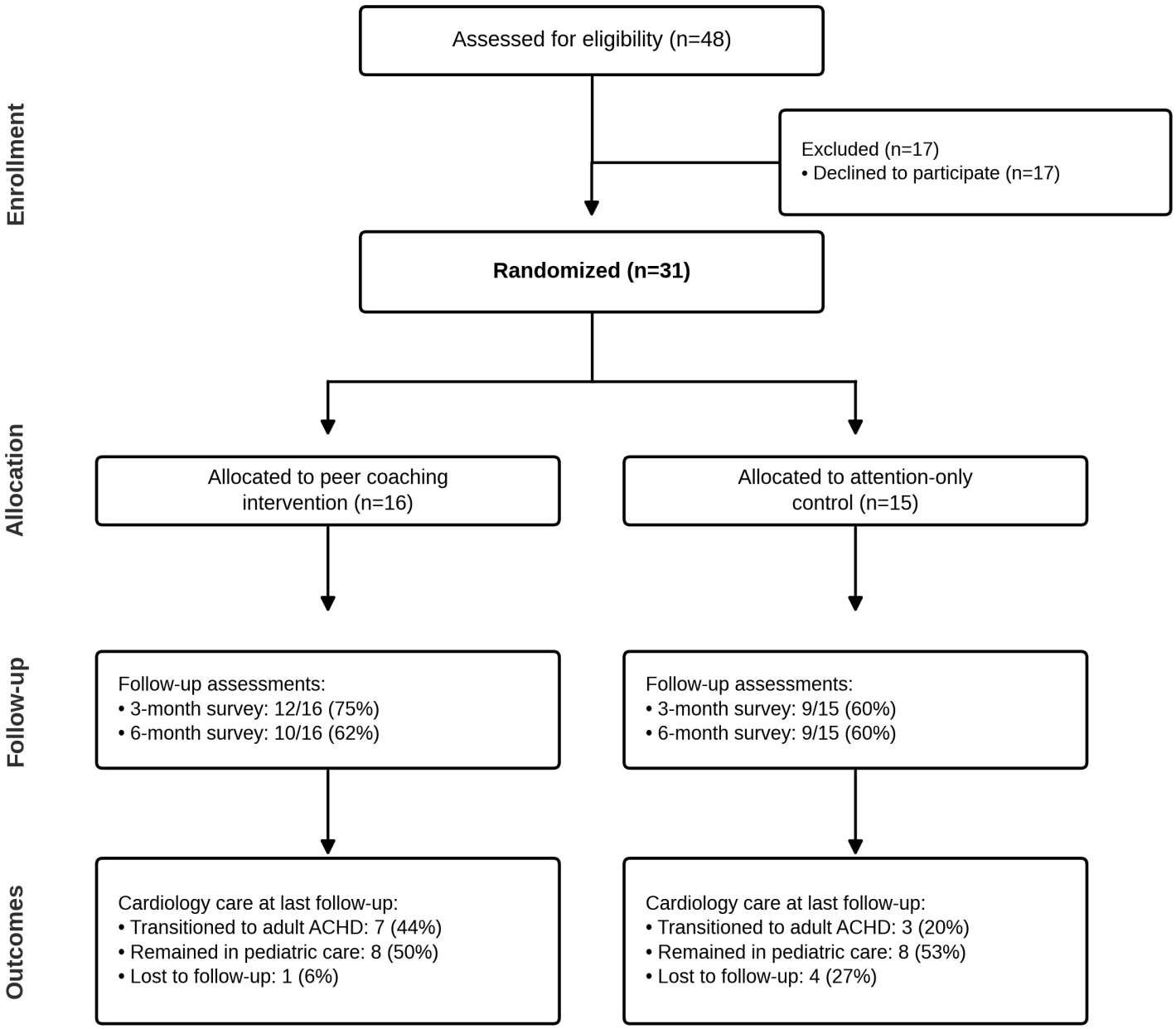


Figure 1

CONSORT flow diagram. Adolescents and young adults (18–26 years) with congenital heart disease were screened for eligibility, randomized 1:1 to a 6-month peer coaching intervention or attention-only control, and completed self-report surveys at baseline, 3 months, and 6 months. Participants were followed for an additional 18 months to determine cardiology care continuity and for successful transition to adult congenital heart disease (ACHD) management via electronic health review.