

Original Article

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Factors associated with a lower chance of having gaps in care in adult congenital heart disease

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Abstract

Background: To promote good health in patients with congenital heart disease (CHD), prevention of gaps in care is essential, as adverse prognosis is associated with care gaps. A well-organised, formal transition programme may help prevent loss to follow up after leaving paediatric care. To inform the development of a transition programme, we investigated factors associated with care gaps in adults with CHD. **Methods:** Between 15 October 2018 and 15 November 2019 data on patient characteristics and patient experiences with transition-related education, difficulties, and gaps in care were collected and assessed in 87 adults with CHD. Two groups (with gaps in care versus without gaps) were compared to identify informative differences using chi-squared, Fisher's exact tests, or Wilcoxon rank-sum tests. To assess the relationship between care gaps and identified variables, factors with significant difference ($p < 0.05$) in bivariate analyses were employed as covariates in multivariable logistic regression analysis. **Results:** About half of the study cohort reported having gaps in care. In a multivariate model, patients having thorough discussion about the importance of receiving adult care in paediatric care were 70% less likely to experience gaps (odds ratio 0.303, 95% CI 0.14, 0.66). Forty-seven percent of patient-perceived barriers to transitioning originated from negative feelings associated with transfer. **Conclusion:** Gaps in care are highly prevalent in adults with CHD. For a transition programme to be most effective, curriculum development may need to consider the differential impact of various factors and target areas to mitigate the psychological stress associated with transfer.

The population of adults with congenital heart disease (CHD) is rapidly growing. Their number has increased dramatically over the past 50 years as a result of advances in surgical technology and medical management for CHD. Currently, the number of adults with CHD exceeds that of the paediatric population with CHD in North America.¹ To promote a favourable prognosis in aging patients with CHD, it is important that patients remain in ongoing specialised cardiology care and receive regular screening for potential clinical sequelae. This is necessary, as most moderate and severe forms of CHD are prone to deterioration of prior repairs or to physiologic deterioration with the onset of age-related cardiac disease later in life. Common comorbidities in the CHD population such as arrhythmias, atherosclerotic disease, and heart failure are associated with a poor functional status, low quality of life, and the need for re-intervention, hospitalisation, and mortality.² The American Heart Association recommends that patients with at least moderate CHD complexity be followed by adult congenital heart disease (ACHD) specialised clinicians at least every 2 years.³ However, studies have shown that 61%–83% of ACHD patients are either lost to follow up or not seen at ACHD-specialised centres for an extended period of time after leaving paediatric care.^{4–6} This is concerning as gaps in care are associated with adverse health outcomes in the ACHD patients. Among ACHD patients evaluated as a new patient in an ACHD centre, those with gaps in care are more likely to be symptomatic, receive a new cardiac diagnosis, and are three times more likely to require urgent cardiac interventions compared to those without gaps.⁶ Additionally, a loss-to-follow up is an independent predictor of mortality in ACHD patients while a follow up in ACHD specialised care is associated with decreased mortality.^{7,8} These findings underscore the need for patients with CHD to receive ongoing clinical care in ACHD specialised centres throughout life. It is thus essential to prevent loss-to-specialised care follow up and gaps in care. Given that lapses in care among patients with CHD typically take place around the time of transfer from paediatric to adult-oriented care, health professionals have developed educational transition programmes with the goal of ensuring continuity of care and to facilitate smooth, uninterrupted transfer from paediatric to adult providers.^{4–6,9} Nevertheless, many institutions lack a structured transition programme and among those with transition programmes, studies investigating the efficacy of these programmes are rare and suggest room for improvement.^{10–12} In the present study, we attempted to inform the development of a patient-centered transition programme in a local ACHD centre as a patient-centered approach is associated with increased patient satisfaction, adherence to

care, and improved health outcomes.^{13,14} To accomplish this, we examined demographic, clinical, and care transition related patient-reported data in adults with CHD to identify factors associated with gaps in care.

Material and methods

Between 15 October 2018 and 15 November 2019, patients followed in the Centre for ACHD at the University of Texas Southwestern Medical Centre were offered participation in an ACHD registry. Informed consent was obtained from each patient and the study protocol conforms to the ethical guidelines of the 1975 Declaration of Helsinki as reflected in a priori approval by the institution's human research committee. This study was approved by the institutional review board at the University of Texas Southwestern Medical Centre. The study included adults ≥ 18 years with the diagnosis of CHD and the capability to consent. At the time of a regularly scheduled clinical visit, participants were asked to complete self-reported questionnaires related to their experiences with transition from paediatric to adult cardiology care and perceived health status. In cases where there was missing information about transition experiences, patients were called and questionnaires were completed via telephone. The transition questionnaire was developed by the authors using existing data on care transitioning to collect information about gaps in cardiology care, patient experiences with education on care transition, barriers to transitioning, and a sense of preparedness for transitioning.^{15,16} Supplemental Table 1 displays all question items included in each category. The self-assessed health status survey was specifically designed for ACHD patients and developed by the principal investigator (A.M.C.). This survey asks patients to self-evaluate their health on 5-, 6-, and 7-likert point scales over the 2 weeks prior to the survey completion date. It consists of five health domains: physical limitation, symptoms, arrhythmia, quality of life, and anxiety/depression. The summary and individual domain scores range from 0 and 100 and higher scores indicate better health status. This questionnaire has been previously validated in ACHD patients and its psychometric analysis and scoring have been previously reported.¹⁷ Clinical data were retrospectively collected via chart review.

All analyses were performed using SAS v 9.4 (SAS Institute, Cary, NC). The level for statistical significance was set at $p < 0.05$. Frequencies and medians with interquartile ranges were calculated for the full sample. Participants were categorised as having a gap in care if patients with cardiac complexity \geq moderate level experienced gaps ≥ 2 years or if those with simple complexity experienced gaps ≥ 5 years. Factors of interest were compared between 2 groups (with and without gaps in care) with contingency tables and chi-squared or Fisher's exact tests for categorical variables, and with medians and interquartile ranges and Wilcoxon rank-sum tests for continuous variables. Factors found to be statistically different ($p < 0.05$) between the 2 comparison groups in bivariate analyses were adjusted as covariates in multivariable logistic regression analysis to assess their associations with gaps in care.

Results

Participant characteristics

Of 136 participants consented for this study, 31 patients were excluded from the analysis (1 with Marfan syndrome; 4 who

did not receive paediatric care in the United States; 12 with late diagnosis of CHD in adulthood, and 14 who did not complete a study-required survey). Of 105 patients who completed the transition questionnaire, the information about gaps in cardiology care was available in 87 patients. Characteristics for the overall sample ($n = 105$) and the 2 compared groups are presented in Table 1. The age of respondents ranged from 18 to 75 years (median 34); 51% were women; 86% were Caucasian; and 96% had at least moderate heart defect complexity. While the majority of patients reported having been thoroughly educated on their heart condition, the importance of medication compliance, receiving adult cardiology care, and physical activity; their experience with education on other health behaviours, mental health, and independence was relatively poor (Fig 1).

Barriers to care transitioning

Forty-two percent of respondents wished that they had been better prepared for transitioning and 28% had difficulties with transitioning. Patient-perceived barriers to transitioning included limited access to ACHD specialists (34%), leaving long-standing relationships with paediatric providers (26%), unfamiliarity or negative expectations about ACHD care (13%), insurance issues (12%), feeling not ready for transfer (8%), and the lack of awareness for the need of ACHD care (7%) (Fig 2).

Gaps in care

Of 87 patients who provided the information about gaps in care, 48% reported having gaps in care (ranging from 3 to 45 years) and 59% and 36% had moderate and great heart defect complexity, respectively. Patients with gaps in care were significantly older (37.5 versus 25, $p = 0.0004$), younger when last seen by a paediatric cardiologist (17 versus 20, $p = 0.0003$), had fewer cardiac surgeries (1 versus 2, $p = 0.0165$), and were more likely to be symptomatic (71.7 versus 86.7, $p = 0.0187$) compared to those without gaps. Patient experience with transition education for those with and without gaps in care is presented in Supplemental Table 2. Those without gaps in care were more likely to have received thorough information on the importance of medication compliance, the importance of receiving adult care, and physical activity in paediatric care. In a multivariate regression model accounting for five covariates having significance in bivariate analysis including age and age last seen by a paediatric cardiologist, patients who reported having a thorough discussion about the importance of receiving adult care were 70% less likely to experience gaps in care (odds ratio 0.30, 95% CI 0.14, 0.66) (Table 2).

Discussion

In the present study, we investigated the prevalence of and variables associated with gaps in care to inform the development of a patient-centered transition programme for CHD patients. We found that 48% of the study cohort reported having care gaps. The assessment of demographic, clinical, and patient-reported data revealed that among various factors including education topics presented to patients while in paediatric care, having a thorough discussion specifically about the importance of receiving adult care was associated with a 70% lower chance of experiencing gaps in care. Additionally, 47% of patient-perceived barriers to transitioning into adult care had to do with negative feelings associated with transfer. These findings suggest that the impact of transition education on promoting patient willingness to seek ongoing

Table 1. Patient characteristics

Variable	Study Cohort (n=105)	Gaps in Cardiology Care*		P-value
		No Gap (n=45)	≥2 Years (n=42)	
Age (Median, years) [range]	34 [18-75]	25 [18-63]	37.5 [22-75]	0.0004
Men	51 (49%)	22 (49%)	20 (48%)	0.9057
Race				0.4445
White	90 (86%)	40 (89%)	34 (80%)	
Black	8 (8%)	4 (9%)	4 (10%)	
Other	7 (6%)	1 (2%)	4 (10%)	
Hispanic	14 (13%)	8 (18%)	5 (12%)	0.3556
Education				0.2849
Grade School or High School	33 (33%)	13 (29%)	15 (39%)	
College	50 (49%)	21 (48%)	20 (51%)	
Graduate School	18 (18%)	10 (23%)	4 (10%)	
Employment				0.0895
Yes	82 (84%)	32 (74%)	35 (95%)	
Unemployed	6 (6%)	4 (9%)	1 (3%)	
Disabled	5 (5%)	4 (9%)	0	
Retired	2 (2%)	1 (2%)	1 (3%)	
Student	3 (3%)	2 (5%)	0%	
Congenital Heart Disease Complexity				0.3248
Simple	4 (4%)	2 (4%)	2 (5%)	
Moderate	55 (52%)	20 (44%)	25 (59%)	
Great	46 (44%)	23 (51%)	15 (36%)	
Medical History				
Smoking	22 (21%)	4 (9%)	10 (24%)	0.0807
Arrhythmia	40 (38%)	13 (29%)	19 (45%)	0.114
Permanent Pacemaker	14 (13%)	7 (16%)	5 (12%)	0.5922
Implantable Cardioverter Device	5 (5%)	2 (4%)	1 (2%)	1
Non-cardiac diagnosis	87 (86%)	35 (78%)	37 (88%)	0.203
Cardiac Surgery before 19 years	93 (89%)	39 (87%)	36 (86%)	0.8976
Hypertension	33 (31%)	10 (22%)	14 (33%)	0.2466
Diabetes	6 (6%)	3 (7%)	2 (5%)	1
Cholesterol	10 (10%)	3 (7%)	5 (12%)	0.4746
Kidney	3 (3%)	0%	1 (2%)	0.4828
Cerebrovascular Attack	5 (5%)	2 (4%)	2 (5%)	1
American Heart Association Physiological Stage				0.073
A	13 (12%)	4 (9%)	9 (21%)	
B	33 (31%)	16 (36%)	9 (21%)	
C	56 (54%)	22 (49%)	24 (57%)	
D	3 (3%)	3 (6%)	0	
Regularly Seen by ACHD Specialist ≥1year*	54 (62%)	39 (87%)	36 (86%)	
Age Last Seen by Pediatric Cardiologist (Years), Median [range]	18 [3.5-43]	20 [10-43]	17 [3.5-40]	0.0003
Number of Cardiac Surgeries, Median [range]	2 [0-8]	2 [0-8]	1 [0-5]	0.0165
Seen by ACHD MD	79 (91%)	41 (91%)	38 (90%)	1

(Continued)

Table 1. (Continued)

Variable	Study Cohort (n=105)	Gaps in Cardiology Care*		P-value
		No Gap (n=45)	≥2 Years (n=42)	
Patient-assessed Health Status	81.9 [65.3-90.3]	82.7 [65.3-90.8]	81.3 [58.5-89]	0.8952
Physical Limitation	78.3 [55-85]	78.3 [56.7-85]	78.3 [51.7-85]	0.7952
Symptoms	84.7 [67.3-93.3]	86.7 [73.3-96.7]	71.7 [55.3-92.7]	0.0187
Arrhythmia	88.9 [71.7-100]	83.3 [73.3-100]	88.9 [57.8-100]	0.4971
Quality of Life	78.6 [58.3-82.1]	78.6 [54.8-82.1]	82.1 [59.5-85.7]	0.3721
Anxiety/Depression	87.5 [70-97.5]	87.5 [70-100]	88.8 [68.8-97.5]	0.8725

*Responses were available in 87 patients. Results are presented as frequencies (percentages) and median with interquartile ranges.

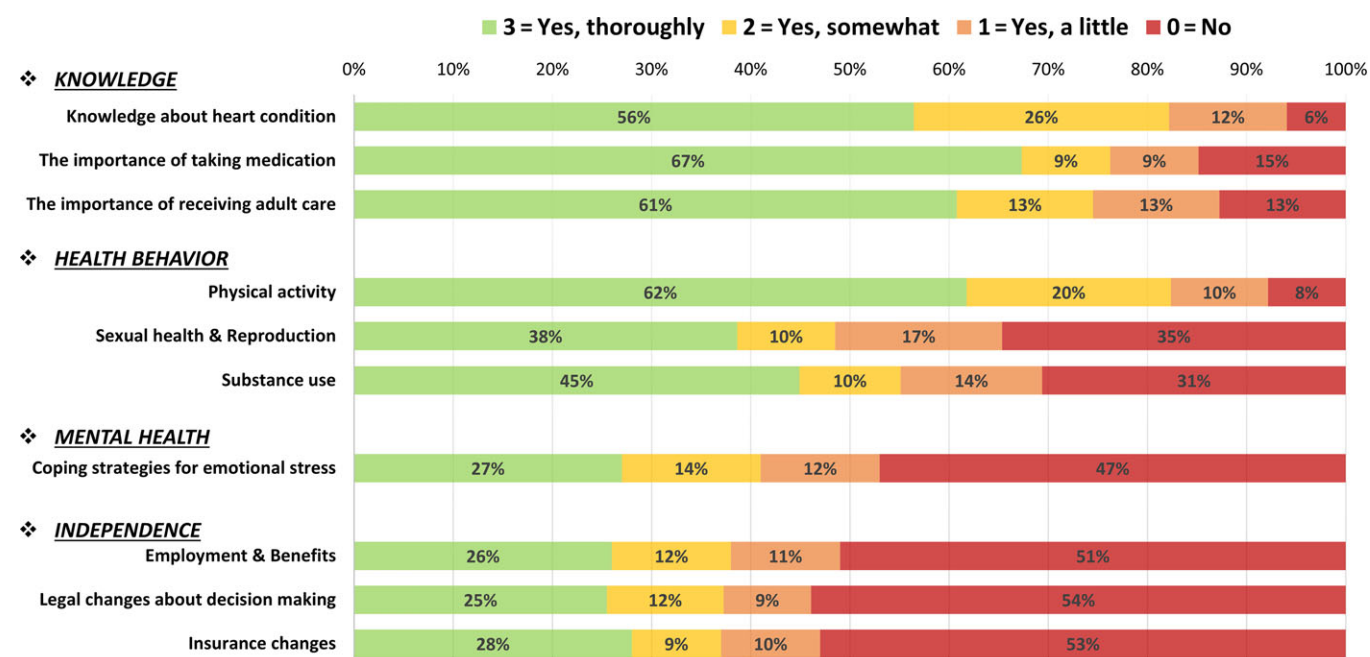


Figure 1. Patient experience with transition-related education.

care may vary by the type and thoroughness of educational information discussed. Furthermore, by targeting the specific sources of transfer-related psychological stress for intervention, a transition programme may effectively facilitate successful transfer and prevent gaps in care in patients with CHD.

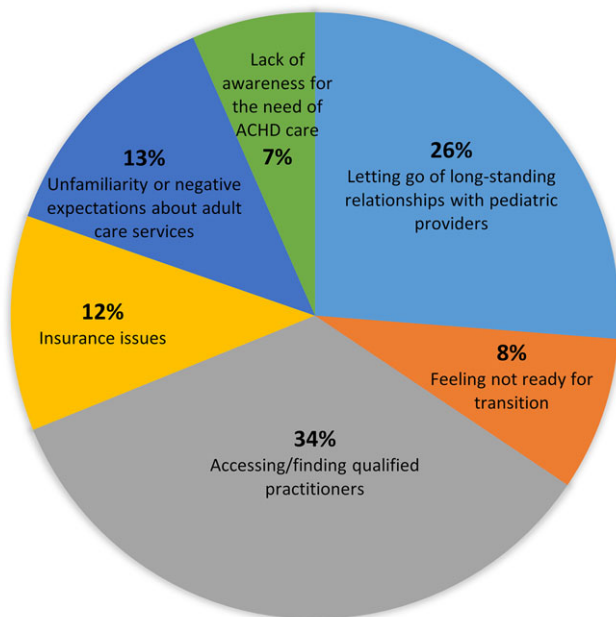
In the present study, 48% of the study cohort experienced gaps in cardiology care. A relatively high prevalence of care gaps found in this study is consistent with data previously demonstrated in a few studies (42% and 63%).^{6,9} These studies are similar in that their data were derived from ACHD centres in the United States, care gaps were defined as either ≥ 2 or > 3 years, and patients’ age range was very wide. This suggests that the prevalence of care gaps may vary by factors associated geographical locations and the assessment criteria used to determine the number of patients with care gaps. A careful evaluation of various studies should be made to assess the prevalence of gaps in care in this patient population.

To our knowledge, the present study is the first to assess the relationship between specific educational domains and gaps in

care. Our data show that patients who were thoroughly educated on the importance of receiving adult care by paediatric care teams were 70% less likely to experience a lapse in care (p = 0.0027), while no association was found between other education domains and gaps in care. This implies that raising awareness in patients of the need for ACHD care may most effectively motivate patients to seek ongoing care. Without awareness, patients may be prone to leave care especially in the absence of symptoms or functional limitations.⁹ In fact, lack of awareness was found to be the most common cause of gaps in care among ACHD patients.⁶ Given that lapse in care begins mostly around the time of transfer from paediatric to adult-oriented care, many institutions have developed transition programmes to ensure continuity of care in patients by facilitating a smooth, uninterrupted transfer from paediatric to adult care.^{4-6,9} These programmes aim to promote a sense of control and independence in patients by equipping patients with knowledge and skills necessary to manage their own health as an adult. The American Heart Association recommends that

Table 2. Multivariable logistic regression predicting gaps in care

Covariates	Odds ratio (95% CI)	p-value
Age (years)	1.08 (1.03, 1.14)	0.0034
Age last seen by paediatric cardiologist (years)	0.88 (0.80, 0.97)	0.0109
Number of cardiac surgeries	0.59 (0.32, 1.09)	0.0932
Discussed the importance of taking medication: Yes, thoroughly -versus- Yes, somewhat or a little or No	1.29 (0.59, 2.80)	0.5255
Discussed the importance of receiving adult care: Yes, thoroughly -versus- Yes, somewhat or a little or No	0.30 (0.14, 0.66)	0.0027

BARRIERS TO PAEDIATRIC TO ADULT CARE TRANSITIONING**Figure 2.** Patient-perceived barriers to care transitioning.

transition programmes for patients with CHD include education on medical, physical, emotional, social/relational, and education/vocational domains, health behaviours, and personality/identity.¹⁸ Previous studies investigating the effectiveness of transition programmes have demonstrated improved health-related knowledge, a lower rate of loss-to-follow up, and shorter time beyond clinical recommendation until making the first appointment in an ACHD clinic in programme participants compared to non-participants.^{10,11,19} These programmes provided various health-related and self-care information, including CHD lesion education and the importance of long-term follow up. However, the associations between education domains and outcome variables were not examined in these studies. Future research is warranted to investigate if certain education domains have greater impact on preventing gaps in care than others. If this is the case, the type and thoroughness of educational information to be discussed should be considered when designing a transition programme curriculum.

The present study also revealed a potentially novel target for intervention in a transition programme. Based on our data, about half of patient-perceived barriers to transitioning originated from negative feelings associated with needing to leave behind what has been familiar for many years and transfer into a new, yet unknown care environment. This suggests that patient's knowledge gap about adult-centered care as well as a relational gap between patient and adult care services may be potential targets for intervention in a transition programme. Previous studies reporting patient expectations and experiences with transition demonstrated that young patients with CHD prefer to be the primary recipient of communication, want to be better informed about adult care services, desire a sense of control in adult care, and anticipate amiable adult care staff.^{20–22} Provision of necessary education about adult care services in the manner patients desire to receive may thus effectively prepare patients for transitioning and reduce barriers.

By including paediatric provider referral to ACHD-specialised care, a transition programme may play a significant role in bridging the relational gap between patient and adult care services. Studies have shown that patients referred by paediatric providers to ACHD-specialising centres were more likely to transfer into adult care successfully and experience shorter gaps in care.^{12,23,24} Although the mechanisms underlying this association are unclear, one may speculate a potential role paediatric referral may play in mitigating patient's negative emotions about transfer. When a patient's paediatric cardiologist makes referral, patients may become more receptive and trusting toward ACHD care providers because they were personally selected by someone they trust. This process additionally removes from patients the psychological stress and burden associated with the effort to find a new ACHD provider on their own. And to further facilitate rapport building and to increase patients' familiarity with adult care service teams, a transition programme could schedule a joint clinic visit where paediatric patients can meet both paediatric and adult care providers prior to transfer and coordinate a pre-transfer tour of the ACHD centre. By bridging the relational and knowledge gaps, a transition programme may thus effectively reduce barriers to transitioning and by extension prevent gaps in care.

Lastly, the present study suggests that psychological education on coping strategies should complement education on the importance of ongoing care in a transition programme. When young patients learn about the necessity of ongoing care for the management of potential risks of clinical sequelae, they may become distressed and try to cope with health-related stress in unhealthy ways, such as denial of the impact of CHD on life. In fact, psychiatric disorders (e.g., depression and anxiety) develop early in life, are highly prevalent in ACHD patients, and are associated with adverse prognosis when left untreated.^{25–27} Cardiac denial, which is linked with increased depressive symptoms in ACHD patients, may result in patients leaving care, if left unchecked.²⁸ Thus, to optimise the effectiveness of a transition programme, thorough information on coping and psychological education should be provided.

There are limitations to the present study. As patient-reported data is subjective in nature, a recall and response bias is unavoidable. A retrospective chart review may result in incomplete data. Our findings are meant to generate hypotheses and are not generalisable as it provides a cross-sectional analysis of data derived from a small number of the study participants seen in a local ACHD centre. Due to a limited number of

patients with simple cardiac lesion complexity in the study cohort, our data may be more representative of patients with moderate or great CHD complexity.

Conclusion

Gaps in care are highly prevalent in the ACHD patient population. To optimise health in ACHD patients who are prone to care gaps after leaving paediatric care, a structured transition programme needs to be developed to facilitate successful transfer from paediatric to adult care and to promote patient willingness to seek ongoing care. A transition programme may effectively accomplish these goals with the provision of well balanced, thorough information on targeted topics and by bridging the relational gap between patient and adult care.

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Conflicts of interest. None.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (survey) and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the institutional committees (at the University of Texas Southwestern Medical Centre).

Supplementary material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S1047951121000524>

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