

Congenital Heart Disease

Prevalence and Predictors of Gaps in Care Among Adult Congenital Heart Disease Patients

HEART-ACHD (The Health, Education, and Access Research Trial)

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- Objectives** The goal of this project was to quantify the prevalence of gaps in cardiology care, identify predictors of gaps, and assess barriers to care among adult congenital heart disease (adult CHD) patients.
- Background** Adult CHD patients risk interruptions in care that are associated with undesired outcomes.
- Methods** Patients (18 years of age and older) with their first presentation to an adult CHD clinic completed a survey regarding gaps in, and barriers to, care.
- Results** Among 12 adult CHD centers, 922 subjects (54% female) were recruited. A >3-year gap in cardiology care was identified in 42%, with 8% having gaps longer than a decade. Mean age at the first gap was 19.9 years. The majority of respondents had more than high school education and knew their heart condition. The most common reasons for gaps included feeling well, being unaware that follow-up was required, and complete absence from medical care. Disease complexity was predictive of a gap in care with 59% of mild, 42% of moderate, and 26% of severe disease subjects reporting gaps ($p < 0.0001$). Clinic location significantly predicted gaps ($p < 0.0001$), whereas sex, race, and education level did not. Common reasons for returning to care were new symptoms, referral from provider, and desire to prevent problems.
- Conclusions** Adult CHD patients have gaps in cardiology care; the first lapse commonly occurred at age ~19 years, a time when transition to adult services is contemplated. Gaps were more common among subjects with mild and moderate diagnoses and at particular locations. These results provide a framework for developing strategies to decrease gaps and address barriers to care in the adult CHD population. (J Am Coll Cardiol 2013;61:2180-4)
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Advances over the past 4 decades in diagnosing and treating congenital heart disease (CHD) in children have resulted in >85% survival into adulthood. The current population of adults in the United States with CHD is estimated at approximately 1 million (1,2). Most CHD patients require lifelong cardiology care, and published guidelines recommend care from specialists in adult CHD for approximately half of this population (1,3–5).

Previous studies report that many adult patients are lost to cardiac follow-up, some with gaps in care of ≥ 10 years (6). In the adult CHD population, a lapse in medical care may result in adverse outcomes. Single-center studies have noted that patients with a gap in care are more likely to require urgent cardiac interventions or have undertreated cardiac-related medical conditions (6–8). Small cohort studies of patients with congenital heart and other chronic pediatric-onset diseases have likewise suggested that potential barriers to accessing specialized care include deficiency of patient education regarding their condition and the need for regular follow-up, absence of sufficient health insurance, lack of available qualified specialty centers, and negative experiences in adult-oriented care (9–11).

The Alliance for Adult Research in Congenital Cardiology, a North American collaboration of adult congenital heart centers dedicated to research (12), and the Adult Congenital Heart Association, a national patient advocacy organization, sought to explore the prevalence and duration of gaps in care and the types of barriers to care experienced by adult CHD patients as a means to developing future targeted interventions to limit the occurrence and impact of such deficiencies.

Methods

Patient population. The study population comprised adults (18 years of age and older) with CHD on their first presentation to 1 of 12 participating adult CHD care programs based at Oregon Health and Sciences University, Portland, Oregon; University of California Medical Center, Los Angeles, California; University of Washington Medical Center, Seattle, Washington; Children's Hospital Boston, Boston, Massachusetts; Ohio State University Medical Center, Columbus, Ohio; University of Colorado Medical Center, Denver, Colorado; Medical College of Wisconsin, Milwaukee, Wisconsin; Columbia University Medical Center, New York, New York; Hershey Medical Center, Hershey, Pennsylvania; Cincinnati Children's Hospital, Cincinnati, Ohio; Children's National Medical Center, Washington, DC; and the Hospital of the University of Pennsylvania, Philadelphia, Pennsylvania. Patients were required to have a diagnosis of CHD and to be a new patient to the adult CHD clinic between January 1, 2009, and December 31, 2010. New patients were defined as those never previously seen in the adult CHD program at that site. Patients were excluded if they did not have CHD or were unable to complete a survey written at an eighth-grade reading

level. De-identified data from all centers were sent to the data-coordinating center at the Adult Congenital Heart Association.

Study design. A multicenter, prospective, cross-sectional study was performed with a questionnaire administered to subjects at their first visit to the adult CHD center. The questionnaire included multiple topics focused on gaps in and barriers to cardiology care. A gap in cardiology care was defined as a >3-year interval between any cardiology appointments (internal medicine, pediatric or adult congenital cardiology). Demographic variables collected included sex, race, ethnicity, and education level. Clinical variables included referral source, CHD diagnoses (≤ 5), and a series of questions regarding the presence and duration of gaps in cardiology care and reasons for leaving and returning to cardiology care. Enrolled subjects were asked to record the number of gaps in cardiology care since the age of 18 years, the age at which the gaps occurred, and the duration of the gaps. For rating barriers to care, we asked subjects what caused them to stop seeing their cardiologist. As it was thought that a decision to leave care might be multifactorial, subjects were asked to rate 19 factors from 1 = strongly disagree to 5 = strongly agree. If no choices were appropriate, they were asked to fill in the response "other." The "other" responses ranged from "did not think I needed follow-up from a cardiologist" to "changed insurance" to "my parents stopped taking me." The results were evaluated by frequency of response for the group and by categories of complexity of CHD. As the subjects were all new patients to the adult CHD center, they were also asked what prompted the return to cardiology care. There were 14 potential options and subjects were asked to respond yes or no to each. The self-reported CHD diagnoses were confirmed by the local research team, and each patient was categorized as having anatomically simple, moderate, or complex CHD based on the most complex diagnosis and the categories detailed in the 32nd Bethesda guidelines (2). It was reported to the data-coordinating center if the self-reported diagnosis did not match the actual diagnosis. The local research team confirmed additional clinical information by medical record review. The study was approved by each participating site's institutional review board, and all participants provided written informed consent.

Data analysis. Continuous variables are summarized by mean and SD or median and interquartile range (25th and 75th percentiles), depending on normality of distribution. Categorical variables are represented by frequencies and percentages. The prevalence of gaps in care, underlying reasons, duration, and age at onset were characterized by descriptive statistics. Univariate and multivariate logistic regression models assessed demographic and knowledge-based predictors of gaps in care, from which odds ratios and 95% confidence intervals were derived. Two-tailed values of $p < 0.05$ were considered statistically significant. Analyses

Abbreviation and Acronym

CHD = congenital heart disease

were performed with SAS software version 9.2 (SAS Institute Inc., Cary, North Carolina).

Results

Characteristics of the study population. A total of 922 subjects were recruited from the 12 participating adult CHD centers. There was at least 1 adult CHD center representing each of the 4 main census regions of the United States. The number of subjects per site ranged from 14 to 249 (Table 1). The group was 54% female and 83% white, non-Hispanic. Subject self-reporting suggested that 73% had more than a high school education and 38% completed a bachelor’s degree or graduate school. Classification of anatomic complexity of CHD categorized 27% of patients as mild, 50% as moderate, and 23% as severe. As a metric of knowledge regarding their own CHD, subjects were asked to name their heart condition, and 75% identified it correctly.

Gaps in care. Forty-two percent of subjects reported a gap in cardiology care. Within this population, 36% had mild, 50% had moderate, and 14% had severe CHD. Eight percent of patients had at least 1 gap in care lasting >10 years, and 14% of patients experienced ≥2 gaps in care. The typical age at the first gap in care occurred during the transitional period of young adulthood (mean, 19.9 ± 9.1 years; median, 19 years). The complexity of CHD was associated with gaps in care: 59% of mild, 42% of moderate, and 26% of severe disease subjects reported care gaps (p < 0.0001) (Fig. 1).

Clinic location was a significant predictor of having a cardiology care gap (p < 0.0001). In programs in Colorado, Oregon, and Washington State, >50% of patients reported experiencing a gap in care (Table 1). In contrast, sex, race, education level, and knowledge of disease name were not

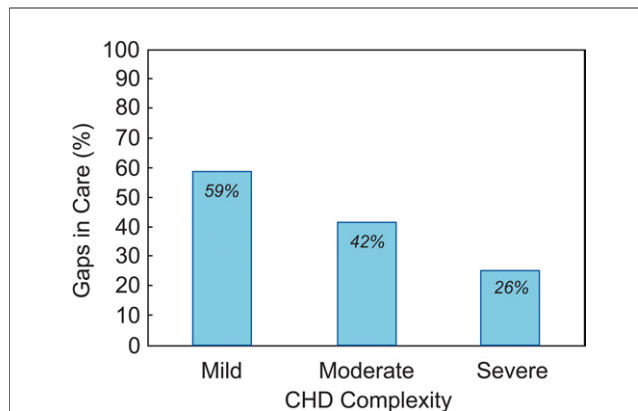


Figure 1 Gaps in Cardiology Care by Disease Complexity

The percentage of respondents reporting gaps in cardiology care by congenital heart disease (CHD) diagnosis complexity. Complexity definition per 32nd Bethesda conference guidelines (2).

predictive of gaps. On multivariate analysis, subjects with mild or moderate CHD resulted in a 4.1- or 2.2-fold increased prevalence of cardiology care gaps, respectively, compared with those having severe disease (p < 0.0001). Also, coming to care at an adult CHD program in Colorado (p < 0.001), Oregon (p < 0.002), and Washington State (p < 0.027) remained strong predictors of having had a gap in cardiology care.

Reasons for leaving and returning to care. Of the 19 factors listed for ratings as potential contributors to a gap in cardiology care, the top 5 responses for the study population had mean Likert scores of 2.4 to 3.3 (Table 2). The highest rated responses varied among subjects with differing CHD complexities. “Changing or losing insurance” and “financial

Table 1 Total Number of Participants per Site and Proportion at Each Site Reporting Gap in Care

Adult CHD Clinic	City	Total No. (%) of Patients Recruited	% Reporting Gap
Oregon Health and Sciences University	Portland	111 (12)	59
University of California Medical Center	Los Angeles	24 (2.6)	22
University of Washington Medical Center	Seattle	87 (9.4)	51
Boston Children’s Hospital	Boston	249 (27)	33
Ohio State University Medical Center	Columbus	95 (10.3)	37
University of Colorado Medical Center	Denver	87 (9.4)	61
Medical College of Wisconsin	Milwaukee	63 (6.8)	42
Columbia University Medical Center	New York	17 (1.8)	29
Hershey Medical Center	Hershey	82 (8.9)	45
Cincinnati Children’s Hospital	Cincinnati	36 (3.9)	42
Children’s National Medical Center	Washington, DC	52 (6.2)	36
Hospital of the University of Pennsylvania	Philadelphia	14 (1.5)	21

CHD = congenital heart disease.

Table 2 Reported Reasons Why Participants Had a Gap in Cardiology Care

Reason	Likert Score, Mean ± SD
Felt well	3.3 ± 1.6
Did not need follow-up	2.8 ± 1.5
Not receiving medical care	2.7 ± 1.6
Moved	2.5 ± 1.7
Changed or lost insurance	2.4 ± 1.7
Lost track of time	2.4 ± 1.6
Perceived myself as “fixed”	2.4 ± 1.5
Was recommended to have care every 3 yrs	2.3 ± 1.5
Primary care physician did not recommend	2.3 ± 1.5
Parents stopped taking me	2.2 ± 1.5
No longer needed follow-up	2.1 ± 1.5
Financial problems	2.1 ± 1.5
Worried about getting bad news	1.9 ± 1.3
Primary care physician did cardiac tests	1.8 ± 1.3
Personal problems	1.8 ± 1.3
“Wanted a break” from focusing on my heart	1.7 ± 1.2
Cardiology staff did not understand medical condition	1.5 ± 1.0
A specific, difficult experience relating to my heart care	1.4 ± 0.9
Cardiology staff did not understand social/emotional needs	1.3 ± 0.9

Complexity	Reason	Likert Score, Mean ± SD
Mild	Felt well	3.2 ± 1.6
	Did not think needed follow-up	2.8 ± 1.5
	Lost track of time	2.5 ± 1.6
	Told to follow up every ≥3 yrs	2.5 ± 1.6
	Primary did not recommend it	2.4 ± 1.5
	Not receiving any medical care	2.4 ± 1.6
	Parents stopped taking me	2.4 ± 1.6
Moderate	Felt well	3.3 ± 1.5
	Did not think needed follow-up	3 ± 1.4
	Not receiving any medical care	2.7 ± 1.6
	Changed or lost insurance	2.5 ± 1.7
	Moved	2.5 ± 1.6
Severe	Felt well	3.5 ± 1.6
	Not receiving any medical care	3.1 ± 1.7
	Changed or lost insurance	3.0 ± 1.8
	Moved	2.8 ± 1.7
	Financial problems	2.7 ± 1.6

Mild, moderate, and severe diagnosis criteria based on 32nd Bethesda Guidelines, 2001.

problems” rated highly for the more complex CHD patients. “Lost track of time” and “decreased parental involvement” were rated higher on the list for patients with milder complexity of CHD (Table 3).

The most common reasons for return to care were a desire to prevent potential problems, a recommendation from another health care provider, and new symptoms or health problems (Table 4). Of those subjects referred by a health care provider, 31% were referred by an adult cardiologist, 30% by a pediatric cardiologist, and 13% by a primary care provider.

Discussion

This large cross-sectional study characterizes gaps in cardiology care and barriers to care experienced by adults with CHD and, as such, provides insights into areas to potentially target for intervention. Nearly half of patients experienced a >3-year gap at some point in their cardiology care. The presence of gaps in care among this multicenter group of patients resembles the gaps found in smaller single-center studies, with the first gap in care typically occurring at age 19 to 20 years (6,13). This timing reflects a period when patients are more apt to leave a pediatric clinician and enter an internal medicine or adult-oriented health care system and is also an age at which patients may be relocating or changing insurance providers. The presence and timing of this gap in care are consistent with those cited in other literature concerning health care transition, which similarly demonstrates that patients are often lost to follow-up or have an increase in emergency department admissions during young adulthood (9,10,13–17).

The study was conducted at a variety of adult CHD clinics across the United States, and clinic site was associated with the experience of a gap in care. The reasons for this finding are unclear, and it is difficult to draw specific

conclusions from our study because we did not track where respondents had been seen and medically cared for before their gaps in care. Some proposed explanations include the impact of regional geography on the ability to travel, demographics of the population in or coming to the city, insurance availability in the state, or even the age of the adult CHD program. This finding deserves further investigation because it suggests there may be geographic barriers to achieving optimal adult CHD care and outcomes.

CHD complexity was also related to interruptions in care. Although a majority of patients with mild heart disease experienced gaps in care, it is possible that some were instructed to return to care at longer intervals than those prescribed to patients with more complex disease. The possibility of such discrepancies in physician-suggested duration between visits may have affected the potential for subsequent care gap (5). Recognizing the increased risk of adverse events and need for more urgent interventions on returning to care after a gap, it is of great concern that the majority of subjects who reported gaps had moderate or severe complexity of CHD anatomic diagnoses.

The stated reasons for gaps in care were informative. “Feeling well” was the primary contributor chosen as a reason for a gap in care, regardless of the underlying complexity of the anatomic heart disease. This information highlights that many adults with CHD do not relate symptomatology that would otherwise bring them to medical care; age-appropriate reiteration of the rationale behind guidelines supporting the need for lifelong surveillance and care is recommended for all patients (and parents when appropriate) in pediatric and adult cardiology care settings. Likewise, strategies for protecting access for adults with CHD to sufficient health insurance appear warranted to facilitate maintenance in cardiac care.

Despite our subjects reporting a high level of general education, a large proportion, nonetheless, experienced cardiology care gaps. As we surveyed adults with CHD sufficiently

Reason for Return to Care	Yes (%)
Desire to prevent potential problems	70
Recommendation from other health care provider	65
New symptoms or health problem(s)	53
Recommendation from family/friends	47
Desire to learn more about my heart	46
Concern about potential deterioration	45
New health insurance	26
Emergency department visit	23
Other life changes (e.g., marriage, new job)	23
Better financial situation	19
Interest in getting pregnant	14
New adult CHD care services available	7
Recommendation from Adult Congenital Heart Association/ other health advocacy group	6
Media story on CHD	3

CHD = congenital heart disease.

informed to re-present to cardiology care, we recognize that our findings may significantly underestimate the medical knowledge vacuum that currently exists for the large numbers of adults with CHD who are not receiving care from established adult CHD centers. We therefore suggest that another potential target for intervention to decrease gaps in cardiac care for adults with CHD is greater engagement and education, coupled with improved awareness of and access to available resources, for referring internists, family practitioners, primary care physicians, and both internal medicine and pediatric cardiologists. The advice of a health care provider was the second most common reason that patients came to adult congenital cardiology care. This strategy is aligned with current American College of Cardiology/Adult Congenital Heart Association national PATCH (Provider Action for Treating Congenital Hearts) programming, currently targeting similar goals for internal medicine and pediatric cardiologists. Taking the potential etiologies for gaps in care and barriers to care into account, the prevalence of gaps in care remains striking, and there appear to be accessible targets for action. Continued effort for further detailed analysis of comprehensive existing and novel datasets appears warranted and with potential to affect public health.

Study limitations. Although this study was large and comprehensive, limitations are recognized. Self-reports of the presence and timing of gaps in care were not independently corroborated and are open to potential for confounding by both recall bias and patient sense of implications of their responses. The survey was conducted only at established adult CHD centers, and participants were new to the clinics. Patients who were not intellectually capable of completing the questionnaires were excluded from participation. As such, the results may not be representative of adult CHD patient populations outside of the participating specialty centers or with significant developmental delay. Finally, the subjects were asked about a gap in any cardiology care, not specialized adult congenital cardiology care, as the authors were concerned that some subjects may have difficulty differentiating the types of cardiologists or practices, and there is no certification for training and competency in adult CHD care at this time. We also cannot account for patients who were never seen and may still be lost to care, and who therefore were not reflected in the study. Thus, the true frequency of gaps in specialized adult congenital cardiology care is likely significantly underestimated.

Conclusions

Adult CHD patients often have interruptions in cardiology care. A first gap in care is most commonly recognized during the late teen years, concurrent with the typical time of transition from pediatric to adult-oriented medical care. Gaps were more common among those respondents with anatomic diagnoses that were classified to be of moderate and mild complexity and from respondents receiving care at particular geographic clinic locations. These results provide a foundation for further study and for consideration of

public health strategies to decrease barriers to, as well as gaps in, cardiology care for the adult CHD population.

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