Journal of the American College of Cardiology
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Published by Elsevier Inc.

Vol. 60, No. 23, 2012
ISSN 0735-1097/$36.00
http://dx.doi.org/10.1016/j.jacc.2012.09.015

Referral Patterns and Perceived Barriers to Adult Congenital Heart Disease Care

Results of a Survey of U.S. Pediatric Cardiologists

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Objectives This study sought to elucidate referral patterns and barriers to adult congenital heart disease (ACHD) care, as perceived by pediatric cardiologists (PCs).

Background Management guidelines recommend that care of adults with moderate/complex congenital heart disease be guided by clinicians trained in ACHD.

Methods A cross-sectional survey was distributed to randomly selected U.S. PCs.

Results Overall response rate was 48% (291 of 610); 88% (257 of 291) of respondents met inclusion criteria (outpatient care to patients >11 years of age). Participants were in practice for 18.2 ± 10.7 years; 70% were male, and 72% were affiliated with an academic institution; 79% stated that they provide care to adults (>18 years). The most commonly perceived patient characteristic prompting referral to ACHD care was adult comorbidities (83%). The most perceived barrier to ACHD care was emotional attachment of parents and patients to the PC (87% and 86%, respectively). Clinician attachment to the patient/family was indicated as a barrier by 70% of PCs and was more commonly identified by responders with an academic institutional affiliation ($p = 0.001$). A lack of qualified ACHD care providers was noted by 76% of PCs. Those affiliated with an academic institution were less likely to identify this barrier to ACHD care ($p = 0.002$).

Conclusions Most PC respondents in the United States provide care to ACHD patients. Common triggers that prompt referral and perceived barriers to ACHD care were identified. These findings might assist ACHD programs in developing strategies to identify and retain patients, improve collaborative care, and address emotional needs during the transition and transfer process. (J Am Coll Cardiol 2012;60:2411–8) © 2012 by the American College of Cardiology Foundation

The American College of Cardiology 2008 guidelines for the management of adults with congenital heart disease recommend that care of adults with moderate and complex congenital heart disease (CHD) be guided in collaboration with clinicians trained in adults with congenital heart disease (ACHD) (1). A review of data from approximately 90 self-described ACHD programs in the United States indicates that the number of ACHD patients seen in these specialized clinics is far below targeted estimates (2–6); it is likely that a substantial number of ACHD patients continue to be cared for by pediatric cardiologists. Pediatric cardiologists might choose or feel obligated to continue caring for or to assume care for ACHD patients for a variety of valid or perceived reasons. To develop effective strategies to improve access to and quality of ACHD care for all adult survivors, it is imperative to better understand referral patterns and perceived barriers to specialized care. There-

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Manuscript received June 13, 2012; revised manuscript received August 31, 2012, accepted September 11, 2012.

Abbreviations and Acronyms

ABP = American Board of Pediatrics

ACHD = adults with congenital heart disease

CHD = congenital heart disease

fore, we sought to characterize patterns of referral to ACHD care and identify barriers to such care, as perceived by pediatric cardiologists.

Methods

Survey design. We conducted a cross-sectional mail survey of clinicians in the United States certified by the American Board of Pediatrics (ABP) to practice pediatric cardiology. Access to our study population was requested from the ABP in May 2010 and approved in August 2010. From a total of 1,824 clinicians certified in pediatric cardiology by the ABP at the time of our request, 1,766 had registered addresses in the United States and therefore were retained for sampling and randomly assigned to sampling replicates stratifying across 4 geographic regions (Northeast, South, Midwest, and West). A power analysis was run to determine minimum sample size needed/group to detect a difference of 20 percentage points across the regions in terms of the prevalence of pediatric cardiologists taking care of at least 20 patients >40 years of age. A minimum of 60 surveys/region was determined to be sufficient to detect differences with a power of 0.8 and an alpha of 0.05. Surveys were sent until a minimum of 60 pediatric cardiologists from each region met inclusion criteria. Selection criteria were verified at the point of survey entry. Clinicians not actively seeing patients over the age of 11 years in the outpatient setting were excluded. The survey was distributed by the U.S. Postal Service to addresses provided by the ABP between November 2010 and July 2011. No less than 1 month after the initial survey was mailed, a reminder notice was sent to subjects who had not previously returned their survey. The database was closed to further entries on November 1, 2011. The project was approved by the local institutional review board at Boston Children's Hospital.

Survey tool. The survey tool was developed over a 12-month time frame, through a working group of 10 clinicians and researchers with an interest in healthcare transition. The working group included physician, nursing, physician assistant, and social worker representation. Questions were developed on the basis of a review of the healthcare transition published data including a recent national survey (7) and guided by a survey methodologist (S.Z.). The final survey included a total of 20 questions within the following 6 categories: 1) inclusion criteria; 2) demography of ACHD care; 3) transitioning assessment and education; 4) referral patterns to ACHD care; 5) perceived barriers to ACHD care; 6) resources; 7) demographic data; and 8) an open-ended question inviting further input on the transition and transfer process.

Transitioning education and assessment was defined for survey participants as encompassing disease knowledge; understanding of medication use and side effects; symptoms requiring urgent care; congenital/genetic anomalies in offspring; impact of high-risk behaviors; and disease impact on education, vocation, and insurability.

The section regarding demography of ACHD care asked clinicians if they provided care to patients in various age groups (i.e., 11 to 14, 15 to 16, 17 to 18, 19 to 21, 22 to 24, 25 to 30, 31 to 40, 41 to 50, and >50 years) and whether they felt comfortable providing such age-appropriate care. Response options for each age group were "yes" "no" or "don't know". The section on transitioning inquired whether transitioning education/assessment was provided to patients and, if so, in what manner (formal vs. informal) and at what age of initiation. Sections regarding referral patterns and barriers to referral included questions regarding characteristics that prompt referral to an ACHD program and barriers to transfer. For each characteristic prompting transfer and for each perceived barrier, respondents were provided with the options: "yes" "no" or "don't know". The resource section addressed the desire for resources to improve the delivery of transition education and to streamline the transfer process.

Statistical analysis. Descriptive analyses of clinician demographic data were summarized with mean ± SD for continuous variables and proportions for categorical variables. Demographic and regional differences were analyzed with Pearson's chi-square or Fisher exact test for categorical variables and analysis of variance for continuous variables. Barriers to and impetus for the transitioning of patients into adult care were ranked, and differences in clinician beliefs were assessed with chi square analysis. In the multivariate analysis, a multiple logistic regression model was used to identify provider factors that might be associated with provision of ACHD care to patients older than 18 years of age. Factors identified in the univariate analysis with p value <0.2 were initially added to the logistic regression model. Final model results are presented in the tables. Multiple logistic regression models were also run for the top 3 identified incentives and barriers to transitioning of care to identify provider characteristics. A 2-sided p value of <0.05 was considered indicative of statistical significance. Data analysis was performed with SAS software (version 9.2, SAS Institute, Cary, North Carolina). Survey results were reported in aggregate so that clinician confidentiality was ensured.

A content analysis approach to the qualitative data interpretation was employed (8,9). Comments about the perceptions of participants with regard to their experiences constituted the units of analysis. The text was separated into meaning units that were condensed. The condensed meaning units were summarized and labeled with a code. The codes were reviewed for similarities and differences and sorted into categories and then studied for underlying meanings threaded through the whole as themes.