

Do we have the ACHD physician resources we need to care for the burgeoning ACHD population?

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Abstract

Background: Delivery of care to the adult congenital heart disease (ACHD) population has been limited by a shortage in the ACHD physician resources. There is limited data regarding the adequacy of the ACHD physician resources in the United States and our population estimates are extrapolated from Canadian data. Therefore, we proposed to evaluate the adequacy of ACHD physician: patient ratios in the United States at both national and regional levels.

Methods: Data from the Adult Congenital Heart Association (ACHA) website along with metropolitan area and statewide population data from 2016 US Census Bureau estimates were analyzed. Physicians listed on the ACHA website were cross-referenced with ABIM to verify ACHD board certification status.

Results: There are 115 self-identified ACHD programs and 418 self-identified ACHD physicians listed in the ACHA website. There are 320 board-certified ACHD cardiologists in the United States today, including 161 not listed in the ACHA website. Regarding ratios of ACHD-certified physicians to patients, the best served metropolitan statistical area (MSA) is Raleigh-Cary, NC, and the worst served MSA is Riverside-San Bernardino-Ontario, CA. The best served State is Washington, DC, and the worst served State is Indiana.

Conclusions: The ACHD population continues to grow, and the looming national physician shortage is likely to greatly affect the ability to meet the complex needs of this growing population. In order to bring the ACHD patient: physician ratio to 1000:1, a minimum of 170 additional ACHD board-certified physicians are needed now.

KEYWORDS

congenital heart disease, physician, program, United States

1 | INTRODUCTION

Congenital heart diseases (CHD), defined as the persistence of any structural abnormality present at birth that involves the heart and/or great vessels, are the most common birth defects and the leading cause of infant mortality.¹ This definition excludes channelopathies, other genetic arrhythmia disorders, and cardiomyopathies.² Adult

congenital heart disease (ACHD) is defined as the survival of a patient with CHD to 18 years of age, either with or without surgical repair or other anatomical palliation. Recent advances in diagnosis, medical and surgical management of CHD have resulted in improved survival of these patients. From 1987 to 2005, mortality decreased by more than 30% in patients with CHD and the median age at death increased by 15 years.³ A Canadian population-based study

estimated that the prevalence of CHD in adults (18 years of age and older) was 6.1 per 1000 in 2010.⁴ Based on this study, the US ACHD population is expected to increase at a rate of 4.5% per year. However, the number of physicians specialized to treat this population is not increasing in proportion to the growth of the ACHD population, thus resulting in failure to adequately transition pediatric CHD patients to specialized ACHD care. Therefore, health care systems are currently challenged to deliver multidisciplinary specialized care to this growing population.

Recommendations for optimal delivery of care to the ACHD population were first made in Canada by a panel of experts formed by members of the Canadian Adult Congenital Heart (CACH) network and the Canadian Cardiovascular Society. These recommendations were published in the *Canadian Journal of Cardiology* in 1998⁵ and were then updated in 2001⁶ and 2009.⁷ Similarly, recommendations from the 32nd Bethesda conference in 2000 emphasized the importance of strategic plans to deliver optimal care to the ACHD population.⁸ The updated ACC/AHA ACHD Guidelines published by Stout et al in September 2018 suggest that those patients with moderate to complex CHD should be seen by an ACHD specialist no less frequently than annually.⁹

The current workforce of ACHD-trained cardiologists in the United States is estimated to be too small to serve the population needs. Data in the United States are limited and our population estimates are extrapolated primarily from Canadian data. In 2008, Marelli et al determined that the United States had an estimate of 1.5 million ACHD patients, of which approximately 50% had moderate-complex lesions.¹⁰ This estimate also determined that there would be a 4.5% per annum increase in the ACHD population, extrapolating to a current estimate of 2.3 million US ACHD patients, and 1.15 million moderate-complex ACHD patients. The aim of this study is to evaluate the adequacy of ACHD physician:patient ratios in the United States at both national and regional levels.

2 | METHODS

Data from the Adult Congenital Heart Association (ACHA) website, a publically available database of self-reported information from ACHD centers, was analyzed in May 2018 along with metropolitan area and statewide population data available from 2016 estimates from the US Census Bureau. The ACHA website is the most comprehensive listing of ACHD care locations nationwide and includes data, self-reported by each program and updated annually, with names and certifications of physicians as well as an estimate of the number of annual outpatient clinic visits. For purposes of this analysis, number of annual outpatient clinic visits, rather than total number of patients served, was used since total estimated population of ACHD patients is not currently reported on the ACHA website. Physicians listed on the ACHA website were cross-referenced with American Board of Internal Medicine (ABIM) data to verify ACHD board certification of listed physicians. Data were stored on a Microsoft Excel spreadsheet, and each program was sorted based on geographic location,

both by State/territory and by Metropolitan Statistical Area (MSA). Washington, DC, a federal territory, and not an actual State, was considered a State for purposes of analysis of the data.

3 | RESULTS

There were 115 self-identified programs in the ACHA database, accounting for 110 112 ACHD patient visits per year. Programs represent 78 MSAs. Only three MSAs with > 1 million residents did not have an ACHD program at the time of data analysis (Providence RI, Richmond VA, and Buffalo NY). Only eight states do not have ACHD programs; the combined population of all eight states is 2.2% of the US population (Figure 1).

The ACHA directory includes 418 physicians self-identified as being ACHD physicians, of which only 159 (38%) are board-certified in ACHD. There are 320 Board-Certified ACHD Cardiologists in the United States today, including 161 who are not listed in the ACHA database. Programs average 5.4 total physicians and 2.0 ACHD-boarded physicians. Of note, 14 programs on the ACHA directory do not list a single ACHD-certified physician.

The largest MSA (New York City), with ~20 million residents, has six programs and accounts for 5622 ACHD visits annually. The smallest MSA (Morgantown, WV) has 138 380 residents and accounts for 600 annual ACHD visits. Regarding ratios of ACHD-certified physicians to patients, the worst-served MSA is Riverside-San Bernardino-Ontario, CA, with 4.5 million residents:physician. The best-served MSA with >1 million residents is Raleigh-Cary, NC, with 325 000 residents:physician. The best-served State is Washington, DC, with 340 585 residents:physician. The worst-served State with any ACHD-certified physician is Indiana with 6.3 million residents:physician. Nine states with ACHA programs do not have a single ACHD-certified physician, the largest of which is New Jersey, with over 9 million residents (Figure 2).

4 | DISCUSSION

Determining the ideal number of ACHD physicians is unclear, but can be estimated with current recommendations. The estimated total population in the United States by US Census bureau as of 1 July 2016 was 326 929 143. It is estimated that there are 2.3 million ACHD patients in the United States, of which half have moderate-to-complex CHD. Using the recommendation to have one ACHD regional program (with three physicians per program) for every 2 million people of the general population,¹⁰ there should be 163 programs and 490 ACHD physicians. Our results demonstrate that there are currently 115 self-identified programs in the ACHA website, short of the estimated 163 programs needed. Furthermore, based on the ABIM website, there are 320 Board-Certified ACHD cardiologists in the United States today, including 161 who are not listed in the ACHA database. As such, if we use the general US population to guide our estimate, an additional 170 board-certified

ability to provide ACHD care. Remote oversight or telemedicine may be helpful to achieve this goal.

Subspecialty training in ACHD is crucial to meet the needs of this population. In 2015, subspecialty board certification in ACHD was initiated, administered by the American Board of Internal Medicine. Currently, diplomates in ACHD can attain this board certification either via a “practice pathway” or a “training pathway.” The practice pathway, which allows “grandfathering” of physicians with adequate experience (defined as at least 3 years of clinical practice after finishing fellowship and a critical mass of ACHD experience), but without formal 2-year ACHD fellowship training, was able to certify physicians in 2015, 2017, and finally in 2019. After the 2019 exam, the only remaining pathway will be via the training pathway, which will require a dedicated 24-month ACHD fellowship at the conclusion of either an adult or pediatric cardiology fellowship. Additionally, the fellowships after 2019 must be accredited by the American Council of Graduate Medical Education (ACGME) in order for fellows to be eligible to sit for ACHD boards when they finish.

ACGME-accredited fellowship programs require 18 months of full-time clinical training and 6 months of elective clinical and/or research experience. The trainee should spend 9–12 months on inpatient service and/or ACHD consultative service, 3 months on ACHD imaging (including echocardiography and cardiac magnetic resonance imaging), 2 months on cardiac catheterization and 1 month in the intensive care unit caring for postoperative patients.¹¹ Recently, a study was conducted to assess the consequences of this training curriculum on recently graduated ACHD fellows.¹² Surveys were sent to all 30 physicians who completed formal ACHD training in the United States between 2015 and 2017, of which some did a 1-year ACHD fellowship and most did a 2-year ACHD fellowship. The study showed that the training curriculum successfully met most of the needs for ACHD jobs. It allowed trainees to acquire the

skills needed to adequately assess and manage the complexities of the ACHD population and to secure a more ideal job. However, the average entry-level salary was \$250 000, which is much lower than a general adult cardiology salary at most programs in private or academic practice, despite the need for two additional years of intense training. Additionally, the study noted that most jobs available required ACHD “program building,” with only 9.5% of trainees feeling comfortable to build a program immediately after graduation. The study suggested integrating specialty tracks, ensuring uniformity in the quality of training between programs, and promoting leadership skills in order to improve career prospects.

The problem is also quantitative. There are currently only 20 ACGME accredited ACHD fellowships (Figure 3). Programs vary considerably in terms of how many fellows they train, and some fellowships exist on paper but have never trained a fellow. The larger programs train two ACHD fellows per year, but the majority train either one or two fellows every 2 years. The number of fellow positions available depends on funding sources, which can change unpredictably. Assuming there is an average of 1.5 annual training positions per program, or 30 fellow positions annually, in order to train an additional 170 ACHD physicians would require nearly 6 years in order to meet the immediate needs for care. In addition, there is no guarantee that this increase in the number of formally trained ACHD physicians will serve to properly bridge the gap in care. After 2 full years of training, it is likely that the providers will want ACHD to be a major part of their practice. Given the findings by Ephrem et al,¹² it is likely that new graduates will gravitate toward already established centers in big metropolitan areas. This may help with covering some of the ACHD care need in the metropolitan area as shown by the capture-recapture analysis performed by Book et al.¹³ However, it is unlikely to cover the needs in nonmetropolitan areas where ACHD may not be the overwhelming part of the job

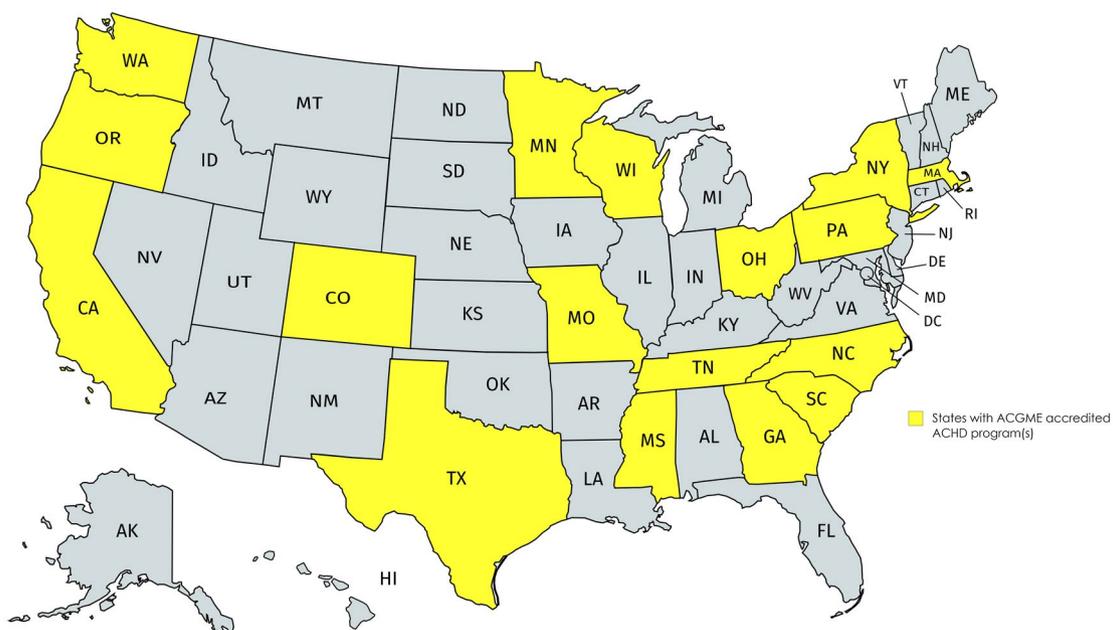


FIGURE 3 States with ACGME accredited ACHD programs

description. Indeed, a provider is less likely to train for two additional years on top of an already protracted specialization process in order for this new training to be a small portion of his/her practice. This solution is likely to be found in better optimizing the currently available ACHD providers and allowing forms of outreach to cover the needs, in addition to increasing ACHD exposure during training for general cardiology fellows so that they are able to recognize ACHD patients, tend locally to the low complexity ones, and know when to refer to the major centers.

With regard to general training, there is a lot of ground to cover before we reach a more optimal situation. Of note, prior to 2015, adult cardiology fellowships only required 6 hours of training in ACHD; in 2015, the 4th Core Cardiovascular Training Statement (COCATS 4) was published, and provided a framework for Level I and Level III training in ACHD. Level I training requires a month of ACHD training for all general adult cardiology fellows; Level III training requires subspecialty training in ACHD training at the conclusion of general fellowship. Of note, unlike virtually every other adult cardiology subspecialty, at the time of this paper, Level II training for ACHD does not exist per COCATS 4 guidelines.¹⁴ It would be therefore interesting to look at the experience described by Dr. Menachem who included 6 formal months of intensive clinical ACHD training as part of his general cardiology to better bridge the gap of care in his future practice.¹⁵ Formalizing this kind of experience into a level II training for ACHD would provide an opportunity to increase exposure to ACHD during fellowship and consequently more dissemination of a minimal fund of knowledge of ACHD in the community.

Finally, a previously taboo conversation is now starting to happen in ACHD. So far, all the emphasis has been on making the provider available for the patient. But recently there has been some conversation about educating patients to try to gravitate toward areas with availability of ACHD care as they are planning ahead in their lives. This is being done cautiously as the patients have already enough of a burden to bear. But this sense of empowering patients and making them active members of their care is gaining ground.

5 | LIMITATIONS

The ACHA website dataset is limited as a self-reported data set and as such there is bias in the amount of patients who may be involved in care in a given center. Additionally, it is also possible that a physician or provider may be listed as affiliated with more than one program as faculty in a densely populated region and/or a very rural state where physicians in a single large city might go to more than one program. Additionally, several large cities that aren't listed in the ACHA directory are actually served as "outreach" programs by existing ACHD centers, and this is not currently accounted for in the way the data are described in the ACHA directory. The premise of our study is based upon data collected in Canada in a system-with single-payer health care economics which allows for adequate patient tracking in a manner that is currently incompatible with US delivery models.

6 | CONCLUSION

Only 10% of estimated moderate-complex ACHD patients appear to be "in care" at ACHD centers in the United States. The ACHD population continues to grow, and the looming national physician shortage is likely to greatly impact the ACHD population as senior pediatric and ACHD cardiologists retire. In order to meet the minimum criteria based on ACC/AHA guidelines for the Care of Adults with Congenital Heart Disease, at a bare minimum, an additional 170 board-certified ACHD physicians are needed immediately, but the current supply of training fellowships is inadequate to fill this need in the near future, and will take at least 6 years with the current training pipeline. Current discussions about the 2-year training program and how it can be potentially made to evolve, along with new ideas regarding ACHD know-how dissemination are happening in the ACHD community as we integrate the outcome of the current model. Additional research to encourage prospective ACHD fellows to continue to be interested, despite the lower salary compared to other adult cardiology jobs, as well as increased funding for ACHD fellowships, is needed, and alternative funding sources of ACHD fellowships need to be explored. Finally, exploring dynamics on the patient side of the equation is a new development that merits follow-up.

ACKNOWLEDGMENTS

The authors would like to thank Andrea Tennancour MSN, CCRN-CMC, NP-C, for her critical review of the manuscript.

CONFLICT OF INTERESTS

The authors declare that they have no conflicts of interest with the contents of this article.

AUTHORS CONTRIBUTIONS

Collected the data, conducted the analyses, and wrote the manuscript: Ezzeddine, Moe, and Kay

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REFERENCES

1. Dolk H, Loane M, Garne Ester, European Surveillance of Congenital Anomalies Working Group. Congenital heart defects in Europe: prevalence and perinatal mortality, 2000 to 2005. *Circulation*. 2011; 123(8):841-849.
2. Kelleher AA. Adult congenital heart disease (grown-up congenital heart disease). *Contin Educ Anaesth Crit Care Pain*. 2011;12(1):28-32.

3. Khairy P, Ionescu-Ittu R, Mackie AS, Abrahamowicz M, Pilote L, Marelli AJ. Changing mortality in congenital heart disease. *J Am Coll Cardiol*. 2010;56(14):1149-1157.
4. Marelli AJ, Ionescu-Ittu R, Mackie AS, Guo L, Dendukuri N, Kaouache M. Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. *Circulation*. 2014;130(9):749-756.
5. Connelly MS, Webb GD, Somerville J, et al. Canadian consensus conference on adult congenital heart disease 1996. *Can J Cardiol*. 1998;14(3):395-452.
6. Therrien J, Gatzoulis M, Graham T, et al. Canadian Cardiovascular Society consensus conference 2001 update: Recommendations for the management of adults with congenital heart disease - Part II. *Can J Cardiol*. 2001;17(10):1029-1050.
7. Silversides CK, Salehian O, Oechslin E, et al. Canadian Cardiovascular Society 2009 Consensus Conference on the management of adults with congenital heart disease: complex congenital cardiac lesions. *Can J Cardiol*. 2010;26(3):e98-e117.
8. Webb GD, Williams RG. Care of the adult with congenital heart disease: introduction. *J Am Coll Cardiol*. 2001;37(5):1166.
9. Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC guideline for the management of adults with congenital heart disease: executive summary: a report of the American College of Cardiology/American Heart Association Task Force on clinical practice guidelines. *J Am Coll Cardiol*. 2018.
10. Marelli AJ, Therrien J, Mackie AS, Ionescu-Ittu R, Pilote L. Planning the specialized care of adult congenital heart disease patients: from numbers to guidelines; an epidemiologic approach. *Am Heart J*. 2009;157(1):1-8.
11. Acar P. *How best to train doctors in adult congenital heart disease?* Milano, Italy: Elsevier Masson; 2017.
12. Ephrem G, Alshawabkeh L. Contemporary ACHD training and the reality of the field in the United States. *Int J Cardiol*. 2018.
13. Book WM, John K, Raskind-Hood C, Glidewell MJ, Riehle-Colarusso T, Hogue C. Use of capture-recapture to estimate prevalence of congenital heart defects among adolescents and adults in five Atlanta, Georgia counties: 2008-2010. *J Am Coll Cardiol*. 2016;67(suppl 13):998.
14. Warnes CA, Bhatt AB, Daniels CJ, Gillam LD, Stout KK. COCATS 4 Task Force 14: training in the care of adult patients with congenital heart disease. *J Am Coll Cardiol*. 2015;65(17):1887-1898.
15. Menachem JN, Khairy P. Advanced heart failure in the ACHD population: finding the fellows' role in a growing field. *J Am Coll Cardiol*. 2017;69(15):1986-1989.

How to cite this article: Ezzeddine FM, Moe T, Ephrem G, Kay WA. Do we have the ACHD physician resources we need to care for the burgeoning ACHD population? *Congenital Heart Disease*. 2019;14:511-516. <https://doi.org/10.1111/chd.12771>