

STATE OF THE ART ARTICLE

The Long Road to Better ACHD Care

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ABSTRACT

The care of adult patients with congenital heart defects in the United States is spotty at best, and needs to improve greatly if the needs of these patients are to be met. The care of American children with congenital heart defects is generally excellent. Pediatric cardiac services are well established and well supported.

The care of adults with congenital heart disease (CHD) is well established in only a few American centers. While there are an increasing number of clinics, they are generally poorly resourced with relatively few patients. If located in adult cardiology programs, they are usually minor players. If located in pediatric cardiac programs, they are usually minor players as well. Training programs for adult CHD (ACHD) caregivers are few, informal, and poorly funded.

To improve the situation, we need perhaps 25 well-resourced and well-established regional ACHD centers in the United States. We need to stop the loss to care of CHD patients at risk of poor outcomes. We need to educate patients and families about the need for lifelong and skilled surveillance and care. We need to effect an orderly transfer from pediatric to adult care. We need to strengthen the human resource infrastructure of ACHD care through the training and hiring of healthcare professionals of a quality equivalent to those working in the pediatric care environment. We need to demonstrate that adult care is high quality care. We need more high-quality ACHD research. The ACHD community needs to establish its credibility with pediatric cardiac providers, adult cardiology groups, with governments, with professional organizations, and with research funding agencies.

Accordingly, there is a need for strong political action on behalf of American ACHD patients. This must be led by patients and families. These efforts should be supported by pediatric cardiologists and children's hospitals, as well as by national professional organizations, governments, and health insurance companies. The goal of this political action should be to see that ACHD patients can receive high-quality lifelong surveillance, that we lose fewer patients to care, and that the staff and other services needed are available nationwide.

Key Words. Congenital Heart Disease; Adults; Healthcare Delivery

My subject today is "The Long Road to Better ACHD Care." Indeed, all of us working in the adult congenital heart disease (ACHD) field are on one of these roads, and we all have a long way to travel until our clinics and our field reaches the desired level of maturity and excellence. Unlike some roads that have already been built and whose course can be shown on a map, our roads have not yet been finished and we in the ACHD community will need to make sure we have a lot of say about how these roads will be built, and where they will

go. Each of our long roads could lead to an excellent place where the wonderful results of childhood cardiac treatments continue through fulfilled adult lives, or our long road could lead us into a wilderness where our hopes for patients are not fulfilled, and where our patients will be unable to enjoy the potential we believe they have.

While I will describe two evolving roads, providing an overview of the ACHD roads in North America, there are many such roads which have been started. The road will be different in the United States from the road in Canada. Each of these may be different from the road that is being built in other countries. ACHD centers with a lot of support will build a different road than will

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ACHD centers without much support or many resources. ACHD centers attached to adult cardiology programs will build a different road than will ACHD centers attached to pediatric cardiac programs.

In the course of this lecture, I will review the development of pediatric cardiology and pediatric cardiac services in the United States and Canada, and follow with some comments about the comparative development of ACHD services in North America. I will reflect on how pediatric cardiologists and adult congenital heart cardiologists are both similar and different. I will then reflect on how ACHD can make progress in the future so that time rewards our efforts and our patients with continuous and appropriate growth and development. We have a lot of work to do, and I will describe this work under the headings of ACHD political action, building our credibility as an ACHD community, and enhancing the relevance of our ACHD community. I will end by calling for a new process to begin in the United States, and possibly in Canada and elsewhere, to forge a comprehensive planning process for the development and evolution of a solid system of ACHD care. Progress to date has been much too slow, and there is no overarching plan for the growth and maturation of ACHD care in the United States. Such an action plan is needed.

The Development of Pediatric Cardiology in the United States and Canada

Pediatric cardiology and cardiac surgery began a period of rapid growth in the 1960s, once open-heart surgery and diagnostic heart catheterization became widely available. Those were exciting times! Blue babies were made pink! Babies with transposition of the great arteries were surviving for the first time in history. There was great excitement about the saving of the lives of more and more children born with heart defects. This led to an enthusiastic commitment on the part of all concerned to realize the promise of better cardiac care for babies and children across North America. Resources flowed into childhood cardiac care. Cardiac services were expanded in children's hospitals. Divisions of pediatric cardiology and cardiac surgery were organized and formalized. Training programs were established, and people who were needed to look after the children were trained to do so. Patient volumes grew, and results improved progressively. Research grew and research resources accumulated in these pediatric

cardiac centers. New professional societies were created to support and advance the activities of the people involved in the delivery of childhood cardiac care. Pediatric cardiac providers assumed prominent roles in national societies, such as the American Heart Association and the Canadian and provincial Heart Foundations. Pediatric cardiology and cardiac surgery topics occupied increasingly prominent roles in national and international meetings. These have been heady times for pediatric cardiologists and congenital heart surgeons and their colleagues! Over the past 50 years, excellence in pediatric cardiac care improved and improved, and became available across the United States and Canada in regional centers of excellence.

Almost all these components of the development of pediatric cardiac services in North America need to be replicated to a large degree for the development of ACHD care as well. But more of that later.

The Comparative Development of ACHD in the United States and Canada

As a consequence of the successes of pediatric cardiac programs and at the same time, ACHD services began to develop slowly and unevenly. The founders of ACHD—Joseph K. Perloff in the United States, Jane Somerville in Britain, and John Morch in Canada—were often lonely voices in the 1970s and 1980s. By the 1990s, there were a group of 15 ACHD centers identified across Canada which had organized themselves to advance the care of their patients. By the year 2000, similar efforts were beginning in the United States, and substantial progress has been made since then. The survival of adult patients with CHD incited interest that was lukewarm at best. Keeping adults alive was definitely less exciting than keeping babies alive! Hospitals and cardiology divisions and governments and insurance providers showed at most limited interest, and more often indifference, to better ACHD care. Heart disease was big in our society and in adult institutions, but it was coronary disease and valve disease and cardiomyopathies and heart failure and arrhythmias, not CHD, that dominates the adult environment. Against this competition, ACHD interests were usually suppressed. While pediatric cardiac services had enjoyed a flood of resources, only a trickle flowed towards ACHD, even in the best and busiest centers. Even Joe Perloff had to work hard to keep his center at UCLA afloat

against strengthening resistance. We in Toronto were similarly kept busy begging for resources needed for ACHD care.

ACHD cardiology and cardiac surgery have not yet become organized and formalized as was the case in pediatrics. ACHD research to date has enjoyed modest successes, and very few research resources have been accumulated. While professional societies have begun to show some interest in the field, this has been very recent, and much more needs to happen. The place of ACHD in national societies such as the American Heart Association and the Canadian and provincial Heart Foundations will be defined, although the challenge is greater since our pediatric colleagues have been representing CHD in these organizations. In the past few years, the American College of Cardiology has shown a considerable interest in ACHD, a gratifying development. The prominence of ACHD papers and symposia at national and international meetings has greatly increased in the United States, less so in Canada.

Pediatric and ACHD Professional Comparisons

Let's think now about the professionals who deliver pediatric and adult congenital heart services in North America. Pediatric cardiologists generally devote their entire careers to pediatric cardiology. ACHD cardiologists, including those with a pediatric cardiology background, usually dedicate only a part of their time to their ACHD practices, typically because they have to earn a living doing other things that pay better.

The role of pediatric cardiac surgeons in pediatric institutions is well established, but their role in managing the same patients as adults is much more uneven and less clear, especially in the United States where many surgeons seem to feel that they can handle any patient referred to them. How is a patient with a congenital heart defect best served when a cardiac surgical procedure is needed as an adult? Who is best qualified to do the surgery? The answers vary greatly from one location to another, and the interests of the patients are not always uppermost when these decisions are taken, especially in the United States.

Pediatric cardiac nursing is well established, and even encompasses subspecialty areas. By contrast, ACHD nursing (including nurse practitioners, physician assistants, and other cardiac care associates) is not well established, and training programs for ACHD nursing have not been developed. ACHD nurses today are mainly individuals

who have made a personal commitment to the field, and who have learned on the job. We need many more ACHD nurses, in time with strengthening credentials.

Pediatric echocardiography services are well-established. There are excellent and well established groups across North America. There are excellent pediatric cardiology imagers and excellent pediatric sonographers. Such is not the case for adult congenital heart patients. There are very few adult cardiologists with training and expertise in ACHD echos, even though some cardiologists are willing to read and report complex ACHD echoes that they have not been trained to interpret. Very few sonographers in North America have been trained and/or are substantially experienced in echo studies on complex ACHD patients.

And so it goes. Competence and excellence are the rule in pediatric electrophysiology, but not in ACHD electrophysiology. Competence and excellence in CHD abound in pediatric catheterization laboratories, but are hard to find in adult cath labs. Similar challenges exist when our patients need magnetic resonance or other special imaging studies.

High-quality people in all these disciplines are needed to build a solid foundation for the teams working in the ACHD centers in both the United States and Canada. Our ACHD infrastructure needs major development and strengthening if we are to meet the continuing and diverse needs of our patients.

The Importance of Strong Regional ACHD Centers

In this lecture, I wish to focus in particular on what we called "regional ACHD centers" in the 32nd Bethesda Conference documents.¹⁻⁵ These are the large multidisciplinary centers of excellence that are able to capably meet all the potential needs of ACHD patients over their lifetime. In the 32nd Bethesda Conference report, we called for the development of 30-50 regional centers of excellence across the United States serving populations of 5-10 million each. In fact, given the limited regional coordination potential in the United States, I suspect we should aim for approximately 30 regional care centers, each serving a population base of up to 20 million. In Canada, there are 15 ACHD centers, five of which are to varying degrees multidisciplinary centers of excellence, often also serving patients from other ACHD care centers in Canada.

What can we expect in the future? Will we ever build the 30 regional ACHD centers in the United States? Will the five regional care centers in Canada be properly staffed and supported? Will ACHD services in these regional centers ever be able to match the quality and range of pediatric cardiac services? Is it just a matter of time before we catch up qualitatively and semiquantitatively with our pediatric brethren, or will ACHD services be permanently inferior? How often will ACHD regional care centers be able to develop successfully within adult hospitals and adult cardiology divisions? Would these regional ACHD centers be more successfully developed in partnership with pediatric congenital heart services as compared with adult cardiology services?

The Way Forward for ACHD Care

How will adult congenital heart services improve in the future? What are the elements of our potential success or failure? Who needs to be involved? Who needs to lead these processes?

I will review three areas of endeavor that need to occur concurrently and over time. The first is political action. The second is for the ACHD community to establish its credibility. The third is for the ACHD community to enhance its relevance.

ACHD Political Action

Successful political action will be critically important to the improvement of ACHD services in the future. In so saying, I use the term “political” to imply not only governmental representation, but representation at all levels—community, professional, institutional, organizational, financial, and governmental.

When I was working in Toronto, I made the mistake of believing that I and my colleagues should be the advocates for ACHD patients at the divisional, hospital, university, and government levels. I spent a lot of time doing this over 15 years, and had very little to show for it. I was mistaken to have done it that way. We used to bring patients along in support of our professional advocacy. I realize now that I had it backwards.

The primary players in ACHD political action must be patients and families. The patients and families must create their own organizations that are strong, coherent, and persistent enough and intelligent enough to represent their own interests to the people who make decisions that impact their lives and their care. They are the only ones with

potential political clout, and the only ones whose interests will be seen as legitimate. Those of us working in the ACHD field as healthcare professionals can clearly provide important support and encouragement to the patients and families, but we cannot and should not take the lead, except in our own institutions.

Of course, there are people and groups outside the ACHD community whose cooperation and support would be extremely important in advancing the interests of ACHD patients and their families.

First among these are pediatric cardiologists, the people who helped save their lives and who sustained these patients for the next 15 or 20 years; the people who were important, trusted, and often beloved by these families and patients. If pediatric cardiologists were to more consistently help patients transfer to competent lifelong ACHD care, this would be a huge step to help ensure that their patients will continue to receive high-quality care for the rest of their lives. By helping their patients find the adult care they need, wherever it may be, pediatric cardiologists can become the lifelong partners of their patients and their families.

The second group from whom support is needed are the children’s hospitals, where care was provided for so many years. In my opinion, children’s hospitals should have done and should still be doing what they can to ensure that their graduates with chronic health conditions are directed to programs that can provide continued excellence in care as adults. To the present, I believe that children’s hospitals have largely dropped the ball in meeting this responsibility. Children’s hospitals have not done enough to ensure that their graduates receive equivalent care beyond the pediatric age range. As a consequence, many patients are left to try to find their own way in an adult medical environment that is often not welcoming as well as one without the trained staff they need. Children’s hospitals can do better, and should be pressured by patients and families to do better.

Then there are the national societies and professional organizations that can assist, obstruct, or ignore ACHD patients such as The American Heart Association in the United States, the Provincial Heart Foundations and the Canadian Heart Foundation in Canada, the American College of Cardiology, the American Board of Pediatrics in the United States, and the Canadian Cardiovascular Society in Canada. These and other organizations could be helpful in advancing the interests of ACHD patients. These organiza-

tions should be the targets of political action in the first instance, and hopefully will become important participants and collaborators thereafter.

Then there are the governments and government agencies, and even health insurance companies in the United States. The Adult Congenital Heart Association has held two lobby days in Washington, DC with the objective of putting the ACHD agenda before a large number of legislators and their staffs on Capitol Hill. This type of effort needs to continue and to be expanded. The Adult Congenital Heart Association collaborated with a group of key healthcare professional opinion leaders to do work with NHLBI focused on the research needs of ACHD patients. This resulted in an important manuscript from their working group published in *JACC*⁶ that needs to be built upon. The Adult Congenital Heart Association (ACHA) likewise has been working with the Centers for Disease Control (CDC) in Atlanta to explore what mutual interests the ACHA, the ACHD community, and the CDC might identify and work together to advance.

What Should the Goals of Political Action Be?

1. In the United States, the first goal should ideally be universal healthcare. Too many adults with complex ACHD are denied expert care because they are not able to access the care they need. At the very least, we need to increase the number of patients who can be brought into the tent and who can be offered expert care.
2. In the United States, we need to stop losing children and adolescents and adults with complex CHD to follow-up. This has been the history of ACHD care in the United States to date, and we must do better going forward. There is no more important priority in the United States than to “stop the bleeding” from the “lost to care” crisis. When adults receive regular expert care, the focus can shift to regular surveillance and problem prevention, and hopefully replace the all too common current scenario of late intervention after a series of complications, a situation that I call the “ACHD train wreck.”
3. In both Canada and the United States, more resources are needed to meet the legitimate needs of ACHD patients. Resources are needed to train ACHD personnel to increase the number of ACHD caregivers and to strengthen their qualifications. We need training curricula, training programs, credentialing, and employment for the people graduating with ACHD training. We need this not only for cardiologists, but also for nurses, sonographers, echocardiographers, and many other types of individuals who will be needed to provide comprehensive interdisciplinary care to these patients. We need the infrastructure required to provide both inpatient and outpatient services of high quality to these patients. These types of services should be regionally provided and regionally coordinated rather than being made available in all hospitals and cardiology practices.
4. Another important goal of political action is to obtain the resources to support ACHD research. We must continually discover what the best childhood treatment strategies are for different conditions based on long-term follow-up data. In so doing, we in the ACHD community should provide important feedback to our pediatric colleagues to help them revise and tailor their treatment strategies. To do so, it is critically important that we create an evidence-base upon which to make treatment decisions that, to this time, have largely been empiric.

Establishing the Credibility of the ACHD Community through Quality Measures

In the United States, we need to provide evidence that we are delivering high-quality ACHD care. There are now approximately 65 centers that have identified themselves as ACHD clinics. Most have been started within the past 5 years. In my opinion, we need to distinguish between centers with the potential to become multidisciplinary full-service regional ACHD centers (one of the 30), and those without such potential. Simply because of their newness, most of the current American ACHD clinics, I would venture to say, are a bit like a town in the western movies, storefronts without much behind them. The clinics that are going to continue to serve ACHD patients will need to grow and mature. The situation is different in Canada, where the 15 regional centers have existed for at least 17 years, so none of them are startups. Even there, however, the excellence and success of Canadian centers has been uneven, and their performance, like ours in the United States, has not yet been evaluated.

Indeed, we need to begin documenting our provision of high-quality ACHD care. We need to develop measures of quality care that can help us to improve our services, and that can potentially

enable patients to decide where to go for care, and perhaps insurers to decide where to send their subscribers for care.

To establish our credibility, we need to improve our professional education. More and more people working in ACHD clinics should have been formally educated in the discipline, replacing those of us who have learned on the job without ever having been formally trained. Indeed, we need to broaden our professional education to go beyond cardiologists and surgeons and to include nurses, physician assistants, sonographers, and other members of our teams.

To establish our credibility, we need to produce more high-quality research. To a large extent, the days of single center observational studies have largely passed. While there will still be a place for them, the emphasis has got to shift fundamentally. We need more basic science and translational research. We need to understand CHD in ways we never have before. We need to do population-based and outcomes research using some of the data resources that are now abundantly available, but hitherto not used by clinicians. We need to get beyond our individual and institutional egos, and focus on designing multicenter research trials to answer many questions that have been asked for many years, but are still waiting for an answer. We need to get beyond the cardiac and cardiology aspects of ACHD research, and become more holistic and inclusive, inviting nurses, psychologists, educators, geneticists, hepatologists, and others with different perspectives to contribute to our knowledge base.

Indeed, the foundation has been established to begin multicenter ACHD research in the United States through the Alliance for Adult Research in Congenital Cardiology (AARCC) group. This American group already has four multicenter trials underway, and is aiming toward substantial research funding from the granting agencies. We wish this group every success. The Canadian Adult Congenital Heart Network is also hosting some multicenter research projects, and will hopefully build on the success of the very important CARPREG study led by Dr. Sam Siu.⁷ The Québec group (Alliance for Congenital Quebec Interinstitutional Research; ACQUIRE) is continuing to host and plan multicenter ACHD research, as it has already done successfully.⁸⁻¹⁰

And then we have to establish our credibility with a variety of groups with which we need to work. We need to improve our legitimacy with the providers of pediatric cardiac services. This is par-

ticularly true in the United States where pediatric cardiologists have often not been supportive of ACHD clinics, and often for good reasons that we need to ensure will no longer be valid going forward. Those of us in the ACHD community working in adult hospitals with adult cardiology divisions need to improve our legitimacy within our institutions and within our divisions. Very important work needs to be done to improve our legitimacy with governments and government agencies whose support will be critically important to our eventual success in both Canada and the United States. We need to improve our legitimacy in our professional organizations. We need to establish not only our training credentials and certification requirements, but also our recertification and CME programs. We need to be sure that ACHD takes its appropriate place in organizations like the national heart associations, which have to this point supported pediatric cardiac services, but not so much their adult continuation. We will most importantly need the support of our pediatric cardiology colleagues in order to move forward. We need to show the research supporting agencies that we are a disciplined, committed, and capable community who can deliver the goods when we take on important research endeavors.

Increasing the Relevance of the ACHD Community

At the moment, the ACHA estimates that we are only looking after 30 000 of the 500 000 American adults with complex congenital heart defects. We may talk a lot, but we are not doing a lot yet. We need to greatly increase the number of complex ACHD patients in ACHD care, particularly in the United States. We need to do this mainly through ensuring a high degree of success in graduating complex adolescent and young adult CHD patients into adult care. We need to earn and be granted the support of the pediatric cardiology community to do this. We as ACHD practitioners need to be seen as and indeed to become valued colleagues of our pediatric cardiologists.

We need to establish our role as ACHD services within our institutions. If we live in adult hospitals with adult cardiac programs, we need to establish our relevance in ways that are seen as valuable within our institutions. If we live in pediatric hospitals and with pediatric cardiology programs, we need likewise to establish our relevance and our roles. Regardless of where our base is, we need to be more successful in bridging the historically profound communication gaps between pediatric and

adult medicine, and figuring out how to establish functioning interfaces to help us avoid some of the communications pitfalls that have existed in the past.

The Need for a Comprehensive ACHD Action Plan

Having said all this, I would like to put forward some recommendations that could help us move forward as an ACHD community. I believe the time is right to begin planning a concerted effort to develop ACHD services in the United States, and possibly in Canada. I believe all the groups needed to or with an interest in helping to develop and mature ACHD services should be brought together to assess where we stand, to develop future goals, to craft a strategic plan including realistic timelines, and a process to ensure that we keep moving forward.

We do not have time to allow the various needs of ACHD patients to be met slowly and sequentially as has been happening to the present time. We do not just need cardiologists trained in the discipline, although we certainly need many more cardiologists with special training in many of our clinics. We need to train and hire the nurses, the sonographers, and the other members of the teams who will be caring for our patients, in all our ACHD centers, especially the 30 regional care centers of excellence.

We need to have a discussion about whether we are still going to focus on the Bethesda vision of developing regional centers of excellence that can provide all possible care to ACHD patients. If so, we need to develop a plan as to how many we need, and where to locate them. We will need institutional support at many levels for these initiatives. We need to decide whether the regional ACHD centers will be primarily associated with pediatric cardiac services or adult cardiac services.

We need to create a training plan for the personnel who will be needed to provide ACHD services. We need to create training programs and we need to secure the funding to make this happen.

We need to nurture the future leaders of our disciplines. We need to nurture the future leaders of our healthcare professional groups, as well as our patient and family organizations. The work that we are doing will go on for a long time, and we need to ensure that our work has the benefit of excellent leadership on a continuing basis.

It has now been 7 years since the recommendations of the 32nd Bethesda Conference were pub-

lished describing a vision of how ACHD services might best be delivered in the United States.¹⁻⁵ In the interim, some progress has been made, but we need so much more. I believe it is now time to move to the next level, and to decide how best to develop ACHD healthcare in the United States. We will never achieve our goals only by adding up local initiatives. We need to take the vision of the 32nd Bethesda Conference and make more of it happen over the next decade or two.

Indeed, I believe that it is also time for a similar visioning and planning process to occur in Canada. While ACHD care in Canada is certainly in much better shape than in the United States, I believe it could become much better yet through the same type of comprehensive planning process.

We have all come to Toronto for the past few days because we are committed to our ACHD patients and to ACHD care. As a community, we continue to grow. We have done good things. But ACHD patients need more, and will continue to need much more. If we as a joint professional and patient/family community can move to the next level and begin a realistic and detailed planning process to meet the needs of our ACHD patients, the long road ahead will indeed be worth traveling. If we do, many more patients will be able to get the type of care that Bill Williams delivered to so many through his career. I look forward to traveling down this road with you and with our patients and their families and others who want to help us realize the vision of better ACHD care.

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