

# Adult congenital heart disease: education, education, education

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Adult patients with congenital heart disease (CHD) are the beneficiaries of successful pediatric cardiac surgery and cardiology programs around the world.<sup>1</sup> Over half of them would have died before reaching adulthood had it not been for surgical intervention in infancy and childhood. This success in treatment is exemplified by the fact that 96% of children with CHD who survived infancy will live to at least 15 years of age.<sup>2</sup> It has been estimated that there are currently over 250,000 adults with CHD in the UK, approximately 1,000,000 in the US and similar numbers in proportional terms in Europe and the rest of the world.<sup>3</sup> The prevalence will continue to grow exponentially as more patients survive early interventions and adult patients with CHD live longer.<sup>4,5</sup> Although the outlook for patients with CHD has been transformed, most early interventions have not been curative. It is estimated that approximately 50% of adult patients with CHD face the prospect of further surgery, arrhythmia, heart failure and—if managed inappropriately—of premature death.<sup>6</sup> The complexity of the anatomy and physiology, and symptoms, that these patients present in adulthood, often exceed the expertise of physicians who are not trained specifically in CHD, including those with a general cardiovascular background.<sup>3,4,6</sup> The increased workload of caring for this group of patients is therefore both quantitative and qualitative.<sup>7</sup> In addition, there is a pressing need for research into late pathophysiologic mechanisms in this expanding patient population and into the efficacy of further medical, catheter-based and surgical therapy. This viewpoint argues that education is the key to translating research advances into improved care of adults with CHD, including the large number of adult CHD patients who, sadly, do not receive cardiac follow-up.

We need to reach out and educate a broader professional audience on the principles and challenges regarding the care of the patient with CHD. This broader audience should include general cardiologists and physicians,

obstetricians, other hospital specialists, family doctors and health allied professionals.<sup>8</sup> While the CHD aficionados will continue to educate themselves using the endless opportunities for continuing medical education, we need to expand our educational portfolio and extend our efforts to reach a wider audience. Although high-level, sophisticated and somewhat esoteric material has been the main academic drive for many individuals or teams working in the field, and remains essential for maintaining and improving tertiary practice, a change in emphasis is required—towards educational efforts at a more-basic level, which are accessible and clear to this broader target audience. Widely available guidelines, more-basic textbooks and more publications in general cardiology and medical journals, are a few tools that could be used to achieve this goal. In other words, we need to highlight the main issues and basic principles of managing adult CHD to a larger professional body. Although desirable, it is not possible to provide comprehensive, total healthcare for an adult CHD patient in a tertiary center for many reasons, including geography, lack of capacity and need for local emergency care.<sup>2,4,7</sup> It is therefore essential that we engage and support this broader professional group in the management of adult CHD patients to achieve the common goal of improved patient care. Furthermore, we need a stronger representation of adult CHD in medical school curricula. This is not only because of its rich clinical material that students cherish, but also because of the pressing need to encourage clinicians to join the field of adult CHD early in their career development by alerting them to the fascinating clinical and academic adult CHD opportunities that exist.

In addition, we need to support the education of CHD patients on medical and surgical aspects of their condition. Moreover, we need to discuss lifestyle issues—such as exercise, pregnancy, contraception, career planning and insurability—with our patients early on in their

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treatment. These issues are often more important to patients and their families than details about their anatomy, physiology or even previous operations. More educational material needs to be provided to our patients, and we need to encourage them to create their own health files and become proactive about their health. Copying clinic letters and discharge summaries to patients could be a sensible way to start. We need to extend our deliberate discussions with them in areas that can be complex, such as moderate to high risk pregnancy<sup>8</sup> or moderate to high risk elective operations or reoperations.<sup>4,6</sup> We should allow them time to consider the options and ultimately support them in their final decision. Most of these challenging areas carry a lower risk when these discussions take place early and a clear plan of action is formulated and agreed upon. It is true that all this will require more of our time and more of the limited resources available, but I don't think there are any good alternatives or room for compromise. In brief, we need to strengthen our relationship with our patients and patient support groups, creating a proactive—not reactive—advisory model and establishing a life-long partnership with them. This approach is particularly fitting for adult CHD patients who are largely young adults, highly motivated, have excellent survival profiles,<sup>9</sup> and are therefore likely to benefit from such a relationship for a long period of time.

Finally, we need to educate the public: the general public; the 80% or more of patients with CHD who do not receive specialist follow-up, and as a result are subjected to poorer outcomes; and the government and other funding bodies whose support is crucial for additional resource allocation. There should be more public support and more funding for an area concerned with the most common inborn defect, which has a worldwide distribution and inflicts young individuals, and their families, who strive to lead a full life despite variable levels of physical disability. If the patients with CHD who are lost to follow-up were aware of these issues and the benefits of life-long follow-up, they would seek expert advice. This would put enormous pressure on any adult

CHD center, already operating at maximum capacity.<sup>7,10</sup> With time, however, it will create the conditions and demand the resources for staged expansion of both tertiary and secondary adult CHD services, which is long overdue. After all, patients have, or should have, a stronger voice and more lobbying power than health-care professionals. Persistent representation of the enormous need for adult CHD treatment to governments and other professional funding bodies, such as the British Heart Foundation, the NIH, the American College of Cardiology, the American Heart Association and the European Society of Cardiology is clearly required to secure the resources needed to improve clinical infrastructure, promote education and continue research.

Only through educated professionals, educated adult CHD patients and an educated public can we truly extend the outstanding results of pediatric cardiology and cardiac surgery into adulthood and enable every patient with CHD to enjoy their full life potential.

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#### Competing interests

The author declared he has no competing interests.