Adult congenital heart disease: time for a national framework

Congenital heart disease (CHD) is one of the most common inborn defects, occurring in approximately 0.8% of newborn infants. Adults with congenital heart disease are the beneficiaries of successful paediatric cardiac surgery and cardiology programmes across the United Kingdom. Had it not been for surgical intervention in infancy and childhood, 50% or more of these patients would have died before reaching adulthood. This success story of medicine has created a significant population of young adults, who require lifelong cardiac and non-cardiac services.[1] Many of them face the prospect of further surgery, arrhythmia intervention and, if managed inappropriately, an increased risk of heart failure and premature death.

There are approximately 250 000 adults with CHD in the UK. This number will continue to grow as more children survive early interventions. A 400% increase in adult out-patient clinic workload was recently reported in Canada.[2] In the UK, the need for follow-up of patients with moderate to severe complexity CHD over the age of 16 years has been estimated at 1,600 new cases per year.[3]

Some patients with structural and/or valvular congenital heart disease do not present until late during adulthood.[4] Turner *et al* in this issue (see pages 99-102) present two case histories with such patients who required and benefited from tertiary care.[5] Not every adult with CHD needs tertiary care expertise, but it is required for: the initial assessment of suspected or known CHD; follow-up and continuing care of patients with moderate to severe lesions; further surgical and non-surgical intervention; and risk assessment prior to non-cardiac surgery and pregnancy. This means the increased workload of caring for adults with CHD is both quantitative and qualitative, with clear implications for adult cardiology and NHS resources.

The importance of adult CHD as a subspecialty has been recognised by the Calman UK training body. Basic training in adult CHD is now mandatory for cardiology specialist registrars. It is also recognised that selected individuals will need to train more comprehensively in this field. The American College of Cardiology Task Force states that a minimum of two years' full-time training is needed to become clinically competent, to pursue an academic interest and to train others effectively.[6] The small number of centres offering comprehensive training in adult CHD worldwide, coupled with lack of resources, remain major obstacles in achieving this goal.

Michael A Gatzoulis
GUCH series editor

The first set of guidelines for the management of the adult with CHD, originally commissioned by the Canadian Cardiovascular Society, was recently revised by an international panel of experts[7] and is now available on the web (website: www.rbh.nthames.nhs.uk/cardiology/consensus). Similar guidelines are being developed by UK and European bodies. National and international curricula in adult CHD are also being developed to disseminate existing information on the management of the adult with CHD and to stimulate research. A new group of cardiologists specialised in adult CHD is clearly required to ensure uncompromised lifelong care for this patient population. The case is more compelling following recent recommendations from the Bristol report. Furthermore, there is a need for research on factors that might influence the late outcome of this expanding patient population and on the effects of medical, catheter and surgical intervention. Clinical and research resources must be allocated for this large patient group.

These multiple needs can only be fulfilled through a national framework (table 1). Such a model of care, training and research for the adult with CHD would be in keeping with recent UK NHS guidelines and has been implemented, in part, in Canada. Within this framework, general cardiologists with an interest in this area need to be supported locally – eg.

Table 1. National Framework for Adults with CHD: objectives

- To establish a **network of national and regional centres** for the adult with CHD
- To foster professional **specialist training** in adult CHD
- To co-ordinate a **national registry** for adults with CHD
- To support **research** in adult CHD

in district general hospitals – and helped to work with both tertiary and primary care physicians to provide for the adult with CHD. Paediatric cardiology expertise also needs to be utilised and transition care programmes need to be developed to ensure seamless continuity of care for this patient population. In addition, databases shared amongst paediatric, adult and non-tertiary care centres, with easy access to tertiary facilities, are required to promote this multi-level collaboration. Patient advocate groups need to continue to develop and participate actively in this process.

Adults with CHD are no longer a rare or 'odd' patient group, that only single individuals or centres can truly provide for. Time has come for a British Adult Congenital Heart (BACH) network, supported by the Department of Health, relevant professional societies and funding bodies, including industry. There has never been a better time for the NHS to take a leadership role and support nationwide care for the ever increasing number of adults with CHD.

Editors' note

Two further articles on adult congenital heart disease can be found in this issue:
- GUCH: experience in a district general hospital (pages 92-8).
- atrial septal defects (pages 99-102).

References

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Michael A Gatzoulis
Director
Adult Congenital Heart Programme,
and Consultant Cardiologist
Royal Brompton Hospital, Sydney Street,
London, SW3 6NP.
(email: m.gatzoulis@rbh.nthames.nhs.uk)