Adult congenital heart disease: follow-up and the role of the district general hospital

The number of patients with congenital heart disease surviving into adulthood has increased due to the success of surgical and percutaneous interventions;[1] 96% of children with congenital heart disease who survive infancy will live beyond their 15th birthday. But although such patients survive, few are cured and many will ultimately develop further complications related either to the underlying lesion or to the surgery they have undergone. Physicians looking after these patients have to manage both increasing numbers and increasingly complex cardiac pathology. It is perhaps timely to ask how such patients should be followed up.[2-5]

For patients living in big cities, follow-up in the regional referral centre is both logical and practical but what of those living further away?[4]

The role of the DGH

In the UK, district general hospitals (DGHs) are organised to deal with most medical problems and are one option for managing these patients. In this issue (see pages 19–22), Rekhraj and Freeman[6] show an example of what can be done. They report on their extensive experience of how they deal with patients with transposition of the great arteries at the Norfolk and Norwich University Hospital.

In general, most patients find that travel to their DGH is relatively straightforward and often much easier than a trip to the referral centre.[4] Patients with medical emergencies, both cardiac and non-cardiac, will almost certainly be referred to the DGH in the first instance. At a minimum, it is important that patients with adult congenital heart disease should be known to their local hospital so that in the event of any emergency, sensible decisions can be made about their management. Obstetric care is often more convenient in the local hospital, although some patients will need to have pregnancy monitored very closely and delivery planned to take place in the referral centre.[7,8] (Even then, the DGH will have to be able to cope with emergencies developing during pregnancy or to occasionally deal with premature labour). Similarly, care of patients at the end of life can be demanding in this group, as in any other, when death occurs in young adults. There is little qualitative data available[9] but it seems likely that care by a supportive group based on the local DGH may be preferable to recurrent trips and stays away from home in the referral-centre.

Its limitations

We need to be aware of the limitations of the DGH.[9,10] Above all, in most cases the expertise immediately available is likely to be significantly less than at the referral centre; this applies primarily to the cardiologists caring for such patients but also to the whole team including nurses, cardiology technicians, radiologists, anaesthetists and obstetricians. The DGH is also less likely to have the technology available in the major centres. With the spread of technology to the DGH, this difference is diminishing but the expertise in the DGH is usually focused on patients with common acquired adult problems. These are often very different from the problems faced by adults with congenital heart disease. Recent national developments, such as the setting up of designated pulmonary arterial hypertension centres,[11,12] (e.g. the Eisenmenger centre at the Royal Brompton Hospital) may further widen the existing expertise gap.

This means that the follow-up care of patients with adult congenital heart disease currently involves a decision between the expedience of the local referral centre and the expertise available in a potentially distant referral centre. To help resolve this dilemma, two policies need consideration.

1. Education

A long-term priority is the training of sufficient specialists in adult congenital heart disease.[1] This is now a recognised subspecialty in cardiology training in the UK.[10] Although such a policy is essential, it will take time. Moreover, the newly fully trained specialists are likely to be deployed in the referral centres and although the overall standard of care will rise, paradoxically the expertise gap between referral centres and the periphery could widen.

In the short term there needs to be continuing education of practitioners in post.[1] This applies not only to junior and senior cardiologists, but also to all those involved in the care of patients with adult congenital heart disease including general physicians, anaesthetists, obstetricians, general practitioners, cardiac physiologists and nurses. All of the above belong to professional bodies that have some responsibility for continuing education. Guidelines have been laid down for training programmes and so there is a framework in place for training.

2. Organisation

Careful organisation of the care of patients with adult con-

genital heart disease[13,14] would also seem likely to improve outcomes.[3,4,8-10] There are many different structures for delivery of such care. We would suggest the core features of such care should include:

- A lead cardiologist in the DGH to co-ordinate the care of local patients.
- A designated referral centre with appropriate facilities and capacity to investigate and treat referrals. There needs to be an agreement about how and where patients should be investigated; investigations should only be carried out where appropriate expertise is available, to avoid unnecessary duplication of tests/risk taking and waste of resources. A cardiologist from the referral centre to take on the responsibility (with his/her team) of being the main receiver of referrals from a specific DGH.
- The referral centre cardiologist and his team to be immediately available for advice and, where necessary, to have the capacity to accept patients with problems for admission.
- The DGH and referral centre cardiologists need to be able to interact and to work together to manage out-patients. Getting this right is probably the most important component of the administrative package. Different DGHs will develop different structures depending on local expertise and geography. Our preference is to run a joint outreach clinic where we see patients together. This has worked well in our experience.[4] Advances in technology such as video-conferencing and the electronic patient record should further help this interaction.[13]

Conclusion

The cardinal features of the organisation of care of such patients are outlined in several working party reports,[2,3,5,10] and we endorse these recommendations.

Patients with adult congenital heart disease are growing in number and posing increasing and complex management challenges. Providing them with an appropriate long-term follow-up scheme is an essential issue for the coming years.

Conflict of interest

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David J Gwilt
Consultant Cardiologist
Department of Cardiology,
Milton Keynes General Hospital,
Standing Way, Eaglestone, Milton Keynes,
Buckinghamshire, MK6 5LD.

Michael A Gatzoulis
Professor of Cardiology,
Congenital Heart Disease and
Consultant Cardiologist,
Adult Congenital Heart Centre and
Centre for Pulmonary Hypertension,
Royal Brompton Hospital and the
National Heart and Lung Institute,
Imperial College, Sydney Street,
London, SW3 6NP.

Correspondence to: Dr DJ Gwilt
(E-mail: david.gwilt@mkgeneral.nhs.uk)

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