

Heart failure service for patients with congenital heart diseases

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Patients with adult congenital heart diseases (ACHD) frequently develop heart failure (30-50%).¹

Current recommendations specify that ACHD patients with heart failure should be managed in specialist centres with adequate experience in managing such conditions.^{2,3}

The heterogeneity of CHD lesions often makes treatment difficult and these patients are rarely managed in general hospitals, so adult cardiologists may lack experience and expertise in managing these complex cases.

Furthermore, conventional community heart failure services (i.e. for up titration of medical therapy) and cardiac rehabilitation programmes are often limited to specific conditions (i.e. left ventricular failure or even LVEF<35%) and as such, not accessible to ACHD patients with heart failure.

OBJECTIVES

Our aim was to create a dedicated specialised heart failure service for patients with ACHD who are under the care of Barts Heart Centre in London, which has over 10000 patients under follow-up.

Specifically, the service would allow all patients with ACHD who develop heart failure (HF) to benefit from (1) a timely access to expert review with a multidisciplinary (MDT) support from the wider ACHD team,

(2) initiation and up-titration of appropriate medical and device therapies, (3) improved access to heart transplant services and (4) improved access to palliative care.

METHODS

To achieve these goals we have taken the following steps:

TEAM

The service was initiated with the appointment of a heart failure consultant with experience in managing ACHD patients. A dedicated ACHD clinical nurse specialist (CNS) with an interest in heart failure was also deployed to the service. The CNS is undergoing training in non-medical prescribing.

The CLINIC

We have established a dedicated clinic which is called the "Heart Function" clinic, with consultant and CNS appointment slots, which provides sufficient capacity to review heart failure patients within 2 or 6 weeks depending on the urgency (as per NICE guidelines).⁴

HEART TRANSPLANT

We have strengthened the collaboration with the ACHD Heart Transplant Centre at the Freeman Hospital by attending their transplant multidisciplinary team meetings, and delivering joint 6-monthly clinics at Barts Heart Centre and ad hoc joint video clinics.

PALLIATIVE CARE

We have improved the access to the local Palliative care team and secured a rapid access to inpatient and outpatient palliative care multidisciplinary team services.

OUTCOME MEASURES

According to current recommendations to monitor health status and patient reported outcome measures, we have secured a license for and implemented Minnesota Living with Heart Failure Questionnaire (MLHFQ) in a standard clinical assessment of patients in the ACHD Heart Function Clinic.

DATABASE

We are collecting clinical and outcome data of patients in the Heart Function Clinic in a dedicated database and we are working towards better integration of this database with the electronic patient record system at Barts Heart Centre.

RESULTS

Since April 2020 when the service was started, we have reviewed and provided ongoing care to 121 ACHD patients with heart failure. Just under the half of patients (44%) had systemic right ventricular failure or a failing Fontan circulation. (Figure) Of the patients with left ventricular systolic dysfunction, over 45% had Tetralogy of Fallot. To our knowledge this is the largest ACHD heart failure service in the UK.

All patients were reviewed in the clinic within 2 weeks from referral. We have reviewed 10 patients in the joint Heart Transplant Clinic with the Freeman Hospital.

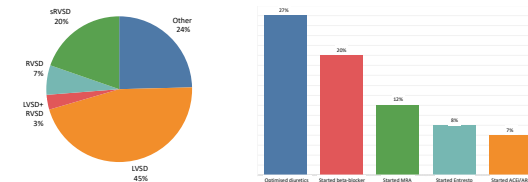


Figure: Pie-chart shows the distribution of unique congenital lesions and underlying reasons of heart failure. Box-plot shows the alterations to the medical therapy following a review in the Heart Function Clinic. ACEI - angiotensin converting enzyme inhibitor, ARB - angiotensin II receptor blocker, LVSD - left ventricular systolic dysfunction, MRA - mineralocorticoid receptor antagonist, RVSD - right ventricular systolic dysfunction, sRVSD - systemic right ventricular systolic dysfunction

Around 2 in 3 patients (66%) had their management altered at initial review. Modification to medical therapy is presented in the Figure.

Four new patients were accepted for heart transplant, doubling the existing Barts patients waiting. The time from a referral for a transplant to the Transplant MDT shortened to 13 days from previous mean of 188 days.

Six patients were referred to Palliative Care and were reviewed within 5 days of the referral.

We are recording patient reported outcome measures together with changes in clinical status and in therapy at all clinical appointments.

CONCLUSIONS

We have established a dedicated Heart Failure service for patients with ACHD. The service provides patients with a timely access to specialist HF review, MDT support and appropriate therapy and allows feed-back to the wider team on how best to manage these patients.

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