NHS BLOOD AND TRANSPLANT

CARDIOTHORACIC ADVISORY GROUP

CLINICAL CHARACTERISTICS OF URGENT PATIENTS

SUMMARY

BACKGROUND

1 This paper summarises the clinical data provided in the initial registration form for urgent heart registrations between 1 April 2013 and 31 March 2014.

DATA ANALYSIS

2 Data on 213 urgent heart registrations for 203 patients registered between 1 April 2013 and 31 March 2014 were obtained. The urgent heart category was not reported for 6% of adult registrations and 21% paediatric registrations In addition 6% of adult registrations and 9% of paediatric registrations were made under the 'Other' category.

ACTIONS

3 Members are encouraged to ensure that all information on the initial Urgent Heart Recipient Registration form is provided both accurately and in a timely manner.

4 Basic validation, as agreed by CTAG in April 2014, will be performed on the data provided in these forms at the time of listing when IT resource becomes available.

.5 A number of changes to the form are to be made in order to clarify the registration process and to support validation.

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Statistics and Clinical Studies **September 2014**

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BACKGROUND

1 The current urgent heart registration forms were introduced in May 2008 to collect more comprehensive data on the clinical condition of urgent patients. Inclusion criterion for adult urgent patients were also introduced and audited on the forms.

2 Each new registration onto the urgent heart allocation scheme (UHAS) should be accompanied by an initial Urgent Heart Recipient Registration form. For patients who remain on the urgent list for more than 7 days, Urgent Heart Recipient Weekly Update forms should be submitted each week.

3 It was agreed by CTAG in April 2014 that basic validation should be performed on the data provided in the initial registration form before a patient is listed on to the UHAS. This will be implemented when IT resource becomes available.

4 In the meantime, this paper summarises the clinical data provided in the initial registration form for urgent heart registrations between 1 April 2013 and 31 March 2014. Data provided in the weekly updates are not presented.

DATA

5 Data on 213 urgent heart registrations for 203 patients registered between 1 April 2013 and 31 March 2014 were obtained from the manual records kept by the Organ Donation and Transplantation (ODT) Duty Office. Initial registration forms could not be located for five of these registrations. Data for these registrations have been classed under the 'Not reported' categories in this paper.

RESULTS

6 A total of 170 adult urgent heart registrations and 43 paediatric urgent heart registrations were made between 1 April 2013 and 31 March 2014.

7 **Table 1** shows the urgent heart registration category and key criteria for urgent listing. The most common category for adult patients to be listed under was high dose inotropes and for paediatric patients, ECMO. 6% of adult patients were registered under the 'Other' category while 9% of paediatric patients were registered under this category. The urgent category was not reported for 6% of adult patients and 21% of paediatric patients.

Table 1 Urgent heart registration category, Level 2 Critical Care status and Cardiac Index criterion status for all adult and paediatric urgent patients, 1 April 2013 – 31 March 2014

	Adult		Paediatric	
	N	**%**	**N**	**%**
	170	100	43	100
Category				
Short-term MCSD	20	12	5	12
MCSD with device-related complications	30	18	0	0
IABP	18	10	0	0
ECMO	3	2	10	23
High-dose inotropes	64	38	8	19
Combination of inotropes	13	8	-	-
Non-invasive ventilation	0	0	-	-
Paediatric≤15kg on ventilation and inotropes	-	-	7	16
Other	11	6	4	9
Not reported	11	6	9	21
Inpatient in Level 2 Critical Care				
Yes	136	80	42	98
No	25	15	0	0
Not reported	9	5	1	2
Cardiac Index (CI)<2l/min/m^2				
VAD or ECMO	42	25	13	30
Not on VAD or ECMO and CI<2	97	57	11	26
Not on VAD or ECMO and CI=>2	19	11	4	9
Not reported	12	7	15	35

8 There was one case of non-compliance in August 2014 such that a paediatric patient at Great Ormond Street was incorrectly registered under Category 51 ("Paediatric with short-term MCSD: Mechanical circulatory support for acute haemodynamic decompensation using a short-term right, left or bi-ventricular device (including Berlin Heart), implanted as a specific bridge-to-transplantation"). This patient had in fact been implanted with a long-term HVAD and went on to receive a heart transplant through the UHAS.

9 A table of reasons (from 19 September 2013 onwards) for listing under the 'Other' category is recorded in the **Appendix** based on the information discussed and agreed with the UHAS adjudication panel.

10 **Table 2** shows the VAD, ECMO, IABP and inotrope status of all urgent patients registered. 28% of adult patients were on a VAD at time of listing, 2% were on ECMO and 12% were on IABP. The corresponding figures for paediatric patients were 23%, 21% and 5%, respectively. 60% of adult patients and 86% of paediatric patients were on inotropes at the time of listing. It should be noted that the classification of high dose inotropes in Table 2 does not account for milrinone as the current categorisation for urgent listing under high does inotropes states ' milrinone >0.375µg/kg/min or adjusted to achieve therapeutic milrinone levels of 100-300 ng/ml (which may correspond to a lower dose in patients with impaired renal function)'.

Table 2 VAD, ECMO, IABP and Inotrope status for all adult and paediatric urgent patients, 1 April 2013 – 31 March 2014

	Adult		Paediatric	
	N	%	N	%
	170	100	43	100
VAD				
None	113	66	32	75
Left	38	22	4	9
Right	1	1	0	0
Both	8	5	6	14
Not reported	10	6	1	2
ECMO				
No	156	92	32	74
Yes	4	2	9	21
Not reported	10	6	2	5
IABP				
No	137	81	38	88
Yes	21	12	2	5
Not reported	12	7	3	7
Inotropes				
Yes – high dose*	20	12	7	16
Yes – low dose	67	39	29	68
Yes – unknown dose	15	9	1	2
No inotropes	57	34	3	7
Not reported	11	6	3	7

* The following are defined as 'high dose' inotropes: dopamine>5µg/kg/min, dobutamine>7.5µg/kg/min, epinephrine>0.05µg/kg/min, enoximone>5µg/kg/min, levosimandan - any dose.

11 **Table 3** shows the laboratory results for patients at time of urgent listing. Laboratory investigations were not reported on all initial registration forms.

Table 3 Laboratory investigations data for adult and paediatric urgent patients, 1 April 2013 – 31 March 2014

	Hb (g/dl)	WCC ($x10^9$/l)	Serum creatinine (µmol/l)	Serum bilirubin (µmol/l)	CRP (mg/dl)
Adults					
N	139	154	154	149	140
Mean	11.8	8.2	105.5	24.6	29.6
Standard deviation	3.0	3.0	53.7	19.7	40.3
N (high*)	-	16	8	14	49
Paediatrics					
N	36	37	38	35	30
Mean	11.8	9.9	72	14.6	30.4
Standard deviation	2.4	4.9	121.1	11.9	35.5
N (high*)	-	10	1	1	9

* 'High' here means:
- WCC >12 $x10^9$/l
- Serum creatinine >200 µmol/l
- Serum bilirubin >50 µmol/l
- CRP >25 mg/dl

CONCLUSION

12 The clinical characteristics of patients registered on the urgent list, 1 April 2013 – 31 March 2014, indicates that the urgent heart category was not reported for 6% of adult registrations and 21% for paediatric registrations. In addition 6% of adult registrations and 9% of paediatric registrations were made under the 'Other' category.

13 There was one noted case of non-compliance where a paediatric patient was incorrectly registered on to the urgent heart waiting list and received a heart transplant through the urgent heart allocation scheme.

ACTION

14 Members are encouraged to ensure that all information on the initial Urgent Heart Recipient Registration form is provided both accurately and in a timely manner.

15 Basic validation, as agreed by CTAG in April 2014, will be performed on the data provided in these forms at the time of listing when IT resource becomes available.

.16 A number of changes to the form are to be made in order to clarify the registration process and to support validation. These are specifically;

- To make the descriptions of Categories 59 and 9 ('registering as 'Other' for adult and paediatric, respectively) consistent and include the request for documentation of approval by the Adjudication Panel and the Chairman of the Cardiothoracic Advisory Group (or deputy) .
- A description of the registration process for registering a patient under Category 59 or 9 including an NHSBT audit email address (as agreed by CTAG in April 2014).
- To amend the description of Category 5 (high dose inotropes category) to separate patients on milrinone >0.375µg/kg/min from those patients on milrinone levels 'adjusted to achieve therapeutic milrinone levels of 100-300 ng/ml'.

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Appendix

Table A1 Reasons for urgent listing under the 'Other' Category (Categories 9 and 59) as discussed by the UHAS Adjudication Panel, registrations between 19 September 2013 and 17 September 2014

Patient	Adult/Paed	Month	Reason
1	Adult	September 2013	Advanced heart failure Heartmate LVAD in situ for Ischemic DCM Surgical partial LVAD replacement for a fractured driveline. Driveline later fractured again. Due to the refractory infection, there is no alternative strategy. If not accepted as urgent or should the patient experience additional severe complications we would refer to palliative care
2	Adult	October 2013	Severe bi-ventricular failure S/p central VA ECMO with Complications S/p HVAD implantation for DCM Significant AV regurgitation and borderline right heart function with high RA pressures. Deteriorating. Backup strategy would be an additional right heart assist but patient is small.
3	Paed	October 2013	Patient undergone multiple previous palliative surgeries for a univentricular circulation (right atrial isomerism, total anomalous pulmonary venous drainage, unbalanced CAVSD, transposition of the great arteries, pulmonary stenosis) and had a TCPC (Fontan). Condition deteriorated over past weeks and admitted to hospital following a collapse. Paediatric ACHD teams agree patient is near end of life and no other therapy (such as VAD) can be employed as a bridge to transplantation.
4	Adult	October 2013	Irreversible pulmonary hypertension, becomes profoundly hypoxic due to a significant right to left shunt through a large PDA whenver we try to reduce V-V ECMO support, although with good blood pressure on no inotropes. ECMO is providing oxygenation, but thought that a lot of the cardiac output comes from the right ventricle. Left ventricle is small and there is concern over it's ability to handle the full cardiac output if bilateral lung transplant is performed. Fully conscious, in effectively single organ failure.
5	Adult	October 2013	Danon's disease. ECHO: severe LVH, impaired systolic function but very severe diastolic dysfunction. RVH, mildly reduced systolic function. LV gradually getting less hypertrophied with worsening systolic function. Listed for a routine heart transplant. Since become more dyspnoeic, raised RA and PA pressure, treated with increasing diuretic dose and admitted to hospital multiple occasions. Sodium falling and creatinine risingInotropes are very likely to cause arrhythmias. Diastolic dysfunction of both ventricles and a LVAD is unlikely to work well. Urgent heart transplantation is the only option and prognosis without a transplant is very poor because of worsening haemodynamics and increasing frequency of ventricular arrhythmia.

6	Adult	December 2013	Listed for a routine heart transplant. ARVC. Recurrent VT/VF episodes which are causing recurrent ICD shocks. Recently sustained a head injury through LOC. Patient back in sinus rhythm and stable from an organ perfusion point of view. Severe biventricular impairment by echo but cardiac output at rest is preserved. Concern that if patient goes home, they will either be re-admitted again within hours or days, or die through an intractable VT storm before they make it back for a bivad.
7	Adult	January 2014	Short history of dyspnoea. Very poor biventricular function, chambers only slightly dilated on ECHO. Needed inotropes but deteriorated and had HeartWare BiVads placed. Listed for a routine heart transplant. Increasing dyspnoea, found to have a right pleural effusion. VAD flows not significantly changed, ECH showed asystole. Attempted cardioversion (on the grounds that this might be fine VF) but to no effect. The risk of thrombus formation is high (asystole and BiVADs).
8	Adult	September 2014	VAD patient on routine heart list. Previously managed at home on Rifampicin and Daptomycin for over 2 years. Recently admitted to hospital with high temperature and raised inflammatory markers - antibiotics have been changed to Meropenum and Gentamicin. High HLA antibodies making the likelihood of a transplantable organ being found very unlikely.