

The suitability of discharge information for parents of infants with single functioning ventricle heart condition: evolution of a Congenital Heart Assessment Tool (CHAT) for Parents

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Background

Whilst advances in the care of infants with complex congenital heart disease (CHD) have resulted in remarkably improved prognosis, death between first and second surgical stage has remained a concern in the UK and America particularly for those with single cardiac ventricle anatomy.¹⁻⁸ This has prompted the development of home monitoring programs (HMP) to encourage early identification at home, of infants vulnerable to potentially life threatening events^{4, 5, 9-13}. However to date no randomised controlled trials have been published and therefore the robustness of the available research is debatable. In 2011 a research proposal was developed by KG (Coventry University) in collaboration with the team at Birmingham Children's Hospital and Little Hearts Matter (LHM) to undertake a Feasibility Study (randomised controlled trial) to test the feasibility of using a Congenital Heart Assessment Tool (CHAT) as part of a home monitoring programme (HMP) for infants with single ventricle heart conditions and those with systemic shunt dependent heart conditions. A consultation event [funded by a Patient and Public Involvement (PPI) Bursary from the NIHR West Midlands Research Design Service] was hosted by LHM in September 2011 during which a Focus Group was facilitated by KG with a small group of parents to ascertain their views regarding the implementation of a home monitoring programme. The Focus Group was transcribed, thematically analysed and subsequently contributed to the development of the content of the online survey and the Congenital Heart Assessment Tool (CHAT) which is being reported in this poster presentation.

Aim

The aim of this phase of the larger study was to find out retrospectively, parents' views and experiences relating to the discharge information that they received when their infant was discharged home from the specialist cardiac centre after the first stage of treatment, to inform the development of an assessment tool for parents [and will be the focus of this poster]. The online survey also aimed to explore how parents dealt with the transition of going home with their infant, how they adapted to the new situation and whether the information that they were given helped in that transition, which is also being explored prospectively as part of the larger feasibility study and will not be reported here.

Method

A retrospective, mixed methods approach was employed to collect quantitative and qualitative data through an online survey during November 2012 – March 2013. A convenience sample of all parents who are members of Little Hearts Matter (National CHD Charity) with children aged between 0-3 years (n=62 families) who were discharged home from a UK specialist heart centre, after the first stage of treatment for single functioning heart ventricle were invited to participate in this study. The parents approached were from all over the UK, representing a variety of ethnic groups and geographical areas. Ethical approval for the study was obtained through Coventry University Research Ethics Committee.

Conclusion

Care was provided for these families in 11 different specialist cardiac units across the UK. The results suggest that there is little consistency across the units in relation to the discharge information that parents receive. The number of treatments or measurements that continued at home were minimal for the families that took part in this survey (Table 3). Administering medications was the only treatment that every family was involved in on a daily basis. Some families also explained the problems they experienced in relation to feeding their infant at home and this was seen as anxiety provoking for some. Not all discharge information received was felt to be of good quality (chart 1) with just over 50% responding that the information was excellent or good. Therefore improvements can be made to the quality and consistency of discharge information for these families of infants with complex congenital heart disease.

Congenital Heart Assessment Tool

The results of the online survey (both the qualitative and quantitative data) contributed to the development of a Congenital Heart Assessment Tool (CHAT), which uses a traffic light system, for parents to use at home. The tool was reviewed by the External Advisory Group and included PPI. The Feasibility of this tool is currently being explored as part of the RCT that commenced at BCH in August 2013, with the aim being to enable sample size calculations for a larger multi-centred study.

Results – this section provides a small sample of the results

Table 1 Demographics

	N	%
Number of survey responses	22/62	35.5
Answered as a couple	6/22	27.3
Answered by father	1/22	4.5
Answered by mother	15/22	68.2
Antenatal diagnosis	17	77.3
Postnatal before discharge	3/5	13.6
Infant's Diagnosis as described by respondent:		
Hypoplastic left heart	14	63.6
Tricuspid Atresia	3	13.6
Pulmonary Atresia	4	18.2
Hypoplastic right heart	1	4.5

Table 2 Teaching and Information received prior to discharge

	No teaching %	Taught signs general to all cardiac babies %	Taught signs specific to my baby %	No written instructions given %	Given general cardiac written instruction %	Given specific written instructions for my baby %	Given Other written information e.g. LHM booklet %
Wound care	36.4	45.5	18.2	50	36.4	4.5	4.5
Breathing	27.3	36.4	36.4	36.4	36.4	9.1	4.5
Measuring oxygen saturation	54.5	18.2	27.3	59.1	4.5	22.7	9.1
Skin colour	22.7	40.9	36.4	31.8	27.3	18.2	9.1
Heart rate	68.2	4.5	27.3	59.1	13.6	13.6	9.1
Body temperature	59.1	22.7	18.2	63.6	18.2	4.5	9.1
Activity level	31.8	31.8	36.4	36.4	27.3	18.2	9.1
Feeding	27.3	40.9	31.8	50	18.2	9.1	13.6
Weight	18.2	50	31.8	45.5	22.7	13.6	9.1

Chart 1

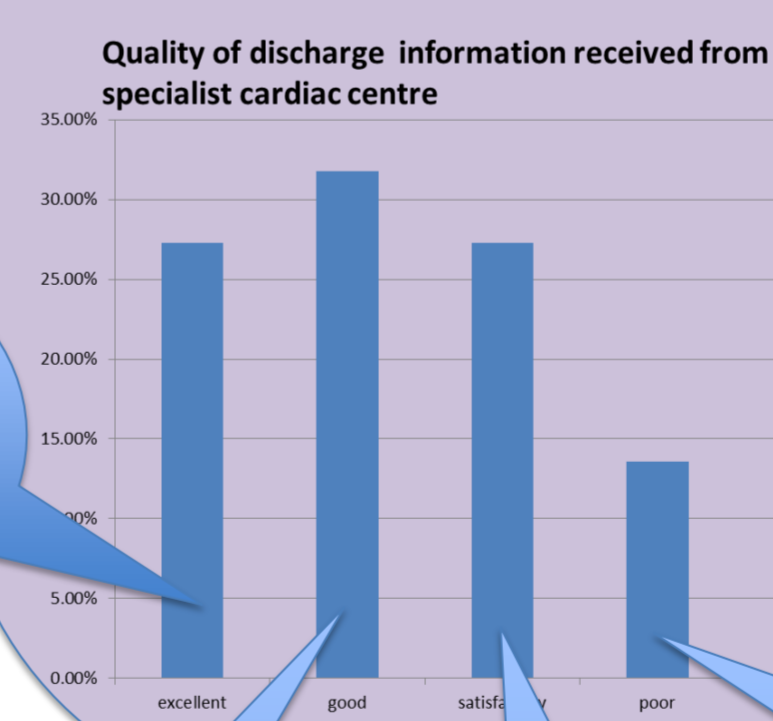


Table 3 Treatments /measurements that continued at home

	More than once a day	Daily	Twice weekly	Weekly
Oxygen saturation monitoring	0	2	1	2
Weight	0	2	1	5
INR	0	1	0	0
Medication	22	NA	NA	NA
NG feeds	2	NA	NA	NA

"I think I would have felt even more frightened without some kind of guidelines"

"I relied on that information to know if things were going right"

[would have liked] "to be better prepared for the signs of going into heart failure or becoming ill"

"We received some very vague statements when leaving along the lines of "you are the parents you will know when there is a problem"

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Affiliations

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