

Preliminary Feedback regarding a Congenital Heart Assessment Tool (CHAT) for Parental Early Assessment and Home Monitoring of Infants with Complex Congenital Heart Disease.



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Background

Functional single ventricle heart condition is one of the most frequently encountered life-threatening cardiac deformities present at birth,^[1] and requires several surgical operations over two to three stages. However, whilst advances in medical and surgical care have resulted in remarkably improved prognosis, the number of infants dying between the first two stages has remained a concern with a mortality of up to 15%.^[2-7] This has prompted the development of home monitoring programmes (HMP) to encourage early recognition of infants that are at risk of potentially life threatening events between the first two stages.^[6,8-11]

The study commenced in August 2013 and hoped to recruit 60 families over 15 months, based on previous admission data. However the first Research Nurse took early retirement in December 2013 and so the study was suspended until April 2014 when the Wellcome Trust Clinical Research Facility took over day to day management. In the interim period 15 families were missed (see recruitment data below).

One of the study's aims is to determine whether a Congenital Heart Assessment Tool (CHAT) and/or HMP (daily measurement of the infant's oxygen saturations and weight at home) is suitable and of benefit to parents of infants with single ventricle heart conditions or those with systemic shunt Dependent Heart conditions. The CHAT design was informed by the results of a focus group and online survey; and the aims and principles of paediatric early warning scores^[12-30] to alert parents of deterioration through observation of their infant's clinical signs, incorporating a colour coded traffic light system for ease of use.^[31]

Aim

The aim of this poster is to present a parental early warning system called the Congenital Heart Assessment Tool [referred to by parents as CHAT] that was designed for home parental use alongside a home monitoring programme; and to present preliminary qualitative feedback from the families in Group A and B (n=5) who participated in the feasibility study between August 2013 - March 2014.

Three families were recruited to group C during this time and therefore did not use the CHAT

Recruitment

Time Period	Pending	Recruited	Refusal	Ineligible	Missed	Deceased	Running
August 2013- March 2014		8	5	7	15	4	39
April -August 2014	2	3	2	3	1	7	57 (18)

Study Design

A mixed methods study

Phase 1: A focus group (FG) (September 2011) and a retrospective online survey (OS) (November 2012) to inform the development of the CHAT tool and the feasibility study.

Phase 2: A prospective randomised controlled feasibility study (FS) which commenced in August 2013. One of the aims of the FS being to evaluate the feasibility and effectiveness of the CHAT used in conjunction with a home monitoring programme (Group A) compared with the CHAT alone (Group B) and standard discharge care (Group C). Parents are recruited before their infant is discharged home after Stage 1 Surgery and participate until they return for Stage 2 surgery, approximately 4-6 months later depending on their infant's condition

Parents in all three groups are invited to talk about their experience during interviews before discharge (T0), 2 weeks after discharge (T1), 8 weeks after discharge (T2) and after Stage 2 surgery (T3).

One section of the CHAT

Parent's Traffic Light System	Green – low risk	Amber – Intermediate Risk	Red- High Risk
		if any of these signs are present ring for advice from Ward – if in doubt call 999	if any of these signs are present ring 999
Infant's Activity	Behaves normally e.g. Content/smiles	Quieter than normal, not feeding as normal	Not responding to normal activity
	Stays awake or awakens quickly (as normal)	Sleeping more than normal	Does not wake or if roused does not stay awake
	Normal crying easily resolved by feeding, comfort, nappy change	Responding less during normal activity	Weak, high-pitched or continuous cry or no crying at all
		Slightly irritable	

Congenital Heart Assessment Tool

The CHAT includes specific signs of deterioration that parents who completed the OS wanted more information about, relating to signs of heart failure^[32] in this group of infants with complex congenital heart disease.

Feedback from parents during the FG and OS, indicated a need for individualised information. The CHAT is therefore individualised to each infant's specific clinical signs and includes baseline vital signs at discharge and preferred parameters (e.g. oxygen saturation) as set by their Consultant.

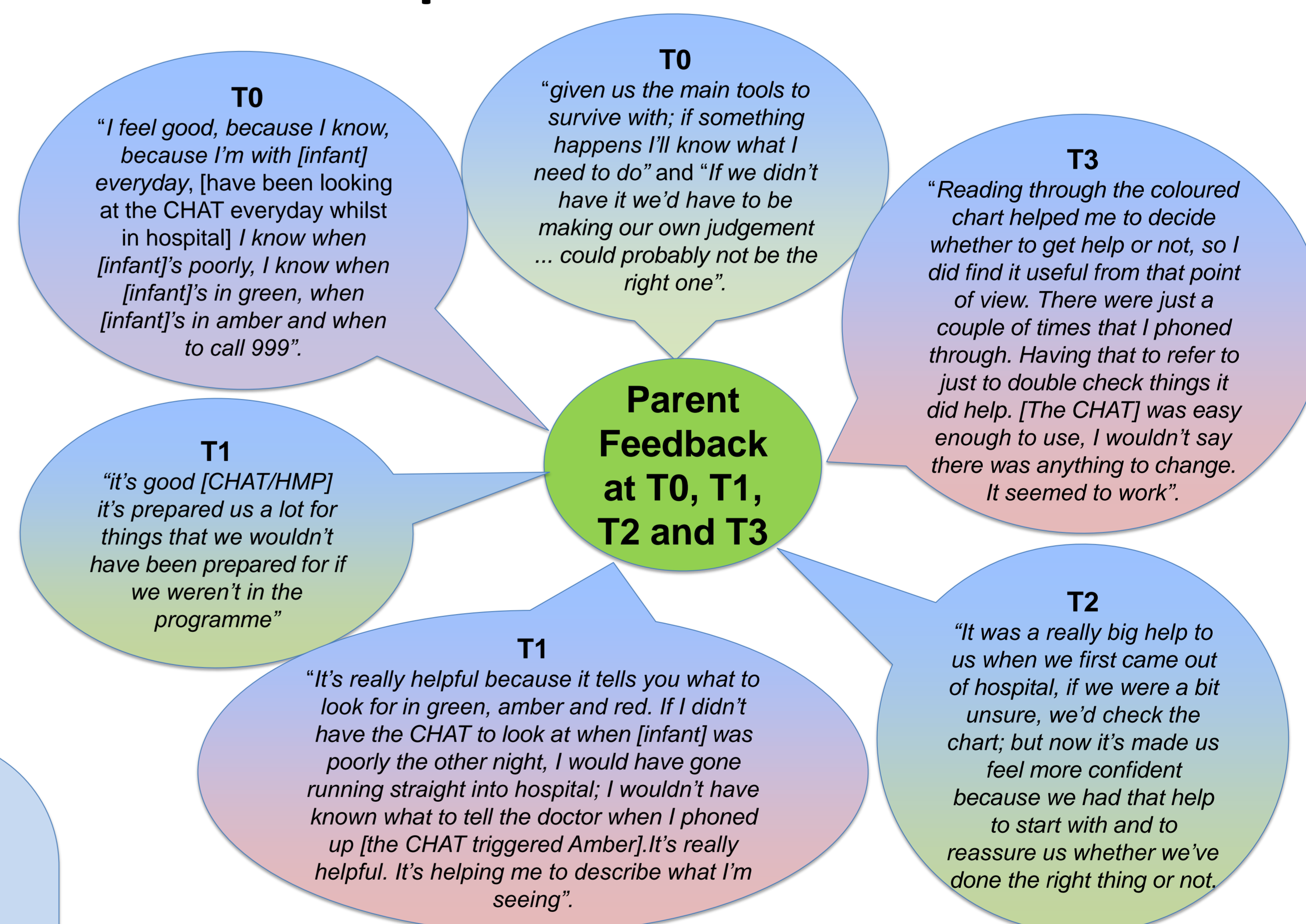
Individualised teaching is provided prior to discharge (as requested by parents in the FG and OS) to ensure understanding of how to assess their infant and interpret the significance of the signs by using the CHAT. Parents in Groups A and B are asked to use the CHAT daily to assess their infant's clinical condition; results are recorded in a diary. The CHAT can be used at any other time if their infant's condition has changed.

The CHAT is divided into three columns, green (low risk), amber (intermediate risk) and red (high risk). Parents are asked to assess their infant's activity level, skin colour, breathing, circulation, feeding and weight against the information in each of the three columns

If the CHAT assessment is green parents are directed to 'carry on as normal'; amber triggers a phone call to the ward to discuss management; a red response, indicates the infant is seriously ill, parents are advised to phone 999 immediately.

Amber telephone conversations and the management advice given are documented by ward staff, this is regularly cross-checked against the parent's diary by the research nurses. The number of calls received by ward staff and any emergency (red) readmissions of infants in the study are also being monitored.

A Sample of Parent's Comments



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Conclusion

The results of the OS suggested a lack of consistency regarding discharge information given to parents nationally; and parents felt that the quality of the information given could be improved. These results informed the development of a CHAT. Preliminary qualitative feedback from the parental interviews has all been positive and suggests that the CHAT is easy to use, enhances confidence, provides reassurance and enables informed early parental decision making regarding accessing advice and treatment.

Mixed methods of data collection and analysis will continue as the study progresses. The results will be disseminated at the end of the study (2015) and will determine the need for a future multi centred study.

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