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]. 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 [3,4].

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 Welcome 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 study (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 (or 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 (PEWS) to alert parents of deterioration through observation of their infant’s clinical signs, incorporating a colour coded trolley light system for ease of use [5].

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 is 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 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.

Aim
The aim of this poster is to present a parental early warning system called the Congenital Heart Assessment Tool (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. These three families were recruited to Group C during this time and therefore did not use the CHAT.

CONGENITAL HEART ASSESSMENT TOOL (CHAT)

The CHAT includes specific signs of deterioration that parents who completed the OS wanted more information about, relating to signs of heart failure 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 easy to use, enhances confidence, provides reassurance and enables informed early parental decision making regarding accessing advice and treatment.

A Sample of Parent’s Comments

TO “I feel good, because I know, because I’m with [infant] everyday, I have been looking at the CHAT everyday whilst in hospital. I know when [infant’s] pressure is low, I know when [infant] is in green, [infant] is in amber and when to call 999”

TO “I think the main tools to survive with, if something happens ‘I know what I need to do’ and ‘if I didn’t have it we’ll have to make our own judgement...’ probably won’t be the right one”.

TO “It’s really helpful because it tells you what to look for in green, amber and red. If I didn’t have the CHAT to look at when [infant] was poorly the other night, I woudn’t have gone running straight into hospital; I wouldn’t have known what to tell the doctor when I phoned up the CHAT”.

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

Infant’s Activity
Behaves normally e.g. Content/semi
Stays awake or awakens quickly (as normal)
Normal crying easily reassured by feeding, comfort, happy change

Parent’s Feedback at T0, T1, T2 and T3

TO “It’s really helpful because it tells you what to look for in green, amber and red. If I didn’t have the CHAT to look at when [infant] was poorly the other night, I woudn’t have gone running straight into hospital; I wouldn’t have known what to tell the doctor when I phoned up the CHAT”.

TO “It’s really helpful. It’s helping me to describe what I’m seeing”.

TO “I was a really big help to us when we first came out of hospital, we were a bit unsure, we’d check the chart, but now it’s made us feel more confident because we had that help to start with and to reassure us whether we’ve done the right thing or not.

Aim
The study will utilise existing data from the feasibility study, and will be used to inform the design of a larger scale prospective study.

References
5. Gaskin K. A pilot study to test the feasibility and effectiveness of a CHAT for parents of infants with a hypoplastic heart, with single ventricle heart condition. BSc(Hons) thesis, University of Worcester, 2014

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 been all 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.

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