Acceptability of a Parental Early Warning Tool: Outcomes from a Feasibility Study of Parental Home Monitoring and Assessment

Background
Home monitoring programmes (HMP) were developed to encourage early recognition of deterioration in infants who are at risk of potentially life threatening events between the first and second surgical stages and focus on parents obtaining daily measurements of their infant’s oxygen saturations (SpO2) and weight (wt). In this study, the role of a Congenital Heart Assessment Tool (CHAT), was assessed as an additional part of the HMP package. The CHAT was designed for ease of use and incorporated a traffic light system enabling parents to assess the severity of their infant’s condition through individualised parameters. Green assessment directed parents to ‘carry on as normal’, amber triggered a phone call to the ward to discuss management; a red response, indicated the infant was seriously ill and parents were advised to phone for an ambulance immediately.

Aim
The principle aim was to explore the feasibility of a Congenital Heart Assessment Tool (CHAT) and the acceptability of the CHAT and HMP from the parents’ perspective, emerging from interviews with parents (see table 2).

Method
A mixed methods approach was adopted. Data was collected at four time points: at discharge (T0); 2 weeks after discharge (T1), 8 weeks after (T2) and after stage two surgery (T3) using self-report tools, semi-structured interviews and daily diaries. Parents were recruited between August 2013 and February 2015. After obtaining consent parents were randomised into one of three groups: Group A, measured SpO2 and wt. and assessed their infant daily using the CHAT; Group B, used the CHAT alone or Group C, received standard discharge care. Participation ended when their infant returned for stage 2 cardiac surgery. 13 families were recruited (see table 1).

Contact with HCPs
• There were no interstage deaths amongst the entire patient group
• In total 15 contacts were made with CHAT by parents, in all three groups (see table 3).
• Both the CHAT and HMP were helpful in triggering contacts; mostly related to respiratory signs, rather than a primary cardiac problem.
• One Red CHAT triggered an admission emergency to the local hospital, infant JT8 was discharged the next day.
• JT8 red trigger was based on CHAT warning signs and corresponding O2 saturation changes (Figures 1-2).
• Amber CHAT trigger for NK4 and corresponding HMP can be seen in Figures 4.
• These two infants JT8 and NK4 were admitted for further surgical interventions following scheduled appointments at the hospital and not relating to a CHAT/HMP trigger.
• Two of the families in Group A did not record any of the daily measurements and did not return the daily diaries.
• One mother in group B contacted HCPs for advice based on her own perceptions of her infant’s condition rather than using the CHAT, as the CHAT had given her the confidence to know what was normal for her infant

Table 1. Recruitment
<table>
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<th>Recruitment (hospital survivors)</th>
<th>Interviews with Mothers (n, %)</th>
<th>Interviews with Fathers (n, %)</th>
<th>Group (n)</th>
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<th>CHAT Red (n)</th>
<th>Contact with HCPs</th>
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Table 2. Number of Interviews

Table 3. CHAT Triggers & contact with HCPs

Parents’ perceptions - HMP
Two key themes emerged from the interviews with Group A parents:
1. Parents were worried about becoming reliant on the equipment (before discharge)
2. Parents did not follow the HMP strictly on a daily basis
• Parents used the oxygen saturation monitor when they were worried as it was ‘more reassuring than the scales’
• The scales were ‘a hindrance more than helpful’, weighing became ‘a chore and a burden, especially when they were getting behind with other aspects of their infant’s care’

Parents’ perceptions - CHAT
Four key themes emerged from the interviews with Group A and B parents about their perceptions of the CHAT:
• Had prepared them for the signs that they needed to look out for at home
2. Was easy to use
3. Had increased their confidence
4. Gave them reassurance to call for advice when they noticed that something was different

Conclusions
The CHAT is a valuable addition to HMPs and gives parents greater confidence and reassurance in monitoring their child. There were zero interstage deaths in the study. Both the CHAT and the standard HMP stimulated contact with HCPs. However, three families in group A who took part in the interviews (table 2) found the weighing scales unhelpful. One mother in group B described how she sought HCP advice independently of the CHAT, after developing confidence through use of the CHAT in the early days of being at home.

Limitations
Small recruitment numbers made statistical comparison difficult. Language barriers were an obstacle to recruitment and need to be considered for future studies.

Some parents were offered monitoring via community teams as standard discharge care, therefore did not need the test to take part in the study

There was a lack of consistent documentation recorded by ward staff following contact with parents for CHAT triggers; and incomplete data recorded by group A and B parents in their diaries

Affiliations:
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