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

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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 stage 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) (see table 4) as part of a home monitoring programme (HMP) for parents going home with their infant between the first and second stage of surgery for complex congenital heart disease, including single ventricle and systemic shunt dependent conditions. This paper also reports on how many times parents made urgent contact with health care professionals (HCPs) (see from tables 3 and 3) 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: 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 daily, 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).

Recruitment (hospital survivors) Table 1. Recruitment Table 2. Number of Interviews Table 3. CHAT Triggers & contact with HCPs

Parent’s T/LS

<table>
<thead>
<tr>
<th>CHAT Amber</th>
<th>CHAT Red</th>
<th>Contact with HCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group (n)</td>
<td>(n)</td>
<td>(n)</td>
</tr>
<tr>
<td>Parent’s T/LS</td>
<td>Amber – Intermediate</td>
<td>Red – High Risk</td>
</tr>
<tr>
<td>A</td>
<td>Blue or pale than usual or no change</td>
<td>Not responding to normal activity</td>
</tr>
<tr>
<td>B</td>
<td>Blue or pale than usual or no change</td>
<td>Not responding to normal activity</td>
</tr>
<tr>
<td>C</td>
<td>Blue or pale than usual or no change</td>
<td>Not responding to normal activity</td>
</tr>
</tbody>
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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:

1. Had prepared them for the signs that they needed to look out for at home
2. Was easy to use
3. 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 feel the need 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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