Psychosocial adjustment and adaptation in parents of infants with complex congenital heart disease going home for the first time following first stage cardiac surgery: A Prospective Review

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Background
The fragility of infants with complex congenital heart disease (CHD), such as a functionally univentricular heart, being discharged home for the first time has been recognised1 and home monitoring programmes have been implemented in order to promote surveillance of pulse oximetry and daily weights in infants who are at risk of sudden death between first and second stage of cardiac surgery, have reported timely intervention and improved inter-stage survival2,3,4,5,6,7. However few studies consider the responsibility placed on the parents who are undertaking this home monitoring at this heightened time of vulnerability. Furthermore there is a dearth of evidence considering parents’ resilience, or the psychosocial impact of adopting a medical role at home on the parents, siblings or wider family.

Method
The study adopted a mixed methods approach to data collection and analysis. Parents (n=17, 13 mothers, 4 fathers) of infants (n=13) being discharged from a specialist cardiac centre in the UK were recruited into a home monitoring programme feasibility study, which commenced in August 2013 and ended in February 2015.

The study randomised into 3 arms: Group A were discharged home with digital scales, a pulse oximeter and a traffic light tool called the Congenital Heart Assessment Tool (CHAT). The CHAT tool uses a red, amber, green color coding system to give an early indication of deterioration in the infants’ condition. Group B were discharged home with the CHAT tool only and Group C were randomised to standard discharge care.

The parents completed semi-structured interviews at 4 time points:
- T0 before discharge (see box 1 and 2)
- T1 2 weeks post discharge
- T2 8 weeks post discharge
- T3 following the second surgical intervention (approximately 4-6 months post discharge).

Baseline demographic data is presented in table 1.

Parents were asked to complete three validated self-report tools which scored for depression (PHQ9), anxiety disorder (GAD7) and parental confidence (Maternal Confidence Score8,9,10). The PHQ9 scores were used to identify moderate to high risk for GAD7 or PHQ9 (see orange shading on charts 1-4) consented to their General Practitioner being informed of the result:
- PHQ9 Scores 11-15 = moderately severe, 16-20 = severe depression
- GAD7 scores 11-15 = moderate anxiety, 16-21 = severe anxiety
- MCS scores range between 0-70, higher scores equate to higher levels of confidence

Table 1 Parent demographics at T0

<table>
<thead>
<tr>
<th>Parent</th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>23</td>
<td>30</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Employment</td>
<td>Full time</td>
<td>Part time</td>
</tr>
<tr>
<td>Distance from home</td>
<td>45 miles</td>
<td>15 miles</td>
</tr>
<tr>
<td>Distance from hospital</td>
<td>0.5 miles</td>
<td>5 miles</td>
</tr>
</tbody>
</table>

Table 2 Parented interviews demonstrated fear of:
- The unknown, uncertainty
- Being alone, isolation
- Loss of safety and security of hospital environment
- Having no monitors at home
- Something happening
- Not knowing what to do or who to contact
- Not having enough information, knowledge or skill

Table 3 Wilcoxon Signed Ranks Test

<table>
<thead>
<tr>
<th>Time point</th>
<th>MCS T0 - T3</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paired 1 GAD7 T0 - T3</td>
<td>4.64</td>
<td>0.005</td>
</tr>
<tr>
<td>Paired 2 PHQ9 T0 - T3</td>
<td>6.57</td>
<td>2.76</td>
</tr>
</tbody>
</table>

Conclusion
While the sample size made it difficult to inferentially test the data (GAD7, PHQ9, MCS), the qualitative data demonstrated that dynamic processes occurred for all of the families. Most parents psychologically adapted and adjusted over time; however, maladaptation may have related to ongoing parental uncertainty regarding their infant’s condition and the unpredictable risk of their illness.

References