

# 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 recognised<sup>[1]</sup> and home monitoring programmes have been implemented in order to promote early identification of deterioration and speedy intervention<sup>[2,3,4,5]</sup>. Studies incorporating home 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 survival<sup>[2-5]</sup>. 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.

## Aim

The study presented here prospectively explored psychosocial adaptation and adjustment (anxiety, depression & confidence) in parents going home for the first time with their infants following first stage cardiac surgery for complex CHD

## 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 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<sup>[6]</sup>), general anxiety disorder (GAD7<sup>[7]</sup>) and parental confidence (Maternal Confidence Score<sup>[8]</sup>) at T0, T1, T2, T3 (as above). Those parents scoring 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 moderately severe anxiety 15-21 severe anxiety
- MCS scores range between 0-70, higher scores equate to higher levels of confidence

Chart 1 Mothers' Anxiety Scores

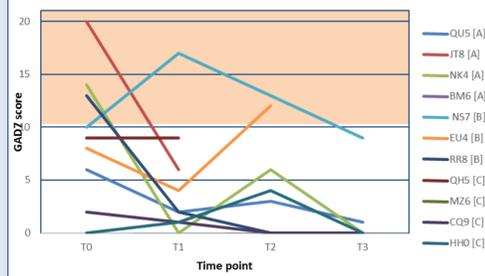


Chart 2 Fathers' Anxiety Scores

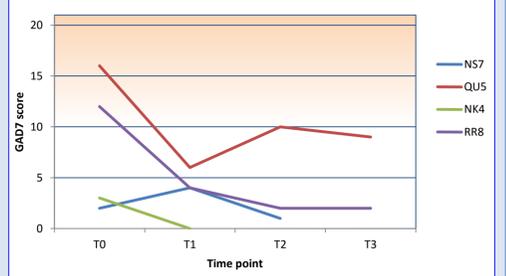


Chart 3 Mothers' Depression Scores

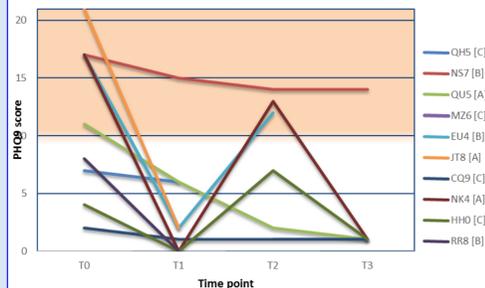


Chart 4 Fathers' Depression Scores

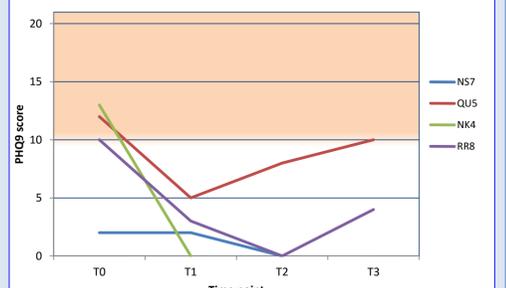


Chart 5 Mothers' Confidence Scores

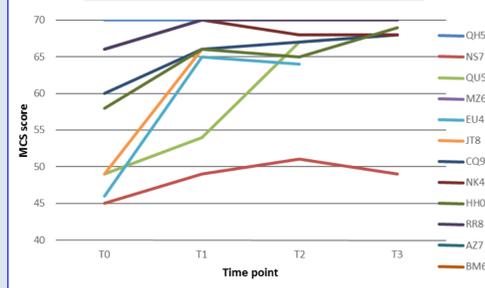
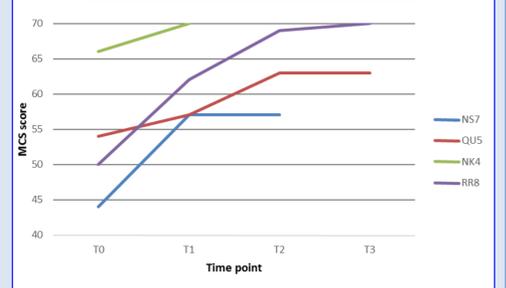


Chart 6 Fathers' Confidence Scores



In charts 1-4 parents demonstrate a trend of high anxiety and depression scores before discharge (T0), improving over time (T1); with scores increasing again for some parents before stage 2 surgery (at T2). Parents' confidence scores (charts 5 and 6) increased over time with some reduction in confidence scores before stage 2 surgery (at T2).

The paired samples t-test (for parametric data) was used to examine mean parental scores for GAD7 and PHQ9 over time from T0 to T3 (see table 2). The Wilcoxon signed ranks tests (for non-parametric data) was used to examine mean parental confidence scores over time from T0 to T3 (see table 3). GAD7, PHQ9 and MCS mean scores were compared with parental demographics, however there were no statistically significant relationships between psycho-social functioning and postcode deprivation index, parity, education, employment, or distance from home (in table 1). Caution needs to be taken when interpreting the statistics due to the small sample size.

Table 1 Parent demographics at T0

Parent's Age	Mother (n=12)	Father (n=0)
<21	1	
21-25	2	
26-30	4	
31-40	5	
Employment	Mother (n=13)	Father (n=13)
Employed for wages	0	6
Self-employed	1	2
Out of work and looking for work	0	0
Out of work but not currently looking for work	12	2
A homemaker	0	0
Maternity/paternity leave	0	0
Sick leave	0	3
Postcode Deprivation Index	Mother (n=13)	Father (n=13)
0-5,000	7	
5,000 - 10,000	2	
10,000-15,000	3	
15,000-20,000	0	
20,000-25,000	1	
25,000-30,000	0	
30,000+	0	
Distance from Specialist Cardiac Hospital	Mother (n=13)	Father (n=13)
<20 miles	6	
20-30 miles	2	
30-40 miles	2	
50-100 miles	2	
>100 miles	1	
Ethnicity	Mother (n=13)	Father (n=13)
White - British	10	8
White - Irish	1	
White - European	0	0
Black or Black British	2	1
British Asian	0	2
Other	0	1
Time of Diagnosis	Number of responses (n=13)	
Antenatal	12	
Postnatal	1	

### Box 1 At T0 ALL (n=17) parent 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

### Box 2 At T0 parent interviews (n=4) demonstrated signs of:

- Post traumatic stress disorder
- Shock
- Devastation
- Helplessness
- Detachment and dissociation
- Parenting from afar
- Trauma of lasting images

Table 2 Paired samples t-test

	mean	S.D.	95%CI lower	95%CI upper	t (n)	sig. 2 tailed	p
Pair 1 GAD7 T0 - T3	5.64	5.82	1.73	9.55	3.21 (16)	0.009	<0.01
Pair 2 PHQ9 T0 - T3	6.64	5.77	2.76	10.51	3.82 (16)	0.003	<0.01

Table 3 Wilcoxon Signed Ranks Test

	Z	sig. 2. tailed	p
MCS T0 - T3	-2.83	0.005	<0.01

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## Conclusion

Whilst 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 unpredictability of their prognosis.

Whilst the aim of the study was not to specifically identify parents at risk of post traumatic stress disorder (PTSD)<sup>[9]</sup>, the implications for practice refer to a need for early recognition of symptoms as potential predictors of parental PTSD. This would ensure that support can be offered for both parents to modulate the responses and assist in adaptive processes where there is a high risk of psychological maladaptation.

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