The impact of morbidities following pediatric cardiac surgery on family functioning and parent quality of life

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Running head: Family outcomes after paediatric cardiac surgery

Study registration
The study has ethical approval from London City Road Research Ethics Committee (14-LO-1442).
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Conflicts of interest
None

Abstract

Background

We previously selected and defined nine important postoperative morbidities linked to paediatric cardiac surgery, and prospectively measured their incidence following 3090 consecutive operations. Our aim was to study the impact of these morbidities on family functioning and parental quality of life over 6 months in a subset of cases.

Methods

As part of a prospective case matched study in five of the ten children's cardiac centers in the UK, we compared outcomes for parents of children who had a 'single morbidity', 'multiple morbidities', 'extracorporeal life support (ECLS)' or 'no morbidity'. Outcomes were evaluated using the PedsQL Family impact module (FIM) at 6 weeks and 6 months post-surgery. Outcomes were modelled using mixed effects regression, with adjustment for case mix and clustering within centers.

Results

We recruited 340 patients with morbidity (60% of eligible patients) and 326 with no morbidity over 21 months. In comparison to the reference group of 'no morbidity', after adjustment for case mix, at 6 weeks parent health-related quality of life (HRQoL) and total FIM sores were lower (worse) only for ECLS ($p<0.005$), although a higher proportion of parents in both the ECLS and multi-morbidity groups had low/very low scores ($p<.05$). At 6 months, parent outcomes had improved for all groups but parent HRQoL and total score for ECLS remained lower than the 'no morbidity' group ($p<.05$) and a higher proportion of families had low or very low scores in the ECLS (70%) group ($p<.01$).

Conclusions

Postoperative morbidities impact parent HRQoL and aspects of family functioning early after surgery, with this impact lessening by 6 months. Families of children who experience postoperative morbidities should be offered timely psychological support.

Introduction

Survival rates after pediatric cardiac surgery are now very high, allowing for other outcomes such as rates of specific adverse events, neurodevelopmental and psychosocial outcomes and health-related quality of life to be studied. The inter-relationship of many of these outcomes is evident – for example the association between post-operative seizures or neurological events and longer term neurodevelopmental and psychosocial outcomes. Post-operative complications are thus an increasing focus as further improvements in outcome are sought.

The psychological impact on parents of children with congenital heart disease (CHD) and its treatment has been well documented,[1 23] together with the influence of parent functioning on child psychosocial outcomes.[4 56] Furthermore, recent research has emphasized the importance of environmental and parental factors as correlates of maternal quality of life.[7] That cardiac surgery in their children, and a subsequent stay in intensive care, can be traumatic for parents is not in doubt. However, the psychological impact of peri/post-operative morbidities on parents has not been evaluated, thus precluding the opportunity for developing and implementing targeted interventions to better support parents, with potential longer-term benefits for both them and their children.

As part of a mixed-methods, multi-center prospective case matched cohort study, we measured the impact of early morbidities linked to pediatric cardiac surgery on children and their families. Earlier stages of our project have been published, including the selection[8] and definition[9] of nine key surgical morbidities that were considered to be the most important based on consensus of clinicians and parent representatives (acute neurological event, renal replacement therapy, necrotizing enterocolitis (NEC), major adverse events (cardiac arrest, reopening of chest on ward/intensive care unit, major haemorrhage, tissue injury to limb or vital organ, never event), extracorporeal life support (ECLS), post-surgical infection, prolonged pleural effusion or chylothorax, unplanned re-intervention, and feeding problems)

and the incidence of these morbidities amongst 3090 consecutive surgical admissions at five of the ten children's heart centers in the UK between October 2015 and June 2017.[10] We have also reported the impact of the selected morbidities on the quality of life of children and mental health of their parents at 6 weeks and 6 months after surgery.[11] In this manuscript we report the impact on parental health-related quality of life (HRQoL) and family functioning at the same time points. Our hypothesis was that ECLS and multiple morbidities would have a greater impact on parental HRQoL and family functioning than single morbidities or no morbidity.

Methods

Ethical approval for the study was granted by London City Road Research Ethics Committee (14-LO-1442); all participants provided written consent.

Participants were parents of children <17 years of age who underwent cardiac surgery (either electively or as an emergency) in one of five participating centers in the UK. Families had to be resident in the UK and able to speak and understand English. All patients recruited to the study either had one or more of the selected nine surgical morbidities (*morbidity case*) or they did not have a morbidity and were recruited as a matched (based on age and case complexity) control for a recruited patient with a morbidity (*morbidity-free control*). Details of recruitment and matching have been described previously.[12] Clinical and demographic data were collected at baseline, with a focus on variables previously linked to early mortality and/or health-related quality of life, details of which are provided in Table 1 and supplementary material Tables A-C. Details about recruitment and data collection processes are provided in supplementary material Table D.

Table 1: Demographic and clinical characteristics of patients recruited to the impact study and those followed up at 6 weeks and 6 months

	Recruited to Impact (N=666)	At 6 weeks (N=469)	At 6 months (N=392)
Age at initial procedure: mean (sd) (years)	1.3 (3.0)	1.4 (2.8)	1.5 (2.9)
Low weight	193/624 (30.9)	124/435 (28.5)	94/363 (25.9)
Gender (male)	374 (56.2)	276 (58.9)	220 (56.1)
No morbidity	326 (49.0)	240 (51.2)	199 (50.8)
Single morbidity	195 (29.3)	145 (30.9)	120 (30.6)
Extra-corporeal life support	27 (4.0)	11 (2.3)	10 (2.5)
Multiple morbidities	118 (17.7)	73 (15.6)	63 (16.1)
Cardiac Diagnosis			
E – least complex disease	168 (25.2)	121 (25.8)	106 (27.0)
D	196 (29.5)	140 (29.8)	103 (26.3)
C	124 (18.6)	91 (19.4)	72 (18.4)
B	90 (13.5)	57 (12.2)	56 (14.3)
A – most complex disease	88 (13.2)	60 (12.8)	55 (14.0)
Univentricular heart condition (yes)	134 (20.1)	92 (19.6)	84 (21.4)
Acquired comorbidity (yes)	97 (14.6)	67 (14.3)	60 (15.3)
Congenital comorbidity (yes)	121 (18.2)	85 (18.2)	77 (19.6)
Severity of illness risk (yes)	124 (18.6)	72 (15.4)	66 (16.8)
Premature (yes)	60 (9.0)	42 (9.0)	32 (8.2)
Down syndrome (yes)	56 (8.4)	41 (8.7)	28 (7.1)
Additional cardiac risk factors (yes)	56 (8.4)	31 (6.6)	30 (7.7)
Cardiac procedure			
Palliative	155 (23.3)	102 (21.8)	88 (22.5)
Reparative	359 (53.9)	259 (55.2)	207 (52.8)
Ambiguous	152 (22.8)	108 (23.0)	97 (24.7)
No bypass	92 (13.8)	62(13.2)	53 (13.5)
Up to 90 minutes	198 (29.7)	142 (30.3)	120 (30.6)
More than 90 minutes	376 (56.5)	265 (56.5)	219 (55.9)
Ethnicity (white)	501/604 (83.0)	368/438 (84.0)	314/373 (84.2)
2 or more carers (yes)	523/558 (93.7)	390/413 (94.4)	331/347 (95.4)
Family income (>25k)	361/570 (63.3)	281/424 (66.3)	236/353 (66.9)
Mother's education level (degree or higher)	263/571 (46.1)	204/421 (48.5)	182/356 (51.1)

Research nurses undertook data collection with families at 6 weeks and 6 months after surgery. In situations where a child was still in hospital at follow-up, data were collected where possible. Data were collected face-to-face, electronically or by telephone, depending on parents' preferences.

Family impact was assessed with the PedsQL Family Impact Module (FIM),[13] a generic measure comprising 36 items (eight subscales) which assesses parents' self-reported HRQoL and family functioning as a result of their child's health. It takes approximately 10 minutes to complete. Individual subscale scores, parent HRQoL summary score, family function summary score and a total score were computed, each with a range of 0-100, where higher scores equated to better perception of function.

Data analysis

Due to lower than expected recruitment of children with some specific single morbidities, and hence small numbers in individual categories, morbidities were categorized as single morbidity (one of the selected morbidities excluding ECLS), multiple morbidity (more than one selected morbidity excluding ECLS) and ECLS (on ECLS +/- other morbidities).

Mean (SD) FIM (individual subscale, parent HRQoL, family impact and total) scores were summarized for each morbidity group and controls at 6 weeks and 6 months. The distribution of the scales is also displayed graphically with box plots.

Mixed-effects regression models were used to explore the impact of the four morbidity categories (none, single morbidity, multiple morbidity and ECLS) on outcomes at 6 weeks and at 6 months. Models were adjusted for pre-specified covariates (weight, age, functionally univentricular heart, cardiac diagnosis category, specific procedure type category, bypass time, acquired comorbidity, congenital comorbidity other than Down syndrome, additional cardiac risk factors, prematurity, Down syndrome and severity of illness indicator, all previously defined in detail).[12] Furthermore, we adjusted all models for 4 family factors: family income, ethnicity, mothers' education and number of carers in the family, each as a binary factor. All models included a random factor for patient, nested within matched pairs, to account for the correlation between matched pairs. Multiple imputation

using chained equations was used for missing values. The Normality assumption of the models was checked.

Using the “no morbidity” group as the reference category, we present absolute differences and 95% confidence intervals for the 3 morbidity groups, for each outcome.

To place our findings into context, we also explored and described how the FIM (parent HRQoL and family functioning summary and total scores) for the study population compared to data from parents of healthy children. We used normative mean values and standard deviations for the overall FIM[14] to identify any scores that could be categorized as low (falling 1-2SD below the normative mean) or very low (more than 2SD below the normative mean), expressing those with low/very low scores as frequencies (proportions) in each morbidity group.

Stata v14 was used for all analyses.

Results

We recruited 340 patients who had experienced one or more of the selected morbidities after cardiac surgery, representing 60% of all eligible patients and 326 controls (666 patients in total), 558 of whom were case-control matched.

Detailed descriptions of the case mix have been presented previously and are shown in Table 1 and Table A (supplementary material), but in summary our cohort comprised 410 (77%) children <12 months old at the time of surgery; 135 (20%) had functionally univentricular hearts and 121 (18%) had congenital comorbidities other than Down syndrome. Most children were of white ethnicity (n=501; 83%) and lived with both parents (n=523; 94%) in households with an annual income above the UK median (n=361; 63%).

Loss to follow-up

Nineteen (3%) patients had died by the six-week follow-up, with 70 (11%) still in hospital. A further 20 patients had died by six months, with 5 still in hospital. Complete FIM data were available for 469 at 6 weeks (72% of surviving patients) and 392 at 6 months (63%).

Comparing those for whom FIM data were available with those with missing data at 6 weeks and 6 months, the only differences on baseline factors was at 6 weeks where the proportion with baseline severity of illness risk factors and acquired cardiac risk factors was higher in those with missing data.

Morbidities

Figures 1 and 2 show the parent HRQoL and family functioning summary scores at 6 weeks and 6 months according to the presence of no selected morbidity, each individual single morbidity, multiple morbidities and ECLS. Analysis of the impact of morbidity, after adjusting for covariates, showed that there was a significant negative impact on parent HRQoL and total score at the 6-week follow up in the ECLS group ($p<0.005$) but the single morbidity and multi-morbidity categories were not statistically significantly different to the no morbidity category. On individual subscales there were significant differences between the ECLS and no-morbidity groups on the physical ($p<.005$), emotional ($p<.001$), social ($p<.05$) and activities ($p<.05$) subscales. There were no significant differences for family function scores by morbidity category. By 6 months the impact on the families in the ECLS group had lessened but remained evident for parent HRQoL and total score ($p<.05$) and on the physical, emotional, worry and activities subscales ($p<.05$) (Table 2).

Table 2: Mean (SD) Family Impact scores at 6 weeks and 6 months post-operation by four morbidity groups and adjusted comparison of outcome by morbidity groups. Normative data are also shown.

Family Impact Module (6 weeks)	No Morbidity (n=240)	Single Morbidity (n=145)	ECLS Morbidity (n=11)	Multi Morbidity (n=73)	Normative sample (n=929)[14]	Single v None Difference^ (95% CI) P value	ECLS v None Difference^ (95% CI) P value	Multi v None Difference^ (95% CI) P value
Parent HRQoL	73.7 (19.5)	69.4 (21.6)	49.0 (21.6)	66.7 (20.6)	69.4 (15.5)	-2.4 (-6.4, 1.6) 0.23	-16.8 (-27.9, -5.6) 0.003**	-5.2 (-10.4, -0.01) 0.05
Family function	74.1 (22.6)	72.9 (24.9)	61.1 (12.8)	70.2 (21.9)	65.5 (18.5)	-0.3 (-5.2, 4.6) 0.92	-7.3 (-18.6, 4.0) 0.21	-1.4 (-7.0, 4.3) 0.64
Family total	72.3 (18.9)	69.2 (20.7)	49.2 (16.7)	66.5 (18.1)	70.8 (14.5)	-1.5 (-5.4, 2.3) 0.43	-13.9 (-23.7, -4.1) 0.005**	-3.8 (-8.5, 1.0) 0.12
Subscales								
Physical	70.6 (21.6)	66.5 (23.1)	47.3 (20.5)	63.2 (23.4)	64.9 (17.4)	-2.1 (-6.7, 2.4) 0.36	-15.8 (-26.9, -4.3) 0.005**	-5.7 (-11.6, 0.2) 0.06
Emotional	74.7 (23.1)	68.8 (25.9)	40.0 (22.0)	67.7 (24.8)	67.6 (17.9)	-4.0 (-8.6, 0.7) 0.10	-24.1 (-37.8, -10.4) 0.001**	-5.9 (-12.0, 0.2) 0.06
Social	75.3 (25.7)	70.3 (27.0)	53.4 (25.7)	69.1 (24.2)	74.4 (19.1)	-2.4 (-7.4, 2.6) 0.35	-14.7 (-27.4, -2.1) 0.02*	-4.1 (-10.7, 2.5) 0.22
Cognitive	75.1 (24.3)	72.7 (26.8)	56.4 (27.8)	67.6 (28.3)	73.5 (18.6)	-1.3 (-6.5, 3.9) 0.62	-12.3 (-26.1, 1.5) 0.08	-5.0 (-12.0, 2.0) 0.16
Communication	71.9 (25.0)	70.2 (24.8)	39.4 (22.1)	67.6 (23.3)	81.9 (17.7)	-0.03 (-5.3, 5.2) 0.99	-12.0 (-26.3, 2.3) 0.10	-1.1 (-7.3, 5.0) 0.72
Worry	63.7 (23.2)	61.7 (24.8)	36.8 (25.7)	59.2 (22.8)	78.1 (20.1)	-1.0 (-6.0, 4.1) 0.71	-13.3 (-26.8, 0.1) 0.05	-2.8 (-9.0, 3.4) 0.38
Activities	63.4 (29.4)	59.5 (32.5)	25.8 (21.1)	53.7 (30.2)	63.2 (22.5)	-2.2 (-8.5, 4.1) 0.49	-19.6 (-36.5, -2.6) 0.02*	-4.9 (-12.9, 3.0) 0.23
Relationships	80.5 (22.6)	81.0 (24.2)	82.3 (14.4)	80.2 (22.9)	67.0 (19.4)	0.90 (-3.9, 5.7) 0.71	0.01 (-11.1, 11.1) 0.99	0.80 (-4.8, 6.4) 0.79

Family Impact Module (6 months)	No Morbidity (n=199)	Single Morbidity (n=120)	ECLS Morbidity (n=10)	Multi Morbidity (n=63)	Normative sample (n=929)	Single v None Difference^ (95% CI) P value	ECLS v None Difference^ (95% CI) P value	Multi v None Difference^ (95% CI) P value
Parent HRQoL	75.6 (18.3)	74.1 (20.4)	62.3 (22.3)	68.9 (20.7)	69.4 (15.5)	-1.0 (-5.5, 3.5) 0.66	-14.0 (-27.0, -1.1) 0.03*	-3.4 (-8.7, 1.8) 0.20
Family function	78.1 (20.4)	77.2 (21.2)	64.4 (23.5)	73.5 (22.0)	65.5 (18.5)	-0.2 (-4.9, 4.4) 0.92	-12.1 (-25.0, 0.8) 0.07	-2.2 (-8.0, 3.6) 0.46
Family total	74.6 (17.4)	73.2 (19.2)	60.1 (21.6)	68.5 (19.2)	70.8 (14.5)	-0.7 (-4.8, 3.4) 0.73	-13.4 (-25.2, -1.7) 0.03*	-3.1 (-8.0, 1.9) 0.23
Subscales								
Physical	73.9 (22.3)	71.9 (24.6)	57.5 (25.0)	67.4 (23.0)	64.9 (17.4)	-1.3 (-6.7, 4.1) 0.63	-15.2 (-29.3, -1.0) 0.04*	-3.2 (-9.4, 3.1) 0.32
Emotional	74.9 (21.9)	73.1 (23.3)	54.5 (29.6)	68.5 (24.2)	67.6 (17.9)	-1.2 (-6.0, 3.7) 0.63	-19.9 (-37.2, -2.6) 0.03*	-3.5 (-9.7, 2.8) 0.28
Social	77.6 (23.8)	75.4 (22.7)	67.5 (31.6)	71.5 (25.1)	74.4 (19.1)	-1.5 (-6.4, 3.4) 0.54	-13.8 (-29.7, 2.0) 0.09	-2.8 (-9.0, 3.4) 0.38
Cognitive	76.8 (20.6)	76.6 (23.4)	71.5 (29.8)	69.1 (26.7)	73.5 (18.6)	0.07 (-5.3, 5.5) 0.98	-7.0 (-23.1, 9,2) 0.40	-4.3 (-10.9, 2.3) 0.21
Communication	71.1 (24.5)	72.1 (24.2)	54.2 (22.3)	66.3 (24.7)	81.9 (17.7)	0.5 (-4.5, 5.5) 0.84	-11.6 (-25.0, 1.8) 0.09	-2.3 (-8.9, 4.2) 0.49
Worry	66.9 (22.8)	64.0 (24.2)	48.0 (26.7)	59.9 (24.2)	78.1 (20.1)	-1.3 (-6.1, 3.5) 0.59	-13.9 (-27.6, -0.3) 0.05*	-3.4 (-9,7, 2.9) 0.29
Activities	71.1 (27.6)	68.5 (29.2)	46.7 (32.7)	61.0 (30.8)	63.2 (22.5)	-1.1 (-7.8, 5.6) 0.75	-22.1 (-41.2, -3.0) 0.02*	-5.5 (-13.2, 2.1) 0.16
Relationships	82.3 (21.2)	82.4 (20.5)	75.0 (22.1)	81.0 (21.6)	67.0 (19.4)	0.3 (-4.3, 4.9) 0.90	-6.1 (-18.5, 6.3) 0.34	-0.2 (-6.2, 5.9) 0.96

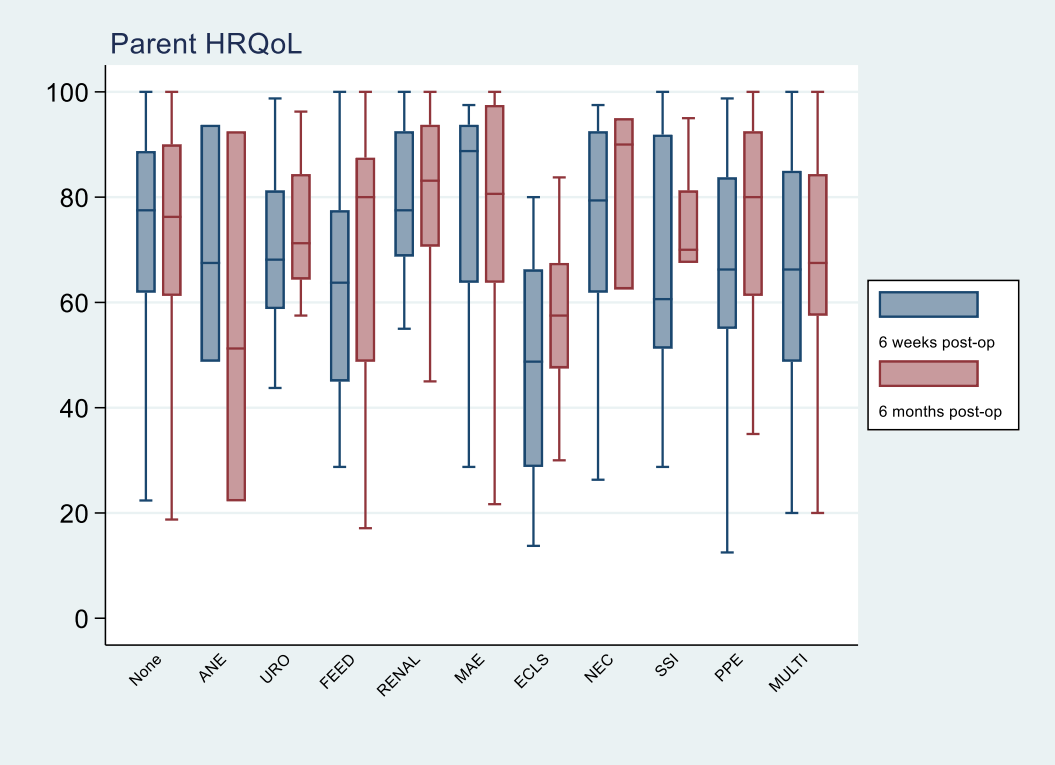


Figure 1: FIM parent health-related quality of life scores by no morbidities, individual morbidities and multiple morbidity at 6 weeks and 6 months

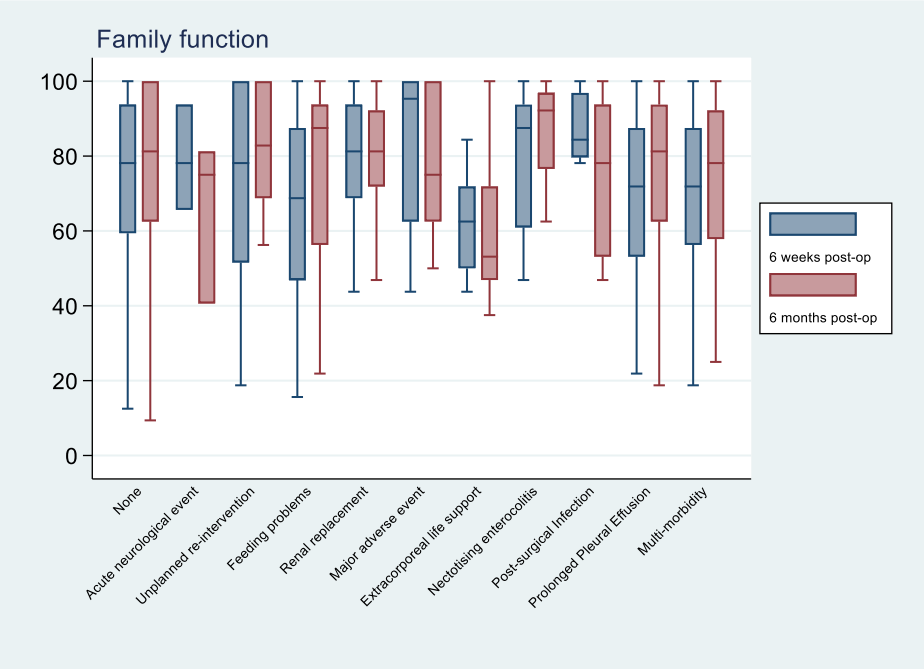
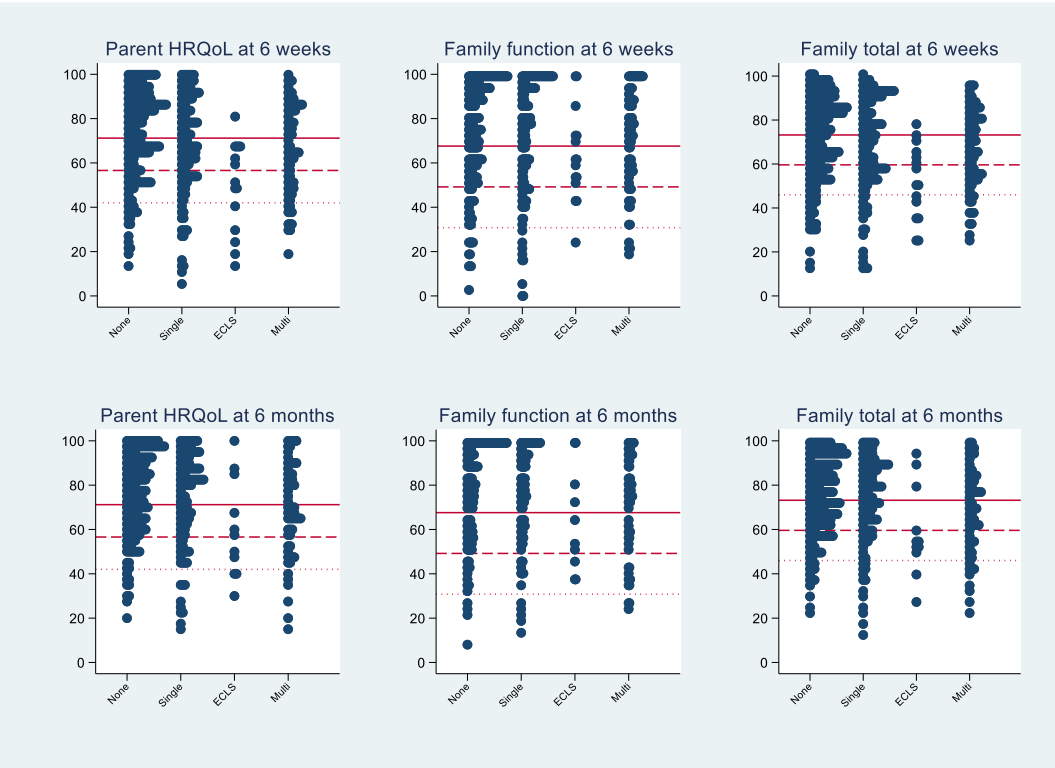


Figure 2: FIM family impact scores by no morbidities, individual morbidities and multiple morbidity at 6 weeks and 6 months

The boxplots show FIM scores for no selected morbidities, for each selected morbidity in isolation and multiple morbidities (blue for 6 weeks post-operation and red for 6 months post-operation). The middle heavy bar represents the median, the box represents the IQR 25th (Q1) to 75th centiles (Q3), and the outer lines ending in a bar represent the threshold for lowest and highest deciles.

Looking at the outcomes descriptively in terms of families with low/very low total FIM scores (Figure 3), a higher proportion of families reported a negative impact of their child's health than would be expected in a healthy population in all groups at 6 weeks (Table 3), with the ECLS and multiple morbidity groups reporting the greatest impact: ECLS 8/11 (73%) low/very low scores and multiple morbidity 29/73 (40%) low/very low scores. By 6 months the family impact reported by the no morbidity and single morbidity groups appeared similar to a healthy population, whereas those families affected by ECLS or multi-morbidities reported some residual impact: ECLS 7/11 (70%) low/very low scores; multiple morbidities 19/63 (30%) low/very low scores.



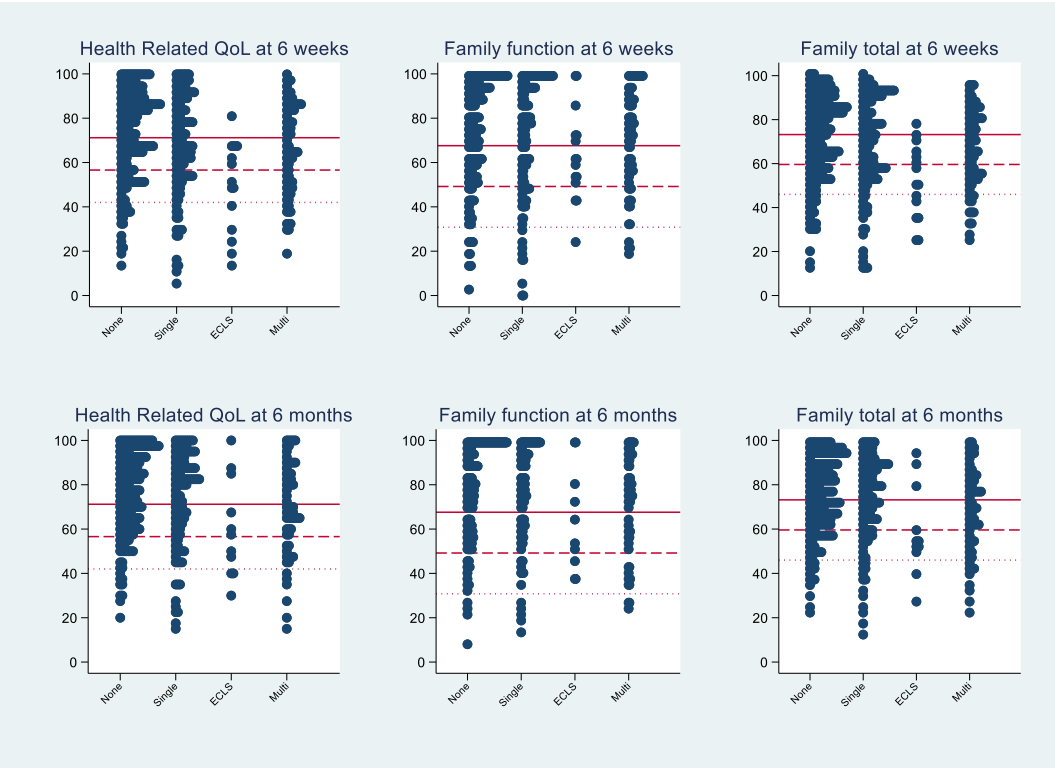


Figure 3: Distribution of FIM scores by no morbidities, single morbidity and multiple morbidity at 6 weeks and 6 months (solid line indicates mean of normative sample, dashed line indicates one standard deviation below the mean of normative sample (low score) and dotted line indicates two standard deviations below the mean of normative sample (very low score).

Table 3: Number (%) of low/very low Family Impact Module scores by morbidity groups at the two time points

A low score lies 1-2 SD below the normative mean (expected % for a normal healthy population is 13.6%) and a very low score lies more than 2 SD below the normative mean (expected % for a normal healthy population is 2.5%); 16.1% would be expected to have low/very low scores

6 week time point	**No Morbidity (total N=240)**	**Single Morbidity (total N=145)**	**ECLS (total N=11)**	**Multi Morbidity (total N=73)**	**Single v None Odds ratio (95%CI) P value**	**ECLS v None Odds ratio (95%CI) P value**	**Multi v None Odds ratio (95%CI) P value**
Family Impact Module scale	**Low / Very Low Score N (%)**	**Low / Very Low Score N (%)**	**Low / Very Low Score N (%)**	**Low / Very Low Score N (%)**			
Parent quality of life	49 (20.4)	38 (26.2)	6 (54.5)	26 (35.6)	1.4 (0.8, 2.3) 0.25	4.5 (1.3, 14.8) 0.01	2.4 (1.3, 4.6) <0.01
Family function	31 (12.9)	30 (20.7)	2 (18.2)	14 (19.2)	1.8 (1.0, 3.3) 0.05	1.7 (0.3, 11.0) 0.56	1.9 (0.9, 4.1) 0.09
Family total	61 (25.4)	49 (33.8)	8 (72.7)	29 (39.7)	1.4 (0.9, 2.3) 0.16	5.9 (1.5, 22.6) 0.01	2.0 (1.1, 3.7) 0.02
6 month time point	**No Morbidity (total N=199)**	**Single Morbidity (total N=120)**	**ECLS (total N=10)**	**Multi Morbidity (total N=63)**			
Family Impact Module Scale	**Low / Very Low Score N (%)**	**Low / Very Low Score N (%)**	**Low / Very Low Score N (%)**	**Low / Very Low Score N (%)**			
Parent quality of life	31 (15.6)	24 (20.0)	4 (40.0)	17 (27.0)	1.2 (0.7, 2.2) 0.48	3.1 (0.8, 11.7) 0.1	1.9 (0.9, 4.0) 0.07
Family function	16 (8.0)	14 (11.7)	3 (30.0)	11 (17.5)	1.4 (0.7, 2.9) 0.32	7.4 (1.8, 30.8) <0.01	2.4 (0.9, 6.2) 0.06
Family total	39 (19.6)	25 (20.8)	7 (70.0)	19 (13.2)	1.0 (0.6, 1.8) 0.96	10.7 (2.4, 46.9) <0.01	1.8 (0.9, 3.5) 0.10

Discussion

This is the first study of which we are aware to prospectively assess the impact of surgical morbidities on short-term parental HRQoL and family function outcomes. Our multi-center design enabled us to collect outcome data at several time points from a representative population of children undergoing cardiac surgery in the UK. After adjustment for case mix and family demographic factors, our results encouragingly showed that at 6 weeks it was only the ECLS group who showed a greater impact on parent HRQoL and total score compared to those in the no-morbidity group. Furthermore, based on the presence of morbidity, overall family functioning was not impacted in any of the morbidity groups. Our hypothesis was therefore not supported. At six months the impact in the ECLS group had lessened although differences were still evident in terms of parent HRQoL and total score. Of note, however, was the disparity in subscale scores within the family function domain, particularly at 6 weeks. Scores in the ECLS group were lower on scales measuring worry, communication and activities but all groups had relatively high scores, indicating less impact, on the scale measuring family relationships.

Comparisons with other populations

The proportions of parents scoring with low/very low total scores indicating greater family impact, were higher for all groups at 6 weeks than would be expected in a normative sample, suggesting that having a child with CHD undergoing cardiac surgery has an impact on families irrespective of whether the child has any peri- or post-operative morbidities, supporting previous findings.[1 2 4 5] Not surprisingly, the presence of morbidity was associated with higher proportions of low/very low scores. The impact had lessened by 6 months for the no-morbidity and single morbidity groups but some of those affected by ECLS or multi-morbidities continued to report scores indicative of impact on parental HRQoL. Our findings of worse parent HRQoL in families of children with CHD compared with healthy norms supports other findings.[15]

Comparisons with data from a community sample indicated that worry and communication scores were lower (greater impact) but relationship scores were higher (less impact) in all morbidity groups.[14] Similar findings were found for parents of children who were admitted to paediatric intensive care for critical illness or acute brain injury.[16] This suggests that cardiac surgery and other critical illnesses may have a less detrimental impact on certain aspects of family functioning or it may be that there are limitations in the FIM to detect differences in some areas. Some parents may also have experienced post-traumatic growth[17] following their child's diagnosis and cardiac surgery, recently reported to a 'moderate to great' degree in relation to experiences of CHD.[18]

Although elevated levels of parental stress have been reported following cardiac surgery as well as ECMO, [19-21] family impact has not been well studied previously. Our findings demonstrate the residual effects on parental HRQoL of highly stressful situations during their child's hospitalisation and the need for ongoing interventions targeting parental adjustment to, and coping with, their child's surgery and surgical morbidities. Perhaps surprisingly, and despite the strong evidence of the need for trials of psychosocial interventions for parents of children with CHD, a recent systematic review identified just four trials of mental health interventions for parents of children with CHD in intensive care.[22] All the trials demonstrated efficacy in reducing maternal anxiety and/or enhancing maternal coping, confidence or family functioning but the quality of the evidence was very low and no evidence of efficacy was found for improving either parent or child quality of life. More recently parents' preferences for interventions to address their psychosocial needs across the continuum of care which are individualised, formalised and multidisciplinary have been identified.[23] In the UK, as elsewhere, provision of psychological support varies widely and, whilst parents in all centers in the UK should have access to psychological support, it is unlikely that the needs of all parents are being adequately met. Identifying what individual parents need is the first step to providing early, targeted intervention.

Limitations

We recruited 60% of eligible patients and had a response rate in terms of FIM data of approximately 74% but we were not able to collect data from the families of children who had died or from those who were very sick in PICU, thus introducing a source of bias. Furthermore, the lower than anticipated incidence of some specific morbidities prevented us from determining the impact on families of these single morbidities. The main findings relate to the ECLS group; although small in number, they experienced important adverse medical outcomes.[10] We only collected data from one parent/carer in each family, predominantly mothers, limiting the generalisability of the findings to all parents. As the questionnaire required at least one parent to understand English, the exclusion of non-speaking English families is likely to be a source of bias. The prospective, observational nature of the study and its design also precluded determination of causality.

Conclusions

Postoperative morbidities after paediatric cardiac surgery, particularly the requirement for ECLS, impact parental HRQoL and elements of family functioning, especially in the first postoperative weeks, with this impact lessening by 6 months after surgery. Appropriate pre-operative preparation about the risks and associated consequences of morbidities to normalize experiences and manage expectations needs to be undertaken, together with provision of family psychological support when children do experience postoperative morbidities. Ensuring that access to appropriate information and support is equitable (in terms of gender, culture and ability to speak English) needs to be prioritized. Finally, longitudinal research needs to address any longer-term impacts of morbidity as well as increasing understanding about factors that foster resilience and adaptive coping.

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