Supplementary Materials

Table 1 : Demographic Characteristics of participating vs non participating patients

|  |  |  |  |
| --- | --- | --- | --- |
| **Risk Variable**  | **Participating Patients** **N = 306 (%)** | **Non Participating Patients** **N = 248 (%)** | **Chi-square p- value** |
| **Sex**  |   |  | 0.893 |
| Female  | 135 (44.1) | 108 (43.6) |  |
| Male  | 171 (55.9) | 140 (56.5) |  |
| **Age** |  |  | 0.768 |
| Neonate  | 124 (40.5) | 96 (38.7) |  |
| Child  | 138 (45.1) | 117 (47.2) |  |
| Infant  | 44 (14.4) | 35 (14.1) |  |
| **Univentricular Heart**  | 45 (14.7) | 32 (12.9)  | 0.774 |
| **Congenital non cardiac malformations** | 37 (12.1) | 40 (16.1) | 0.353 |
| **Complexity of CHD18** |  |  | 0.702 |
| A (most complex) | 40 (13.1) | 28 (11.3) |  |
| B | 30 (9.8)  | 29 (6.8) |  |
| C | 62 (20.3) | 48 (19.4) |  |
| D | 87 (28.4) | 82 (33.1) |  |
| E (least complex) | 87 (28.4) | 61 (24.6) |  |
| **Perioperative morbidities (complications)** |  |  | 0.538 |
| No morbidities  | 153 (50.0)  | 131 (52.8) |  |
| Single morbidity | 92 (30.1) | 68 (27.4) |  |
| extracorporeal life support or multimorbidity excluding extracorporeal life support | 61 (19.9)  | 49 (19.8)  |  |
| **Type of Operation** |  |  | 0.120 |
| Reparative  | 173 (56.5) | 134 (54.0) |  |
| Palliative | 54 (17.7) | 60 (24.2) |  |
| Ambiguous  | 79 (25.8)  | 54 (21.8) |  |
| **Ethnicity**  |  |  | <0.001 |
| White – any  | 247 (80.7)  | 183 (73.8)  |  |
| Nonwhite  | 46 (15.0) | 41 (16.5) |  |
| Unknown  | 13 (4.3)  | 24 (9.7) |  |
| **Mother’s Education** |  |  | 0.010 |
| Secondary School | 124 (40.5)  | 135 (54.4) |  |
| First degree | 103 (33.7)  | 61 (24.6) |  |
| Higher degree | 45 (14.7)  | 19 (7.7) |  |
| Unknown  | 34 (11.1)  | 33 (13.3)  |  |
| **Household income**  |  |  | 0.559 |
| <10k | 17 (5.6)  | 24 (9.7)  |  |
| 10-25k | 66 (21.6)  | 58 (23.4)  |  |
| 25-50k | 122 (39.9)  | 89 (35.9)  |  |
| 50k | 65 (21.2)  | 44 (17.7) |  |
| Unknown  | 36 (11.8)  | 33 (13.3)  |  |
| **Number of carers**  |  |  | 0.363 |
| 1 | 6 (2.0) | 12 (5.2) |  |
| 2 | 257 (84.0)  | 189 (76.2) |  |
| >3 | 10 (3.3) | 4 (1.6) |  |
| unknown | 33 (10.8) | 42 (16.9)  |  |

Table 2: Demographic characteristics of the study cohort and each Ages and Stages Questionnaires-3 colour score

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Risk Variable**  | **Total Cohort N = 306 (%)**  | **Green N = 117 (%)**  | **Amber N = 57 (%)**  | **Red N = 132 (%)**  |
| **Sex**   |   |   |   |   |
| Female  | 135 (44.1)  | 45 (38.5)  | 29 (50.9)  | 61 (46.2)  |
| Male  | 171 (55.9)  | 57 (48.7)  | 33 (57.9)  | 81 (61.4)  |
| **Age**  |   |   |   |   |
| Neonate  | 124 (40.5)  | 8 (6.8)  | 3 (5.3)  | 113 (85.6)  |
| Infant  | 138 (45.1)  | 75 (64.1)  | 46 (80.7)  | 17 (12.9)  |
| Child  | 44 (14.4)  | 20 (17.1)  | 9 (15.8)  | 15 (11.4)  |
| **Univentricular Heart**   | 45 (14.7)  | 12 (10.3)  | 6 (10.5)  | 24 (18.2)  |
| **Congenital non cardiac Malformations**  | 37 (12.1)  | 16 (13.7)  | 8 (14.0)  | 12 (9.1)  |
| **Complexity of Congenital Heart Disease**   |   |   |   |   |
| A (most complex) | 40 (13.1)  | 14 (12.0)  | 5 (8.8)  | 21 (10.6)  |
| B  | 30 (9.8)  | 12 (10.3)  | 5 (8.8)  | 13 (9.9)  |
| C  | 62 (20.3)  | 10 (8.6)  | 6 (10.5)  | 46 (34.9)  |
| D  | 87 (28.4)  | 40 (34.2)  | 26 (45.6)  | 21 (15.9)  |
| E (least complex) | 87 (28.4)  | 26 (22.2)  | 16 (28.1)  | 45 (34.1)  |
| **Postoperative morbidities**  (complications) |   |   |   |   |
| No morbidities  | 153 (50.0)  | 56 (47.9)  | 30 (52.6)  | 67 (50.8)  |
| Single morbidity  | 92 (30.1)  | 31 (26.5)  | 14 (24.6)  | 47 (35.6)  |
| extracorporeal life support or multimorbidity excluding extracorporeal life support | 61 (19.9)  | 15 (12.8)  | 14 (24.6)  | 32 (24.2)  |
| **Type of Operation**  |   |   |   |   |
| Reparative  | 173 (56.5)  | 54 (46.2)  | 39 (68.4)  | 80 (60.6)  |
| Palliative  | 54 (17.7)  | 21 (18.0)  | 8 (14.0)  | 25 (18.9)  |
| Ambiguous  | 79 (25.8)  | 27 (23.1)  | 11 (19.3)  | 41 (31.1)  |
| **Ethnicity**   |   |   |   |   |
| White – any  | 247 (80.7)  | 83 (70.9)  | 49 (86.0)  | 115 (87.1)  |
| Nonwhite  | 46 (15.0)  | 17 (14.5)  | 6 (10.5)  | 23 (17.4)  |
| Unknown  | 13 (4.3)  | 3 (2.6)  | 3 (5.3)  | 7 (5.3)  |
| **Mother’s Education**  |   |   |   |   |
| Secondary School  | 124 (40.5)  | 44 (37.6)  | 25 (43.9)  | 55 (42.7)  |
| First degree  | 103 (14.7)  | 41 (35.0)  | 16 (28.1)  | 46 (34.9)  |
| Higher degree  | 45 (14.7)  | 12 (10.3)  | 8 (14.0)  | 35 (18.9)  |
| Unknown  | 34 (11.1)  | 5 (4.3)  | 9 (15.8)  | 20 (15.2)  |
| **Household income**   |   |   |   |   |
| <10k  | 17 (5.6)  | 6 (5.1)  | 5 (8.8)  | 6 (4.6)  |
| 10-25k  | 66 (21.6)  | 22 (18.8)  | 13 (22.8)  | 31 (23.5)  |
| 25-50k  | 122 (39.9)  | 43 (36.8)  | 20 (22.8)  | 59 (20.5)  |
| >50k  | 65 (21.2)  | 25 (21.4)  | 13 (22.8)  | 27 (20.5) |
| Unknown  | 36 (11.8)  | 6 (5.1)  | 7 (12.3)  | 23 (17.4)  |
| **Number of carers**   |   |   |   |   |
| 1  | 6 (2.0)  | 0 (0.0)  | 3 (5.3)  | 3 (2.3)  |
| 2  | 257 (84.0)  | 89 (76.1)  | 49 (86.0)  | 119 (90.2)  |
| >3  | 10 (3.3)  | 5 (4.3)  | 0 (0.0)  | 5 (3.8)  |
| unknown  | 33 (10.8)  | 8 (6.8)  | 6 (10.5)  | 19 (14.4) |

Table 3: Results for the univariate logistic regression for secondary outcomes: Red vs Amber and Green for each individual domain across risk variables AND results of the multivariate logistic regression for secondary outcomes including risk factors below p = 0.05 in the univariate analysis

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Risk Variable (number of observations) | Univariate Odds ratio (95% Confidence Interval) | P – value  | Adjusted Odds ratio (95% Confidence Interval) | P - value |
|  |  |  |  |  |
| **Communication**  |  |  |  |  |
| Sex: male vs female (306) | 1.1 (0.6, 2.2) | 0.698 | N/A |  |
| Age: neonate vs infant and child (261) | 85.7 (11.6, 634.1) | <0.001 | 1 (omitted) | N/A |
| Univentricular heart: yes vs no (305) | 2.5 (1.1, 5.4) | <0.001 | 3.1 (0.3, 33.7) | 0.347 |
| Congenital non cardiac malformations: yes vs no | 0.3 (0.1, 1.5) | 0.144 | N/A |  |
| Complexity of congenital heart disease: high (AB) vs low (CDE) (305) | 2.2 (1.1, 4.4) | 0.028 | 0.3 (0.1, 1.6) | 0.165 |
| Perioperative morbidities (complications): none vs any (298) | 1.1 (0.6, 2.2) | 0.849 | N/A |  |
| Operation: palliative vs reparative (305) | 0.6 (0.3, 1.4) | 0.243 | N/A |  |
| Operation: palliative vs reparative (305) | 0.6 (0.3, 1.7) | 0.356 | N/A |  |
| Operation: reparative vs ambiguous (305) | 1.0 (0.5, 2.3) | 0.920 | N/A |  |
| Ethnicity: white vs non white (292) | 1.7 (0.7, 3.8) | 0.211 | N/A |  |
| Mothers' education: degree vs no degree (271) | 1.0 (0.5, 2.0) | 0.941 | N/A |  |
| Household income : </+25kPa vs >25kPa (269) | 0.7 (0.4, 1.6) | 0.432 | N/A |  |
| Number of carers: 1 vs >1 (272) | 0.8 (0.1, 6.7) | 0.803 | N/A |  |
|  |  |  |  |  |
| **Gross Motor** |  |  |  |  |
| Sex: male vs female (304) | 1.1 (0.6, 2.2) | 0.698 |  |  |
| Age: neonate vs infant and child (304) | 180.8 (65.8, 495,6) | <0.001 | 1 (omitted) | N/A |
| Univentricular heart: yes vs no (304) | 2.3 (1.2, 4.4) | 0.012 | 0.4 (0.1, 1.0) | 0.062 |
| Congenital non cardiac malformations: yes vs no (304) | 0.4 (0.2, 0.9) | 0.032 | 0.3 (0.1, 1.3) | 0.116 |
| Complexity of congenital heart disease: high (AB) vs low (CDE) (304) | 1.3 (0.7, 2.2) | 0.437  | N/A |  |
| Perioperative morbidities (complications): none vs any (304) | 1.3 (0.8, 2.1) | 0.401 | N/A |  |
| Operation: palliative vs reparative (304) | 0.9 (0.5, 1.7) | 0.657 | N/A |  |
| Operation: palliative vs reparative (304) | 1.2 (0.6, 2.5) | 0.590 | N/A |  |
| Operation: reparative vs ambiguous (304) | 1.4 (0.8, 2.5) | 0.221 | N/A |  |
| Ethnicity: white vs non white (291) | 1.2 (0.6, 2.3) | 0.601 | N/A |  |
| Mothers' education: degree vs no degree (270) | 0.9 (0.5, 1.4) | 0.556 | N/A |  |
| Household income : </+25kPa vs >25kPa (268) | 0.89 (0.52, 1.52) | 0.663 | N/A |  |
| Number of carers: 1 vs >1 (271) | 1.1 (0.7, 2.1) | 0.929 | N/A |  |
|  |  |  |  |  |
| **Fine Motor**  |  |  |  |  |
| Sex: male vs female (304) | 1.8 (0.7, 2.1) | 0.586 | N/A |  |
| Age: neonate vs infant and child (304) | 6.6 (3.3, 13.0) | <0.001 | N/A |  |
| Univentricular heart: yes vs no (304) | 1.7 (0.8, 1.6) | 0.178 | N/A |  |
| Congenital non cardiac malformations: yes vs no (306) | 0.5 (0.2, 1.6) | 0.272 | N/A |  |
| Complexity of congenital heart disease: AB vs CDE (304) | 0.8 (0.4, 1.8) | 0.653 | N/A |  |
| Perioperative morbidities (complications): none vs any (304) | 1.6 (0.9, 3.0) | 0.112 | N/A |  |
| Operation: palliative vs reparative (304) | 0.5 (0.3, 1.0) | 0.08 | N/A |  |
| Operation: palliative vs reparative (304) | 0.6 (0.2, 1.3) | 0.168 | N/A |  |
| Operation: reparative vs ambiguous (304) | 1.1 (0.5, 3.4) | 0.879 | N/A |  |
| Ethnicity: white vs non white (291) | 1.6 (0.8, 3.4) | 0.217 | N/A |  |
| Mothers' education: degree vs no degree (270) | 1.0 (0.5, 1.9) | 0.988 | N/A |  |
| Household income : </+25kPa vs >25kPa (268) | 1.1 (0.7, 3.0) | 0.351 | N/A |  |
| Number of carers: 1 vs >1 (271) | 1.0 (0.1, 9.0) | 0.984 | N/A |  |
|  |  |  |  |  |
| **Problem Solving** |  |  |  |  |
| Sex: male vs female (300) | 1.1 (0.6, 2.1) | 0.722 | N/A |  |
| Age: neonate vs infant and child (300) | 10.6 (4,7, 23,6) | <0.001 |  |  |
| Univentricular heart: yes vs no (300) | 1.2 (0.5, 2.8) | 0.669 | N/A |  |
| Congenital non cardiac malformations: yes vs no (300) | 0.5 (0.1, 1.6) | 0.212  | N/A |  |
| Complexity of congenital heart disease: high (AB) vs low (CDE) (300) | 1.0 (0.5, 2.1) | 0.988 | N/A |  |
| Perioperative morbidities (complications): none vs any (293) | 1.2 (0.6, 1.2) | 0.715 | N/A |  |
| Operation: palliative vs reparative (300) | 1.3 (0.5, 3.1) | 0.615 | N/A |  |
| Operation: palliative vs reparative (300) | 1.4 (0.5, 3.8) | 0.488 | N/A |  |
| Operation: reparative vs ambiguous (300) | 5.8 (1.3, 25.5) | 0.019 | N/A |  |
| Ethnicity: white vs non white (288) | 1.1 (0.5, 2.5) | 0.830 | N/A |  |
| Mothers' education: degree vs no degree (266) | 1.1 (0.6, 2.2) | 0.737 | N/A |  |
| Household income : </+25kPa vs >25kPa (266) | 1.7 (0.8, 3.7) | 0.157 | N/A |  |
| Number of carers: 1 vs >1 (261) | 1.0 |  | N/A |  |
|  |  |  |  |  |
| **Personal Social** |  |  |  |  |
| Sex: male vs female (302) | 0.9 (0.5, 1.6) | 0.672 | N/A |  |
| Age: neonate vs infant and child (302) | 14.0 (6.0, 32.3)  | <0.001 |  |  |
| Univentricular heart: yes vs no (302) | 1.6 (0.7, 3.4) | 0.266 | N/A |  |
| Congenital non cardiac malformations: yes vs no (302) | 0.8 (0.4, 1.7) | 0.622 | N/A |  |
| Complexity of congenital heart disease: high (AB) vs low (CDE) (302) | 1.2 (0.6, 2.4) | 0.622 | N/A |  |
| Perioperative morbidities (complications): none vs any (304) | 1.4 (0.8, 2.6) | 0.284 | N/A |  |
| Operation: palliative vs reparative (302) | 1.0 (0.4, 2.4) | 0.972 | N/A |  |
| Operation: palliative vs reparative (302) | 1.5 (0.6, 3.9) | 0.358 | N/A |  |
| Operation: reparative vs ambiguous (302) | 1.5 (0.4, 2.4) | 0.972 | N/A |  |
| Ethnicity: white vs non white (290) | 1.6 (0.7, 3.4) | 0.270 | N/A |  |
| Mothers' education: degree vs no degree (268) | 0.8 (0.4, 1.6) | 0.581 | N/A |  |
| Household income : </+25kPa vs >25kPa (268) | 1.0 (0.5, 2.0) | 0.982 | N/A |  |
| Number of carers: 1 vs >1 (267) | 1.0 (1.4, 2.4) | 0.0 | N/A |  |

Missing data were found in the following domains and variables: communication - sex (1 missing), age (45 missing), univentricular heart (1 missing), complexity of disease (1 missing), preoperative morbidities (8 missing), operative type (1 missing), ethnicity (14 missing), mothers educations (35 missing), household income (37 missing), number of carers (34 missing)

Gross motor - sex (2 missing), age (2 missing), univentricular heart (2 missing), complexity of disease (2 missing), perioperative morbidities (2 missing), operative type (2 missing), ethnicity (15 missing), mothers educations (36 missing), household income (38 missing), number of carers (35 missing)

Fine motor - sex (2 missing), age (2 missing), univentricular heart (2 missing), complexity of congenital heart disease (2 missing), preoperative morbidities (2 missing), operative type (2 missing), ethnicity (15 missing), mother’s education (36 missing), household income (38 missing), number of carers (35 missing)

Problem solving - sex (6 missing), age (6 missing), univentricular heart (6 missing), congenital non cardiac malformations (6 missing), complexity of congenital heart disease (6 missing), preoperative morbidities (13 missing), operation type (6 missing), ethnicity (18 missing), mothers education (40 missing), household income (40 missing), number of carers (45 missing)

Personal social - sex (4 missing), age (4 missing), univentricular heart (4 missing), congenital non cardiac malformations (4 missing), complexity of congenital heart disease (4 missing), preoperative morbidities (2 missing), operation type (4 missing), ethnicity (16 missing), mothers education (38 missing), household income (38 missing), number of carers (39 missing)

\*The coefficient and odds ratio for Age: neonate versus infant and child in the adjusted odds ratio for communication and gross motor domains are omitted due to perfect/quasi-complete separation issues in the data

Table 4: Demographic characteristics of patients included in the post-operative assessment and patients who completed both the post-operative and toddler assessments

|  |  |  |  |
| --- | --- | --- | --- |
| **Risk Variable**  | **Post-operative assessment N = 306 (%)**  | **Post-operative assessment AND Toddler Assessment N = 87 (%)** | **Chi-square p-value**  |
| **Sex**   |   |  | 0.402 |
| Female  | 135 (44.1)  | 34 (39.1) |  |
| Male  | 171 (55.9)  | 57 (60.9) |  |
| **Univentricular Heart**   | 45 (14.7)  | 7 (8.0) | 0.106 |
| **Congenital non cardiac Malformations**  | 37 (12.1)  | 1 (1.1) | 0.002 |
| **Complexity of Congenital Heart Disease**   |   |  | 0.121 |
| A (most complex) | 40 (13.1)  | 8 (9.2) |  |
| B  | 30 (9.8)  | 7 (8.0) |  |
| C  | 62 (20.3)  | 26 (30.0) |  |
| D  | 87 (28.4)  | 16 (18.4) |  |
| E (least complex) | 87 (28.4)  | 30 (34.4) |  |
| **Postoperative morbidities**  (complications) |   |  | 0.456 |
| No morbidities  | 153 (50.0)  | 43 (49.4) |  |
| Single morbidity  | 92 (30.1)  | 32 (36.8) |  |
| extracorporeal life support or multimorbidity excluding extracorporeal life support | 61 (19.9)  | 12 (13.8) |  |
| **Type of Operation**  |   |  | 0.049 |
| Reparative  | 173 (56.5)  | 9 (10.3) |  |
| Palliative  | 54 (17.7)  | 45 (51.7) |  |
| Ambiguous  | 79 (25.8)  | 33 (37.9) |  |
| **Ethnicity**   |   |  | 0.385 |
| White – any  | 247 (80.7)  | 73 (83.9) |  |
| Nonwhite  | 46 (15.0)  | 13 (14.9) |  |
| Unknown  | 13 (4.3)  | 1 (1.1) |  |
| **Mother’s Education**  |   |  | 0.255 |
| Secondary School  | 124 (40.5)  | 25 (28.7) |  |
| First degree  | 103 (14.7)  | 34 (39.1) |  |
| Higher degree  | 45 (14.7)  | 16 (16.5) |  |
| Unknown  | 34 (11.1)  | 12 (13.8) |  |
| **Household income**   |   |  |  |
| <10k  | 17 (5.6)  | 3 (3.4) | <0.001 |
| 10-25k  | 66 (21.6)  | 12 (13.8) |  |
| 25-50k  | 122 (39.9)  | 36 (41.4) |  |
| >50k  | 65 (21.2)  | 24 (27.6) |  |
| Unknown  | 36 (11.8)  | 12 (13.8) |  |
| **Number of carers**   |   |  | 0.760 |
| 1  | 6 (2.0)  | 11 (12.6) |  |
| 2  | 257 (84.0)  | 72 (82.8) |  |
| >3  | 10 (3.3)  | 4 (4.6) |  |
| unknown  | 33 (10.8)  | 0 (0.0) |  |

Table 5: Changes in Ages and Stages Questionnaires-3 colour scores at the toddler assessment compared to at the post operative assessment with previously statistically significant risk variables

|  |  |
| --- | --- |
| Risk Variable  | Change in ASQ-3 Colour Score at Toddler assessment compared to post operative assessment (%) |
| Total Children N = 87 | Better N = 43 (49.3) | No change N = 30 (34.5) | Worse N = 13 (16.1) |
| Univentricular heart conditions N = 7 | 3 (42.9) | 4 (57.1) | 0 (0.0) |
| Age at Surgery: Neonate N = 59 | 39 (66.1) | 17 (28.8) | 3 (5.1) |
| Age at Surgery: Infant N = 28 | 5 (17.9) | 12 (42.9) | 11 (39.3) |



Figure 1: CONSORT flow diagram showing the participant selection process for the post-operative, and toddler assessments



Figure 2: Chart depicting the division of Ages and Stages Questionnaires-3 colour scores across all age categories from 6 to 53 months