**Supplementary Material**

|  |  |  |
| --- | --- | --- |
| Questionnaire | Variable(s) | Description |
| Family Information Form *21 Items* | Demographic | Assesses family developmental stage including relationship to child, birth order, planned or unplanned pregnancy, siblings, nights in hospital, unplanned hospital visits, other medical conditions, medications, parent age, parent education and occupation. |
| Life Stress Inventory (formerly Inventory of Life Changes) *43 Items* | Stress | Measure of family stress level over the past year and 43 stressful events.1  |
| State-Trait Anxiety *40 Questions* | Stress | Questionnaire assesses two types of anxiety. Trait anxiety is one’s tendency towards becoming anxious while state anxiety is transient, situational feelings in the moment.2  |
| Pediatric Inventory for Parents *42 Questions* | Stress | Questionnaire assesses stress appraisal with frequency and level of difficulty with communication, emotional functioning, medical care, and parent role.3  |
| Impact on the Family Scale *15 Items* | Stress | Questionnaire assesses overall stress appraisal.4  |
| Coping Health Inventory for Parents *45 Questions**Measures a parent’s response to managing demands when child has serious or chronic medical condition.* | Coping | 3 Subscales: (1) Maintaining family integration, cooperation, and an optimistic definition of the situation; (2) Maintaining social support, self-esteem, and psychological stability; and (3) Understanding the medical situation through communication with other parents and consultation with medical staff.5  |
| Inventory of Parent’s Experiences *38 Questions* | Coping | Questionnaire assesses the parent social support network and their satisfaction with parenting.6  |
| Family Inventory of Resources for Management *69 Questions* | Coping | Measures social, psychological, community and financial resources families believe they have available to them.5  |
| Family Hardiness Index*20 Questions* | Coping | Measures family’s perception of commitment, challenge, and control.5  |
| Family Assessment Device*12 Questions* | Family Function | Measures family functioning.7  |
| Perceived Quality of Life*20 Questions* | Quality of life | Measure’s degree of satisfaction with physical, social, and cognitive functioning.8  |
| Family Member Well-being Index*8 Questions* | Well-being | Measures family member’s well-being in terms of health, tension, energy, depression, fear, anger, sadness, and worry.5 |

Supplementary Table S1. Self-report questionnaires used in Family Adaptations Study

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | **n** | **Estimate (Slope)** | **Standard Error** | **P-value Overall** | **R2** |
| **Demographic and Clinical Variables** |  |  |  |  |  |
| Gestational age (weeks) | 309 | -0.19 | 0.34 | 0.572 | 0.00 |
| Birth weight (kg) | 313 | 0.00 | 0.00 | 0.669 | 0.00 |
| Male gender | 316 | -0.65 | 0.97 | 0.506 | 0.01 |
| Non-white or Hispanic race/ethnicity | 306 | 1.08 | 1.08 | 0.318 | 0.01 |
| CHD diagnosed prenatally  | 316 | -1.58 | 1.07 | 0.143 | 0.02 |
| Genetic syndrome diagnosis ₐ | 328 | -1.35 | 2.12 | 0.608 | 0.01 |
| Non-syndromic abnormality diagnosis ₐ | 328 | 1.42 | 1.27 | 0.532 | 0.01 |
| Age at Norwood (days)\*  | 247 | 0.14 | 0.07 | 0.044 | 0.04 |
| Age at Stage II (months) | 235 | 0.01 | 0.01 | 0.541 | 0.00 |
| LOS post-Norwood (weeks) | 312 | 0.01 | 0.01 | 0.551 | 0.00 |
| LOS post-Stage II (weeks)  | 296 | 0.03 | 0.01 | 0.067 | 0.03 |
| Number of complications Norwood hospitalization  | 271 | 0.37 | 0.23 | 0.108 | 0.02 |
| Number of complications Interstage | 186 | -0.19 | 0.61 | 0.756 | 0.00 |
| Number of complications Stage II hospitalization | 175 | -0.39 | 0.52 | 0.448 | 0.01 |
| Number of complications post-Stage II discharge | 257 | 0.15 | 0.34 | 0.656 | 0.00 |
| Other surgery post-Norwood | 290 | 0.14 | 0.27 | 0.593 | 0.00 |
| Other surgery post-Stage II  | 273 | 1.10 | 0.77 | 0.158 | 0.02 |
| Parent age (years)  | 321 | -0.13 | 0.07 | 0.085 | 0.02 |
| Parent education  | 328 |  |  | 0.101 | 0.04 |
| High school or less versus college degree |  | 0.27 | 1.24 |  |  |
| Some college versus college degree |  | 2.06 | 1.04 |  |  |
| Graduate/professional degree versus college degree |  | -0.71 | 1.13 |  |  |
| Single parent versus married/partnered | 323 | 1.97 | 1.27 | 0.217 | 0.01 |
| **Stress Variables** |  |  |  |  |  |
| Inventory of Life Changes\*\*\*  | 328 | 0.01 | 0.00 | 0.0006 | 0.06 |
| State-Trait Anxiety Index (State anxiety score)\*\*\*  | 318 | 0.28 | 0.03 | <0.0001 | 0.39 |
| State-Trait Anxiety Index (Trait anxiety score)\*\*\*  | 318 | 0.31 | 0.03 | <0.0001 | 0.32 |
| Pediatric Inventory for Parents\*\*\*  | 249 | 0.13 | 0.01 | <0.0001 | 0.48 |
| **Coping Variables** |  |  |  |  |  |
| Coping Health Inventory for Parents | 291 | 0.00 | 0.02 | 0.816 | 0.00 |
| Inventory of Parents Experiences\*\*\*  | 323 | -1.71 | 0.49 | 0.0006 | 0.06 |
| Family Inventory of Resources for Management\*\*\*  | 293 | -0.08 | 0.02 | <0.0001 | 0.10 |

Supplementary Table S2. Bivariable repeated measures regression modeling for IES-R Intrusion Subdomain Score. \*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.001. LOS, length of stay. IES-R, Impact of Event Scale-Revised.

a. Total n includes a category for “unknown”, which is not presented. The total n includes all participating parents across all timepoints. The statistical model used, repeated measures regression, accounts for this by treating all data entries for the same infant as correlated with each other, rather than as independent information.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | **n** | **Estimate (Slope)** | **Standard Error** | **P-value Overall** | **R2** |
| **Demographic and Clinical Variables** |  |  |  |  |  |
| Gestational age (weeks) | 317 | -0.28 | 0.32 | 0.378 | 0.01 |
| Birth weight (kg) | 321 | 0.00 | 0.00 | 0.779 | 0.00 |
| Male gender | 324 | -1.11 | 0.91 | 0.221 | 0.02 |
| Non-white or Hispanic race/ethnicity | 314 | 0.82 | 1.04 | 0.432 | 0.01 |
| CHD diagnosed prenatally  | 324 | 0.36 | 1.02 | 0.725 | 0.00 |
| Genetic syndrome diagnosis ₐ | 258 | -2.03 | 1.92 | 0.292 | 0.00 |
| Non-syndromic abnormality diagnosis ₐ | 338 | -0.24 | 1.17 | 0.917 | 0.00 |
| Age at Norwood (days) | 251 | 0.06 | 0.07 | 0.398 | 0.01 |
| Age at Stage II (months) | 238 | 0.003 | 0.01 | 0.820 | 0.00 |
| LOS post-Norwood (weeks)  | 319 | -0.03 | 0.01 | 0.070 | 0.03 |
| LOS post-Stage II (weeks) | 303 | 0.00 | 0.01 | 0.736 | 0.00 |
| Number of complications Norwood hospitalization | 280 | -0.09 | 0.21 | 0.685 | 0.00 |
| Number of complications Interstage\*  | 190 | 1.43 | 0.59 | 0.018 | 0.07 |
| Number of complications Stage II hospitalization | 178 | -0.002 | 0.55 | 0.997 | 0.00 |
| Number of complications post-Stage II discharge | 265 | -0.18 | 0.33 | 0.578 | 0.00 |
| Other surgery post-Norwood  | 297 | -0.43 | 0.25 | 0.094 | 0.02 |
| Other surgery post-Stage II | 280 | -0.22 | 0.78 | 0.776 | 0.00 |
| Parent age (years)  | 331 | -0.10 | 0.07 | 0.133 | 0.01 |
| Parent education | 338 |  |  | 0.541 | 0.01 |
| High school or less versus college degree |  | 1.05 | 1.07 |  |  |
| Some college versus college degree |  | 0.68 | 0.91 |  |  |
| Graduate/professional degree versus college degree |  | -0.51 | 0.93 |  |  |
| Single parent versus married/partnered  | 332 | 2.16 | 1.10 | 0.145 | 0.02 |
| **Stress Variables** |   |   |   |   |   |
| Inventory of Life Changes\*\*\*  | 338 | 0.01 | 0.00 | <0.0001 | 0.08 |
| State-Trait Anxiety Index (State anxiety score)\*\*\*  | 325 | 0.19 | 0.02 | <0.0001 | 0.27 |
| State-Trait Anxiety Index (Trait anxiety score)\*\*\*  | 324 | 0.21 | 0.03 | <0.0001 | 0.20 |
| Pediatric Inventory for Parents\*\*\*  | 252 | 0.07 | 0.01 | <0.0001 | 0.22 |
| **Coping Variables** |   |   |   |   |   |
| Coping Health Inventory for Parents | 291 | -0.02 | 0.02 | 0.356 | 0.01 |
| Inventory of Parents Experiences\*\*\*  | 333 | -1.53 | 0.40 | 0.0002 | 0.07 |
| Family Inventory of Resources for Management\*\*\*  | 298 | -0.08 | 0.02 | <0.0001 | 0.11 |

Supplementary Table S3. Bivariable repeated measures regression modeling for IES-R Avoidance Subdomain Score. \*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.001. LOS, length of stay. IES-R, Impact of Event Scale-Revised.

a. Total n includes a category for “unknown”, which is not presented. The total n includes all participating parents across all timepoints. The statistical model used, repeated measures regression, accounts for this by treating all data entries for the same infant as correlated with each other, rather than as independent information.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | **n** | **Estimate (Slope)** | **Standard Error** | **P-value Overall** | **R2** |
| **Demographic and Clinical Variables** |  |  |  |  |  |
| Gestational age (weeks) | 319 | -0.30 | 0.29 | 0.300 | 0.01 |
| Birth weight (kg) | 323 | 0.00 | 0.00 | 0.386 | 0.01 |
| Male gender  | 326 | -1.51 | 0.80 | 0.060 | 0.03 |
| Non-white or Hispanic race/ethnicity | 318 | 0.70 | 0.92 | 0.444 | 0.01 |
| CHD diagnosed prenatally  | 326 | -1.02 | 0.90 | 0.263 | 0.01 |
| Genetic syndrome diagnosis ₐ | 262 | -0.92 | 1.63 | 0.573 | 0.01 |
| Non-syndromic abnormality diagnosis ₐ | 339 | 1.00 | 1.03 | 0.610 | 0.01 |
| Age at Norwood (days)\*  | 253 | 0.11 | 0.05 | 0.047 | 0.04 |
| Age at Stage II (months) | 240 | 0.01 | 0.01 | 0.356 | 0.01 |
| LOS post-Norwood (weeks) | 321 | 0.00 | 0.01 | 0.921 | 0.00 |
| LOS post-Stage II (weeks)  | 305 | 0.02 | 0.01 | 0.154 | 0.02 |
| Number of complications Norwood hospitalization | 280 | 0.13 | 0.19 | 0.517 | 0.00 |
| Number of complications Interstage | 190 | 0.25 | 0.48 | 0.612 | 0.00 |
| Number of complications Stage II hospitalization | 178 | 0.18 | 0.42 | 0.671 | 0.00 |
| Number of complications post-Stage II discharge | 266 | -0.13 | 0.28 | 0.645 | 0.00 |
| Other surgery post-Norwood | 299 | 0.00 | 0.23 | 0.986 | 0.00 |
| Other surgery post-Stage II | 282 | 0.18 | 0.65 | 0.783 | 0.00 |
| Parent age (years)\*  | 332 | -0.13 | 0.06 | 0.028 | 0.03 |
| Parent education  | 339 |  |  | 0.184 | 0.03 |
| High school or less versus college degree |  | 1.15 | 0.97 |  |  |
| Some college versus college degree |  | 1.20 | 0.82 |  |  |
| Graduate/professional degree versus college degree |  | -0.68 | 0.87 |  |  |
| Single parent versus married/partnered  | 333 | 2.26 | 1.00 | 0.108 | 0.03 |
| **Stress Variables** |   |   |   |   |   |
| Inventory of Life Changes\*\*\*  | 339 | 0.01 | 0.00 | <0.0001 | 0.07 |
| State-Trait Anxiety Index (State anxiety score)\*\*\*  | 328 | 0.26 | 0.02 | <0.0001 | 0.51 |
| State-Trait Anxiety Index (Trait anxiety score)\*\*\*  | 327 | 0.30 | 0.02 | <0.0001 | 0.46 |
| Pediatric Inventory for Parents\*\*\*  | 249 | 0.11 | 0.01 | <0.0001 | 0.54 |
| **Coping Variables** |   |   |   |   |   |
| Coping Health Inventory for Parents  | 293 | -0.02 | 0.02 | 0.156 | 0.01 |
| Inventory of Parents Experiences\*\*\*  | 335 | -1.52 | 0.36 | <0.0001 | 0.08 |
| Family Inventory of Resources for Management\*\*\*  | 298 | -0.08 | 0.01 | <0.0001 | 0.16 |

Supplementary Table S4. Bivariable repeated measures regression modeling for IES-R Hyperarousal Subdomain Score. \* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001. LOS, length of stay. IES-R, Impact of Event Scale-Revised.

a. Total n includes a category for “unknown”, which is not presented. The total n includes all participating parents across all timepoints. The statistical model used, repeated measures regression, accounts for this by treating all data entries for the same infant as correlated with each other, rather than as independent information.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Variable** | **n** | **Category** | **Estimate (Slope)** | **Standard Error** | **P-Value Overall** | **R2** |
| **Demographic and Clinical Variables** | 328 |  |  |  |  | 0.18 |
| Parent |  | Father versus mother | -3.16 | 0.67 | <0.0001 |  |
| Timepoint |  | Time 1 versus Time 3 | 3.66 | 0.82 | 0.0001 |  |
|   | Time 2 versus Time 3 | 1.92 | 0.84 |   |
| **Stress and Coping Variables** | 244 |   |   |   |   | 0.58 |
| State-Trait Anxiety Index (Trait anxiety score) |  |  | 0.15 | 0.03 | <0.0001 |  |
| Pediatric Inventory for Parents  |  |  | 0.11 | 0.01 | <0.0001 |  |
| Parent |  | Father versus mother | -1.52 | 0.65 | 0.024 |  |

Supplementary Table S5: Multivariable repeated measures regression modeling for IES-R Intrusion Subdomain Score. Parent age and education were substantially correlated; only parent age was included in the multivariable modeling but was not significant in the final model. Time 1 post-Norwood ~8 weeks infant age. Time 2 post-Stage II ~6 months child age. Time 3 final follow-up ~16 months child age. The final combined model was the same as the model for stress and coping variables

a. Total n includes a category for “unknown”, which is not presented. The total n includes all participating parents across all timepoints. The statistical model used, repeated measures regression, accounts for this by treating all data entries for the same infant as correlated with each other, rather than as independent information.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | **n** | **Estimate (Slope)** | **Standard Error** | **P-Value Overall** | **R2** |
| **Demographic and Clinical Variables** | 190 |  |  |  | 0.07 |
| Number of complications during interstage |   | 1.43 | 0.59 | 0.018 |   |
| **Stress and Coping Variables**  | 228 |   |   |   | 0.31 |
| Pediatric Inventory for Parents  |  | 0.06 | 0.01 | <0.001 |  |
| Family Inventory of Resources for Management |  | -0.06 | 0.02 | 0.0006 |  |

Supplementary Table S6: Multivariable repeated measures regression modeling for IES-R Avoidance Subdomain Score. Number of other surgical procedures during Norwood hospitalization and Stage I hospital LOS were substantially correlated; only Stage I LOS was included in the multivariable modeling but was not significant in the final model. The final combined model was the same as the model for stress and coping variables

a. Total n includes a category for “unknown”, which is not presented. The total n includes all participating parents across all timepoints. The statistical model used, repeated measures regression, accounts for this by treating all data entries for the same infant as correlated with each other, rather than as independent information.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Variable** | **n** | **Category** | **Estimate (Slope)** | **Standard Error** | **P-Value Overall** | **R2** |
| **Demographic and Clinical Variables** | 339 |   |   |   |   | 0.20 |
| Parent |  | Father versus Mother | -1.73 | 0.49 | 0.0007 |  |
| Timepoint |  | Time 1 versus Time 3 | 3.49 | 0.61 | <0.0001 |  |
|   | Time 2 versus Time 3 | 3.10 | 0.62 |   |
| **Stress and Coping Variables**  | 243 |   |   |   |   | 0.69 |
| State-Trait Anxiety Index (Trait anxiety score) |  |  | 0.22 | 0.03 | <0.0001 |  |
| Pediatric Inventory for Parents  |  |  | 0.08 | 0.01 | <0.0001 |  |
| Inventory of Parents Experiences |  |  | 0.72 | 0.34 | 0.036 |  |

Supplementary Table S7: Multivariable repeated measures regression modeling for IES-R Hyperarousal subdomain score. Parent marital status and education were substantially correlated; only marital status was included in the multivariable modeling but was not significant in the final model. Time 1 ~8 weeks infant age. Time 2 ~6 months child age. Time 3 ~16 months of child age. The final combined model was the same as the model for stress and coping variables

a. Total n includes a category for “unknown”, which is not presented. The total n includes all participating parents across all timepoints. The statistical model used, repeated measures regression, accounts for this by treating all data entries for the same infant as correlated with each other, rather than as independent information.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Family Inventory of Resources** | **Inventory of Life Changes** | **Inventory of Parents Experiences**  | **Pediatric Inventory for Parents** | **State Anxiety Score** | **Trait Anxiety Score** | **Coping Health Inventory for Parents** |
| Family Inventory of Resources | 1 |  |  |  |  |  |  |
| Inventory of Life Changes | -0.38\* | 1 |  |  |  |  |  |
| Inventory of Parents Experiences  | 0.42\* | -0.26\* | 1 |  |  |  |  |
| Pediatric Inventory for Parents | -0.22 | 0.30\* | -0.26\* | 1 |  |  |  |
| State Anxiety Score | -0.33\* | 0.29\* | -0.37\* | 0.61\* | 1 |  |  |
| Trait Anxiety Score | -0.59\* | 0.31\* | -0.45\* | 0.50\* | 0.77\* | 1 |  |
| Coping Health Inventory for Parents | 0.19 | -0.09 | 0.25 | 0.03 | -0.26\* | -0.24\* | 1 |

Supplementary Table S8. Pearson correlation coefficients between stress and coping factors. \*p < 0.05.

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