# Impact of Surgical Complexity on Health# Related Quality of Life in Congenital Heart Disease Surgical Survivors

ORIGINAL RESEARCH

# Impact of Surgical Complexity on Health-Related Quality of Life in Congenital Heart Disease Surgical Survivors

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***Background*—**Surgical complexity and related morbidities may affect long-term patient quality of life (QOL). Aristotle Basic Complexity (ABC) score and Risk Adjustment in Congenital Heart Surgery (RACHS-1) category stratify the complexity of pediatric cardiac operations. The purpose of this study was to examine the relationship between surgical complexity and QOL and to investigate other demographic and clinical variables that might explain variation in QOL in pediatric cardiac surgical survivors.

***Methods and Results*—**Pediatric Cardiac Quality of Life (PCQLI) study participants who had undergone cardiac surgery were included. The PCQLI database provided sample characteristics and QOL scores. Surgical complexity was defined by the highest ABC raw score or RACHS-1 category. Relationships among surgical complexity and demographic, clinical, and QOL variables were assessed using ordinary least squares regression. A total of 1416 patient–parent pairs were included. Although higher ABC scores and RACHS-1 categories were associated with lower QOL scores ($P<0.005$), correlation with QOL scores was poor to fair ($r=-0.10$ to $-0.29$) for all groups. Ordinary least squares regression showed weak association with $R^2=0.06$ to $R^2=0.28$. After accounting for single-ventricle anatomy, number of doctor visits, and time since last hospitalization, surgical complexity scores added no additional explanation to the variance in QOL scores.

***Conclusions*—**ABC scores and RACHS-1 categories are useful tools for morbidity and mortality predictions prior to cardiac surgery and quality of care initiatives but are minimally helpful in predicting a child's or adolescent's long-term QOL scores. Further studies are warranted to determine other predictors of QOL variation. **(*J Am Heart Assoc*. 2016;5:e001234 doi: 10.1161/JAHA.114.001234)**

**Key Words:** Aristotle Basic Complexity • congenital heart disease surgery • quality of life • Risk Adjustment in Congenital Heart Surgery

In pediatric cardiovascular disease, congenital heart disease (CHD) and acquired heart disease often require reparative or palliative surgical procedures. Advances made in pediatric cardiac intensive care, interventional cardiology, and cardiothoracic surgery have enabled children with heart disease to survive into adulthood. Present early mortality rates for children with the most complex CHD lesions undergoing neonatal surgery are ≈10%.[1] Survivors may experience physical, neurodevelopmental, and psychological morbidities including known complications from cardiac surgery, such as stroke and acute kidney injury, as well as neurodevelopmental issues (eg, attention deficit hyperactivity

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Received July 2, 2015; accepted May 3, 2016.

disorder, language issues, poor executive functioning) and behavioral and emotional problems (eg, posttraumatic stress symptomatology, anxiety, and depression).[2] Resulting complications can often have a profound impact on the lives of patients from both a physical and psychosocial standpoint.

Given the recent decrease in mortality, clinicians and researchers have shifted their focus to prevention of morbidity. Health-related quality of life (QOL) is the influence of a specific disease process or medical therapy on a patient's perceived capacity to participate and find fulfillment in life's physical, psychological, and social experiences.[3] Several investigators have demonstrated that children with heart disease have significantly lower QOL scores when compared with healthy peers in the same age group.[4,5] Marino et al have shown that lower QOL in the CHD population is associated with increasing disease severity and greater numbers of surgical procedures and hospitalizations.[6,7] Although a greater number of surgeries may be associated with lower QOL, no study to our knowledge has examined whether greater surgical complexity is associated with worse long-term QOL. Such a relationship would provide an efficient method of identifying patients at risk.

Risk Adjustment in Congenital Heart Surgery (RACHS-1) categories and Aristotle Basic Complexity (ABC) scores are used to compare quality of care in children undergoing heart surgery.[8–10] Many studies have validated the relationship between these risk stratification scales and mortality and hospital length of stay.[11,12] Given that previous studies have shown that the frequency and severity of complications increase as the technical difficulty of the surgery increases, RACHS-1 categories and ABC raw scores were used for this study because both incorporate a surgical difficulty ranking in their scales.[13,14]

The aim of this study was to examine the relationship between surgical complexity and QOL and to investigate other demographic and clinical variables that might explain variation in QOL in pediatric cardiac surgical survivors. We hypothesized that greater surgical complexity would be significantly associated with worse long-term QOL.

# Methods

## Study Design

This was an ancillary study of the Pediatric Cardiac Quality of Life (PCQLI) validation study, a multicenter cross-sectional survey assessing the QOL of pediatric patients with CHD and acquired heart disease.[6,7,15–19] This sample consisted of patients enrolled from November 2004 to August 2009 at 9 tertiary care pediatric cardiovascular centers in the United States and the United Kingdom. The institutional review boards and ethics committees of all participating institutions approved the study, and parents and patients gave informed consent and assent, as applicable.

## Study Population

Patients who had CHD or acquired heart disease, had undergone at least 1 cardiac surgery or pacemaker procedure, were aged 8 to 18 years, were fluent in English, and attended an outpatient cardiology visit were eligible for participation.[6] Patients were excluded from the study if the outpatient visit was for an acute change in clinical status, if they had a significant comorbid medical condition or major developmental delay, or if they underwent heart transplantation.[6] Parents and guardians had to be fluent in English and without any major developmental delay to participate.[6]

## Data Collection

Predictor variables (surgical complexity), outcome variables (QOL scores), and covariates (demographic, clinical, anatomic, and medical utilization variables) were obtained from the PCQLI data registry.[6,19] Table 1 lists all variables.

### *Predictor variables*

ABC raw score (ABC score) and RACHS-1 categories were used to measure surgical complexity in this study. The ABC score, which is calculated as the sum of mortality risk, morbidity risk, and technical difficulty of the surgery, is used to evaluate quality of care.[8,9] RACHS-1 is a consensus-based method that sorts cardiac operative procedures into 6 categories in order of increasing risk of short-term mortality.[10] ABC scores and RACHS-1 categories were determined through medical chart review by research personnel and confirmed by the principal investigator (B.S.M.). Surgical complexity was defined by the highest ABC score or RACHS-1 category. Certain procedures were not assigned a RACHS-1 category (eg, pacemaker or implantable cardioverter-defibrillator placement, heart transplantation). Higher ABC scores (1.5–15) and RACHS-1 categories (1–6) represent greater surgical complexity.[8–10]

### *Outcome variables*

The PCQLI is a validated, disease-specific QOL measure with patient self-reporting and parent-proxy reporting for pediatric patients (aged 8–18 years) with CHD or acquired heart disease.[6,7,15–19] Higher PCQLI total score (0–100) and Disease Impact (DI) subscale (0–50), and Psychosocial Impact (PI) subscale (0–50) scores represent better respondent-perceived patient QOL.[7] The appropriate forms were administered to all enrolled participants by trained research personnel prior to an outpatient cardiology visit. Inventory

**Table 1.** Study Population Demographics and Clinical Variables

| | Child (n=743) | Parent of Child (n=743) | Adolescent (n=673) | Parent of Adolescent (n=673) |
|---|---|---|---|---|
| Country | | | | |
| United Kingdom, n (%) | 251 (34) | | 246 (37) | |
| United States, n (%) | 492 (66) | | 427 (64) | |
| Demographics | | | | |
| Male, n (%) | 418 (56) | 101 (14) | 390 (58) | 121 (18) |
| Non-Hispanic, n (%) | 706 (95) | 718 (97) | 641 (95) | 652 (97) |
| White, n (%) | 604 (81) | 617 (83) | 567 (84) | 587 (87) |
| Race breakdown, n (%) | | | | |
| Asian | 49 (7) | 50 (7) | 24 (4) | 23 (3) |
| Black/African American | 47 (6) | 48 (7) | 42 (6) | 42 (6) |
| White/Caucasian | 604 (81) | 617 (83) | 567 (84) | 587 (87) |
| >1 Race/other | 43 (6) | 28 (4) | 40 (6) | 21 (3) |
| Parent: college graduate, n (%) | | 312 (43) | | 271 (41) |
| Parent education, n (%) | | | | |
| Less than high school graduate | | 60 (8) | | 78 (12) |
| High school graduate | | 156 (21) | | 151 (23) |
| Some college | | 205 (28) | | 167 (25) |
| College graduate | | 217 (29) | | 193 (29) |
| Postgraduate degree | | 99 (13) | | 78 (12) |
| Age, mean (SD), y | 10±1 | 41±6 | 15±2 | 46±9 |
| Current cardiac status | | | | |
| Single-ventricle anatomy, n (%)* | 188 (27) | | 125 (21) | |
| CHD, n (%) | 693 (93) | | 594 (88) | |
| Original diagnostic category, n (%) | | | | |
| Biventricular CHD without AAO | 400 (54) | | 375 (56) | |
| Biventricular CHD with AAO | 105 (14) | | 94 (14) | |
| Single-ventricle CHD without AAO | 104 (14) | | 78 (12) | |
| Single-ventricle CHD with AAO | 84 (11) | | 47 (7) | |
| AHD with a structurally normal heart | 50 (7) | | 79 (12) | |
| Had pacemaker/ICD procedure, n (%) | 111 (15) | | 134 (20) | |
| Other comorbid conditions | | | | |
| Nonthoracic cardiac procedures, n (%) | 99 (13) | | 77 (11) | |
| Sternotomy, n (%) | 646 (87) | | 562 (84) | |
| Genetic diagnosis, n (%) | 40 (5) | | 26 (4) | |
| History of mental health problems, n (%) | 24 (3) | | 28 (4) | |
| Medical care utilization | | | | |
| Number, median (range) | | | | |
| Doctor visits within the last 12 months | 3 (0–20) | | 3 (0–20) | |
| Daily medications | 2 (1–8) | | 2 (1–10) | |
| Cardiac surgeries | 1 (0–10) | | 1 (0–10) | |
| Pacemaker/ICD procedures† | 2 (0–20) | | 2 (0–13) | |

Continued

**Table 1.** Continued

| | Child (n=743) | Parent of Child (n=743) | Adolescent (n=673) | Parent of Adolescent (n=673) |
|---|---|---|---|---|
| Time since, median years (range) | | | | |
| Hospitalization | 5 (0–13) | | 6 (0–18) | |
| Cardiac catheterization/intervention | 5 (0–13) | | 7 (0–19) | |
| Cardiac surgery | 8 (0–13) | | 11 (0–19) | |
| ABC and RACHS-1 summary data | | | | |
| ABC score | | | | |
| Mean (SD) | 8±3 | | 8±3 | |
| Median (range) | 8 (3–15) | | 8 (3–15) | |
| RACHS-1 category of index operation, n (%) | | | | |
| RACHS-1 category 1 | 56 (8) | | 46 (8) | |
| RACHS-1 category 2 | 228 (33) | | 206 (34) | |
| RACHS-1 category 3 | 248 (36) | | 241 (40) | |
| RACHS-1 category 4 | 74 (11) | | 65 (11) | |
| RACHS-1 category 6 | 86 (12) | | 41 (7) | |
| Health-related QOL | | | | |
| Pediatric cardiac QOL index, mean (SD) | | | | |
| Disease Impact Subscale Score | 35±9 | 36±9 | 37±8 | 36±10 |
| Psychosocial Impact Subscale Score | 35±10 | 37±9 | 39±8 | 38±9 |

AAO indicates aortic arch obstruction; ABC, Aristotle Basic Complexity; AHD, acquired heart disease; CHD, congenital heart disease; ICD, implantable cardioverter-defibrillator; QOL, quality of life; RACHS-1, Risk Adjustment in Congenital Heart Surgery.

*Single-ventricle percentage does not include patients with AHD.

†Must have had a pacemaker or ICD procedure.

completion was monitored to minimize patient–parent discussion.

### *Covariates*

Demographic, clinical, anatomic, and medical utilization data used in the study are listed in Table 1.

## Statistical Analysis

All analyses were conducted using 4 respondent groups: children, parents of children, adolescents, and parents of adolescents. Frequencies, means (standard deviations), and medians (ranges) were calculated to describe distributional characteristics. The relationship between the RACHS-1 categories and PCQLI DI and PI scores were computed and graphed to estimate the magnitude of the relationships between predictors and outcomes. A series of correlation coefficients were computed to assess the relationships between predictor variables (ABC score and RACHS-1 category) and outcome variables (DI and PI scores). Next, a second set of bivariate correlations were computed to assess associations between covariates (demographic and clinical variables) and the aforementioned outcomes using either point biserial correlations for dichotomized variables or Pearson correlation coefficients for continuous variables, as appropriate. Potential collinearity was investigated by examining correlations among all predictors and covariates. Ordinary least squares regression was used to test the impact of surgical complexity on QOL of pediatric cardiac surgery survivors, controlling for selected covariates. Because ABC scores and RACHS-1 categories are often highly correlated, each variable was placed into a separate model. A third model without the predictors was specified and tested to establish the amount of variance explained by model covariates. With a large sample size in all 4 groups, traditional $\alpha$ levels $<0.05$ would result in trivial covariates in the models, so the criterion for model inclusion for covariates was a bivariate correlation with the outcome variables of $|r|\geq 0.15$; however, because the focus of this study was the relationship between surgical complexity and QOL, ABC scores and RACHS-1 categories were kept in the equation even if the standardized estimate fell below the 0.15 criterion. Effect sizes were used to show the minimally important differences and were reported as standardized estimates ($\beta$).[20] Once the

model was specified, a covariate would remain in the final model if the standardized estimates (β) were >0.15. Finally, the amount of variance explained for each model was compared. Correlations were interpreted as poor (≤0.20), fair (0.21–0.40), moderate (0.41–0.60), good (0.61–0.80), or excellent (≥0.81).[21] All analyses were conducted using SAS version 9.2 (SAS Institute).

# Results

## Study Population

A total of 1416 patient–parent pairs (743 children and 673 adolescents) were included. Demographic and clinical characteristics of the study population are shown in Table 1. The mean age was 9.9±1.4 years for children and 15.0±1.6 years for adolescents. Patients were more likely to be male, whereas parents were predominantly female. Both patients and parents were more likely to be non-Hispanic and white. The majority of patients (both children and adolescents) had an original diagnostic category of biventricular CHD without aortic arch obstruction and a current cardiac status of biventricular CHD after repair. Single-ventricle patients accounted for 21% of children and 27% of adolescents. The median number of cardiac surgeries was 1 (range 0–10) for both children and adolescents. The median time since last hospitalization was 4.9 years (range 0–12.9 years) for children and 5.8 years (range 0–18.0 years) for adolescents. The median number of doctor visits within the previous 12 months was 3 (range 0–20) for both groups. The median number of daily medications was 2 (range 1–8) for children and 2 (range 1–10) for adolescents. Table 1 shows mean ABC scores and RACHS-1 categories. No patients had RACHS-1 category 5 in this study. Moreover, 12% of patients could not be assigned a RACHS-1 category because their index operation was a pacemaker or implantable cardioverter-defibrillator placement procedure. Mean PCQLI DI and PI subscale scores are shown in Table 1.

## Association of Predictor and Outcome Variables

As expected, ABC score was highly correlated with RACHS-1 category for both children ($r$=0.89) and adolescents ($r$=0.87), necessitating the building of separate models for the surgical complexity predictor variables ABC score and RACHS-1 category (Table 2). Higher ABC scores and RACHS-1 categories were significantly associated with worse PCQLI DI scores, but correlations were poor to fair ($r$=−0.10 to −0.29) for all groups (Table 2). The associations between RACHS-1 categories and PCQLI PI scores were poor ($r$=−0.07 to −0.19) for all groups (Table 2).

## Association Among Predictor Variables, Covariates, and Outcome Variables

Although there were a number of statistically significant associations among the predictor variables (ABC score and RACHS-1 category), covariates (demographic, clinical, anatomic, and medical utilization variables), and outcome variables (PCQLI DI and PI scores), most correlations were weak (Table 2). Three covariates were consistently associated with DI for all 4 groups: single-ventricle anatomy, number of doctor visits within the previous 12 months, and time since last hospitalization. Single-ventricle anatomy had fair correlation with PCQLI DI scores in all respondent groups ($r$=−0.27 to −0.35) and fair correlation with PCQLI PI scores in all groups ($r$=−0.21 to −0.25) except the child group ($r$=−0.18). Number of doctor visits within the past 12 months had fair to moderate correlation with PCQLI DI scores for all 4 groups ($r$=−0.29 to −0.41) and fair correlation with PCQLI PI scores for both parent respondent groups ($r$=−0.28 to −0.29) but poor correlation with PCQLI PI scores for children and adolescents ($r$=−0.17 to −0.19). Time since last hospitalization had fair correlation with PCQLI DI scores for all groups ($r$=0.28–0.36) and with PCQLI PI scores for parents of children ($r$=0.26) but had poor correlation with PCQLI PI scores for children, adolescents, and parents of adolescents ($r$=0.15–0.19). Although there was a fair association between number of cardiac surgeries and QOL outcomes, number of cardiac surgeries was highly correlated with both RACHS-1 categories and ABC scores. Consequently, the number of cardiac surgeries was not included in the multivariable analysis because of collinearity.

## Multivariable Models to Predict QOL in the Pediatric Cardiac Surgical Population

In multivariable modeling, only 1% to 2% of additional variance in QOL scores (PCQLI DI and PI scores) was explained by ABC score or RACHS-1 category when controlling for covariates. Only in the child and parent of child PCQLI DI models were the ABC score and RACHS-1 category significantly correlated with child and parent of child PCQLI DI score, while controlling for covariates. ABC score and RACHS-1 category were not significantly associated with child and parent of child PCQLI PI scores or adolescent and parent of adolescent PCQLI DI and PI scores.

The models to predict QOL (PCQLI DI and PI) for the 4 respondent groups (child, parent of child, adolescent, and parent of adolescent) were similar (Tables 3 and 4). PCQLI DI scores were significantly lower for single-ventricle patients and for patients with more doctor visits within the previous 12 months. PCQLI DI scores were significantly higher as time since last hospitalization increased. In the child PCQLI DI

**Table 2.** Correlation Matrix for Patient–Parent Pediatric Cardiac Quality of Life Index DI and PI Subscale Scores and ABC Score and RACHS-1 Category by Demographic and Clinical Variables

| | Child | | | | | | Adolescent | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Patient (n=743) | | Parent (n=739) | | ABC Score (n=743) | RACHS-1 Category (n=692) | Patient (n=673) | | Parent (n=673) | | ABC Score (n=673) | RACHS-1 Category (n=599) |
| | DI Score | PI Score | DI Score | PI Score | | | DI Score | PI Score | DI Score | PI Score | | |
| Variable | Corr | Corr | Corr | Corr | Corr | Corr | Corr | Corr | Corr | Corr | Corr | Corr |
| ABC score | −0.20* | −0.10† | −0.20* | −0.12† | | | −0.11† | −0.11† | −0.10† | −0.07 | | |
| RACHS-1 category | −0.23* | −0.13‡ | −0.29* | −0.19* | 0.89* | | −0.16* | −0.12† | −0.20* | −0.13† | 0.87* | |
| Patient is male | 0.01 | −0.02 | 0.01 | −0.02 | −0.13* | −0.10† | −0.15* | −0.13* | −0.06 | −0.07 | −0.10† | −0.05 |
| Patient is white | 0.16* | 0.18* | 0.12* | 0.12† | 0.08‡ | 0.10† | 0.09‡ | 0.11† | 0.03 | 0.02 | 0.08‡ | 0.12† |
| Patient age | 0.10† | 0.11† | −0.03 | −0.12* | 0.00 | −0.01 | 0.05 | 0.02 | 0.04 | 0.06 | −0.12† | −0.06 |
| Parent education: college graduate | 0.13* | 0.17* | 0.14* | 0.12† | −0.01 | −0.05 | 0.09‡ | 0.09‡ | 0.09‡ | 0.14* | 0.00 | −0.03 |
| Single-ventricle anatomy | −0.31* | −0.18* | −0.35* | −0.24* | 0.53* | 0.60* | −0.27* | −0.21* | −0.34* | 0.25* | 0.44* | 0.50* |
| CHD | 0.02 | −0.03 | 0.07‡ | 0.03 | 0.41* | 0.03 | 0.03 | −0.07 | 0.04 | 0.01 | 0.51* | 0.04 |
| Patient has a pacemaker/ICD | −0.11† | −0.06 | −0.17* | −0.11† | −0.23* | 0.10† | −0.09‡ | 0.04 | −0.17* | −0.08‡ | −0.36* | 0.10‡ |
| Nonthoracic surgical procedure | −0.14* | −0.06 | −0.12† | −0.08 | 0.05 | 0.00 | −0.14* | −0.06 | −0.16* | −0.10‡ | 0.07 | 0.06 |
| Sternotomy | −0.12† | −0.08‡ | −0.12† | −0.06‡ | 0.45* | 0.29* | −0.08 | −0.12† | −0.03 | −0.05 | 0.54* | 0.30* |
| Genetic diagnosis | −0.13* | −0.09‡ | −0.11† | −0.02 | −0.03 | −0.03 | −0.12† | −0.08‡ | −0.09‡ | −0.06 | −0.02 | −0.05 |
| History of mental health problems | −0.04 | 0.00 | −0.12* | −0.15* | 0.03 | 0.06 | −0.17* | −0.13* | −0.22* | −0.20* | 0.03 | 0.00 |
| Number of doctor visits within the previous 12 months | −0.29* | −0.17* | −0.37* | −0.29* | −0.02 | 0.00 | −0.35* | −0.19* | −0.41* | −0.28* | −0.02 | 0.10‡ |
| Number of daily medications | −0.16† | 0.02 | −0.34* | −0.18* | 0.23* | 0.28* | −0.36* | −0.24* | −0.37* | −0.23* | 0.15† | 0.21* |
| Number of cardiac surgeries | −0.29* | −0.15* | −0.37* | −0.24* | 0.58* | 0.55* | −0.31* | −0.24* | −0.32* | −0.25* | 0.45* | 0.43* |
| Time since last hospitalization | 0.36* | 0.19* | 0.35* | 0.26* | −0.04 | −0.17* | 0.28* | 0.15* | 0.29* | 0.19* | 0.12† | −0.10‡ |
| Time since last cardiac catheterization/ intervention procedure | 0.27* | 0.13† | 0.29* | 0.16* | −0.01 | −0.17* | 0.24* | 0.14† | 0.23* | 0.12† | 0.15* | −0.09‡ |
| Time since last cardiac operation | 0.29* | 0.15* | 0.24* | 0.10† | −0.01 | −0.11† | 0.22* | 0.12† | 0.25* | 0.17* | 0.11† | −0.05 |

ABC indicates Aristotle Basic Complexity; CHD indicates congenital heart disease; Corr, correlation; DI, Disease Impact subscale; ICD, implantable cardioverter-defibrillator; PI, Psychosocial Impact subscale; RACHS-1, Risk Adjustment in Congenital Heart Surgery.

*$P<0.001$.

†$P<0.01$.

‡$P<0.05$.

model, white children had higher PCQLI DI scores than nonwhite children. Similarly, PCQLI PI scores were significantly lower for single-ventricle patients and for patients with more doctor visits within the previous 12 months. In addition, the child PCQLI PI model included 2 demographic variables, race (white children had a higher PCQLI PI score) and parental education (children with college-educated parents had a higher PCQLI PI score). For the 4 respondent groups, the

**Table 3.** Multivariable Regression Models for Patient–Parent Pediatric Cardiac Quality of Life Index Disease Impact Subscale Score Including ABC Score, RACHS-1 Category, and No Surgical Risk Score

| | ABC Score | | | | RACHS-1 Category | | | | No RACHS-1/ABC | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | b | β | *t* | *P* | b | β | *t* | *P* | b | β | *t* | *P* |
| Child | | | | | | | | | | | | |
| ABC score or RACHS-1 category | −0.40 | −0.12 | −3.12 | 0.0019 | −1.06 | −0.13 | −3.28 | 0.0011 | | | | |
| White | 3.94 | 0.17 | 5.20 | <0.0001 | 4.09 | 0.18 | 5.40 | <0.0001 | 3.72 | 0.16 | 4.90 | <0.0001 |
| Single ventricle | −3.29 | −0.17 | −4.14 | <0.0001 | −3.27 | −0.16 | 5.40 | <0.0001 | −4.58 | −0.23 | −6.67 | <0.0001 |
| Number of doctor visits within the previous 12 months | −0.41 | −0.18 | −4.99 | <0.0001 | −0.42 | −0.18 | −5.07 | <0.0001 | −0.40 | −0.17 | −4.76 | <0.0001 |
| Time since last hospitalization | 0.63 | 0.26 | 7.09 | <0.0001 | 0.60 | 0.24 | 6.71 | <0.0001 | 0.64 | 0.26 | 7.15 | <0.0001 |
| | $R^2$=0.25 (F=45.55, $P$<0.0001) | | | | $R^2$=0.25 (F=46.06, $P$<0.0001) | | | | $R^2$=0.24 (F=53.81, $P$<0.0001) | | | |
| Parent of child | | | | | | | | | | | | |
| ABC score or RACHS-1 category | −0.44 | −0.13 | −3.34 | 0.0009 | −1.40 | −0.17 | −4.22 | <0.0001 | | | | |
| Single ventricle | −4.21 | −0.20 | −5.13 | <0.0001 | −3.73 | −0.18 | −4.42 | <0.0001 | −5.64 | −0.27 | −7.99 | <0.0001 |
| Number of doctor visits within the previous 12 months | −0.68 | −0.28 | −8.00 | <0.0001 | −0.69 | −0.28 | −8.07 | <0.0001 | −0.66 | −0.27 | −7.73 | <0.0001 |
| Time since last hospitalization | 0.53 | 0.20 | 5.74 | <0.0001 | 0.50 | 0.19 | 5.44 | <0.0001 | 0.53 | 0.21 | 5.78 | <0.0001 |
| | $R^2$=0.27 (F=64.60, $P$<0.0001) | | | | $R^2$=0.28 (F=65.96, $P$<0.0001) | | | | $R^2$=0.26 (F=81.22, $P$<0.0001) | | | |
| Adolescent | | | | | | | | | | | | |
| ABC score/RACHS-1 category | 0.04 | 0.01 | 0.28 | 0.7762 | −0.34 | −0.04 | −0.95 | 0.3408 | | | | |
| Single ventricle | −4.18 | −0.20 | −4.81 | <0.0001 | −3.72 | −0.18 | −4.27 | <0.0001 | −4.07 | −0.20 | −5.22 | <0.0001 |
| Number of doctor visits within the previous 12 months | −0.58 | −0.26 | −6.72 | <0.0001 | −0.58 | −0.26 | −6.66 | <0.0001 | −0.58 | −0.26 | −6.73 | <0.0001 |
| Time since last hospitalization | 0.32 | 0.20 | 5.26 | <0.0001 | 0.31 | 0.20 | 5.06 | <0.0001 | 0.32 | 0.20 | 5.28 | <0.0001 |
| | $R^2$=0.20 (37.95, $P$<0.0001) | | | | $R^2$=0.20 (F=36.87, $P$<0.0001) | | | | $R^2$=0.20 (F=50.66, $P$<0.0001) | | | |
| Parents of adolescent | | | | | | | | | | | | |
| ABC score/RACHS-1 category | −0.08 | −0.020 | −0.52 | 0.6037 | −0.36 | −0.04 | −0.92 | 0.3576 | | | | |
| Single ventricle | −5.79 | −0.24 | −6.01 | <0.0001 | −5.49 | −0.23 | −5.66 | <0.0001 | −6.01 | −0.25 | −6.98 | <0.0001 |
| Number of doctor visits within the previous 12 months | −0.81 | −0.32 | −8.57 | <0.0001 | −0.83 | −0.32 | −8.58 | <0.0001 | −0.81 | −0.32 | −8.56 | <0.0001 |
| Time since last hospitalization | 0.33 | 0.18 | 4.94 | <0.0001 | 0.33 | 0.18 | 4.89 | <0.0001 | 0.33 | 0.18 | 4.93 | <0.0001 |
| | $R^2$=0.27 (F=54.64, $P$<0.0001) | | | | $R^2$=0.27 (F=54.83, $P$<0.0001) | | | | $R^2$=0.27 (F=73.85, $P$<0.0001) | | | |

ABC indicates Aristotle Basic Complexity; RACHS-1, Risk Adjustment in Congenital Heart Surgery.

multivariate coefficient of determination for the QOL models ranged from $R^2$=0.20 to $R^2$=0.28 for PCQLI DI models and from $R^2$=0.06 to $R^2$=0.14 for the PI models, indicating that other variables not included in these models may better explain the variance noted in QOL scores among CHD surgical survivors.

**Table 4.** Multivariable Regression Models for Patient and Parent Pediatric Cardiac Quality of Life Index Psychosocial Impact Subscale Score Including ABC Score, RACHS-1 Category, and No Surgical Risk Score

| | ABC Score | | | | RACHS-1 Category | | | | No RACHS-1/ABC | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | b | β | *t* | *P* | b | β | *t* | *P* | b | β | *t* | *P* |
| Child | | | | | | | | | | | | |
| ABC score or RACHS-1 category | 0.21 | −0.06 | −1.39 | 0.1643 | −0.69 | −0.08 | −1.85 | 0.0654 | | | | |
| White | 4.83 | 0.19 | 5.37 | <0.0001 | 5.06 | 0.21 | 5.68 | <0.0001 | 4.71 | 0.19 | 5.56 | <0.0001 |
| College | 3.06 | 0.16 | 4.32 | <0.0001 | 3.18 | 0.16 | 4.52 | <0.0001 | 3.03 | 0.16 | 4.29 | <0.0001 |
| Single ventricle* | −2.79 | −0.13 | −3.00 | 0.0028 | −2.70 | −0.13 | −2.84 | 0.0047 | −3.48 | −0.16 | −4.40 | <0.0001 |
| Number of doctor visits within the previous 12 months | −0.42 | 0.16 | −4.49 | <0.0001 | −0.41 | −0.16 | −4.46 | <0.0001 | −0.41 | −0.16 | −4.41 | <0.0001 |
| | $R^2$=0.12 (F=18.84, $P$<0.0001) | | | | $R^2$=0.13 (F=20.65, $P$<0.0001) | | | | $R^2$=0.11 (F=23.04, $P$<0.0001) | | | |
| Parent of child | | | | | | | | | | | | |
| ABC score or RACHS-1 category | −0.19 | −0.06 | −1.31 | 0.1913 | −0.85 | −0.10 | −2.33 | 0.0199 | | | | |
| Single ventricle | −3.80 | −0.18 | −4.25 | <0.0001 | −3.27 | −0.16 | −3.55 | 0.0004 | −4.43 | −0.21 | −5.84 | <0.0001 |
| Number of doctor visits within the previous 12 months | −0.64 | −0.26 | −7.15 | <0.0001 | −0.66 | −0.27 | −7.34 | <0.0001 | −0.64 | −0.26 | −7.08 | <0.0001 |
| | $R^2$=0.12 (31.75, $P$<0.0001) | | | | $R^2$=0.13 (F=34.07, $P$<0.0001) | | | | $R^2$=0.12 (F=46.66, $P$<0.0001) | | | |
| Adolescent | | | | | | | | | | | | |
| ABC score or RACHS-1 category | 0.01 | 0.003 | 0.07 | 0.9441 | −0.31 | −0.04 | −0.85 | 0.3936 | | | | |
| Single ventricle | −3.44 | −0.18 | −3.90 | 0.0001 | −3.02 | −0.15 | −3.39 | 0.0007 | −3.41 | −0.17 | −4.31 | <0.0001 |
| Number of doctor visits within the previous 12 months | −0.35 | −0.17 | −4.12 | <0.0001 | −0.36 | −0.17 | −4.14 | <0.0001 | −0.35 | −0.17 | −4.13 | <0.0001 |
| | $R^2$=0.06 (14.65, $P$<0.0001) | | | | $R^2$=0.06 (14.82, $P$<0.0001) | | | | $R^2$=0.06 (F=22.00, $P$<0.0001) | | | |
| Parents of adolescent | | | | | | | | | | | | |
| ABC score or RACHS-1 category | −0.01 | −0.001 | −0.03 | 0.9740 | −0.28 | −0.03 | −0.69 | 0.4914 | | | | |
| Single ventricle | −4.60 | −0.20 | −4.58 | <0.0001 | −4.15 | −0.18 | −4.10 | <0.0001 | −4.62 | −0.20 | −5.14 | <0.0001 |
| Number of doctor visits within the last 12 months | −0.66 | −0.27 | −6.81 | <0.0001 | −0.70 | −0.28 | −7.14 | <0.0001 | −0.66 | −0.27 | −6.81 | <0.0001 |
| | $R^2$=0.13 (F=29.94, $P$<0.0001) | | | | $R^2$=0.14 (F=31.45, $P$<0.0001) | | | | $R^2$=0.13 (F=44.99, $P$<0.0001) | | | |

*For model consistency, single ventricles were kept in the ABC and RACHS-1 equations even though the β score was <0.15.

## Discussion

This study demonstrates that although higher surgical complexity and related morbidity correlate with lower QOL in pediatric cardiac surgical survivors, the impact of surgical complexity on long-term QOL is very small. Surgical complexity and demographic, clinical, and anatomic variables explain only, at most, a quarter of the variation in QOL scores. Furthermore, once single-ventricle anatomy, number of doctor visits within the previous 12 months, and time since last hospitalization were accounted for, ABC scores and RACHS-1 categories did not add any significant explanation of variation in QOL scores. ABC scores and RACHS-1 categories are helpful for evaluation of quality of care between different pediatric cardiovascular centers, for facilitating communication between physicians about the level of surgical difficulty, and for predicting in-hospital mortality and hospital length of stay; however, they do not appear to be useful for predicting long-term QOL of pediatric cardiac surgical survivors.

Our research team previously showed that lower QOL in the CHD population is associated with increasing disease severity and greater numbers of surgical procedures and hospitalizations.[6,7] Patients with increasing disease severity and a greater number of surgeries and hospitalizations typically will have had an initial neonatal or infant cardiothoracic surgical procedure that has greater surgical complexity; however, greater surgical complexity was not associated with worse long-term QOL in CHD survivors in this study. This is likely due to the variable surgical results and intensive care morbidity experienced by the high-risk patients having surgery of greater complexity. The patients' underlying CHD and the initial surgical result and complications suffered in the intensive care unit will determine whether these patients require future operations and whether repeated hospitalizations are necessary. In addition, the remoteness of the surgery and the variable medical outcomes that may result over time are likely more important than the complexity of the initial surgery. This is supported by our data showing that time since last hospitalization had fair correlation with the PCQLI DI subscale score, which assesses physical functioning and physical symptoms.

We hypothesize that other factors, not assessed in this study, may better explain variation in QOL than higher ABC scores and RACHS-1 categories. Impaired coping mechanisms of both patient and family, for example, may be a potential explanation for QOL impairments in patients with CHD.[22–24] Several studies in children with CHD and their parents have demonstrated the importance of coping to maximize psychological functioning at different stages of diagnosis and treatment.[25–28] Positive coping strategies have been shown to be associated with higher QOL in other pediatric chronic diseases including reactive airway disease, pediatric cancer, and juvenile idiopathic arthritis.[29–31] Given that coping strategies are important to psychological functioning in CHD survivors and their families and that coping is related to QOL in other pediatric chronic disease groups, interventions directed toward promoting positive coping may provide resilience and improve QOL.

Emerging research is highlighting the significance of neurodevelopmental and psychosocial morbidity associated with heart disease, particularly in children with complex CHD.[2,32–49] The American Heart Association has identified CHD survivors at high risk for neurodevelopmental and psychosocial morbidity and created a set of recommendations to optimize neurodevelopmental and psychosocial outcomes in children with CHD.[2] The prevalence and severity of developmental delay increases with the complexity of CHD and the presence of genetic disorders or syndromes.[2] Complex CHD survivors have a distinctive pattern of neurodevelopmental and behavioral impairment characterized by mild cognitive impairment and academic achievement; deficits in social cognition, core communication skills, and pragmatic language; inattention; hyperactivity and impulsivity; deficits in visual construction and perception; impaired executive functioning; and limitations in gross and fine motor skills.[32–44]

In addition, there is often accompanying psychosocial maladjustment with behavioral and emotional issues such as posttraumatic stress symptomatology, anxiety, and depression in both the surgical survivor and the family.[2,44–49] Many school-age survivors of infant cardiac surgery require supportive services including tutoring; special education; and physical, occupational, and speech therapy. The neurodevelopmental and psychosocial morbidity related to CHD and its treatment often limit ultimate educational achievements, employability, life-long earnings, insurability, and QOL for many patients. A significant proportion of patients with complex CHD may need specialized services into adulthood. Incorporation of new stratification methods and clinical evaluation and management algorithms may result in increased surveillance, screening, evaluation, diagnosis, and management of developmental disorder and disability in the complex CHD population and consequent improvement in neurodevelopmental and behavioral outcomes in this high-risk population. With early identification and treatment of developmental delays, children have the best chance to reach their full potential.

## Limitations

This study has several inherent limitations of the results. First, the study population was taken from a previously recruited study population. Second, although the study sites were geographically diverse with $\leq$30% of the study population coming from a single center, the patient and parent population lacks racial diversity, and parents who responded were predominantly female. Third, certain medical centers do not perform certain surgical and interventional procedures, and this could limit the results. In addition, various operative factors and postoperative complications were not evaluated as predictor variables for lower QOL score. Studying the relationship between postoperative complications and QOL may also account for some of the unexplained variance in QOL scores among cardiac surgical survivors. Finally, both of the validated objective surgical complexity scales used in the analysis were developed, in whole or in part, based on expert consensus, which may lead to inherent bias and limit the results of this study.

## Conclusions

Although higher ABC scores and RACHS-1 categories were significantly associated with worse QOL scores in pediatric cardiac surgical survivors, the correlations were fair to poor and did not explain any additional significant variation in QOL.

ABC scores and RACHS-1 categories are useful tools for morbidity and mortality predictions prior to cardiac surgery and quality of care initiatives but are minimally helpful for predicting a child's or adolescent's long-term QOL. Further studies are warranted to determine other physical, neurodevelopmental, and/or psychosocial variables that may be predictors of the unexplained variance in QOL in this population.

## Acknowledgments

The following persons participated in the enrollment of patients, data collection, and study coordination: *Cincinnati Children's Hospital Medical Center*—Charlotte Andersen, RN, MS, PMP, Sara Medek, MS, Katelyn Mellion, BS, Kaleigh Coughlin, BA, Brett Morgan, BS, Loran Carroll, BS, Melanie Riedel, BS, Michael Whalen, Aimee Baker, MA; *The Children's Hospital of Philadelphia*—Linda Hurd, MSN, CRNP, Janice Prodell, RN, Lynda Ahearn, RN, Lydia Kruge, BA, Anita Pudusseri, BS, Darryl Powell, Andrew Schissler, BSE, Josie Welkom, BA, Stanley O. Dunn, BA; *Children's Hospital Boston*—Annette Baker, MSN, CRNP, Jill Cotter, BA, Danielle Martin, BA, Erica Denhoff, BA, Ellen McGrath, BSN; *University of California San Francisco Children's Hospital*—Elizabeth Tong, RN, MS, David Teitel, MD, Laura Robertson, MD; *Children's Hospital of Wisconsin*—Stuart Berger, MD, Nancy Ghanayem, MD, Lisa Young-Borkowski, MSN, Mary Krolikowski, MSN, Angie Klemm, Mara Koffarnus; *Children's Medical Center at Dallas*—Gloria Williams, BA.

## Sources of Funding

This research was funded by the following: NICHD K23 Grant (5-K23-HD048637-05), American Heart Association Grant (0465467), CHOP Institutional Development Fund, and CCHMC Research Foundation (31-554000-355514).

## Disclosures

None.

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