Longitudinal assessment of health-related quality of life in patients with adult congenital heart disease undergoing cardiac surgery

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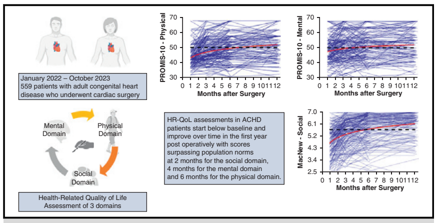
ABSTRACT

Objective: The study objective was to assess longitudinal postoperative health-related quality of life among patients with adult congenital heart disease facilitated by a novel electronic medical record–based patient-reported outcomes follow-up platform.

Methods: From January 2022 to October 2023, 559 patients with adult congenital heart disease underwent cardiac surgery; 491 (88%) completed a 23-element health-related quality of life questionnaire covering 3 domains (physical, mental, and social) yielding 911 assessments. Automated questionnaires via electronic medical record were sent at 7 days preoperatively and postoperatively at 1, 3, 6, and 12 months. Nonlinear multiphase mixed effects models and boosting approach using multivariate trees were used to assess longitudinal trends and the relationship among patient characteristics, clinical variables, and health-related quality of life outcomes.

Results: Mean age of patients was 53 years (range, 19-86), 238 (43%) were female, 109 (20%) were STAT category 3 or 4, postoperative mortality was 0, and stroke was 4 (0.7%). Diagnosis included hypertrophic obstructive cardiomyopathy (276, 50%), anomalous coronary artery (42, 7.5%), congenital aortic valve disease (42, 7.5%), bicuspid aortic valve (64, 12%), and aortic aneurysm (25, 4.5%). Although baseline health-related quality of life scores were below population norms, rapid postoperative increases were seen in physical, mental, and social scores, surpassing population norms between 2 and 6 months. Patients with higher baseline health-related quality of life had higher longitudinal scores. Female patients and those of Black race had higher Area Deprivation Index and lower postoperative physical health-related quality of life scores.

Conclusions: Patients with adult congenital heart disease require lifelong medical surveillance and repeated interventions. Our innovative electronic medical record–embedded time-series tool assessing health-related quality of life after cardiac surgery shows improved patient-reported outcomes across mental, physical, and social domains that endure through at least the first postoperative year. (JTCVS Open 2024;22:407-26)



Automated EMR follow-up shows HR-QoL improves after cardiac surgery in patients with ACHD.

CENTRAL MESSAGE

Patients with ACHD undergoing cardiac surgery at our center exhibit sustained improvement in postoperative patient-reported HR-QoL, surpassing population norms across 3 domains.

PERSPECTIVE

Our innovative EMR tool for assessing HR-QoL among patients with ACHD revealed improved patient-perceived outcomes in mental, physical, and social domains after cardiac surgery. Patients with higher baseline HR-QoL scores experienced increased improvements, advocating for prehabilitation benefits. Social determinants of health disproportionately affect specific domain scores, necessitating elucidation in future research.

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Abbreviations and Acronyms

ACHD	= adult congenital heart disease
ADI	= Area Deprivation Index
CHD	= congenital heart disease
CHSD	= Congenital Heart Surgery Database
EMR	= electronic medical record
HR-QoL	= health-related quality of life
PROMIS-10	= 10-item Patient-Reported Outcome Measurement Information System
STS	= Society of Thoracic Surgeons

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Advances in preoperative and postoperative care for children undergoing surgery for congenital heart disease (CHD) over the past 4 decades have resulted in greater than 85% survival into adulthood.[1] Despite these survival gains, patients with adult congenital heart disease (ACHD) often have complex physiology, and many are left with important anatomic residual defects that impair complete recovery to normal functioning. Because of the chronic nature of their disease, patients with ACHD require careful lifelong medical follow-up and observation, often with the frequent need for imaging and laboratory tests, or hospital admission.[2] Moreover, the majority of these patients will undergo multiple repeated interventions for unrelated acquired heart disease or a combination of congenital-related and acquired heart disease throughout their lifetime.[3-8]

Although the ongoing burden of cardiovascular disease is well known, longitudinal follow-up in ACHD is challenged by fragmented care delivery systems that often inhibit seamless transition from pediatric to adult care.[9] Many patients with ACHD also lack awareness of the severity of their cardiovascular disease and may be relatively uneducated regarding the necessity for lifelong care, even in the absence of overt clinical symptoms. Cumulatively, it is postulated that complicated pathophysiology, chronic disease courses, and fragmented follow-up may detrimentally influence perceived health-related quality of life (HR-QoL) outcomes of patients with ACHD.

Although existing studies have reported HR-QoL outcomes among patients with ACHD,[10] these lack longitudinal perspectives and baseline measures for postintervention comparison. Studies indicate that patients with lower HR-QoL scores have a higher risk of future healthcare use.[11] Integrating patient-reported treatment outcome measures such as the HR-QoL into research and clinical practice is essential for aligning expectations about preoperative risk factors and patients' perceptions about outcomes. Understanding how patients perceive the relative importance of specific outcomes will likely improve the coupling of physician and patient expectations after surgery. However, historical challenges in accessing comprehensive patient data to better understand patient perceptions have been limited by consent issues and multi-hospital system tracking. Fortunately, the ubiquitous adoption of electronic medical records (EMRs) now affords patients, clinicians, and researchers unprecedented access to granular patient-level data. Furthermore, patient-facing platforms, such as MyChart (Epic Systems Corporation), enable digital-virtual interactions between patients and physicians. Leveraging this technology, our center has capitalized by developing a novel EMR-based follow-up platform to assess HR-QoL among our patients with ACHD undergoing cardiac surgery over time. This study reports the results of this initiative among a complex cohort at our center.

PATIENTS AND METHODS

Patients

From January 2022 to October 2023, 559 patients who underwent cardiac surgery for ACHD at the Cleveland Clinic and were sent HR-QoL questionnaires are included (Figure 1). To ensure feasibility within our large-scale assessment framework, preoperative questionnaires were distributed 7 days before surgery. This timing was chosen pragmatically, given that patients are typically not seen at our institution earlier than 7 days before the procedure. Postoperative questionnaires were strategically timed to coincide with routine follow-up visits at 30 days, with subsequent assessments occurring at several intervals during the first year to capture dynamic changes in functional recovery. Patients with ACHD were defined according to the Society of Thoracic Surgeons (STS) Adult Congenital Mortality Risk Model criteria[8] and our center-specific criteria for ACHD (included in Appendix E1). Clinical data were abstracted from the STS Congenital Heart Surgery Database (CHSD). Preoperative, intraoperative, and postoperative data were collected from patients undergoing congenital heart surgical procedures using standardized definitions (https://www.sts.org/registries-research-center/sts-national-database/congenital-heart-surgery-database/data-collection). We also gathered data on the Area Deprivation index (ADI) to integrate the influence of social determinants of health on HR-QoL measures. ADI is a geographic mapping tool that delineates the relative socioeconomic status of neighborhoods based on income, education, employment, and housing quality. Neighborhoods are ranked based on their ADI in comparison with national (ADI: National Percentile) and state (ADI: State Decile) standards, with higher rankings indicating greater socioeconomic disadvantage.[12] HR-QoL data were obtained from the enterprise EMR-based data repository specifically constructed to capture longitudinal HR-QoL data among patients undergoing cardiac surgery since December 1, 2021. These HR-QoL data were linked using patient enterprise medical record to the STS-CHSD clinical data and verified by our registry and clinical team. Use of these data for research was approved by the Cleveland Clinic Institutional Review Board (#24-007, approved January 4, 2024), with patient consent waived.

Heath-Related Quality of Life Assessment

The 10-item Patient-Reported Outcome Measurement Information System (PROMIS-10) is a National Institutes of Health–funded global health generic questionnaire that measures the physical, mental, and social health

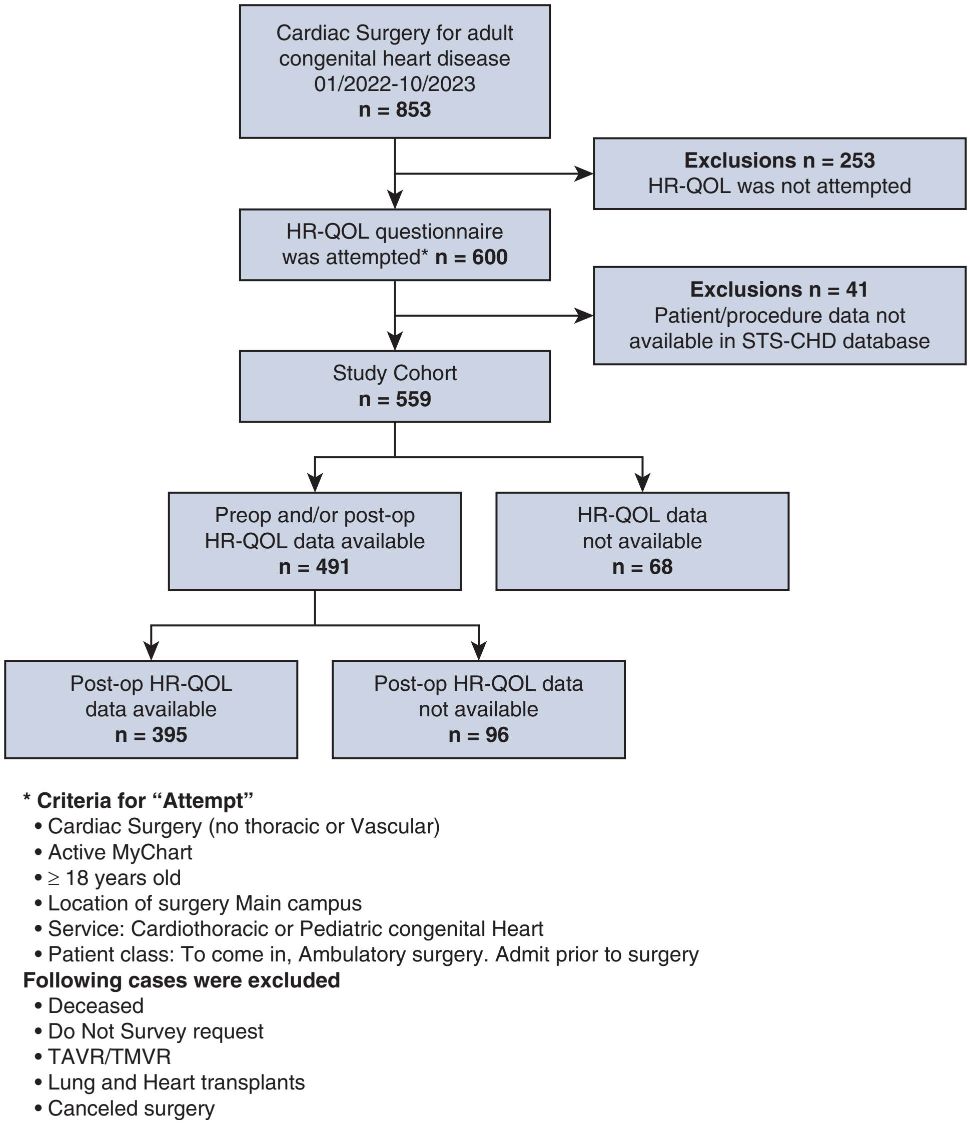


FIGURE 1. Patient flow chart describes inclusion/exclusion of the study cohort and the subcohort with preoperative and postoperative HR-QoL data. *HR-QoL*, Health-related quality of life; *STS-CHD*, Society of Thoracic Surgeons congenital heart disease; *TAVR*, transcatheter aortic valve replacement; *TMVR*, transcatheter mitral valve replacement.

status from the patient's perspective.[13] The PROMIS-10 questionnaire constructs a physical health and a mental health score for each patient that is standardized to the general population.[13] The MacNew Heart Disease HR-QoL questionnaire[14] is a self-administered cardiac-specific survey that was a modification of the interviewer-administered Quality of Life after Myocardial Infarction questionnaire. This assessment consists of 27 items that fall into 3 domains: physical limitations domain scale, emotional function domain scale, and social function domain scale.[15] To minimize completion burden, we used a composite questionnaire that coupled the emotional and social function domains of the MacNew with the physical and mental PROMIS-10 domains. A PROMIS-10 score exceeding 50 indicated superior self-reported physical and mental health compared to a matched age and sex US population. A MacNew social score above 5 indicates enhanced social health compared with peers with cardiac disease. EMR-based questionnaires were provided to patients within their MyChart platform at baseline and at 1, 3, 6, and 9 months postoperatively (Figure 2).

Other End Points

Clinical end points included STS-CHSD–defined major morbidity and 30-day mortality.[16] Major postoperative events included neurologic dysfunction (stroke, cerebrovascular accident, or intracranial hemorrhage grade >2 stroke during lifetime), unplanned cardiac reoperation, renal failure requiring dialysis, readmission within 30 days, mechanical circulatory support, unexpected cardiac arrest, phrenic nerve injury, arrhythmia requiring permanent pacemaker, operative mortality, operative length of stay, and hospital length of stay.

Health-Related Quality of Life Follow-up

Patients completed the 23-element questionnaires through the Epic-based MyChart platform, including HR-QoL data on 3 domains using the PROMIS-10 (mental and physical domains) and MacNew (social domain) questionnaires, performed at approximately 1 month, 3 months, 6 months, and 12 months after cardiac surgery (Figure E1). Patients who

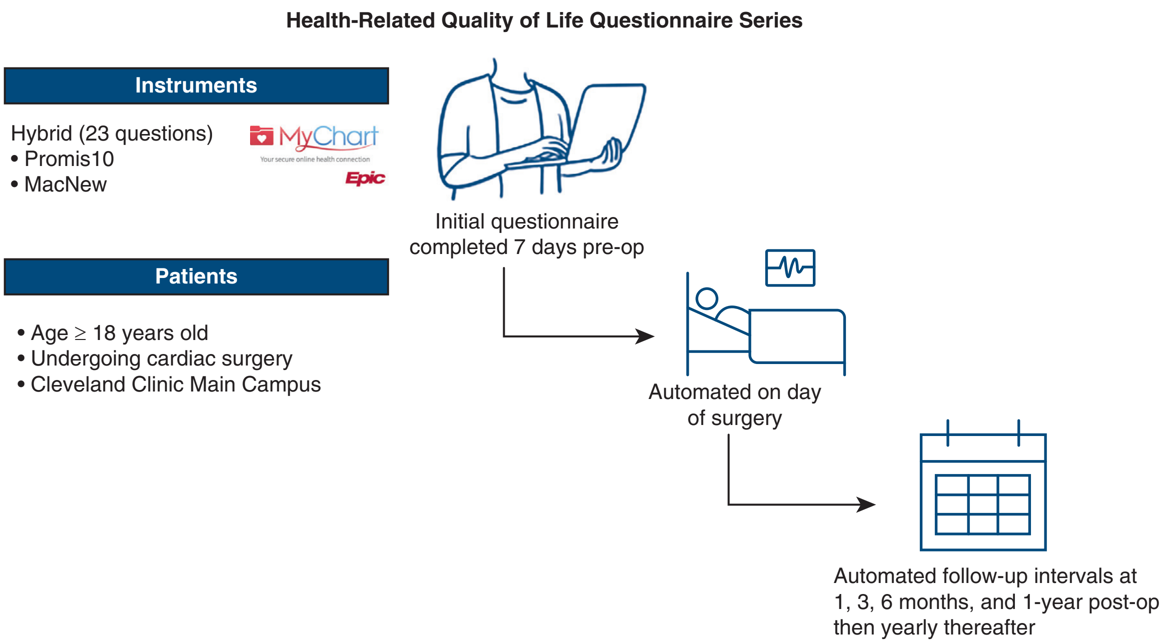


FIGURE 2. EMR-based questionnaires were provided to patients within their EMR and MyChart platform at baseline and 1, 3, 6, and 9 months postoperatively.

were not enrolled in MyChart or who failed to complete their electronic questionnaires (baseline 4.1%, 1 month postoperatively 2.4%, 3 months postoperatively 0.6%, 6 months postoperatively 0.6%, 12 months postoperatively 1.2%) were called by our dedicated clinical follow-up team.

A total of 911 postsurgery HR-QoL measures were available for 395 patients (71% of study cohort) (Figure 1). Median HR-QoL follow-up was 3.2 months, with 10% of the measures obtained at or beyond 12 months.

Of the 559 patients, 491 (88%) have at least 1 HR-QoL datum (in at least 1 of 3 scores) available (Figure 1). Most of them are obtained at approximately 1 month, 3 months, 6 months, and 12 months postsurgery (Figure E1).

Data Analysis

Statistical analyses were performed using SAS version 9.4 (SAS Institute, Inc) and R version 3.6.0 (R Foundation for Statistical Computing). Continuous variables are summarized as mean ± SD or as equivalent 15th, 50th (median), and 85th percentiles when distribution of values was not normally distributed, and comparisons were made using Wilcoxon rank-sum test. Categorical data are summarized by frequencies and percentages, and comparisons were made using chi-square test or Fisher exact test. Time zero for the analysis is the time of the surgical procedure. A multiphase, nonlinear, mixed-effects longitudinal regression model was used to estimate the temporal trend of PROMIS-10 Physical, PROMISE-10 Mental, and MacNew Social scores (continuous longitudinal data) from the repeated assessments on follow-up HR-QoL.[17] The models were implemented using PROC NLMIXED (SAS).

To identify variables modulating the longitudinal measures from 3 domains of HR-QoL, we used boostmtree in R, a boosting tree-based approach based on a marginal model of longitudinal data.[18] For this, we considered variables listed in Appendix E2. Missing data in the covariates were imputed "on-the-fly" as a part of growing the forest object.[19] Variable importance was used to hierarchically order variables in relation to predicted longitudinal HR-QoL scores,[20] which separates an overall effect of covariates into main effects and covariate–time interaction effects. One of the main objectives of this machine-learning approach was to visualize the relation of covariables to postoperative assessments without model assumptions. For this, we used partial dependency plots, which describe the risk-adjusted relationship between the covariate of interest and longitudinal metrics by integrating out the effect of all other covariates.[21] These analyses were carried out using the *boostmtree* package in R.[22]

RESULTS

Patient Characteristics

A general description of patient and procedure characteristics at the time of surgery is shown in Table 1. The mean age of patients was 53 ± 15 years. Overall, 238 patients (43%) were female, with 109 (20%) undergoing STAT category 3 or 4 procedures as defined by the STS-CHSD risk model.[23] Fundamental diagnosis for CHD included hypertrophic cardiomyopathy in 276 patients (50%), anomalous coronary artery in 42 patients (7.5%), congenital aortic (unicuspid or quadricuspid) valve disease in 42 patients (7.5%), bicuspid aortic valve in 64 patients (12%), and aortic aneurysm in 25 patients (4.5%) (Table 1). The baseline HR-QoL scores for PROMIS-10 physical, PROMIS-10 mental, and MacNew social were 44 ± 9.3, 48 ± 9.6, and 4.9 ± 1.3, respectively (Table 1).

In-Hospital Morbidity and Mortality

Of the 559 patients, in-hospital morbidity included neurologic dysfunction persisting at discharge in 4 of 559 (0.72%), unplanned cardiac reoperation in 9 of 559 (1.6%), renal failure requiring dialysis in 2 of 559 (0.36%), 30-day readmission in 31 of 559 (5.6%), mechanical circulatory support in 3 of 559 (0.54%), unexpected cardiac arrest in 3 of 559 (0.54%), and arrhythmia requiring

TABLE 1. Preoperative patient characteristics, diagnosis, and procedure details (N = 559)

Characteristics	n*	No. (%) or mean ± SD
Demography		
Age at surgery (y)	559	53 ± 15
Female	559	238 (43)
Race: Black	548	26 (4.7)
Race: White	548	437 (80)
Race: other	548	85 (16)
Body surface area (m^2)	557	2.1 ± 0.31
Body mass index (kg/m^2)	550	30 ± 6.6
Area Deprivation Index		
National percentile	491	52 ± 26
State decile	491	4.4 ± 2.8
Baseline HR-QoL scores		
PROMIS-10 Physical	347	44 ± 9.3
PROMIS-10 Mental	347	48 ± 9.6
McNew Social	402	4.9 ± 1.3
Symptoms		
STAT Category	545	
1		316 (58)
2		120 (22)
3		89 (16)
4		20 (3.7)
No. of prior cardiac operations	557	
0		409 (73)
1		101 (18)
2		29 (5.2)
3		13 (2.3)
4		4 (0.72)
6		1 (0.18)
Fundamental diagnosis	557	
Anomalous coronary artery		42 (7.5)
Aorta, other		3 (0.54)
Aortic aneurysm		25 (4.5)
Aortic dissection		11 (2)
Atrial septal defect		25 (4.5)
Bicuspid aortic valve (isolated)		28 (5)
Bicuspid aortic valve (not isolated)		36 (6.5)
Coarctation or hypoplastic aortic arch		11 (2)
Congenital aortic valve disease		42 (7.5)
Congenital PV disease		2 (0.36)
Congenital MV disease		12 (2.2)
Connective tissue disorder		15 (2.7)
HOCM/IHSS		276 (50)
Subaortic membrane		12 (2.2)
Tetralogy of Fallot, all types		2 (0.36)
Ventricular septal defect		8 (1.4)
Other		7 (1.3)
Cardiac, noncardiac comorbidities	559	
Asthma		61 (11)
Cardiac dysrhythmia		16 (2.9)
Chronic lung disease (not associated with premature birth)		4 (0.72)
Coagulation disorder, hypocoagulable state secondary to medication		2 (0.36)
Currently taking steroids for any reason other than treatment of adrenal insufficiency		7 (1.3)
Diabetes mellitus, insulin dependent		18 (3.2)
Diabetes mellitus, noninsulin dependent		48 (8.6)
Dyslipidemia		268 (48)
Endocarditis		3 (0.54)
Family history of coronary artery disease		140 (25)
Heart failure		2 (0.36)
Hypertension		51 (9.1)
ICD (automatic ICD) present		50 (8.9)
Immunocompromised		3 (0.54)
Pacemaker present		15 (2.7)
Preoperative complete AV block		13 (2.3)
Preoperative dysrhythmia requiring antidysrhythmia medication		10 (1.8)
Preoperative neurological deficit		8 (1.4)
Renal dysfunction		4 (0.72)
Renal failure requiring dialysis		1 (0.18)
Seizure during lifetime		12 (2.1)
Sleep apnea		20 (3.6)
Neurologic dysfunction (stroke, CVA, or intracranial hemorrhage Grade >2 during lifetime)		16 (2.9)
Tobacco use		200 (36)
Coagulation disorder, hypercoagulable state		1 (0.18)
Currently taking steroids as treatment for adrenal insufficiency		1 (0.18)
Other		433 (77)
Primary procedure	559	
Aortic procedures		93 (17)
Congenital procedures		193 (35)
Other procedures		2 (0.36)
Valve/CABG procedures		271 (48)

HR-QoL, Health-related quality of life; *PROMIS-10*, 10-item Patient-Reported Outcome Measurement Information System; *PV*, pulmonary valve; *MV*, mitral valve; *HOCM*, hypertrophic obstructive cardiomyopathy; *IHSS*, idiopathic hypertrophic subaortic stenosis; *ICD*, implantable cardioverter defibrillator; *AV*, aortic valve; *CVA*, cerebrovascular accident; *CABG*, coronary artery bypass grafting. *Number of patients with data available.

a permanent pacemaker in 25 of 559 (4.5%). There were no operative mortalities, but 1 death was observed at 11 months during the 1-year follow-up period (Table E1). Median hospital length of stay was 5 days (15th, 85th percentiles: 4, 10 days), and median operative length of stay was 5 days (15th, 85th percentiles: 4, 9 days) (Table E1).

Health-Related Quality of Life Data Collection and Follow-up

Of the 559 patients, 491 (88%) have at least 1 HR-QoL data (in at least 1 of 3 scores) available. Sensitivity analysis demonstrated that patients without HR-QoL data were

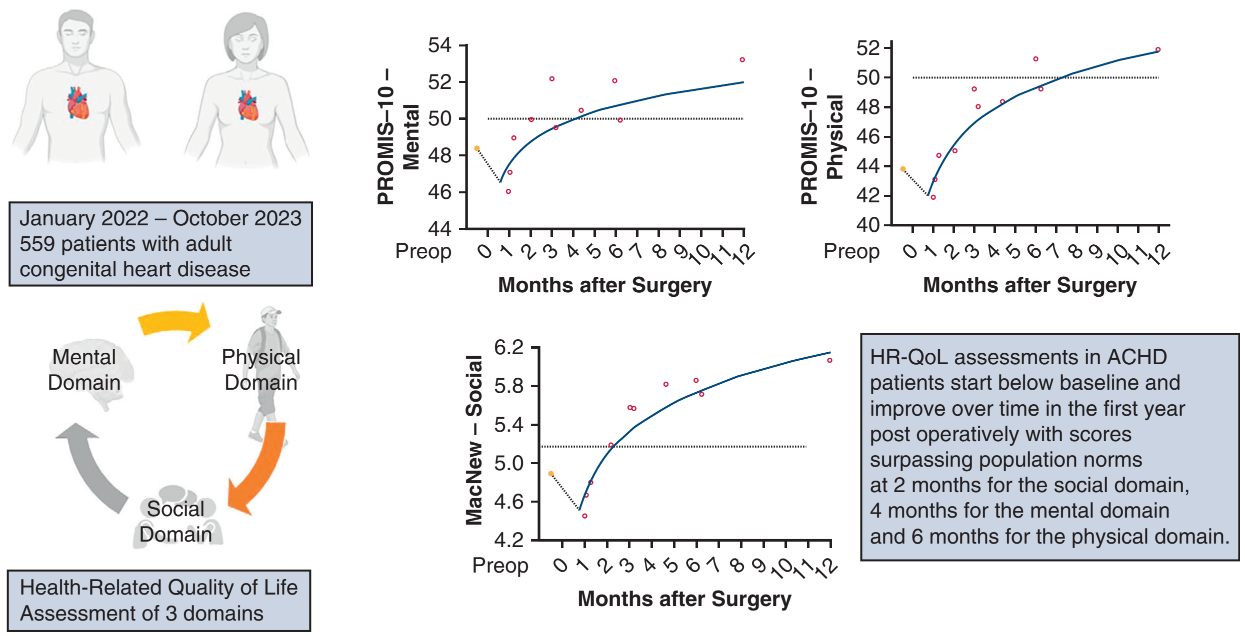


FIGURE 3. Automated EMR follow-up shows HR-QoL improves after cardiac surgery in patients with ACHD. *HR-QoL*, Health-related quality of life; *ACHD*, adult congenital heart disease.

similar to those with HR-QoL data except for race categories, which showed that Black race was associated with a decreased likelihood to complete HR-QoL assessments (Table E2).

Temporal Trends of Health-Related Quality of Life

HR-QoL assessments in patients with ACHD improve over time in the first year postoperatively with scores surpassing population norms at 2 months for the social domain, 4 months for the mental domain, and 6 months for the physical domain (Figure 3). One-month, 6-month, and 1-year estimated scores for physical domain were 43, 49, and 52, respectively (Figure 4, *A*); for mental domain, these were 47, 51, and 52, respectively (Figure 4, *B*); and for social domain, these were 4.7, 5.7, and 6.2, respectively (Figure 4, *C*).

Preoperative Health-Related Quality of Life and Its Effects on Postoperative Well-Being

Higher preoperative PROMIS-10 physical scores were associated with higher postoperative PROMIS-10 physical domain scores; patients with preoperative scores of 50 or greater had higher postoperative scores (Figure 5, *A*). Higher preoperative PROMIS-10 mental scores were associated with higher postoperative PROMIS-10 mental and MacNew social scores, particularly patients with preoperative mental scores of 45 or greater had higher postoperative mental (Figure 5, *B*) and social scores (Figure 5, *D*). Higher preoperative MacNew social scores were also associated with higher postoperative MacNew Social Scores (Figure 5, *C*).

Baseline Patient Characteristics and Postoperative Health-Related Quality of Life Domain Scores

Patients with connective tissue disease had higher postoperative PROMIS-10 physical, PROMIS-10 mental, and MacNew social scores (Figure 6). This finding was further explored to assess whether connective tissue disease was a surrogate for other patient or procedural characteristics. Further analysis showed that patients with connective tissue disease are younger, have lower body mass index, have lower STAT scores, and are more likely to undergo aortic procedures (Table E3).

In patients with higher ADI, the national percentile had lower postoperative PROMIS-10 physical (Figure 7, *A*) and mental scores (Figure 7, *B*). Black race (Figure 7, *C*) and tobacco use (Figure 7, *D*) were correlated with reduced postoperative PROMIS-10 physical scores, with Black patients demonstrating lower scores particularly after 6 months (Figure 7, *C*). Longer operative length of stay was associated with lower early postoperative PROMIS-10 mental scores, with patients staying longer than 21 days having lower early mental scores and no effect seen on the late reported mental scores (Figure 7, *E*). A diagnosis of anomalous coronary artery disease was associated with lower postoperative MacNew social scores (Figure 7, *F*).

Perioperative Measures and Postoperative Health-Related Quality of Life Longitudinal Trends

In patients with connective tissue disease, higher preoperative PROMIS-10 physical, PROMIS-10 mental, and MacNew social scores, and absence of tobacco use were

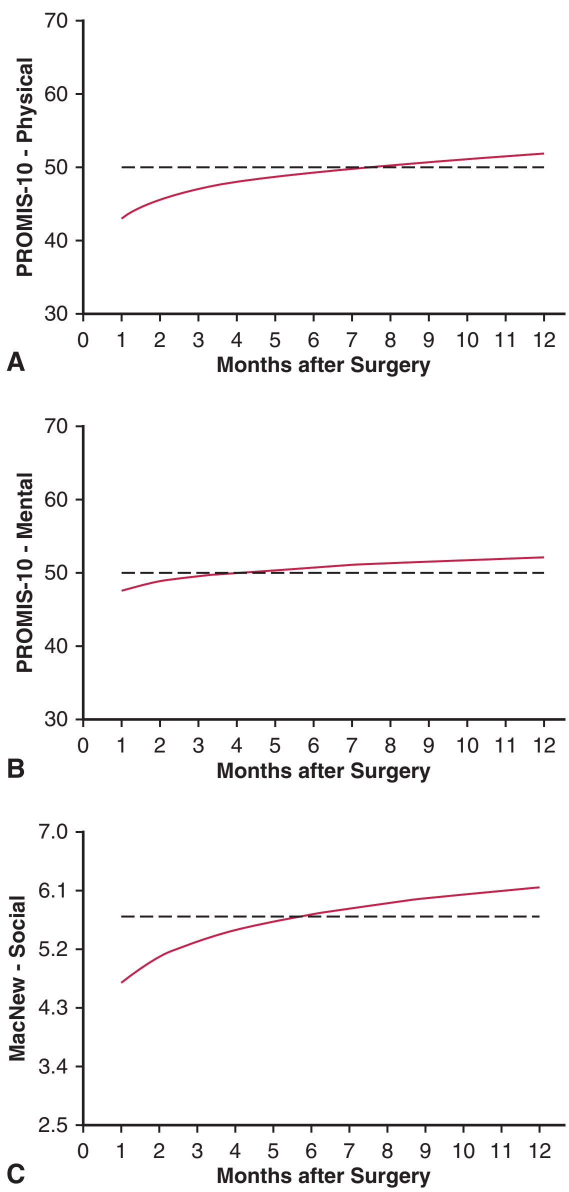


FIGURE 4. Temporal trend of HR-QoL measures after cardiac surgery. *Solid line* (*red*) represents parametric estimates of mean HR-QoL measure after the surgery. *Dash-dash black line* depict the population norm. A, PROMIS-10 Physical score. B, PROMIS-10 Mental score. C, MacNew Social. *PROMIS-10*, 10-Item Patient-Reported Outcome Measurement Information System.

associated with higher postoperative PROMIS-10 physical, PROMIS-10 mental, and MacNew social scores (Figures E2 and E3). Although there was no difference in the early response (up to 3 months after surgery) of PROMIS-10 physical scores between Black and other races, there was a difference in the late response of PROMIS-10 physical scores, with Black race having lower PROMIS-10 physical measures than the other races at 6 months postoperatively (Figure E4).

Impact of Social Determinants of Health on Quality of Life

Patients with lower ADI percentile had higher PROMIS-10 physical and mental (Figure E2) scores, with patients in the lower 15th ADI percentile having higher PROMIS-10 physical scores compared with other patients (Figure E4). Length of stay is associated with an early response of PROMIS-10 mental scores and MacNew social scores, with shorter length of stay being associated with higher early PROMIS-10 mental scores (Figures E2 and E3). There is a late positive correlation with age and higher postoperative MacNew social scores at 1 and 12 months and a negative correlation with increasing body mass index (Figure E3).

In our analysis, we found no association between age and ADI; however, female gender was associated with a higher ADI when compared with male gender (national percentile: female 56 ± 27, male 50 ± 26, $P = .01$; state decile: female 4.8 ± 2.9, male 4.2 ± 2.6, $P = .04$). Black race was found to be associated with a higher ADI when compared with other races (national percentile: Black race: 76 ± 21; race other than black: 51 ± 26, $P < .0001$; state decile: Black race: 6.6 ± 2.7, race other than Black: 4.3 ± 2.7 $P = .0001$).

DISCUSSION

Integration of Findings: Comprehensive Insights and Implications

Our novel EMR-integrated longitudinal instruments for evaluating HR-QoL in patients after ACHD cardiac surgery show a gradual increase in physical, mental, and social domain scores over time, with scores surpassing population norms between 2 and 6 months postoperatively. Patients with higher baseline HR-QoL domain scores had improved longitudinal scores, suggesting that prehabilitation regimens may be highly effective in improving patient-perceived HR-QoL. Social determinants of health were operative in modifying HR-QoL scores among the population with ACHD.

Novel follow-up tool. Our innovative time series tool for assessing HR-QoL in patients with ACHD undergoing cardiac surgery has demonstrated a sustainable and resource-efficient method for automated patient-directed follow-up. The 88% completion rate was unexpected given that most patient-directed outreach has closer to 53% completion rates.[24] Moreover, this completion rate was sustained throughout the 12-month cycle. This approach reduces the need for extensive healthcare personnel involvement in tracking and administering multiple assessments. Additionally, allowing patients to respond at their own convenience may enhance participation rates by accommodating their schedules and reducing the burden of frequent hospital visits. Of note, the initial response rate was only 14%, and only after instituting education and engagement continuously across the entire care team did this improve our current state. This sustained outreach

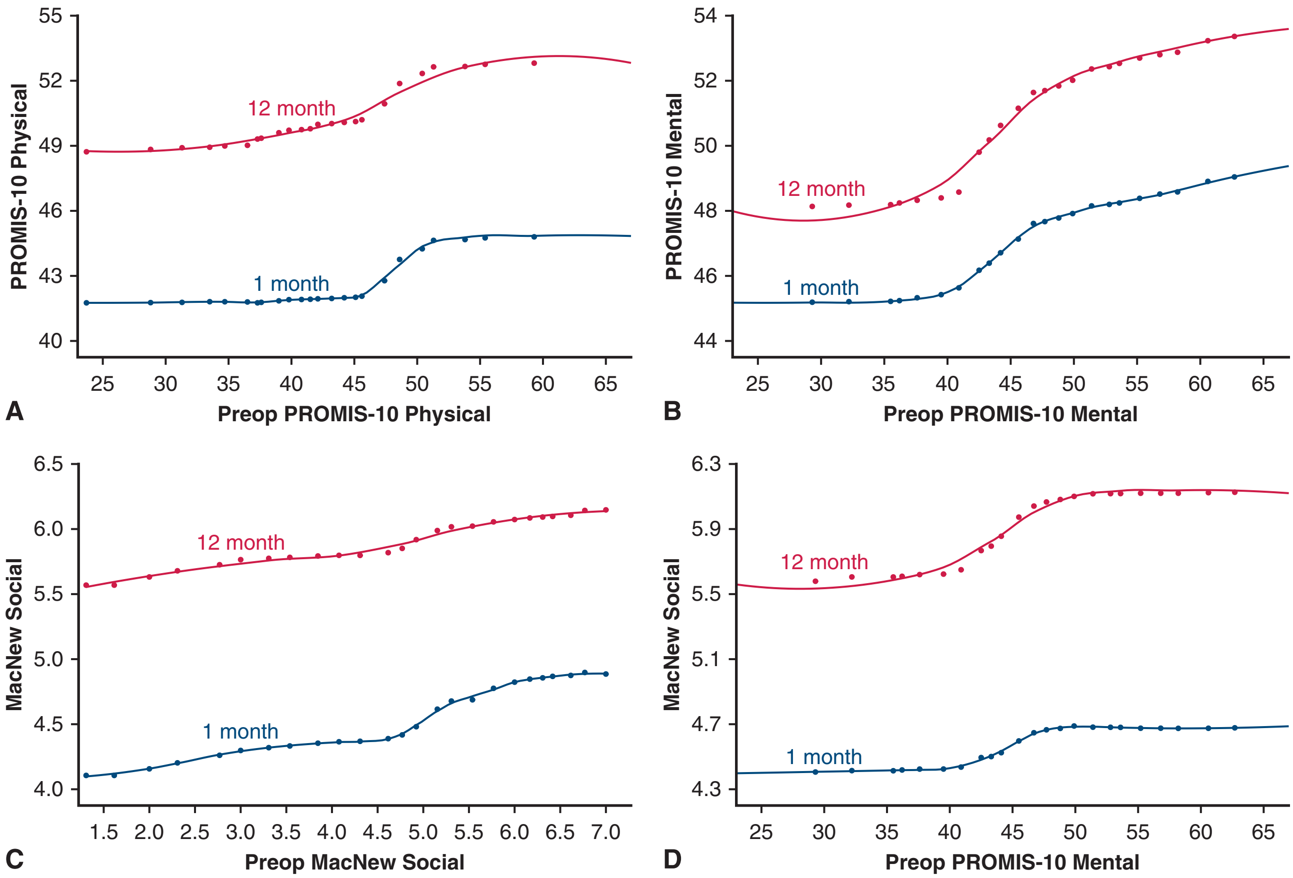


FIGURE 5. Association between preoperative HR-QoL measures and postoperative longitudinal QoL measures after cardiac surgery. Partial dependence plots depicting risk-adjusted association between preoperative HR-QoL and postoperative HR-QoL measures. Symbols (*dots*) are risk-adjusted 1-month (*blue*) and 12-month (*red*) predicted HR-QoL longitudinal measures after cardiac surgery for different values of selected Preoperative HR-QoL measures. Solid lines are smoothed Lowess lines of the symbols. A, Preoperative versus postoperative PROMIS-10 Physical. B, Preoperative versus postoperative PROMIS-10 Mental. C, Preoperative versus postoperative MacNew Social. D, Preoperative PROMIS-10 versus Mental postoperative MacNew Social. *PROMIS-10*, 10-Item Patient-Reported Outcome Measurement Information System.

over time to all facets of the care team throughout the entire arc of care was inspired by the work of Bates and colleagues,[25] in which early extubation among pediatric patients undergoing cardiac surgery was only sustained by continuous reinforcement over the trial period and beyond.

Preoperative Health-Related Quality of Life in the Population With Adult Congenital Heart Disease

Defining the ACHD population involves significant complexities. Thus, we were motivated to establish rigorous criteria for this definition. In our prior research,[5] we adopted a comprehensive approach to identify patients with ACHD. We used multiple data sources, including administrative records, cardiac surgery registries, and the Society of Thoracic Surgeons (STS) Congenital Heart Surgery and Adult Cardiac Surgery Databases. This methodology enabled us to identify and validate a cohort of 7092 adults with confirmed CHD who underwent cardiac surgery at our institution. Our findings revealed a diverse spectrum of CHD conditions, with isolated abnormally cusped aortic valve being the most common, followed by isolated hypertrophic obstructive cardiomyopathy and various combinations of these conditions. Our ACHD patient population aligns with the STS ACHD cohort described by Nelson and colleagues,[7,8] which highlights the prevalence and complexity of ACHD.

Ours is the first study to prospectively follow HR-QoL in patients with ACHD after cardiac surgery and to compare these with preoperative scores. Our data demonstrate that baseline HR-QoL scores for patients with ACHD are below population norms across physical, mental, and social domains, highlighting the perceived pervasive burden of ACHD on all aspects of patients' lives. Patients with ACHD differ from pediatric cohorts who often exhibit the disability paradox,[26,27] in which patients with CHD perceive their own HR-QoL to be higher than age- and gender-matched norms despite important objective functional impairment. One explanation for this discrepancy is that patients with ACHD have a broad range of comorbidities composed of adult-acquired diseases (eg, asthma,

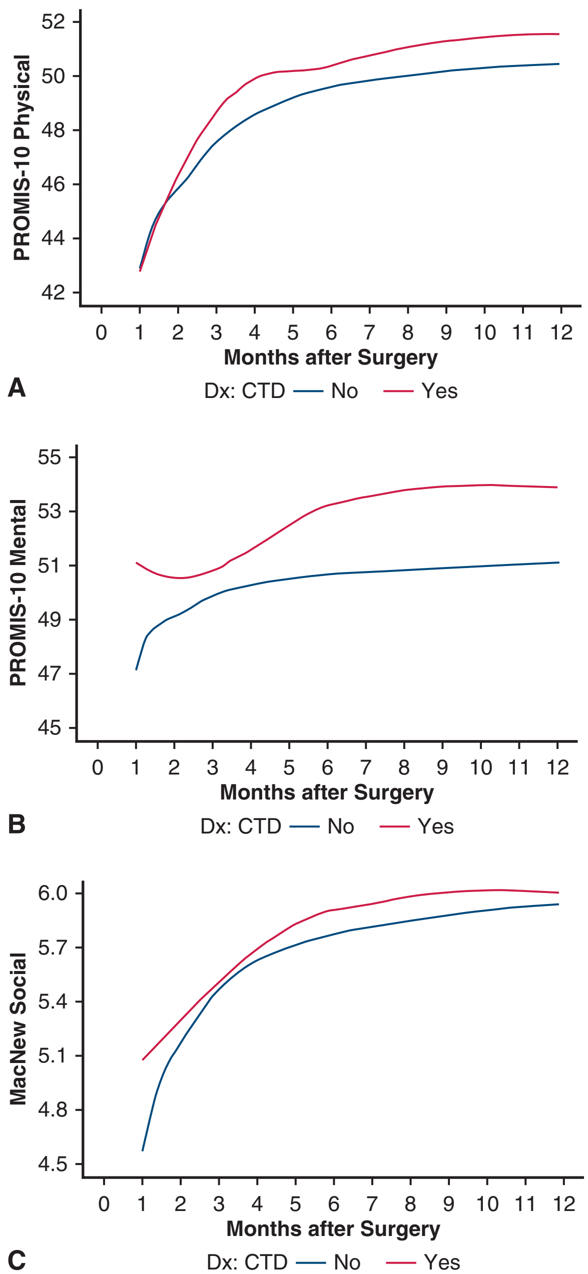


FIGURE 6. Association between patients diagnosed with connective tissue disorder (*CTD*) and postoperative longitudinal QoL measures after cardiac surgery. *Solid lines* are partial dependence plots depicting risk-adjusted association between patients diagnosed with CTD (*red line*) and patients without CTD (*blue line*) and postoperative HR-QoL measures. A, Patients with or without CTD versus postoperative PROMIS-10 Physical. B, Patients with or without CTD versus postoperative PROMIS-10 Mental. C, Patients with or without CTD versus MacNew Social. *PROMIS-10*, 10-Item Patient-Reported Outcome Measurement Information System.

dyslipidemia, diabetes, sleep apnea, tobacco abuse, and hypertension) in addition to CHD-specific physiology (eg, family history of heart disease, arrythmias, complete heart block, automatic implantable cardioverter defibrillator, permanent pacemaker, seizures, and stroke/cerebrovascular accident or intracranial hemorrhage). This increased complexity of the adult population with CHD as opposed to the pediatric cohort could explain their perceived lower HR-QoL. Another explanation is that patients with ACHD may have different expectations than pediatric patients and may value components or elements of HR-QoL differently than pediatric patients.

Time Course of Health-Related Quality of Life Improvement

Previous research has suggested a correlation between surgery and lower HR-QoL in patients with ACHD.[28] Our findings show that cardiac surgery can increase ACHD patient-perceived HR-QoL outcomes across all domains, with improvements continuing throughout the first postoperative year.

In fact, HR-QoL scores surpass population norms at 6 months for the physical domain, 4 months for the mental domain, and 2 months for the social domain and continue to increase thereafter. These data suggest that the increase in social domain functioning may positively impact the response in physical domains later. Clearly, however, this perspective is predicated on the assumption that surgery provided objective relief of a limiting physiologic impairment and on the fact that this study surveys only survivors (ie, there is survivorship bias that may favorably impact our results).

Patient-Related Factors and Health-Related Quality of Life

Higher preoperative domain scores were one of the most consistent factors associated with higher postoperative domain scores. This is highly relevant to the care of patients with ACHD, who often lack longitudinal care during their lifetimes and may present for surgery only when their disease burden is advanced.[29,30] Targeted prehabilitation has been shown to improve preoperative functional status and is likely to pay dividends in improving preoperative HR-QoL scores in addition to their ongoing cardiology treatments.[31]

We were surprised to find that connective tissue disease was associated with higher postoperative HR-QoL assessments, prompting further exploration to resolve confounders. Indeed, a diagnosis of connective tissue disorder surrogated for other patient factors including younger age, lower body mass index, and lower STS-CHSD STAT category. Further, the nature of their disease, which is typically confined to aortic valve disease and accompanying ascending aortic aneurysm, may mean that these patients do not experience the same lifelong physiologic burden of patients with more complicated ACHD and typically undergo primary sternotomy and a single-stage operation (ie, valve-sparing aortic root replacement in our series with excellent outcome).

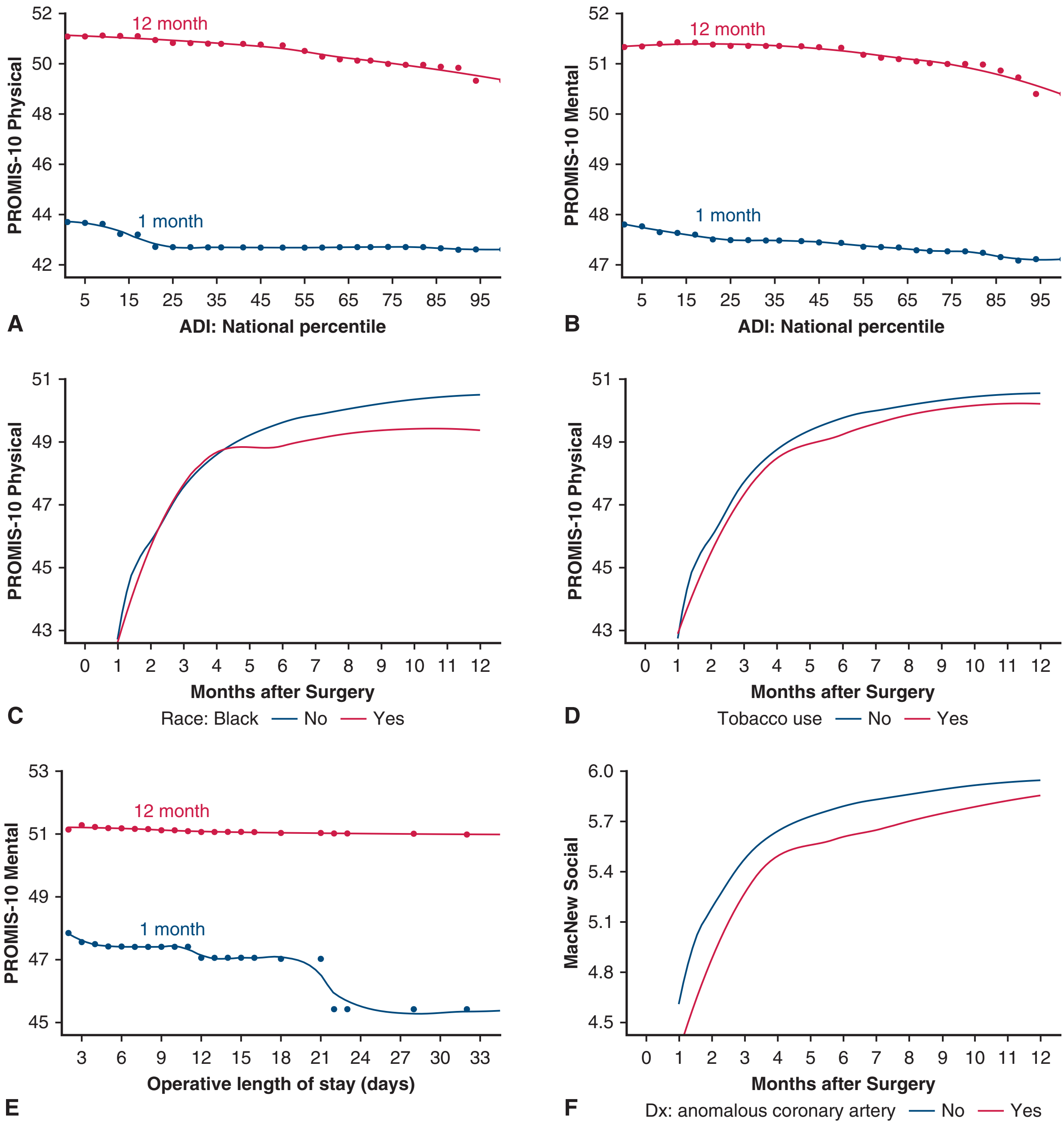


FIGURE 7. Preoperative and operative variables associated with postoperative HR-QoL longitudinal measures after cardiac surgery. Partial dependence plots depicting risk-adjusted association between selected patient/procedure variables and postoperative HR-QoL measures. Symbols (*dots*) are risk-adjusted 1-month (*blue*) and 12-month (*red*) predicted HR-QoL measures after cardiac surgery for different values of selected continuous covariables. *Solid lines* are smoothed lowest lines of the symbols. *Blue-red lines* without symbols depict risk-adjusted predicted HR-QoL measures over time after cardiac surgery for different values of categorical covariables. A, ADI-National percentile versus postoperative PROMIS-10 Physical. B, ADI-National percentile versus postoperative PROMIS-10 Mental. C, Black race versus postoperative PROMIS-10 Physical. D, Tobacco use versus postoperative PROMIS-10 Physical. E, Operative length of stay versus postoperative PROMIS-10 Mental. F, Patient diagnoses with anomalous coronary artery versus MacNew Social. *PROMIS-10*, 10-Item Patient-Reported Outcome Measurement Information System; *ADI*, Area Deprivation Index.

Social determinants of health and associated disparities. Our data highlight that the healthcare disparities that are well researched in ACHD extend to their perceived HR-QoL.[32] Male gender and race other than Black were also associated with improvements in postoperative physical scores. Additionally, our descriptive analysis of the difference between patients with ACHD who participated in the HR-QoL survey versus those who did not shows that Black patients were less likely to complete the questionnaires. Finally, our study found that patients with ACHD with a higher ADI (ie, more deprived) trended toward lower physical and mental postoperative HR-QoL domain scores. Further, female gender and Black race were associated with higher ADI. Our group and others have documented the critical impact of social determinants of health on CHD outcomes.[32-35] Therefore, it is not unexpected that this study shows that specific fragile populations, namely, women and those of Black race, have higher levels of deprivation and lower HR-QoL scores. Patients with ACHD, because of the often fragmented care paradigms and the ongoing physiologic and neurologic sequelae of CHD, are more susceptible to disparities in access to high-quality care.[35] The lack of dependable follow-up tools that foster sustainable connections between patients with ACHD and the healthcare arena further exacerbates the dilemma. The platform that we have developed is one viable solution that has worked in our center and will require further study to assess the feasibility of deployment at other centers.[8]

Health-Related Quality of Life Assessment in Patients With Adult Congenital Heart Disease

The optimal means of assessing HR-QoL outcomes in patients with ACHD is yet to be determined. Most studies assess HR-QoL in patients with cardiac disease assess only 1 domain.[36] We chose to perform a more thorough evaluation by combining the generic PROMIS-10 (physical and mental) assessment with the cardiac-specific MacNew (social) assessment to create a 26-question assessment that would be quick and easy to fill out. Although the PROMIS-10 has been well described for use in the cardiac surgery population,[37] patients showed the largest improvement in the social scores, suggesting that the MacNew assessment, which is a cardiac-specific instrument, may be more sensitive at determining postoperative gains.

Limitations

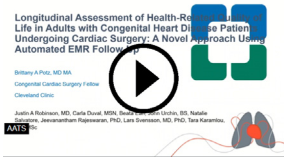
This study was conducted at a single center; therefore, caution should be used when extrapolating the findings to other centers that may have a different case mix. Additionally, the results may not fully apply to the broader ACHD population because of the specific context of our study, which involved 2 congenitally trained surgeons performing highly complex adult congenital cardiac cases. The EMR-based follow-up requires dedicated follow-up champions who can reinforce the importance of the initiative across the entire care team at regular intervals. Our hybrid instrument combines a comprehensive battery of domain assessments; however, there may be unmeasured areas that are not well captured by this hybrid tool. External validation of the hybrid tool was not performed, although the individual domain tools are well validated and there are individual normative values for the individual components of the MacNew.[13-15] Moreover, the use of questionnaires introduces potential biases inherent to such methods. Further limitations include no data on neurodevelopmental and associated genetic syndromes that could potentially impact the interpretation of our findings. Factors such as language barriers, misinterpretation, and nonresponse bias may skew the results and therefore not fully encapsulate the spectra of those affected by ACHD.

CONCLUSIONS

Our novel EMR-integrated longitudinal instruments for evaluating HR-QoL in patients after ACHD cardiac surgery show a gradual increase in physical, mental, and social domain scores over time, with scores surpassing population norms between 2 and 6 months postoperatively. Patients with higher baseline HR-QoL domain scores had improved longitudinal scores, suggesting that prehabilitation regimens may be highly effective in improving patient-perceived HR-QoL. Social determinants of health were operative in modifying HR-QoL scores among the population with ACHD. Further development of patient-directed follow-up platforms holds promise to mitigate the challenges of lifelong follow-up for survivors of CHD.

Webcast

You can watch a Webcast of this AATS meeting presentation by going to: https://www.aats.org/resources/longitudinal-assessment-of-hea-7306.



Conflict of Interest Statement

The authors reported no conflicts of interest.

The *Journal* policy requires editors and reviewers to disclose conflicts of interest and to decline handling or reviewing manuscripts for which they may have a conflict of interest. The editors and reviewers of this article have no conflicts of interest.

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Key Words: adult congenital heart disease, cardiac surgery, quality of life, social determinants of health, survey

APPENDIX E1. INCLUSION CRITERIA FOR ADULT CONGENITAL HEART DISEASE

All patients undergoing surgery for a congenital heart defect.

Patients undergoing valve or aortic surgery with genetic mutations for connective tissue with aneurysm (well-established mutations that are known to cause aortopathy such as FBN1, FBN2, ACTA genes).

Patients with a bicuspid aortic valve at age 35 years or less (plus those who have been followed before the age of 18 years and are currently aged >35 years).

All patients with unicuspid and quadricuspid aortic valves.

Patients with an anterior cleft mitral valve or double orifice mitral valve aged 35 years or less (plus those who have been followed before the age of 18 years and are currently aged >35 years).

All patients with a diagnosis of hypertrophic cardiomyopathy.

APPENDIX E2. VARIABLES CONSIDERED IN THE MULTIVARIABLE ANALYSES

Demography

Age (y), body mass index (kg/m^2), female, race (Black, White, other).

Symptoms

STAT Category

Number of Prior Cardiac Operations

Fundamental diagnosis. Anomalous coronary artery, aortic aneurysm, aortic dissection, atrial septal defect, bicuspid aortic valve (not isolated), coarctation or hypoplastic aortic arch, congenital aortic valve disease, congenital mv disease, connective tissue disorder, HOCM/IHSS, subaortic membrane.

Preoperative comorbidities. Asthma, cardiac dysrhythmia, currently taking steroids for any reason other than treatment of adrenal insufficiency, diabetes mellitus, dyslipidemia, family history of coronary artery disease, hypertension, ICD (automatic ICD) present, pacemaker present, preoperative complete AV block, preoperative dysrhythmia requiring antidysrhythmia medication, seizure during lifetime, sleep apnea, neurologic dysfunction (stroke, CVA, or intracranial hemorrhage grade >2 during lifetime), tobacco use.

Preoperative HR-QoL. PROMIS-10 Physical, PROMIS-10 Mental, MacNew Social.

ADI. National percentile. State Decile.

Procedure. Aortic procedures, congenital procedures, valve/CABG procedures.

Support. CPB time (min), crossclamp time (min).

Complications. Readmission within 30 d. Arrhythmia requiring permanent pacemaker.

Length of stay. Hospital length of stay (d), operative length of stay (d).

HOCM, Hypertrophic obstructive cardiomyopathy; *IHSS*, idiopathic hypertrophic subaortic stenosis; *ICD*, implantable cardioverter defibrillator; *AV*, aortic valve; *CVA*, cerebrovascular accident; *HR-QoL*, health-related quality of life; *PROMIS-10*, 10-item Patient-Reported Outcome Measurement Information System; *CABG*, coronary artery bypass grafting; *CPB*, cardiopulmonary bypass; *ADI*, Area Deprivation Index.

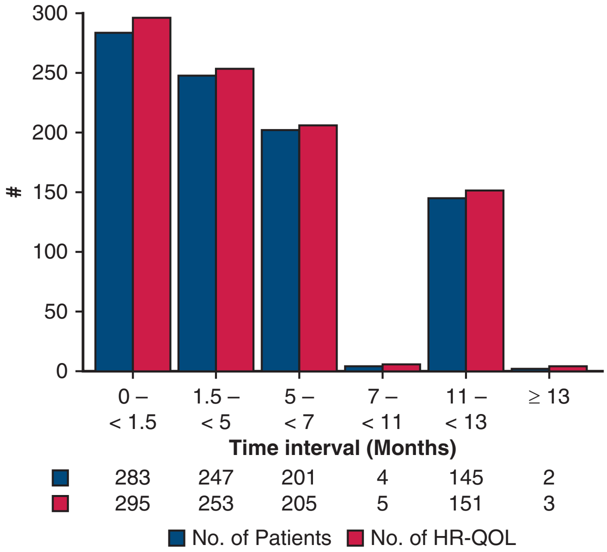

FIGURE E1. HR-QoL follow-up. Bar graph depicts the number of patients (*blue bars*) with number of HR-QoL data (*red bars*) collected at different time intervals after the surgery. Note that, as the bars indicates, most of the postoperative HR-QoL data were collected at approximately 1 month, 3 months, 6 months, and 12 months. *HR-QoL*, Health-related quality of life.

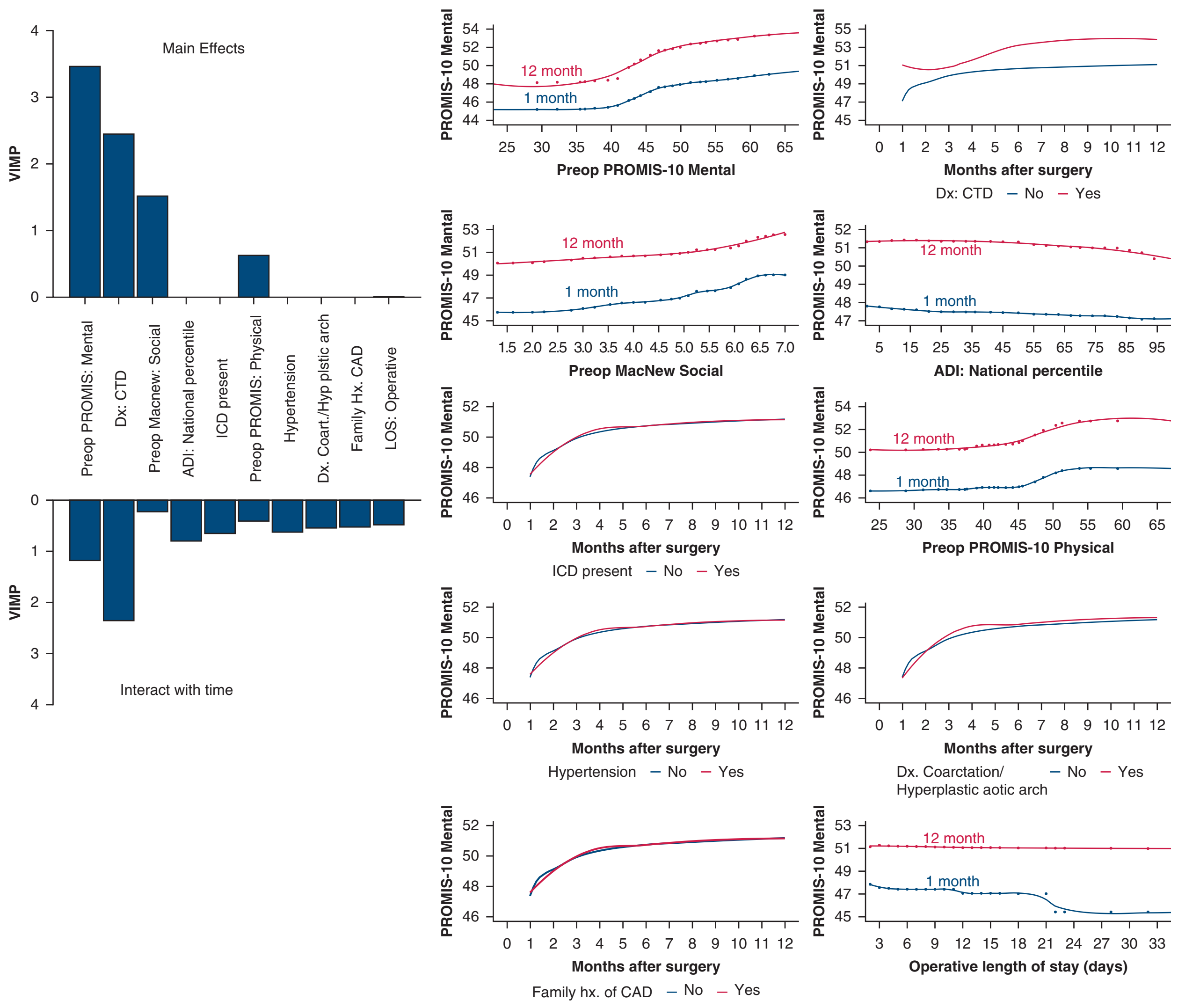

FIGURE E2. Preoperative and operative variables associated with postoperative PROMIS-10 Mental score after cardiac surgery. *Left*: VIMP of the top 10 variables. Variable and bar plots above "0" line depict VIMP of variables that may not change with time (main effects). Variable and bars below the "0" line depict VIMP of variable that changes with time of echo measurement (interaction with time). *Right* 2 columns are partial dependence plots depicting risk-adjusted association between selected patient variables and PROMIS-10 Mental score. Symbols (*dots*) are risk-adjusted 1-month (*blue*) and 12-month (*red*) predicted PROMIS-10 Mental score after cardiac surgery for different values of selected continuous covariables. *Solid lines* are smoothed lowest lines of the symbols. *Blue-red lines* without symbols depict risk-adjusted predicted PROMIS-10 Mental score over time after cardiac surgery for different values of categorical covariables. *CTD*, Connective tissue disease; *HOCM*, hypertrophic obstructive cardiomyopathy; *CPB*, cardiopulmonary bypass.

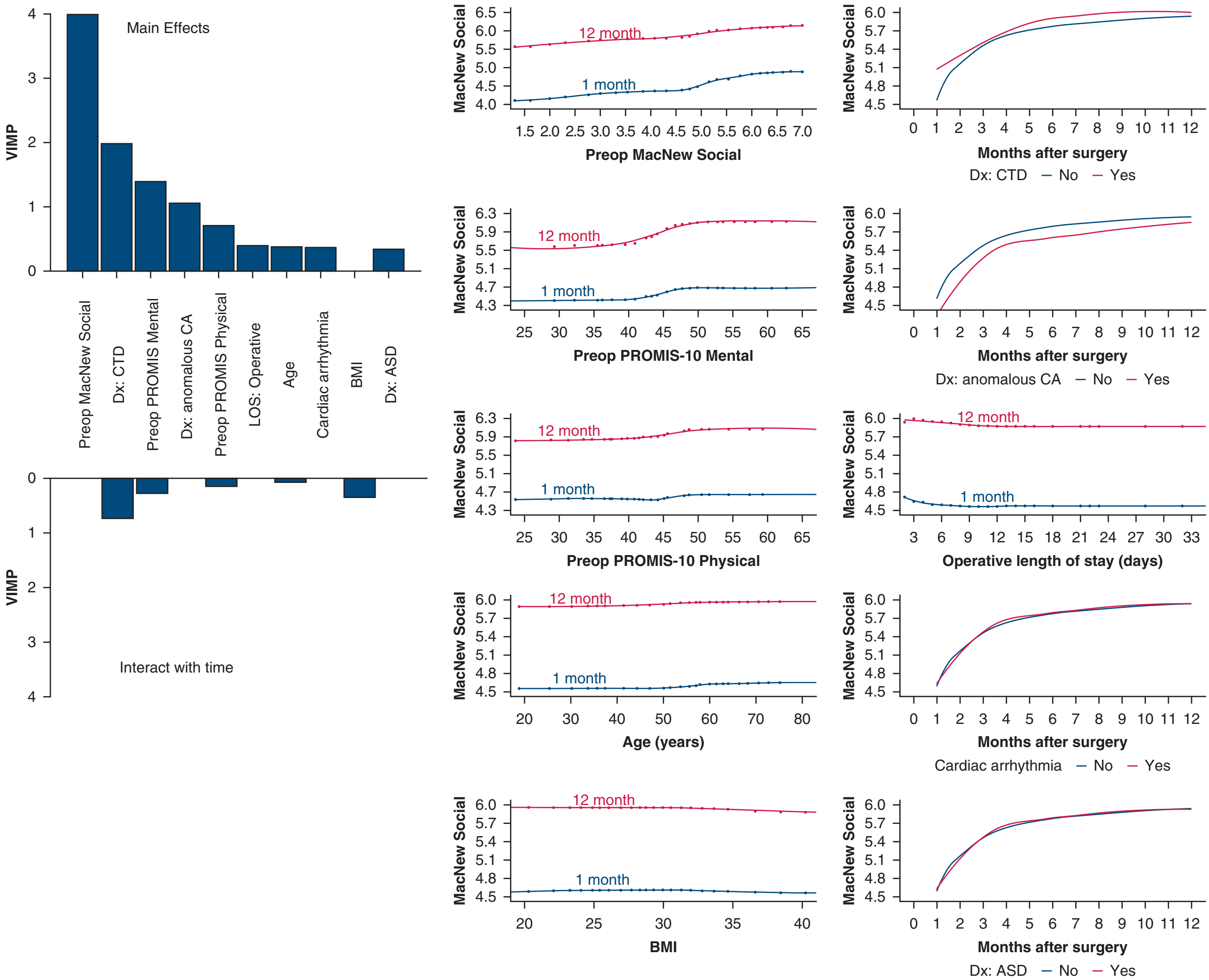

FIGURE E3. Preoperative and operative variables associated with postoperative MacNew Social score after cardiac surgery. *Left*: VIMP of the top 10 variables. Variable and bar plots above "0" line depict VIMP of variables that may not change with time (main effects); Variable and bars below the "0" line depict VIMP of variable that changes with time of echo measurement (interaction with time). *Right* 2 columns are partial dependence plots depicting risk-adjusted association between selected patient variables and MacNew Social score. Symbols (*dots*) are risk-adjusted 1-month (*blue*) and 12-month (*red*) predicted MacNew Social score after cardiac surgery for different values of selected continuous covariables. *Solid lines* are smoothed lowest lines of the symbols. *Blue-red lines* without symbols depict risk-adjusted predicted MacNew Social score over time after cardiac surgery for different values of categorical covariables. *CTD*, Connective tissue disease; *CAD*, coronary artery disease.

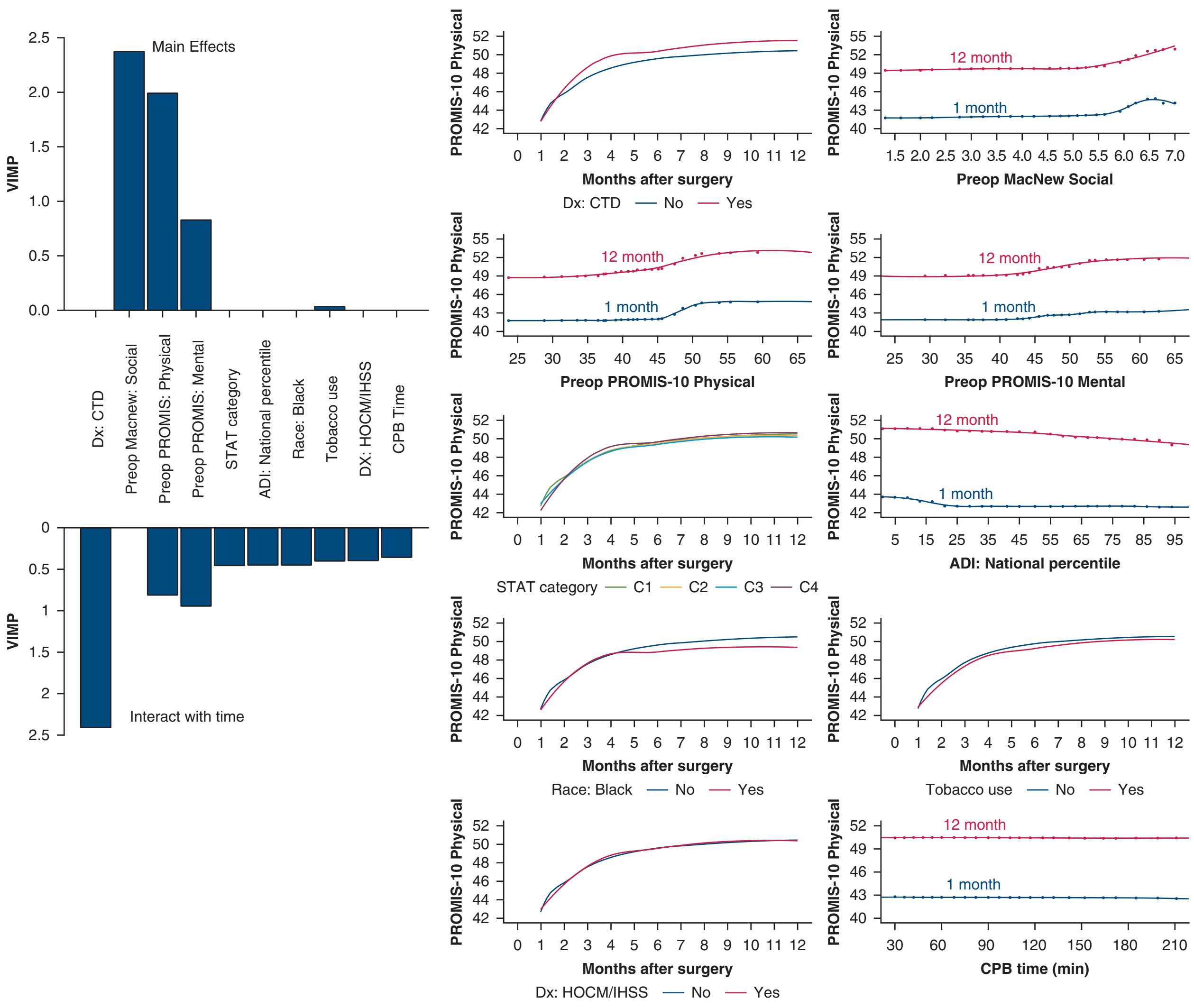

FIGURE E4. Preoperative and operative variables associated with postoperative PROMIS-10 Physical score after cardiac surgery. *Left*: Variable importance (*VIMP*) of the top 10 variables. Variable and bar plots above "0" line depict VIMP of variables that may not change with time (main effects); variable and bars below the "0" line depict VIMP of variable that changes with time of echo measurement (interaction with time). *Right* 2 columns are partial dependence plots depicting risk-adjusted association between selected patient variables and PROMIS-10 Physical score. Symbols (*dots*) are risk-adjusted 1-month (*green*) and 12-month (*brown*) predicted PROMIS-10 Physical score after cardiac surgery for different values of selected continuous covariables. *Solid lines* are smoothed lowest lines of the symbols. *Green-orange lines* without symbols depict risk-adjusted predicted PROMIS-10 Physical score over time after cardiac surgery for different values of categorical covariables. *CTD*, Connective tissue disease; CA, coronary artery.

TABLE E1. In-hospital outcomes (N = 559)

Outcomes	No. (%) or median (15th, 85th percentile)
In-hospital morbidity	
Neurologic dysfunction: stroke	4 (0.72)
Unplanned cardiac reoperation	9 (1.6)
Renal failure requiring dialysis	2 (0.36)
Readmission within 30 d	31 (5.6)
Mechanical circulatory support (includes ECMO)	3 (0.54)
Unexpected cardiac arrest	3 (0.54)
Phrenic nerve injury	0 (0)
Arrhythmia requiring permanent pacemaker	25 (4.5)
Mortality	
Operative mortality	0 (0)
Length of stay	
Operative length of stay (d)	5 (4, 9)
Hospital length of stay (d)	5 (4, 10)

ECMO, Extracorporeal membrane oxygenation.

TABLE E2. Description of patient/procedure variables stratified by patient with postoperative quality of life measure available verse not available (n = 559)

	Postoperative quality of life measure available				
	No (n = 164)		Yes (n = 395)		
Variable	n*	No. (%) or mean ± SD	n*	No. (%) or mean ± SD	*P*
Demography					
Age at surgery (y)	164	52 ± 16	395	53 ± 15	.4
Female	164	77 (47)	395	161 (41)	.18
Race: Black	160	13 (8.1)	388	13 (3.4)	.02
Race: White	160	117 (73)	388	320 (82)	.01
Race: other	160	30 (19)	388	55 (14)	.18
Body mass index (kg/m^2)	164	32 ± 20.3	393	32 ± 22	.3
Body surface area (m^2)	164	2.1 ± 0.31	393	2.11 ± 0.31	.5
Area Deprivation Index					
National percentile	142	53 ± 29	349	52 ± 25	.6
State decile	142	4.6 ± 3.0	349	4.4 ± 2.7	.7
Symptoms					
STAT Category	161		384		.2
1		103 (64)		213 (55)	
2		29 (18)		91 (24)	
3		22 (14)		67 (17)	
4		7 (4.3)		13 (3.4)	
Diagnosis					
Anomalous coronary artery	162	13 (8)	395	29 (7.3)	.8
Aortic aneurysm	162	6 (3.7)	395	19 (4.8)	.6
Aortic dissection	162	3 (1.9)	395	8 (2)	.9
Atrial septal defect	162	5 (3.1)	395	20 (5.1)	.3
Bicuspid aortic valve (not isolated)	162	11 (6.8)	395	25 (6.3)	.8
Coarctation or hypoplastic aortic arch	162	2 (1.2)	395	9 (2.3)	.4
Congenital aortic valve disease	162	11 (6.8)	395	31 (7.8)	.7
Congenital MV disease	162	3 (1.9)	395	9 (2.3)	.8

(Continued)

TABLE E2. Continued

Variable	Postoperative quality of life measure available				
	No (n = 164)		Yes (n = 395)		
	n*	No. (%) or mean ± SD	n*	No. (%) or mean ± SD	*P*
Connective tissue disorder	162	5 (3.1)	395	10 (2.5)	.7
HOCM/IHSS	162	82 (51)	395	194 (49)	.8
Subaortic membrane	162	3 (1.9)	395	9 (2.3)	.8
Cardiac, noncardiac comorbidities					
Asthma	164	19 (12)	395	42 (11)	.7
Cardiac dysrhythmia	164	3 (1.8)	395	13 (3.3)	.4
Currently taking steroids for any reason other than treatment of adrenal insufficiency	164	2 (1.2)	395	5 (1.3)	>9
Diabetes mellitus, insulin dependent	164	4 (2.4)	395	14 (3.5)	.5
Diabetes mellitus, noninsulin dependent	164	14 (8.5)	395	34 (8.6)	>9
Dyslipidemia	164	78 (48)	395	190 (48)	.9
Family history of coronary artery disease	164	38 (23)	395	102 (26)	.5
Hypertension	164	16 (9.8)	395	35 (8.9)	.7
ICD (automatic ICD) present	164	12 (7.3)	395	38 (9.6)	.4
Pacemaker present	164	5 (3)	395	10 (2.5)	.7
Preoperative complete AV block	164	4 (2.4)	395	9 (2.3)	.9
Preoperative dysrhythmia requiring antidysrhythmia medication	164	2 (1.2)	395	8 (2)	.5
Seizure during lifetime	164	4 (2.4)	395	8 (2)	.8
Sleep apnea	164	4 (2.4)	395	16 (4.1)	.4
Neurologic dysfunction (stroke, CVA, or intracranial hemorrhage Grade >2 during lifetime)	164	8 (4.9)	395	8 (2)	.07
Tobacco use	164	59 (36)	395	141 (36)	>9
Procedure					
Aortic procedures	164	28 (17)	395	65 (16)	.9
Congenital procedures	164	62 (38)	395	131 (33)	.3
Valve/CABG procedures	164	73 (45)	395	198 (50)	.2
Support					
CPB time (min)	129	85 ± 52	333	92 ± 54	.14
Crossclamp time (min)	129	66 ± 41	333	72 ± 46	.11
Postoperative complications					
Readmission within 30 d	163	5 (3.1)	395	26 (6.6)	.10
Arrhythmia requiring PPM	164	9 (5.5)	395	16 (4.1)	.4
Length of stay					
Hospital length of stay (d) (median [15th, 85th percentile])	164	6 (4, 11)	395	5 (4, 9)	.2
Operative length of stay (d) (median [15th, 85th percentile])	164	6 (4, 10)	395	5 (4, 9)	.2

MV, Mitral valve; *HOCM*, idiopathic hypertrophic obstructive cardiomyopathy; *IHSS*, idiopathic hypertrophic subaortic stenosis; *ICD*, implantable cardioverter defibrillator; *AV*, aortic valve; *CVA*, cerebrovascular accident; *CABG*, coronary artery bypass grafting; *CPB*, cardiopulmonary bypass; *PPM*, permanent pacemaker. *Number with available data.

TABLE E3. Description of patient/procedure variables stratified by patients with and without connective tissue disorder (n = 559)

	Diagnosis of connective tissue disease				
	No		Yes		
Variable	n	No. (%)	n	No. (%)	*P*
Demography					
Age at surgery (y)	542	53 ± 15	15	46 ± 18	.08
Female	542	229 (42)	15	8 (53)	.39
Race White	531	424 (80)	15	12 (80)	.99
Preoperative body mass index (kg/m^2)	534	30 ± 6.6	14	25 ± 6.7	.003
Symptoms					
STAT category					
1	529	307 (58)	14	9 (64)	.002
2		118 (22)		1 (7.1)	
3		87 (16)		1 (7.1)	
4		17 (3.2)		3 (21)	