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Contributors to disease-specific health knowledge in adults with congenital heart disease: A correlational study

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Abstract

Objective: Growth in the adults with congenital heart disease (ACHD) population represents a challenge to the health care infrastructure. As patients with chronic disease are increasingly held accountable for their own care, contributors to diseasespecific health knowledge, which are known to correlate with patients' participation in care, merit investigation to design patient-focused interventions.

Design: We conducted a single-site, cross-sectional study of ACHD patients. Investigators retrospectively gathered clinical data as well as psychometric and health status assessments completed at the time of enrollment.

Outcome Measures: We investigated the impact of clinical and psychological variables on Leuven Knowledge Questionnaire for Congenital Heart Diseases health knowledge composite scores (HKCS). Variables with significant associations were considered in a stepwise multivariable regression model to determine which combination of variables jointly explained variability in HKCS.

Results: Overall HKCS was associated with the number of prior cardiac surgeries $(r = 0.273; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress <math>(r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: } 0.050-0.467; P = .016), perceived stress \\ (r = 0.260; 95\% \text{ CI: }$ 0.033-0.458; P = .024), SF-36 emotional well-being (r = -0.251; 95% CI: -0.451, -0.024; P = .030), history of noncardiac surgery (P = .037), cirrhosis (P = .048), and presence of implantable cardioverter-defibrillator (P = .028). On multivariable modeling, only the number of cardiac surgeries was found to correlate with HKCS.

Conclusions: While univariate correlations were found between HCKS and several other clinical and psychological variables, only number of prior cardiac surgeries independently correlated with disease-specific health knowledge in ACHD patients. These results suggest that clinical and psychological variables are not impediments to disease-specific health knowledge.

adult congenital heart disease, disease-specific health knowledge, psychology in adult congenital heart disease

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1 | INTRODUCTION

Innovation in the medical and surgical treatment of congenital cardiovascular anomalies has led to a marked improvement in outcomes, with almost 85% of patients surviving into adulthood. Increasing patient lifespans and improved functionality have brought medicine into uncharted territory. Among many new concerns in the population of adults with congenital heart disease (ACHD) is the ability to provide self-care in a health care environment that requires patients with chronic illnesses to become competent medical decision-makers. ²

To this end, ACHD patients may experience inherent disadvantages. Data show that the ACHD patient population has lower rates of high school graduation than the general population and increased psychological dependence on parents into adulthood.³⁻⁵ In an effort to improve the quality and comprehensiveness of care in ACHD patients, exploring behavioral and environmental contributors to health outcomes in this group is warranted.

Several strategies to improve outcomes in patients with chronic health conditions take a patient-centered approach based on the premise that patients who possess appropriate knowledge, motivation, behavior, and confidence can more effectively manage their own health. ^{2,6,7} Such "activated" patients are more likely to receive preventive care, less likely to engage in high risk behaviors such as smoking or overeating, and have better health outcomes including fewer hospitalizations and emergency room visits. ⁸ In ACHD specifically, we recently demonstrated that patients prone to downplaying the impact of their illness are less likely to follow-up at outpatient cardiology appointments. ⁹ Measures to improve patient activation hold promise in ACHD, especially to aid in the transition process from pediatric to adult care that is often associated with loss to medical follow-up and the potential for clinical deterioration. ¹⁰

Disease-specific health knowledge (HK) has been shown to correlate well with patient activation. Working to better convey HK may lead to better-informed patients and potentially to improved outcomes. Disease-specific instruction presents a particular challenge in ACHD, however, given the broad diversity of congenital heart defects and the complexity of corrective procedures. Further, repetitive exposure to cardiopulmonary bypass and genetic intellectual limitation may limit the capacity of ACHD patients to acquire knowledge. In the present study, we evaluated relationship between clinical, psychological, and socioeconomic variables and HK in a population of ACHD patients.

2 | METHODS

We conducted a single-center cross-sectional analysis of patients with ACHD followed in the Center for Adults with Congenital Heart Disease at Washington University School of Medicine in Saint Louis. The study was approved by the institutional review boards at Washington University School of Medicine, the University of Missouri in Saint Louis and Baylor University Medical Center. Informed consent was obtained from each participant and the study protocol conforms to the ethical guidelines of the 1975 Declaration of Helsinki as reflected in a priori approval by each institution's human research committee.

All participants were recruited during regular outpatient office visits with their established ACHD provider at Washington University School of Medicine between April 25, 2013 and October 15, 2014. At the time of their clinical visit, study participation was offered.

Participants were asked to complete a series of 12 validated psychometric questionnaires. The primary outcome of interest, HK, was assessed using the Leuven Knowledge Questionnaire for Congenital Heart Diseases (LKOCHD)-Version 2 English translation. 12 In addition, we included the following questionnaires: (1) an assessment of psychologically relevant demographic information; (2) The Perceived Stress Scale (PSS)¹³: (3) The Cardiac Denial of Impact Scale (CDI)¹⁴: (4) The Beck Depression Inventory-Version II (BDI-II)¹⁵; (5) The Barriers to Care Questionnaire¹⁶; (6) The Anxiety Sensitivity Index (ASI-R)¹⁷; (7) The Multidimensional Scale of Perceived Support Scale (MSPSS)¹⁸; (8) The Beck Anxiety Inventory¹⁹; (9) The Early Life Stress Score²⁰; (10) The Rand 36-Item Short Form Health Survey (SF-36)²¹; and (11) The Shipley-2 assessment for overall cognitive ability.²² All questionnaires were self-administered with the exception of the Shipley-2, which required supervision by a test administrator trained by a professor of psychology. Individuals were allowed to omit any question for any reason. Patients were given the option to complete the questionnaires in the clinic or to take the questionnaires home. Patients who completed the questionnaires in the clinic were provided a private room without interruption and had a study staff member available for questions. Patients who elected to complete the questionnaires at home were provided with a self-addressed and stamped envelope for return. Patients who completed questionnaires at home were required to complete the Shipley-2 questionnaire in clinic at the time of enrollment. Patients who elected to complete the questionnaires at home were called twice in follow-up if questionnaires were not received within 1-2 months after enrollment. No compensation was provided for participation. Questionnaire responses were scored according to established scoring algorithms for each questionnaire as previously published.

Clinical variables were retrospectively collected via chart review by two physicians on the study team via retrospective review of the inpatient and outpatient medical records at Washington University School of Medicine. These clinical variables included (1) rate of outpatient visit compliance (defined as: [number of visits to which a patient arrived]/[number of visits for which a patient no-showed + number of visits which a patient canceled + 1]); (2) degree of anatomic complexity; (3) presence of clinical cyanosis (defined as an oxygen saturation of <90% at a baseline outpatient visit); (4) cardiac diagnoses; (5) number of years of follow-up; (6) number cardiac surgeries; (7) history of noncardiac surgery (a dichotomous variable); (8) number and types of noncardiac diagnoses; (9) medications; (10) history of arrhythmia and type; (11) number of hospitalizations per year while followed in the Washington University ACHD clinic; (12) dates of and reasons for hospitalization; (13) most recent left ventricular ejection fraction (LVEF); (14) most recent right ventricular (RV) function; (15) presence and type of greater than mild valvular heart disease on most recent assessment; (16) presence of implantable cardiac defibrillator (ICD) and/or cardiac pacemaker (PPM); (17) patient age; (18) patient weight at most recent assessment; (19) gender; (20) creatinine clearance calculated

by the Cockcroft-Gault equation; (21) history of cirrhosis; and (22) history of smoking.

We considered both the total health knowledge composite score (HKCS) and each domain [components assessing knowledge of (1) the disease and its treatment; (2) the prevention of complications, including endocarditis; (3) physical activities; (4) heredity; and (5) contraception] of the LKQCHD as separate dependent variables. We used the reciprocal of each of these scores for analysis to afford a more intuitive interpretation, ie, higher scores indicate greater knowledge. We performed correlation analyses to determine which continuous clinical and psychological variables contributed to both the HCKS and individually to each domain of the LKQCHD. We utilized Spearman correlations to overcome skewed distributions and/ or outliers. To assess relations between dichotomous variables HK, we used the Wilcoxon rank-sum test.

Variables with significant correlations (*P* values <.05) were then considered in a stepwise multivariable regression model to determine which variables jointly contributed to variability in overall HCKS. The model was selected based on the corrected Akaike information criterion. The majority of continuous variables were skewed and are reported as median [quarter 1, quarter 3]; dichotomous variables are reported as frequencies (percentages). Results are presented by domain. Analyses were performed with SAS version 9.4 (SAS, Cary, North Carolina).

3 | RESULTS

Among 105 individuals who gave consent, 78 (74%) completed all questionnaires required for study inclusion. Participants who completed the questionnaires were clinically similar to those who did not participate in all aspects except for age and compliance; the participants' median age was 7 years older than nonparticipants and participants had a median compliance score 6.5 percentage points higher than nonparticipants. The median age of the 78 participants was 42 [32, 51] years. Forty-one (52.6%) participants were male and 72 (96.0%) were Caucasian. The median cognitive ability score, as measured via the Shipley-2, was 92.6 [81.9, 102.7] points. The most common CHD lesion complexity was moderate (46.8%), while 21.5% were mild and 31.7% were severe. The rate of individuals meeting criteria for clinical depression was 14.1%. Complete demographic and clinical characteristics of the study participants are in Table 1.

Tables 2 and 3 detail associations between composite HKCS and the separate domains of the LKQCHD with clinical, psychological and demographic variables with continuous variables in Table 2 and dichotomous variables in Table 3. HKCS was significantly associated with the number of cardiac surgeries (r = 0.273; 95% CI: 0.050-0.467; P = .016, perceived stress (r = 0.260; 95% CI: 0.033-0.458; P = .024), and SF-36 emotional well-being (r = -0.251; 95% CI: -0.451, -0.024; P = .030). Correlations between HKCS and patients' Beck Anxiety Index (r = 0.206; 95% CI: -0.025-0.414; P = .079), Beck depression index score (r = 0.195;

95% CI: -0.036-0.404; P = .096) and cardiac denial of impact scale score (r = 0.198; 95% CI: -0.031-0.406; P = .088) trended toward statistical significance. There was no significant correlation between HKCS and medical compliance. HKCS was not significantly associated with age, income, IQ, or level of education. Statistically significant differences in median HKCS were detected between those with and those without a history of a prior noncardiac surgery (0.63 [0.59, 0.69] vs. 0.58 [0.55, 0.62], respectively; P = .037), cirrhosis (0.76 [0.63, 0.83] vs. 0.61 [0.56, 0.68], respectively; P = .048), and implantable cardioverter-defibrillator (0.58 [0.52, 0.64] vs. 0.63 [0.57, 0.69], respectively; P = .028).

Each of the aforementioned statistically significant associations with HKCS was driven by a correlation with just one of the LKQCHD domains. For example, the number of cardiac surgeries showed a statistically significant correlation only with patients' scores on the prevention of complications domain of the LKQCHD r = 0.317; P = .005). The only clinical or psychological variable found to correlate with more than one LKQCHD domain score was number of noncardiac diagnoses, though it did not significantly correlate with overall HKCS.

We next built a multivariable model via stepwise selection using variables having significant relations with HKCS. This model identified only one predictor, the number of cardiac surgeries, as independently associated with HKCS. This model accounted for only 6% of the variability in HKCS.

4 | DISCUSSION

These data add to the growing body of research exploring contributors to ACHD patients' understanding of their health. Our results indicate that an extensive list of clinical and psychological variables which have previously been assumed to correlate with HK fail to predict HK in ACHD patients. These findings suggest that to improve HK acquisition in ACHD patients it may be necessary to focus on factors outside the patient such as care transition and disease-specific patient education.

Among the clinical variables found to be associated with HCKS, many were related to procedural history (number of cardiac and noncardiac surgeries) and clinical consequences of disease (cirrhosis) rather than the complexity of CHD lesions, imaging features, care coordination (frequency of follow-up, compliance with follow-up), or daily requirements for patient self-care (number of medications). These findings may indicate that ACHD patients are more engaged in their health at times when they are focused on procedural risk or clinical deterioration. The associations with cardiac and noncardiac surgeries may be a manifestation of HK reinforcement periprocedurally when patients are compelled to explain their condition to noncardiology specialists or consider how their ACHD may contribute to their overall procedural risk. These experiences may require preparation on the part of the patient and increase overall disease-specific health knowledge. This finding supports prior data showing that personalized interaction prior to procedures improves the process

TABLE 1 Patient characteristics (*N* = 78)

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Variable	Count (%); median [25%, 75%]
Gender (male)	41 (52.6%)
Age (years)	42 [32, 51]
Race/ethnicity ^a	.2 [02, 02]
African American	2 (2.7%)
Caucasian	72 (96.0%)
Hispanic	1 (1.3%)
Education ^a	_ (=:=:=,
High school or less	11 (14.7%)
Some college or greater	64 (85.3%)
Employment status	, ,
Disability	11 (14.7%)
Full-time	41 (54.7%)
Part-time	8 (10.7%)
Retired	12 (16.0%)
Unemployed	3 (4.0%)
Household income ≥ \$75,000 ^b	21 (30.4%)
Married ^a	45 (60.0%)
Religion ^a	61 (81.3%)
Lesion complexity	
Simple	17 (21.8%)
Moderate	36 (46.2%)
Complex	25 (32.1%)
Smoker	4 (5.1%)
Cirrhosis	3 (3.9%)
Clinical cyanosis	5 (6.4%)
History of arrhythmia	55 (70.5%)
Valvular disease	28 (35.9%)
Presence of implantable cardioverter-defibrillator	13 (16.7%)
Presence of permanent pacemaker	24 (30.8%)
Number of noncardiac diagnoses	3 [2, 6]
Number of cardiac surgeries	2 [1, 3]
History of noncardiac surgery ^c	48 (78.7%)
Hospitalization rate per year while following with ACHD specialty care at Washington University	0.20 [0.06, 0.54]
Follow-up (years)	8.1 [4.3, 15.6]
Compliance (%)	70.6 [62.5, 82.4]
Creatinine clearance (ml/min)	109.9 [89.0, 146.0]
Left ventricular ejection fraction (%)	55 [55, 64]
Right ventricular function	
Normal right ventricle function	55 (70.5%)
Mild dysfunction	10 (12.8%)

TABLE 1 (Continued)

TABLE 1 (Continued)	
Variable	Count (%); median [25%, 75%]
Moderate dysfunction	7 (9.0%)
Severe dysfunction	3 (3.9%)
Rudimentary/hypoplastic/no RV	3 (3.9%)
1/(health knowledge composite score)	0.61 [0.56, 0.69]
1/(disease treatment score)	0.71 [0.63, 0.80]
1/(prevention of complications)	0.59 [0.48, 0.69]
1/(physical activity knowledge score)	0.50 [0.50, 1.00]
1/(sexual heredity knowledge score)	0.50 [0.50, 1.00]
1/(contraception knowledge score)	0.50 [0.33, 0.50]
Depression (Beck Depression Inventory-Version II score) ^d	
Minimal (0-13)	55 (74.3%)
Mild (14-19)	8 (10.8%)
Moderate (20-28)	7 (9.5%)
Severe (29-63)	4 (5.4%)
Anxiety (Beck Anxiety Index Score) ^d	
Minimal (0-9)	50 (67.6%)
Mild (10-16)	12 (16.2%)
Moderate (17-29)	7 (9.5%)
Severe (30-63)	5 (6.8%)
Psychometric measures	
Shipley-2 Score	92.6 [81.9, 102.7]
Perceived Stress Score	32 [30, 34]
Cardiac Denial of Impact Scale	22 [18, 25]
Barriers to Care—Skill	92.9 [85.7, 100]
Barriers to Care—Margin	97.7 [90.9, 100]
Barriers to Care—Expected	96.4 [85.7, 100]
Barriers to Care—KAB	100 [100, 100]
Barriers to Care—Pragmatics	88.9 [83.3, 97.2]
Acute Stress Index	22 [11, 37]
Perceived Support Scale—Total	6.3 [5.3, 7]
Perceived Support Scale—Significant Others	6.8 [5.8, 7]

(Continues) (Continues)

TABLE 1 (Continued)

Variable	Count (%); median [25%, 75%]
Perceived Support Scale—Family	6.3 [5.8, 7]
Perceived Support Scale—Friends	6 [5, 7]
Early Life Stress Score	4 [2, 6]
SF-36 Physical Functioning Score	80 [50, 95]
SF-36 Physical Limitations Score	100 [50, 100]
SF-36 Emotional Limitations Score	100 [66.7, 100]
SF-36 Energy Level Score	65 [45, 75]
SF-36 Emotional Well-being Score	80 [60, 92]
SF-36 Social Score	100 [75, 100]
SF-36 Pain Score	90 [67.5, 100]
SF-36 General Health Score	60 [45, 75]

^aMissing 3. ^bMissing 9. ^cMissing 17. ^dMissing 4.

of informed consent and shared decision making. ²² Considered in a different light, our finding that the number of cardiac surgeries positively correlated with improved HK stands in contrast to the to the hypothesis that repeated episodes of cardiopulmonary bypass negatively impact patients' intellect, insight, or capacity to be familiar with their disease, though the HCKS is a distinct intellectual construct from others previously used to explore this phenomenon. ²³⁻²⁶ Although we did not assess for correlations between Shipley-2 scores and any variable other than HK in the present study, participants' median score on the Shipley-2 was within one standard deviation of the normed mean for the assay, which is within the 'average' range for assessed cognitive function.

The present study showed a weak, positive correlation between HCKS and level of perceived stress as well as a weak, negative correlation between HCKS and emotional well-being. This contrasts with prior data showing that patients' health-related quality of life positively correlates with a good knowledge of their cardiac condition, feelings of optimism, adequate social support, and a strong sense of coherence. ²⁷ The present data seem to support the hypothesis that patients might be more engaged when faced with anxiety associated with upcoming surgery or clinical deterioration and appear to support our previous findings in this patient group on the association between anxiety and medical compliance. ⁹

The LKQCHD has been validated in prior studies as a means to assess ACHD patients' understanding of their disease, its treatment, and measures to prevent complications. ²⁸⁻³⁰ In its pilot study, patients of diverse educational background and lesion complexity were found to have sound knowledge regarding treatment regimen, frequency of follow-up, appropriate dental practices, and risks of pregnancy. However, the same analysis found that ACHD patients had poor insight into symptoms of cardiac deterioration,

the reasons underlying need for continued follow-up, risk factors for endocarditis, and the use of intrauterine devices for contraception. Hence, patients appeared to understand the need for and value of appropriate care, but not the reasons underlying physicians' recommendations. That study hinted at an absence of indepth disease-specific health knowledge in the ACHD population which may suggest an opportunity to improve patients' health-related behaviors and outcomes. This knowledge gap should be considered when designing interventions to transition ACHD patients from pediatric to adult care. 28,30

Though others have demonstrated improvements in self-perceived risk and general health knowledge after the transition from adolescence to young adulthood, the results of this study failed to show a relationship between HKCS and age or level of education. As ACHD patients become increasingly independent and accountable for their own care, it will become all the more important that they comprehend their unique disease processes for optimal health trajectories. While we failed to identify major associations between any psychological, clinical, or demographic factor and HK, these results are nevertheless informative. They imply that much of the variability in ACHD patients' HK is not accounted for by traditional measures, and hint at the hypothesis that a systematic program of patient education might succeed in improving HK regardless of presumed health-related intellectual or educational limitation.

This study suffers the limitations inherent to any cross-sectional survey study. Self-reporting may have led to errors a consequence of missing data or poor recall. Furthermore, approximately 65% of participants completed the questionnaires at home, and being in uncontrolled environments may have introduced bias into their answers. All clinical data were collected by chart review and it is possible that some data are incomplete or incorrect. As study participation was voluntary, there was opportunity for selection bias. Only patients who were believed to have the capacity to read and understand the questionnaires were included, effectively excluding individuals with significant intellectual limitations and potentially obscuring an association between intellectual capacity and HK. Although these issues are common to all studies of this kind, it may limit the generalizability of the results. Additionally, this work represents only 78 participants, which limits both the power to detect associations, as well as the generalizability of the results. For example, participants in the present study had higher levels of education than in the general (ACHD) population. Correlations found in this analysis should be considered keeping in mind that the number of statistically significant correlations found is fewer than would be expected by chance. In assessing multiple variables, it is quite probable that correlations found in the present study indeed occurred due to chance. This nevertheless may further reinforce the notion that HCKS does not correlate strongly with commonly measured variables. Finally, the correlations identified in the present study cannot be used to make conclusions about causation, and are intended to be a starting point for future research.

TABLE 2 Correlations between continuous demographic/psychological variables and reciprocals of total HKCS and domain subscores

Continuous variable	1/(Health knowledge score)	1/(Disease treatment knowledge score)	1/(Prevention of complications)	1/(Physical activity knowledge score)	1/(Sexual heredity knowledge score)	1/(Contraception knowledge score)
Age	-0.077	-0.157	0.053	-0.032	-0.214	-0.318
Income	0.100	0.239*	-0.091	0.023	0.206	-0.057
Education	0.025	0.018	0.029	-0.190	0.265*	0.136
Complexity of lesion	0.029	-0.145	0.052	0.229*	0.053	-0.041
Number of cardiac surgeries	0.273*	0.030	0.317*	0.051	0.036	0.286
Number of noncardiac diagnoses	0.075	-0.076	0.260*	-0.237*	-0.119	-0.021
Hospitalization rate per year while following with ACHD specialty care	-0.084	-0.347*	0.221	-0.154	-0.098	-0.156
Encounters per year	-0.154	-0.093	0.002	-0.194	-0.074	-0.107
Index of number of visits arrived at per year versus number missed/the number of years followed	0.087	0.242	-0.064	-0.047	0.132	0.014
Compliance	-0.190	-0.104	-0.038	-0.109	-0.272*	-0.248
Perceived stress score	0.260*	0.219	0.118	0.100	0.294*	0.151
Cardiac denial of impact scale	0.198	0.102	0.116	0.043	0.217	0.215
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1/(Contraception knowledge score)	0.017	0.091	0.103	0.145	-0.012	0.045	-0.241	-0.029	-0.040	0.067	-0.061	0.208	0.260 (Continues)
1/(Sexual heredity knowledge score)	0.087	0.040	-0.026	-0.083	0.051	-0.053	0.054	0.034	0.014	0.159	-0.045	0.131	-0.015
1/(Physical activity knowledge score)	-0.055	-0.127	-0.067	0.064	-0.065	0.067	0.003	0.118	0.129	0.112	0.061	0.067	-0.003
1/(Prevention of complications)	0.183	0.147	-0.029	-0.140	-0.232*	-0.029	0.065	-0.132	-0.022	-0.150	-0.126	0.115	0.172
1/(Disease treatment knowledge score)	0.162	0.003	-0.016	-0.049	0.058	-0.019	0.151	0.041	0.031	0.113	0.020	0.188	0.103
1/(Health knowledge 1/ score) kn	0.195	0.084	-0.035	-0.079	-0.177	-0.011	0.072	-0.065	-0.005	0.003	-0.098	0.206	0.181
Continuous variable	Depression (Beck Depression Inventory- Version II score)	Barriers to care—skill	Barriers to care—margin	Barriers to care—ex-pected	Barriers to care—KAB	Barriers to care— Pragmatics	Acute stress index	Perceived support scale—total	Perceived support scale—significant others	Perceived support scale—family	Perceived support scale—friends	Anxiety (Beck Anxiety Index score)	Early life stress score

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Continuous variable	1/(Health knowledge score)	1/(Disease treatment knowledge score)	1/(Prevention of complications)	1/(Physical activity knowledge score)	1/(Sexual heredity knowledge score)	1/(Contraception knowledge score)
SF-36 physical functioning score	0.070	0.159	-0.134	0.149	0.187	0.023
SF-36 physical limitations score	0.078	0.188	-0.051	0.018	0.146	-0.135
SF-36 emotional limitations score	-0.015	0.086	-0.022	0.001	0.012	-0.220
SF-36 energy level score	-0.127	-0.097	-0.174	0.077	-0.035	-0.107
SF-36 emotional well-being score	*-0.251	-0.120	-0.240*	-0.067	-0.162	-0.026
SF-36 social score	-0.046	0.065	-0.093	-0.001	0.047	-0.199
SF-36 pain score	0.005	0.034	-0.146	0.138	0.163	-0.143
SF-36 general health score	0.000	0.113	-0.170	0.095	0.112	0.043

Note: Statistically significant correlations (P values <.05) are indicated by * .

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		1/(Disease treatment	1/(Prevention of	1/(Physical activity	1/(Sexual heredity	1/(Contraception
Categorical variable	1/(Health knowledge score)	Knowledge score)	complications)	Knowledge score)	Knowledge score)	knowledge score)
Gender	0.344	0.371	0.075	0.809	0.713	I
Race/ethnicity	0.149	0.024*	0.215	0.358	0.262	0.226
Married	0.884	0.456	0.581	0.423	0.727	0.497
Religion	0.161	0.181	969.0	0.077	0.847	0.214
Smoker	0.448	0.682	0.451	0.930	0.443	0.614
History of noncardiac surgery	0.037*	0.86	*800.0	0.840	0.206	0.968
Cirrhosis	0.048*	0.368	0.008*	0.614	0.949	0.614
History of arrhythmia	0.446	0.422	0.181	0.469	0.541	0.779
Presence of implantable cardioverter-defibrillator	0.028*	0.015*	0.065	0.106	0.215	0.979
Presence of permanent pacemaker	0.238	0.039*	0.612	0.660	0.825	0.668
Valvular disease	0.237	0.4	0.075	0.549	0.742	0.826
Clinical cyanosis	0.116	0.782	0.139	0.564	0.105	0.116
History of a cyanotic cardiac lesion	0.258	0.515	0.311	0.029*	0.512	0.216

Note: Statistically significant correlations (P values <.05) are indicated by $^{\ast}.$

In conclusion, we found that HK did not correlate with intelligence, psychological variables, or lesion complexity in a small group of ACHD patients, but it was weakly correlated with number of cardiac surgeries. Future research should explore initiatives aimed at increasing and refining patient education to improve ACHD patients' engagement and understanding in their health.

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CONFLICT OF INTEREST

The authors report no relationships that could be construed as a conflict of interest.

AUTHOR CONTRIBUTIONS

Joshua Saef: Data Collection, Concept/Design, Data analysis/interpretation, Drafting article, Critical revision of article.

Sandeep Sodhi: Data Collection, Data analysis/interpretation, Critical revision of article.

Kristen M. Tecson: Statistics, Critical revision of article, Data analysis/interpretation.

Vanessa al Rashida: Data Collection.

Jong Mi Ko: Statistics, Data analysis/interpretation.

Kamila S. White: Concept/Design, Data Collection, Critical revision of article.

Philip A. Ludbrook: Data Collection, Concept/Design, Data analysis/interpretation, Critical revision of article.

Ari M. Cedars: Data Collection, Concept/Design, Data analysis/interpretation, Drafting article, Critical revision of article.

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REFERENCES

- Moodie D, Coselli J. Adult congenital heart disease. Tex Heart Inst J. 2011;38(6):705-706.
- Clark N. Management of chronic disease by patients. Annu Rev Public Health. 2003;24:289-313.
- Kovacs AH, Sears S, Saidi A. Biopsychosocial experiences of adults with congenital heart disease: review of the literature. Am Heart J. 2005;150:193-201.
- 4. Kokkonen J, Paavilainen T. Social adaptation of young adults with congenital heart disease. *Int J Cardiol*. 1992;36:23-29.
- Ong L, Nolan RP, Irvine J, Kovacs AH. Parental overprotection and heart-focused anxiety in adults with congenital heart disease. Int J Behav Med. 2011;18(3):260-267.

- Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care. J Gen Intern Med. 2005;20(10):953-957.
- Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the patient activation measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res.* 2004;39(4 Pt 1):1005-1026.
- 8. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *J Gen Intern Med.* 2012;27(5):520-526.
- White KS, Pardue C, Ludbrook P, Sodhi S, Esmaeeli A, Cedars A. Cardiac denial and psychological predictors of cardiac care adherence in adults with congenital heart disease. *Behav Modif.* 2016;40(1–2):29-50.
- Campbell F, Biggs CE, Aldiss SK et al. Transition of care for adolescents from paediatric services to adult health services. Cochrane Database of Systematic Reviews. 2016;4:CD009794.
- Hendriks M, Rademakers J. Relationships between patient activation, disease-specific knowledge and health outcomes among people with diabetes; a survey study. BMC Health Serv Res. 2014;14:393.
- Yang HL, Chen YC, Wang JK, Gau BS, Chen CW, Moons P. Measuring knowledge of patients with congenital heart disease and their parents: validity of the "Leuven Knowledge Questionnaire for Congenital Heart Disease". Eur J Cardiovasc Nursing. 2012;11(1):77-84.
- 13. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *J Health Soc Behav.* 1983;24(4):385-396.
- 14. Fowers BJ. The cardiac denial of impact scale: a brief, self-report research measure. *J Psychosom Res.* 1992;36(5):469-475.
- Beck AT, Steer RA, Brown GK. Manual for the Beck Depression Inventory II (BDI-II). San Antonio, TX: Psychological Corporation; 1996
- Seid M, Sobo EJ, Gelhard LR, Varni JW. Parents' reports of barriers to care for children with special health care needs: development and validation of the barriers to care questionnaire. *Ambul Pediatr* 2004;4(4):323-331.
- Peterson RA, Reiss S. Anxiety sensitivity index revised test manual. IDS Publ. 1993.
- 18. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived social support. *J Pers Assess.* 1988;52(1):30–41.
- Beck AT, Steer RA. Manual for the Beck anxiety inventory. San Antonio, TX: Psychological Corporation; 1990.
- 20. Chu DA, Williams LM, Harris AW, Bryant RA, Gatt JM. Early life trauma predicts self-reported levels of depressive and anxiety symptoms in nonclinical community adults: relative contributions of early life stressor types and adult trauma exposure. *J Psychiatr Res.* 2013;47(1):23–32.
- 21. Hays RD, Sherbourne CD, Mazel RM. The rand 36-item health survey 1.0. *Health Econ.* 1993;2(3):217–227
- 22. Shipley WC. Shipley-2: manual; 2009.
- Wernovsky G, Licht DJ. Neurodevelopmental outcomes in children with congenital heart disease – What can we impact? *Pediatric Crit Care Med*. 2016;17(8 Suppl 1):S232–S242.
- Fallon P, Aparício JM, Elliott MJ, Kirkham FJ. Incidence of neurological complications of surgery for congenital heart disease. Arch Dis Child. 1995;72(5):418–422.
- Bellinger DC, Jonas RA, Rappaport LA et al. Developmental and neurologic status of children after heart surgery with hypothermic circulatory arrest or low-flow cardiopulmonary bypass. N Engl J Med. 1995;332(9):549–555.
- Newburger JW, Sleeper LA, Bellinger DC, et al. Early developmental outcome in children with hypoplastic left heart syndrome and related anomalies: the single ventricle reconstruction trial. Circulation. 2012;125(17):2081–2091.
- 27. Wang Q, Hay M, Clarke D, Menahem S. Associations between knowledge of disease, depression and anxiety, social support,

- sense of coherence and optimism with health-related quality of life in an ambulatory sample of adolescents with heart disease. *Cardiol Young.* 2014 Feb;24(1):126–133.
- 28. Van Deyk K, Pelgrims E, Troost E et al. Adolescents' understanding of their congenital heart disease on transfer to adult-focused care. *Am J Cardiol*. 2010;106(12):1803–1807.
- 29. Moons P, DeVolder E, Budts W, et al. What do adult patients with congenital heart disease know about their disease, treatment, and prevention of complications? A call for structured patient education. *Heart*. 2001;86:74–80.
- 30. Van Deyk K, Moons P, Farroni N, et al. Effects of a structured education programme for adult patients with congenital heart disease: a follow-up study. *Acta Cardiol*. 2008;63(1):125–126.
- 31. Jackson J, Tierney K, Daniels CJ, Vannatta K. Disease knowledge, perceived risk and health behavior engagement among adolescents and adults with congenital heart disease. *Heart Lung*. 2015;44(1):39-44.

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