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Prediction of Quality of Life for Children and Adolescents with Cardiac Disease by Clinicians

John M. Costello, MD, MPH¹, Kathleen Mussatto, PhD, RN², Amy Cassedy, PhD³, Jo Wray, PhD, C Psychol⁴, Lynn Mahony, MD⁵, Sarah A. Teele, MD⁶, Kate L. Brown, MPH, MRCP⁴, Rodney C. Franklin, MD, FRCP, FRCPC⁷, Gil Wernovsky, MD⁸, and Bradley S. Marino, MD, MPP, MSCE³

¹Ann & Robert H. Lurie Children's Hospital of Chicago & Northwestern University Feinberg School of Medicine

²Children's Hospital of Wisconsin

³Cincinnati Children's Hospital Medical Center

⁴Great Ormond Street Hospital for Children NHS Trust

⁵University of Texas Southwestern Medical Center

⁶Boston Children's Hospital and Harvard Medical School

⁷Royal Brompton & Harefield NHS Trust

⁸Miami Children's Hospital

Abstract

Objective—To determine whether clinicians could reliably predict health-related quality of life (HRQOL) for children with cardiac disease, the level of agreement in predicted HRQOL scores between clinician sub-types, and agreement between clinician-predicted HRQOL scores and patient and parent-proxy reported HRQOL scores.

Study design—In this multi-center, cross-sectional study, a random sample of clinical summaries of children with cardiac disease and related patient and parent-proxy reported HRQOL scores were extracted from the Pediatric Cardiac Quality of Life Inventory data registry. We asked clinicians to review each clinical summary and predict HRQOL.

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Address correspondence to: John M. Costello, MD MPH, Associate Professor of Pediatrics, Northwestern University Feinberg School of Medicine Director, Inpatient Cardiology & Medical Director, Regenstein Cardiac Care Unit, Department of Pediatrics, Divisions of Cardiology & Critical Care Medicine, Ann & Robert H. Lurie Children's Hospital of Chicago, 225 East Chicago Avenue, Box 21, Chicago, IL 60611-2605, T 312.227.1551 | F 312.227.9765 | jmcostello@luriechildrens.org.

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Results—Experienced pediatric cardiac clinicians (n=140), including intensive care physicians, outpatient cardiologists, and intensive care, outpatient and advanced practice nurses, each predicted HRQOL for the same 21 pediatric cardiac patients. Reliability within clinician subspecialty groups for predicting HRQOL was poor (intraclass correlation coefficients, 0.34-0.38). Agreement between clinician groups was low (Pearson's correlation coefficients, 0.10-0.29). When comparing the average clinician predicted HRQOL scores to those reported by patients and parent-proxies by Bland Altman plots, little systematic bias was present, but substantial variability existed. Proportional bias was found, in that clinicians tended to overestimate HRQOL for those patients and parent-proxies who reported lower HRQOL, and underestimate HRQOL for those reporting higher HRQOL.

Conclusions—Clinicians perform poorly when asked to predict HRQOL for children with cardiac disease. Clinicians should be cognizant of these data when providing counseling. Incorporating reported HRQOL into clinical assessment may help guide individualized treatment decision-making.

Keywords

quality of life; heart defect; congenital; nurse clinicians; physicians

Health related quality of life (HRQOL) may be defined as the influence of a specific illness, medical therapy, or health services policy on the ability of patients to both function in and derive personal satisfaction from various physical, psychological, and social life contexts. Parents of children with cardiac disease routinely rely on counseling from clinicians to obtain information regarding their child's expected outcomes, including risk of mortality and complications, as well as neurodevelopmental outcomes and HRQOL. For children with congenital heart disease (CHD) or acquired heart disease, a variety of factors, including underlying cardiac disease, comorbidities, and perioperative events may all influence long-term physical, psychological and social functioning, which in turn impact HRQOL.(1-9) Despite the importance that parents of pediatric cardiology patients place on counseling provided by physicians and nurses, the accuracy with which they can predict HRQOL is unknown.

The purpose of this study was to determine the ability of clinicians to predict HRQOL as reported by pediatric cardiac patients and their parent-proxies. We first sought to determine the overall reliability of predicted HRQOL scores within clinician specialty groups, and the agreement of these scores across specialty groups. If clinician-predicted HRQOL scores were found to be reliable, we then planned to determine the agreement between clinician predicted HRQOL scores and the *patient* reported HRQOL scores, and between clinician predicted HRQOL scores and *parent-proxy* reported HRQOL scores. We hypothesized that reliability among clinician-predicted HRQOL scores within specialty groups would be high, and that agreement between specialty groups would be at least moderate.

Methods

A stratified random sample of 21 individual patient clinical summaries and linked patient and parent-proxy reported HRQOL Total Scores were extracted from the Pediatric

Cardiology Quality of Life Inventory (PCQLI) data registry. The PCQLI is a disease-specific, HRQOL measure for pediatric heart disease.(10) Data regarding the reliability, validity and generalizability of this instrument have been previously reported.(2, 11-13) PCQLI Total Scores range from 0 to 100 with a higher score indicating a better HRQOL.

De-identified clinical summaries were created for individual patients who have previously participated in the PCQLI Validation Study(2) and received care at Cincinnati Children's Hospital Medical Center, The Children's Hospital of Philadelphia, Boston Children's Hospital, Children's Hospital of Wisconsin, or the Children's Medical Center at Dallas, all located in the United States, or Great Ormond Street Hospital for Children, the Royal Brompton Hospital or Birmingham Children's Hospital, all located in the United Kingdom. The clinical summaries included patient demographics, education, cardiac diagnoses, comorbidities, cardiac procedures, number of hospital admissions, presence of central nervous system injury or mental health problems, current medications and number of outpatient physician encounters in the last 12 months, as well as parental educational and socioeconomic data. The sample of summaries was stratified based on age group (children age 8 to 12 years and adolescents age 13 to 18 years), PCQLI total score (stratified by quartile), and heart disease complexity: (1) "mild" biventricular CHD patients without intervention; (2) biventricular CHD patients following surgery or catheter-based intervention; (3) functionally single ventricle CHD patients following a Fontan-type procedure; and (4) acquired heart disease. Stratification reflected the overall distribution of heart disease complexity in the PCQLI data registry. An example of a patient clinical summary is shown in Figure 1 (available at www.jpeds.com). Table I describes the demographic and clinical information for the 21 study patients and their parent-proxies.

Pediatric cardiovascular healthcare providers were recruited to participate in the study from six of the children's hospitals listed above and Ann & Robert H. Lurie Children's Hospital of Chicago. Categories of clinicians included cardiac intensivists, outpatient cardiologists, cardiac intensive care nurses, cardiac outpatient nurses, and cardiac advanced practice nurses. Clinicians were required to have at least three years of experience beyond the completion of their clinical training and to spend at least 70% of their professional effort providing direct patient care for children with cardiac disease. Each participating clinician was asked to review the same 21 patient clinical summaries and to generate a predicted HRQOL score for each patient. The clinicians were masked to patient identifiers and individual patient and parent-reported HRQOL scores, but were provided with age-specific means and sample distributions of HRQOL scores from 2,702 patients included in the PCQLI data registry.(2, 11)

To detect intraclass correlation coefficients (ICC) of 0.70, 21 cardiac intensivists, 21 outpatient cardiologists, 21 cardiac intensive care nurses, 21 cardiac outpatient nurses and 21 cardiac advanced practice nurses were needed to review the same 21 clinical summaries. This sample size allowed for an 80% power with a 0.05 significance level to determine the reliability of predicted HRQOL scores within clinician specialty groups. To account for potential clinician dropout, we planned to recruit a total of 140 clinicians.

This multi-center, cross-sectional study was approved by the institutional review boards at each of the seven participating institutions, and written, informed consent was obtained from participating clinicians. The Heart Institute Research Core at Cincinnati Children's Hospital Medical Center served as the data coordinating center for the study.

Statistical Analyses

The ICC was calculated to determine the reliability of the predicted HRQOL scores *within* each clinician category. To assess the agreement *between* predicted HRQOL scores generated by members of each clinician category, Pearson correlation coefficients (PCC) were calculated. Finally, because health care professionals and patient and parent proxies used different methods of measurement to create a HRQOL score, Bland-Altman plots were used to assess agreement between HRQOL data reported by patients and their parents and that predicted by the clinicians. Bland-Altman plots are commonly used to assess agreement between two measurement techniques, including an evaluation of systematic differences between two clinical measurements (systematic bias), an assessment of agreement between two measurements over the range of data (proportional bias), and identification of outliers. (14) Data are reported as count (percent) or mean $\pm$ standard deviation unless otherwise indicated, and were analyzed using SAS© 9.2.

Results

A total of 140 clinicians participated in this study, comprising 27-29 subjects from each of the five sub-specialty clinician categories. Demographic characteristics for these clinicians are summarized in Table II (available at www.jpeds.com), and practice information may be found in Table III (available at www.jpeds.com). Outpatient cardiologists had nearly twice the number of years of experience after fellowship compared with cardiac intensivists. In contrast, years of experience did not differ significantly for the three groups of cardiac nurses. For all five clinician groups, the reliability to predict HRQOL of the 21 study patients was poor, with ICCs ranging from 0.34 – 0.38 (Table IV). The overall reliability for all 140 clinicians was also poor (ICC, 0.34).

The PCCs for HRQOL scores between clinician groups were low, ranging from 0.10 (between intensivists and outpatient cardiologists) to 0.29 [between all physicians (intensivists and outpatient cardiologists combined) and advanced practice nurses] (Table V). Even though the 140 clinicians' overall reliability (within category) and agreement between categories for predicting HRQOL were both low, their mean scores summarized the group's overall prediction for each individual patient. Inspection of Bland-Altman plots indicated that little systematic bias existed between average HRQOL scores predicted by clinicians and both patient and parent-proxy reported HRQOL scores (Figure 2). On average, clinicians overestimated patient reported HRQOL by 6.6 points, and overestimated parent-proxy reported HRQOL by 0.4 points. However, wide variability existed between clinician predicted HRQOL scores and those reported by patients and their parent-proxies, indicating that average clinician predicted scores cannot be used interchangeably with individual patient and parent-proxy scores. For patients and parent-proxies who reported higher HRQOL, proportional bias was evident in that clinicians as a group tended to

underestimate HRQOL, whereas when patients and parent-proxies reported lower HRQOL, clinicians tended to overestimate it. When individual clinician-predicted and patient-reported QOL scores were rank-ordered and then matched, however, agreement was poor. The median number of the 21 possible patient-reported HRQOL ranks correctly predicted by clinicians was 2 (range 0-7). The correlation between years of clinician experience and number of rank-ordered patient-reported HRQOL scores correctly predicted was poor (Spearman correlation coefficient, 0.03; $p=0.75$). No significant correlations were found when this analysis was repeated for each clinician specialty group.

Discussion

Contrary to our primary hypothesis, we found that physicians and nurses who routinely care for cardiac patients had poor reliability for predicting patient and parent-proxy reported HRQOL. No particular subgroup of these clinicians performed better or worse than any other, specifically outpatient clinicians performed no better than those in the inpatient setting. In addition there was poor agreement between clinician categories when predicting patient and parent-proxy reported HRQOL. As a group, clinicians tended to overestimate HRQOL when patients and their parents reported low HRQOL and underestimate it when patients and parents reported high HRQOL. Strengths of this study included the multicenter, multinational design. The relatively large number of participating clinicians was on average highly experienced and had substantial direct contact with the patient population of interest. HRQOL was reported by study patients and their parent proxies using a disease specific HRQOL instrument whose psychometric properties have been previously assessed in the United States and the United Kingdom and shown to be reliable, valid, and generalizable.(2, 11-13)

Our findings suggest that clinicians may make inaccurate assumptions about which patients will have a good HRQOL later in life versus those who will not based largely on clinical considerations. In a recent study, pediatric cardiac extracorporeal membrane oxygenator (ECMO) survivors and their parent proxies reported that on average, HRQOL was not dissimilar to that of other complex pediatric cardiac patients, a finding that may surprise many clinicians.(9) The findings of that study and the current one are important, given the substantial reliance that patients and parents place on clinicians for counseling regarding long term outcomes including HRQOL. When attempting to project forward, clinicians do so without knowledge of patients' and parents' future subjective perception of the outcome that is ultimately achieved. Clinicians should recognize the significant limitations in their ability to predict future HRQOL for individual patients, and thus should be cautious when speculating about such patient-specific outcomes when communicating with patients, parents, and other clinicians. HRQOL outcomes derived from large populations of similar patients may be appropriately incorporated into these discussions, with the clear understanding that average outcomes achieved from such patient populations cannot be extrapolated to the HRQOL experienced by an individual patient. Measurement of HRQOL in children with cardiac disease has been shown to be feasible using either generic or disease-specific instruments.(2, 4, 7, 8, 15, 16) Objective measurement of perceived HRQOL in individual patients and their parent-proxies will help clinicians identify those in need of counseling or intervention.(8, 16)

Several studies have found that parents of children with cardiac disease often perceive the HRQOL of their child to be different than that reported by the child.(1, 6, 8) Although parents spend substantially more time with their children when compared with clinicians, they still perceive their children's HRQOL differently than reported by the child. In retrospect, it is not surprising that participating clinicians, who had no direct contact with the study patients, performed poorly when trying to predict patient or parent-proxy reported HRQOL. Furthermore, pediatric patients, their parents and clinicians who care for them may place varying emphasis on different HRQOL domains.(17) For example, recently published data indicate that children with heart disease place more value on the physical dimension of HRQOL than parents or clinicians, whereas clinicians emphasize the psychological dimension more than patients and parents.(18)

Our findings must be interpreted in light of the limitations of the study design. The novel methodology used in this study has not been previously validated. Patient and parent-proxy HRQOL scores were tabulated from answers to individual questions, whereas clinicians were asked to predict summary scores. Additionally, clinicians were asked to estimate HRQOL after reviewing a written summary of each patient's clinical course. In practice, clinicians (particularly those working in an outpatient setting) are more accustomed to counseling patients about long-term outcomes including HRQOL with the benefit of in-person contact, longitudinal follow-up and knowledge of family values. We do not know what strategies individual clinicians may have employed when assigning HRQOL scores. Provision of the mean and sample distribution of the patient- and parent-reported HRQOL scores may have influenced the clinicians to report scores near the mean values. The PCQLI inventories generate a Total Score, Disease Impact subscale score, and Psychosocial Impact subscale score for each patient. As clinicians were not asked to predict subscale scores, we could not assess for agreement between them and those reported by patients and parent proxies. Future prospective studies may identify mechanisms by which clinicians can better predict HRQOL in children with heart disease and other complex patient populations.

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Abbreviations

HRQOL	health-related quality of life
ICC	intraclass correlation coefficient
PCC	Pearson correlation coefficient

PCQLI Pediatric Cardiac Quality of Life Inventory

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Figure 2.

Bland-Altman plots depicting agreement between average clinician predicted HRQOL scores and A) patient reported HRQOL scores, and B) parent-proxy reported HRQOL scores. In these plots, the open circles represent the mean of the average clinician scores and individual patient (or parent proxy) scores as the x-axis value and the difference between the two scores as the y-axis value. The “Mean” line reflects the mean difference (or estimated systematic bias) between the average clinician scores and individual patient or parent proxy scores. The “1.96 SD” lines reflect 95% limits of agreement between average clinician scores and individual patient or parent proxy scores.

Table 1

Characteristics of 21 study patients.

Characteristic	N (%)
Male gender	10 (48)
Race	
Non-white	4 (19)
White	17 (81)
Cardiac diagnosis category	
“Mild” biventricular CHD without intervention	1 (5)
Biventricular CHD following surgery or catheter-based intervention	10 (48)
Functionally single ventricle CHD s/p Fontan-type procedure	3 (14)
Acquired heart disease	7 (33)
Years Since Last Hospitalization [Mean, SD]	6.5 ± 3.7
Hospitalizations for cardiac surgery	
0	12 (57)
1	5 (24)
2	2 (9)
3	2 (9)
Hospitalizations for cardiac catheterizations or interventional procedure	
0	9 (43)
1	5 (24)
2	5 (24)
3 or more	2 (9)
Hospitalizations, lifetime	
0	7 (33)
1	6 (29)
2	5 (24)
3	3 (14)
Prior non-cardiothoracic surgical procedures	
None	19 (90)
General surgery (not specified)	1 (5)
Spinal Fusion	1 (5)
Physician clinic visits, prior year	
0-1	6 (29)
2-3	8 (38)
4-6	5 (24)
7-10	2 (19)
History of	
Learning disability	5 (24)
Stroke	1 (5)
Seizure disorder	0
Mental health problems	0

Characteristic	N (%)
Patient age in years [Mean, SD]	12.3 ± 3.1
Type of education	
Full-time	20 (95)
Part-time without tutoring at home	1 (5)
Homebound for medical reasons with tutoring at home	0
Home School	0
Patient education level	
Kindergarten – 5 th grade	9 (43)
6 th – 8 th grade	5 (24)
9 th – 12 th grade	7 (33)
Educational programs (not mutually exclusive)	
None	11 (52)
Learning supports (tutor or learning disability services)	3 (14)
Gifted program	4 (19)
Individualized Education Plan	2 (10)
Self-contained special education classroom (full-time)	1 (5)
Days of missed school in prior year [Median (Range).]	2 (0-30)
Family status	
Both parents	20 (95)
Primarily mother	1 (5)
Multiple Gestations	
No	18 (86)
Yes	3 (14)
Primary Caregiver Education Level	
Less than high school degree	3 (14)
High school graduate	7 (33)
Some college	7 (33)
College graduate	3 (14)
Post graduate degree	1 (5)

Key: CHD = congenital heart disease; SD = standard deviation.

Table 2

Characteristics of 140 participating clinicians.

Characteristic	
Age in years [Mean, SD]	43.2 ± 10.7
Female sex [n (%)]	102 (73%)
Race [n, (%)]	
Non-white	15 (11%)
White	125 (89%)
Number of Children [n (%)]	
0	54 (39%)
1	18 (13%)
2	40 (29%)
3	21 (15%)
4	5 (4%)
5	2 (1%)

Table 3

Practice information of participating cardiac healthcare providers.

Physicians	Intensivist (n=28)	Outpatient Cardiologist (n=28)	
Years since completion of fellowship training	9 ± 5	18 ± 13	
1/2 day outpatient cardiology clinics per month	n/a	11 ± 5	
Weeks of ICU service per year	22 ± 14	n/a	
Nurses	ICU (n=29)	Outpatient (n=28)	Advanced practice (n=27)
Years of clinical experience following graduation of nursing school	15 ± 10	20 ± 13	17 ± 9
Hours of direct cardiology patient contact per week	34 ± 6	30 ± 9	32 ± 12

Data are reported as mean ± standard deviation.

Key: SD = standard deviation; ICU = intensive care unit

Table 4

Clinician predicted HRQOL scores and reliability within clinician categories.

	Intensivist	Outpatient Cardiologist	ICU RN	Outpatient RN	Advanced Practice RN
Predicted HRQOL scores	78.7 ± 11.3	78.6 ± 11.1	82.8 ± 10.4	82.5 ± 9.0	85.5 ± 8.9
Intraclass correlation coefficient	0.35	0.36	0.34	0.38	0.35

Data are reported as mean ± standard deviation.

Key: RN = registered nurse; SD = standard deviation

Table 5

Agreement of clinician predicted HRQOL scores between clinician categories.

	CICU MD vs. CICU RN	CICU MD vs. OutPt MD	OutPt MD vs. OutPt RN	CICU RN vs. OutPt RN	All MDs vs. All RN	All MDs vs. APNs	CICU RN vs. APN	OutPt RN vs. APN
PCC	0.19	0.10	0.20	0.14	0.22	0.29	0.14	0.17

Key: APN = advanced practice nurse; CICU = cardiac intensive care unit; MD = medical doctor; Outpt = outpatient; PCC = Pearson's correlation coefficient; RN = registered nurse.