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ORIGINAL ARTICLES

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

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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 multicenter, 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.

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 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. *(J Pediatr 2015;166:679-83).*

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

CHD	Congenital heart disease
HRQOL	Health-related quality of life
ICC	Intraclass correlation coefficient
PCQLI	Pediatric Cardiac Quality of Life Inventory

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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 Cardiac 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 0-100 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 US, 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 8-12 years and adolescents age 13-18 years), PCQLI total score (stratified by quartile), and heart disease complexity: (1) patients with "mild" biventricular CHD without intervention; (2) patients with biventricular CHD following surgery or catheter-based intervention; (3) patients with functionally single ventricle CHD following a Fontan-type procedure; and (4) patients with 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 6 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 3 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

Table I. Characteristics of 21 study patients

Characteristics	N (%)
Male sex	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 status post 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 noncardiothoracic surgical procedures	
None	19 (90)
General surgery (not specified)	1 (5)
Spinal fusion	1 (5)
Physician clinic visits, prior y	
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
Patient age in y (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-5th grade	9 (43)
6th-8th grade	5 (24)
9th-12th 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 y (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)