Validity and Responsiveness of the Pediatric Quality of Life Inventory 4.0 Generic Core Scales in the Pediatric Inpatient Setting

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Abstract

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Importance: Validated patient-reported outcome (PRO) measures sensitive to clinical change are needed to evaluate the effectiveness of quality improvement interventions.

Objective: To evaluate the responsiveness, construct and predictive validity of the Pediatric Quality of Life Inventory (PedsQL^{TM}) 4.0 Generic Core Scales in the pediatric inpatient setting.

Design/Setting/Participants: Prospective, cohort study. Parents/caregivers of patients 1 month-18 years-old (N = 4633) and patients 13-18 years-old (N = 359) admitted to Seattle Children's Hospital between 10/11 - 12/13. Of eligible participants invited to complete the survey (N = 7184), 65% (N = 4637) completed the PedsQL^{TM} on admission and of these 58% (N = 2694) completed the follow-up survey 2-8 weeks after discharge.

Main Outcome Measures: Responsiveness was assessed by calculating improvement scores (difference between follow-up and admission scores). Construct validity was examined by comparing mean improvement scores for known-groups differing by medical complexity. Predictive validity was assessed using Poisson regression to examine associations between admission scores, prolonged length of stay (LOS $\geq$ 3 days), 30-day readmissions or return

emergency department (ED) visits. Similar models examined the association between improvement scores and risk of 30-day readmissions or return ED visits.

Results: The mean PedsQL™ improvement scores (0-100 scale) were Total: 22.1 (standard deviation (SD) 22.7), Physical: 29.4 (SD 32.4), Psychosocial: 17.1 (SD 21.0). Mean PedsQL™ improvement scores were lower for medically complex patients compared to patients without chronic conditions (Total: 13.7, 95% confidence interval (CI) 11.6 – 15.8 versus 24.05, 95% CI 22.44 – 25.66; p <0.001). A 10-point decrement in PedsQL™ Total admission score below the established community-based mean was associated with an increase in risk of prolonged LOS (Total: +15%, 95% CI 13%, 17%), 30-day readmission (Total: +8%, 95% CI 3%, 14%), and ED return visit (Total: +13%, 95% CI 6%, 20%). A 5-point decrement in PedsQL™ Total improvement score below the study sample mean improvement score was associated with an increase in risk for 30-day readmission or ED return visit (Total: +11%, 95% CI 1%, 22%).

Conclusions: The PedsQL™ demonstrated responsiveness, construct and predictive validity in a population of hospitalized pediatric patients, and may be a useful PRO measure for hospital-based clinical effectiveness research.

Introduction

In 2010 the Patient Protection and Affordable Care Act authorized the creation of the Patient Centered Outcomes Research Institute (PCORI), dedicated to supporting comparative effectiveness research focused on outcomes relevant to patients and families.[1] Patient-reported outcome (PRO) measures are increasingly being utilized in pediatric health services research to evaluate outcomes and inform clinical-decision making from the patient and family perspective.[2-4] To measure the effectiveness of clinical interventions, guidelines recommend these measures should be brief, demonstrate a high degree of reliability and validity in multiple patient populations, and include both age appropriate and parallel versions for child and parent-proxy raters.[2,5,6] These measures should also be clearly linked to the delivery of specific health services, and detect meaningful variation in outcomes over multiple assessments.[4,7]

While PRO measures have been used extensively in outpatient settings[8], the majority of these measures used in the inpatient setting have focused on patient experience and satisfaction, largely in adult populations.[9,10] Expanding the evaluation of PRO measures to include health status, health-related quality of life (HRQOL), symptomatology, and functional status provides a more comprehensive evaluation of the clinical effectiveness of inpatient health services from the patient and family perspective. While HRQOL measures have been validated in the adult inpatient setting[11], currently there are no HRQOL measures validated for use in the pediatric inpatient setting.

The Pediatric Quality of Life Inventory (PedsQL^{TM}) 4.0 Generic Core Scales and the PedsQL^{TM} Infant Scales are population HRQOL measures that have demonstrated good reliability and construct validity in a wide variety of general[12-15] and disease-specific populations[16,17], and have also demonstrated responsiveness to meaningful change[18-23]. The PedsQL^{TM} Generic Core Scales instrument consists of four domains: 1) physical functioning, 2)

emotional functioning, 3) social functioning, and 4) school functioning; and includes formats for typically developing children/adolescents ages 2-18 years-old (parent proxy report) and 5-18 years-old (self-report). The minimal clinically important difference (MCID) calculated in previous studies is 4.50 - 6.92 points by parent proxy-report, and 4.36 – 6.66 points by child self-report.[13] The PedsQL™ Infant Scales instrument consists of five domains: 1) physical functioning, 2) physical symptoms; 3) emotional functioning, 4) social functioning, and 5) cognitive functioning; and includes formats for typically developing children ages 1-24 months (parent proxy-report).[15] The format, instructions, response scale, and scoring methods of the Infant Scales are identical to the Generic Core Scales.

The aim of this study was to evaluate the responsiveness, construct and predictive validity of the PedsQL™ Generic Core Scales and PedsQL™ Infant Scales in a population of hospitalized children. We hypothesized improvement in PedsQL™ scores from admission to follow-up would be higher than the MCID published in the ambulatory literature demonstrating unidirectional responsiveness of the measure in the inpatient setting. We also hypothesized PedsQL™ improvement scores would be significantly lower for patients with chronic conditions compared to patients with no chronic conditions. Finally, we hypothesized lower PedsQL™ improvement scores would be associated with higher utilization outcomes such as 30-day readmission or emergency department (ED) visits.

Methods:

Study Population

The study population included patients admitted to Seattle Children's Hospital (SCH) general medical or surgical units between 10/1/2011 and 12/31/2013. These patients were eligible unless they were < 1 month-old, in protective isolation (i.e., immunosuppressed), approached to participate within the last 2 months, admitted for 24 hour video EEG or Ph-probe

study, admitted for suspicion of child abuse, or developmentally delayed. The rational for excluding patients with developmental delays was based on focus groups conducted with caregivers of atypically developing children at our hospital. These parents found the age-appropriate PedsQL™ survey items difficult to answer for their children secondary to having low applicability to their physical and psychosocial abilities.

Recruitment and Data collection

Eligible families were invited to participate within 72 hours of admission by a trained research assistant using a standard protocol for study recruitment and consent/assent. Parents/caregivers (referred to as caregivers from here forward) of admitted patients (ages 1-24 months) were asked to complete the proxy-report PedsQL™ Infant Scales instrument, while caregivers of admitted patients (ages 2-18 years) were asked to complete the proxy-report PedsQL™ Generic Core Scales instrument. Patients (ages 13-18 years) were asked to complete the self-report PedsQL™ Generic Core Scales instrument. Patients determined to be too ill to complete the survey were not invited to participate.

The survey was administered within 72 hours of admission and 2-8 weeks after discharge from the hospital. Caregivers and patients were asked to reflect on the time since their child/they had to come into the hospital (admission survey) and the past 7 days (follow-up survey) when responding to the PedsQL™. The admission survey also collected patient age, gender, race/ethnicity, and caregiver age and education level. Participants were given the option to complete the admission survey either electronically using a laptop computer, or by telephone interview. Follow-up surveys were completed as an online web-based survey or by telephone interview. Surveys were offered in English, Spanish, Vietnamese, Russian, Somali and Chinese, and caregivers or patients who did not speak any of these languages were considered ineligible for the study. Spanish surveys were created using forward and backward

translation methods, and were reviewed by profession interpreters at SCH prior to administration.

All study procedures were reviewed and approved by the Seattle Children's Research Institute Institutional Review Board.

Statistical Analysis

Analysis was conducted using scale scores from the PedsQL™ as the main outcome measure. Each PedsQL™ item was reverse scored and linearly transformed to a 0-100 scale, therefore higher scores reflected better HRQOL. For each caregiver and/or patient respondent, a Total, Physical Health and Psychosocial Health summary score was computed as the sum of the items divided by the number of items answered. The PedsQL™ Total score was composed of the Physical and Psychosocial Health scores. The Physical Health score combined the physical functioning and physical symptoms scales for the Infant Scales. The Psychosocial Health score was composed of the emotional, social and school functioning (or cognitive functioning for the Infant Scales) scale scores. If more than 50% of the items in the instrument were missing, a Total, Physical or Psychosocial Health summary score was not computed (3% of the sample). Mean imputation was used to compute scale scores for surveys with fewer than 50% missing items.

Improvement scores were derived by calculating the difference between the Total, Physical, and Psychosocial Health scores on admission from the Total, Physical, and Psychosocial Health scores at follow-up; therefore, higher improvement scores reflected greater improvement in HRQOL from admission to follow-up.

Responsiveness was analyzed by computing means and standard deviations (SD) of admission and follow-up scores. Paired *t*-tests and Cohen's *d* analyses were conducted to

examine differences and effect sizes between admission and follow-up scores for both caregiver and patient-reported data.

Construct validity was analyzed by comparing means and SD of improvement scores across known groups differing in medical complexity (known-groups discriminant validity). We stratified our study population using the Pediatric Medical Complexity Algorithm[24] (PMCA), which classifies patients as having no chronic illness (NC – e.g. febrile seizure), non-complex chronic illness (NCC – e.g. epilepsy), or complex chronic illness (CC – e.g. epilepsy with chronic respiratory insufficiency), on the basis of up to 3 years of retrospective International Classification of Disease 9th Revision Clinical Modification (ICD-9) codes beginning with the date of admission. We used linear regression to evaluate the difference in mean scores between medical complexity categories. We adjusted for length of stay (LOS) and follow-up time (difference between discharge date and follow-up survey completion date) in our analysis because we hypothesized prolonged LOS ($\geq$ 3 days) or longer time to follow-up survey completion (4-8 weeks) may be associated with decreased or increased improvement scores, respectively. Cohen's *d* effect sizes were derived by comparing unadjusted means and standard deviations of each chronic condition group (NCC and CC) with the NC group.

Predictive validity was analyzed using admission scores as an independent predictor of risk for prolonged LOS, and both admission and improvement scores as independent predictors of risk for 30-day unplanned readmissions and/or return ED visits. We used modified Poisson regression models[25] to determine the risk of prolonged LOS, 30-day unplanned readmissions, and 30-day ED return visits associated with a 10-point decrement in admission score below established community-based population means for the PedsQL™.[17] We used similar models to determine the risk of 30-day unplanned readmissions or 30-day ED return visits associated with a 5-point decrement in improvement score below the study sample mean improvement score. This latter analysis was limited to participants who completed both an admission and

follow-up survey prior to their readmission/ED return visit (N = 25). Readmissions were coded as unplanned using the method developed by Berry et al.[26] All models were adjusted for patient gender, age, race/ethnicity, language, and level of medical complexity, and caregiver age and education.[13] We also adjusted for prolonged LOS in the analysis using improvement scores.

For all analyses, we used a single set of PedsQL™ admission or improvement scores for each caregiver-patient dyad computed by using patient scores if the patient was ≥ 13 years-old and completed the survey, otherwise caregiver scores were used.

Results:

Of the 19,139 patients discharged from the medical or surgical units from 10/1/11 – 12/31/13, 57% (N = 10,866) of families were eligible for study participation. The primary reasons for ineligibility were having a developmental delay (29%, 2,399/8,273) or participation in the study within the last two months (28%, 2,316/8,273). Thirty four percent (N = 3,682) of potentially eligible families were not approached primarily due to unavailability of research assistants during evening and weekend hours. The response rate for eligible families invited to complete the PedsQL™ on admission was 65% (4,637/7,184), and of these 58% completed a follow-up survey (2,694/4,637; 58% by telephone; 42% electronically). The range in time to follow-up survey completion was 2 to 8 weeks. The study sample was similar to the overall medical and surgical unit populations; however, study patients were older and healthier (**Table 1**). Only 1% of the study sample completed the survey in a language other than English or Spanish.

Sensitivity to Clinical Change:

The PedsQL™ demonstrated responsiveness to clinical change with significant improvement in PedsQL™ scores from admission to follow-up with large effect sizes reported by both caregivers and patients (**Table 2**). Improvement scores were highest on the Physical Health domain, and caregiver-patient dyads reported similar scores overall with patients

reporting slightly higher Psychosocial Health scores. The PedsQL™ also demonstrated moderate variability in responsiveness by age, and minimal variability for patients with medical v. surgical conditions (see **Table 6 & 7** for comparison values).

Construct Validity:

The PedsQL™ demonstrated construct validity among known groups differing by medical complexity (**Table 3**). Caregivers and patients in the NC group reported lower PedsQL™ admission scores and higher follow-up scores for all three summary scores, resulting in significantly higher Total, Physical and Psychosocial Health improvement scores than NCC or CC patients.

Predictive Validity:

In adjusted analyses, PedsQL™ Total, Physical and Psychosocial Health admission scores were associated with utilization outcomes (**Table 4**). A 10-point decrement in PedsQL™ Total admission score below the established community-based mean was associated with a 15% increase in risk for prolonged LOS, an 8% increase in risk for 30-day unplanned readmission, and a 13% increase in risk for 30-day ED return visit. A 10-point decrement in PedsQL™ Physical Health admission score below the established community-based mean was associated with a 10% increase in risk for prolonged LOS, a 5% increase in risk for 30-day unplanned readmission, and an 11% increase in risk for 30-day ED return visit. A 10-point decrement in PedsQL™ Psychosocial Health admission score below the established community-based mean was associated with a 12% increase in risk for prolonged LOS, a 9% increase in risk for 30-day unplanned readmission, and a 7% increase in risk for 30-day ED return visit.

Adjusted analyses also indicated that PedsQL™ Total, Physical and Psychosocial Health improvement scores were associated with utilization outcomes (**Table 5**). A 5-point

decrement in PedsQL™ Total improvement score below the study population mean was associated with an 11% increase in risk for 30-day unplanned readmission or ED return visit. A 5-point decrement in PedsQL™ Physical Health improvement score below the study population mean was associated with a 7% increase in risk for 30-day unplanned readmission or ED return visit. A 5-point decrement in PedsQL™ Psychosocial Health improvement score below the study population mean was associated with an 11% increase in risk for 30-day unplanned readmission or ED return visit.

Discussion

This study demonstrated that the PedsQL™ is responsive to clinical change in a unidirectional manner over relatively short periods of time for recently hospitalized pediatric patients. The findings also provide support for the instrument's construct and predictive validity in the pediatric inpatient setting. The PedsQL™ is brief and easy to complete, resulting in a reasonably high response rate for the current study, and support its use to assess the clinical effectiveness of quality improvement interventions in the pediatric inpatient setting.

To our knowledge, this is the first study to evaluate responsiveness of the PedsQL™ in a large diverse population of hospitalized pediatric patients. The magnitude of improvement in PedsQL™ scores in this study was larger than studies in the ambulatory literature measuring responsiveness of the PedsQL™ [18-22], and was significantly higher than the published MCID[13] demonstrating unidirectional responsiveness of the instrument in the pediatric inpatient setting. This is likely a reflection of the degree of decline in physical health perceived by caregivers of patients requiring hospitalization compared to patients managed in the ED or outpatient setting. For example, children and youth requiring hospitalization may not achieve activities of daily living such as maintain adequate oral intake or full ambulation resulting in admission scores that are lower than population means for ill children managed in the ED or ambulatory setting.[12,22]

Improvement in both caregiver and patient-reported PedsQL™ scores was highest for the physical health domain. This is not surprising as short-term inpatient treatment for medical and surgical patients is primarily targeted toward improving a patient's physical health. Those wishing to evaluate quality improvement (QI) interventions using HRQOL outcomes in this patient population should consider focusing on Physical Health improvement scores, as the Total score may blunt the ability to detect the effectiveness of inpatient treatment. Finally, adolescent patients reported higher admission and follow-up scores compared to their caregivers primarily on the Psychosocial Health domain. This is consistent with studies comparing patient-reported and observer-reported HRQOL assessments, which demonstrate caregivers may rate HRQOL more accurately on visible domains such as physical health versus less visible domains such as psychosocial health.[27] This finding provides additional evidence for the importance of obtaining child and adolescent self-report when possible for measures of HRQOL.[28,29]

Patients with non-complex or complex chronic conditions and their caregivers reported significantly lower improvements in HRQOL compared to those with no chronic conditions demonstrating construct validity of the PedsQL™ in the inpatient setting. We expect patients and caregivers of youth with no chronic illness to report lower scores on admission because the decline in physical health prompting inpatient treatment is perceived to be appreciably large relative to their healthy baseline functioning. In contrast, patients and caregivers of youth with complex chronic conditions may not perceive their physical health on admission to be remarkably lower relative to their baseline functioning. This is also supported by our finding that patients with complex chronic illness reported lower scores on follow-up suggesting they return to a lower baseline health status after hospitalization. This is consistent with studies in the ambulatory literature where children with chronic illness report lower baseline HRQOL compared to healthy children.[12-14,17]

Clinical effectiveness research in the pediatric inpatient setting has largely been limited to measuring morbidity, mortality and health care utilization outcomes, primarily related to specific clinical diseases.[30] However, as mortality and readmission are rare events in pediatrics, using these metrics to assess the quality of hospital care has recently been called into question.[26,31,32] In contrast, PROs such as the PedsQL™ may be routinely collected in a population of hospitalized children, and to our knowledge, this is the first study evaluating the predictive validity of the PedsQL™ in the inpatient setting in relation to utilization outcomes. Although the PedsQL™ is a subjective measure based on caregiver or patient perceptions, the findings of this study demonstrate that this measure is associated with more traditional, objective outcomes commonly used to measure the effectiveness of QI interventions. Evaluating QI interventions using all of these outcomes collectively may provide a more comprehensive assessment of the quality of hospital care that is relevant to multiple stakeholders.

The 2010 Patient Protection and Affordable Care Act (ACA) and the emergence of PCORI challenge health systems, providers and researchers to routinely measure outcomes to assist patients and families in making informed decisions that are consistent with their values, preferences and goals. Understanding improvement in HRQOL in pediatric patients during and after hospitalization provides an opportunity to incorporate patient-reported outcomes into comparative effectiveness research. For example, potential applications of the PedsQL™ in the inpatient setting include evaluating the impact of hospital-wide, QI initiatives such as clinical pathways to determine the best processes of care for hospitalized children. By systematically capturing these outcomes through an integrated clinical and research environment, the outcomes of structural and process improvements in clinical care can be measured from the patient and family's perspective.[33] Interventions can then be tailored to more adequately meet patient needs, and improve clinical outcomes relevant to patients and families.

Limitations

This study was conducted at a single-institution potentially limiting the generalizability of the results; however, they are likely comparable to other U.S. tertiary children's hospitals with large referral bases. The sampling design may have led to volunteer bias; however, respondents were largely representative of the overall hospital population. The study had low participation among adolescent patients, and although caregiver proxy-reported scores were similar to adolescent patient self-reports, directly measuring patient outcomes is preferred. We found the greatest improvement in Physical Health scores among study respondents, however we limited our analysis to medical and surgical patients only; and improvement in Psychosocial Health scores may play a more prominent role among patients in other patient populations such as psychiatry or oncology. Although the findings of this study represent gross associations that may be considered obvious, establishing the validity of this instrument was a necessary first step to incorporate HRQOL outcomes in the evaluation of inpatient health services.

Conclusions

The PedsQL^{TM} instrument demonstrates unidirectional responsiveness over relatively short periods of time, as well as construct and predictive validity in a population of recently hospitalized pediatric patients. Given these findings, this measure may be useful to assess the clinical effectiveness of hospital-based QI interventions from the patient and family-centered perspective.

Policy Implications

In regards to comparative effectiveness research, wide-spread validation of PRO measures such as the PedsQL^{TM} in the pediatric inpatient setting may provide national benchmarks to compare hospitals, and promote internal quality improvement strategies to meet these benchmarks. Assessing PROs through a standardized approach in the hospital setting is

consistent with the goals of the ACA which strives to ensure that the clinical effectiveness of health services – both for adults and children – is measured by outcomes relevant to patients and families.

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TABLE 1: Demographics of Respondents in comparison to Medical/Surgical Patients at Seattle Children's Hospital

	Respondents N=4,637	**Medical and Surgical Unit Populations** N=19,139
	N (%)	**N (%)**
Child Age*		
0-2 years	1330 (29)	6601 (34)
2-4 years	845 (18)	3237 (17)
5-12 years	1471 (32)	5303 (28)
13-18 years	991 (21)	3998 (21)
Child Gender		
Female	2172 (47)	8732 (46)
Child Race/Ethnicity*		
White	2613 (56)	9704 (51)
Black	220 (5)	1388 (7)
Hispanic	803 (17)	3316 (17)
Asian	273 (6)	1354 (7)

Other/Mixed	728 (16)	3377 (18)
PMCA Category*		
No chronic illness	1917(41)	5731 (30)
Non-complex chronic	1500 (32)	4430 (23)
Complex chronic	1215 (26)	8956 (47)
Caregiver Education		
< High school	445 (10)	Unavailable
High school graduate	753 (16)	Unavailable
Some college	1569 (34)	Unavailable
≥ Bachelor's degree	1854 (40)	Unavailable
Length of Stay		
< 3 days	3227 (70)	13465 (70)
≥ 3 days	1408 (30)	5674 (30)

*** p < 0.05**

TABLE 2: PedsQL™ Admission, Follow-up and Improvement Scores by Caregiver-Report and Patient-Report

	Caregiver (0-12[a])		Caregiver (13-18)[b]		Caregiver (13-18)[c]		Patient (13-18)[c]	
Total Score	**N**	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean (SD)**
Admission	3646	64.14 (22.12)	628	59.72 (22.41)	359	60.00 (22.36)	359	63.90 (20.28)
Follow-Up	2112	86.46 (14.95)	371	77.79 (19.06)	142	78.58 (17.95)	142	81.99 (17.86)
Improvement	2112	23.13 (22.73)	371	19.20 (22.85)	142	20.01 (19.99)	142	19.52 (21.14)
Effect Size[§]		1.02		0.84		1.00		0.92
Physical Health								
Admission	3629	56.72 (30.75)	624	45.49 (35.35)	357	49.44 (32.71)	357	51.73 (31.04)
Follow-Up	2113	85.85 (19.27)	371	70.89 (26.69)	142	75.16 (25.09)	142	77.30 (25.12)
Improvement	2107	30.10 (31.44)	370	27.04 (36.79)	142	30.31 (30.72)	142	29.76 (32.61)

Effect Size		0.96		0.73		0.99		0.91
Psychosocial Health								
Admission	3533	69.21 (21.07)	611	68.28 (19.78)	348	66.70 (20.84)	348	70.35 (18.83)
Follow-Up	2108	86.74 (14.78)	371	81.27 (17.92)	140	80.60 (17.53)	140	84.59 (16.68)
Improvement	2037	18.14 (21.23)	362	14.02 (19.75)	140	14.33 (18.80)	140	13.90 (19.11)
Effect Size		0.85		0.71		0.76		0.73

[a] Numbers in parenthesis represent patient age in years

[b] Only caregiver completed survey (no patient data available)

[c] Caregiver and patient both completed survey (paired data)

[§] Cohen's *d* effect sizes are designated as small (0.20), medium (0.50), and large (0.80)

PedsQL™ = Pediatric Quality of Life Inventory 4.0 Generic Core Scales

TABLE 3: PedsQL™ Admission, Follow-Up and Improvement Scores† by Level of Medical Complexity‡

	Non-Chronic (NC) N=1,112[a]	Non-complex Chronic (NCC) N=906	Complex Chronic (CC) N=676
Total Score	**Mean (95% CI)**	**Mean (95% CI)**	**Mean (95% CI)**
Admission	63.02 (61.48 – 64.57)	68.30 (66.69 – 69.91)***	66.69 (64.69 – 68.68)***
Follow-Up	86.98 (85.83 – 88.12)	85.40 (84.20 – 86.60)*	80.63 (79.13 – 82.13)***
Improvement	24.05 (22.44 – 25.66)	17.08 (15.40 – 18.77)***	13.66 (11.56 – 15.76)***
Effect size§		0.32	0.40
Physical Health			
Admission	53.88 (51.66 – 56.10)	63.57 (61.25 – 65.88)***	63.33 (60.47 – 66.20)***
Follow-Up	86.58 (85.04 – 88.12)	85.56 (83.95 – 87.17)	81.01 (79.01 – 83.02)***
Improvement	32.81 (30.52 – 35.10)	21.95 (19.55 – 24.34)***	17.20 (14.22 – 20.19)***
		0.35	0.43

Psychosocial Health			
Admission	69.18 (67.70 – 70.66)	71.26 (69.72 – 72.80)*	68.98 (67.07 – 70.89)
Follow-Up	87.13 (86.03 – 88.24)	85.25 (84.09 – 86.41)**	80.29 (78.84 – 81.73)***
Improvement	17.89 (16.36 – 19.42)	13.90 (12.31 – 15.49)***	11.18 (9.18 – 13.17)***
		0.20	0.22

***p* < .05, ****p* < .01, *****p* < .001: Difference in means using NC as referent group**

† Adjusted for time to follow-up survey completion (2-4 weeks versus 4-8 weeks after hospital discharge) and length of stay (< 3 days versus ≥ 3 days)

‡ Level of medical complexity was determined by the Pediatric Medical Complexity Algorithm[24]

§ Cohen's *d* effect sizes are designated as small (0.20), medium (0.50), and large (0.80). Effect sizes were derived by comparing unadjusted means and standard deviations of each chronic condition group (NCC and CC) with the NC group (referent group).

[a] N is based on sample size for total improvement score

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TABLE 4: Risk of Prolonged Length of Stay, 30-day Unplanned Readmission and 30-day ED Return Visits associated with a 10-point decrement in PedsQL™ Admission Score below Established Community-Based Mean Scores

Utilization Outcome	N	Crude RR	95% CI	Adjusted† RR	95% CI
LOS ≥ 3 days					
Total Score	4598	1.15***	1.13 – 1.17	1.15***	1.13 – 1.17
Physical Health	4577	1.09***	1.08 – 1.10	1.10***	1.09 – 1.12
Psychosocial Health	4470	1.13***	1.11 – 1.15	1.12***	1.10 – 1.14
30-day Readmission					
Total Score	4598	1.08**	1.02 – 1.13	1.08**	1.03 – 1.14
Physical Health	4577	1.03	0.99 – 1.06	1.05*	1.01 – 1.09
Psychosocial Health	4470	1.10***	1.05 – 1.16	1.09**	1.03 – 1.15
30-day ED Return Visit					

Total Score	4598	1.11**	1.05 – 1.18	1.13***	1.06 – 1.20
Physical Health	4577	1.08***	1.04 – 1.12	1.11***	1.06 – 1.17
Psychosocial Health	4470	1.07*	1.00 – 1.15	1.07*	1.00 – 1.15

*** p<0.05, ** p<0.01, *** p<0.001**

† Adjusted for patient gender, age, race, language, medical complexity (using the Pediatric Medical Complexity Algorithm[24]), and caregiver age and education.

RR = relative risk; LOS = length of stay; ED = emergency department

PedsQL™ = Pediatric Quality of Life Inventory 4.0 Generic Core Scales

TABLE 5: Risk of 30-day Unplanned Readmission or 30-day ED Return Visits associated with a 5-point decrement in PedsQL™ Improvement Score below Study Sample Mean Improvement Scores

30-day Readmission or ED return visit	N	Crude RR	95% CI	Adjusted† RR	95% CI
Total Score	2425	1.11*	1.02 – 1.22	1.11*	1.01 – 1.22
Physical Health	2422	1.08**	1.02 – 1.13	1.07*	1.00 – 1.14
Psychosocial Health	2348	1.10	0.99 – 1.23	1.11*	1.00 – 1.22

*** p<0.05, ** p<0.01, *** p<0.001**

† Adjusted for patient gender, age, race, language, medical complexity (using the Pediatric Medical Complexity Algorithm[24]), caregiver age and education, and length of stay.

RR = relative risk; ED = emergency department

PedsQL™ = Pediatric Quality of Life Inventory 4.0 Generic Core Scales

TABLE 6: PedsQL™ Admission, Follow-up and Improvement Scores by Age-Group

									Caregiver		Patient	
	Infant (0-1 months)		Toddler (2-4 years)		Young Child (5-7 years)		Child (8-12 years)		Adolescent (13-18 years)		Adolescent (13-18 years)	
Total Score	**N**	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean (SD)**
Admission	1330	64.24 (19.76)	845	67.04 (24.94)	409	63.09 (22.68)	1062	60.87 (21.90)	987	59.82 (22.38)	363	63.92 (20.18)
Follow-Up	788	87.17 (12.42)	491	90.42 (13.01)	241	87.71 (14.65)	592	81.74 (18.12)	581	77.92 (18.90)	152	81.55 (17.94)
Improvement	788	22.01 (20.51)	491	25.14 (25.13)	241	24.92 (22.85)	592	22.22 (23.31)	579	19.08 (22.15)	144	19.37 (21.30)
Effect Size[§]		1.07		1.00		1.09		0.95		0.86		0.91

Physical Health												
Admission	1328	64.60 (19.22)	844	60.78 (33.19)	405	48.37 (35.68)	1052	46.72 (34.73)	982	46.90 (34.45)	362	52.18 (31.10)
Follow-Up	789	87.93 (12.57)	491	91.34 (26.69)	242	85.96 (21.26)	591	78.47 (25.47)	581	72.78 (26.16)	152	76.51 (25.63)
Improvement	787	23.54 (21.12)	370	32.20 (33.25)	240	37.08 (37.18)	589	34.29 (36.91)	142	27.37 (34.89)	144	28.83 (33.58)
Effect Size		1.11		0.97		1.00		0.93		0.78		0.86
Psychosocial Health												
Admission	1306	65.67 (23.00)	802	72.85 (20.63)	398	72.38 (18.28)	1027	69.63 (19.07)	960	67.71 (20.17)	361	70.50 (18.97)
Follow-Up	785	86.62	490	89.83	241	88.69	592	83.54	581	80.72	152	84.25

		(14.46)		(12.98)		(13.26)		(16.47)		(18.15)		(16.49)
Improvement	772	20.98 (23.05)	462	18.43 (20.84)	233	17.24 (17.77)	570	14.42 (19.66)	566	13.88 (19.45)	143	13.83 (18.92)
Effect Size		0.91		0.88		0.97		0.73		0.71		0.73

[§] Cohen's *d* effect sizes are designated as small (0.20), medium (0.50), and large (0.80)

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TABLE 7: PedsQL™ Admission, Follow-up and Improvement Scores† by Medical & Surgical Units

	Medical		Surgical	
Total Score	**N**	**Mean (SD)**	**N**	**Mean (SD)**
Admission	2731	64.28 (21.37)	1906	62.44 (22.98)
Follow-Up	1651	85.74 (15.58)	1043	83.33 (17.02)
Improvement	1651	21.74 (21.69)	1053	22.70 (24.29)
Effect Size§		1.00		0.93
Physical Health				
Admission	2720	57.53 (28.82)	1896	50.47 (34.91)
Follow-Up	1652	85.77 (18.67)	1043	78.99 (25.00)
Improvement	1647	28.26 (29.48)	1041	31.11 (36.41)
Effect Size		0.96		0.85

Psychosocial Health				
Admission	2669	68.37 (20.71)	1837	70.38 (20.72)
Follow-Up	1647	85.71 (15.85)	1043	85.60 (15.33)
Improvement	1611	17.54 (20.82)	998	16.34 (21.23)
Effect Size		0.84		0.77

[†] Score was composed of self-report patient data if available and patient is > 13 years old, otherwise caregiver data was used

[§] Cohen's *d* effect sizes are designated as small (0.20), medium (0.50), and large (0.80)

PedsQL™ = Pediatric Quality of Life Inventory 4.0 Generic Core Scales