Components of Health-Related Quality of Life Most Affected Following Pediatric Critical Illness

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OBJECTIVES: To evaluate which individual elements of health-related quality of life contribute most to decline in overall health-related quality of life status following pediatric critical care.

DESIGN: Retrospective cohort study.

SETTING: Seattle Children's Hospital.

PATIENTS: ICU patients age 1 month to 18 years admitted between December 2011 and February 2017.

INTERVENTIONS: None.

MEASUREMENTS AND MAIN RESULTS: We assessed health-relatedquality of life decline from baseline to postdischarge (median, 6 wk) and determined the individual items of the Pediatric Quality of Life Inventory Infant Scales (< 2 yr) and Generic Core Scales (2–18 yr) with the highest prevalence of decline. We used multivariable regression to estimate the risk of decline in each of seven thematic categories by patient age, baseline health status, diagnosis, Pediatric Risk of Mortality score, and ICU length of stay. Decline from baseline health-related quality of life occurred in 22.5% of 539 patients. Items most commonly affected for infants less than 2 years were primarily emotional (cranky/crying, sleep, and self-soothing). Children 2–18 years most commonly experienced declines in physical functioning (play/exercise, lifting, and pain). Across the entire cohort, declines in categories of energy (31.5%), activity (31.0%), sleep (28.0%), and fear (24.7%) were most commonly endorsed. Risk of decline in each category varied with patient age, medical complexity, and diagnosis.

CONCLUSIONS: Deconditioning, sleep, fear, and pain are important targets for intervention to improve health-related quality of life outcomes for critically ill children.

KEY WORDS: follow-up studies; health-related quality of life; intensive care units; outcome assessment; pediatric

Many children who survive critical illness struggle to regain their prehospitalization health status and experience persistent physical, social, psychologic, and cognitive declines (1–4). Measures of health-related quality of life (HRQL) quantify the impact of health status on physical, mental, emotional, and social functioning (5, 6). HRQL is increasingly used as a global measure of health outcomes in PICU populations (7, 8) and has been identified by families and providers as the most important outcome to assess among PICU survivors (9). Up to one-third of PICU survivors experience impairments in HRQL based on parent proxy-assessment (5, 10–21).

As HRQL is inherently a comprehensive measure that incorporates many facets of a child's functioning and well-being, it is a valuable measure of overall health outcomes. Because HRQL measures incorporate many different areas of functioning, however, identifying changes in overall HRQL does not offer

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specific insight into how declines can be minimized and recovery optimized. No studies have evaluated which of the individual components that comprise comprehensive HRQL measures contribute most to overall score declines following critical care.

Identification of the specific elements of HRQL most commonly affected by an ICU stay may aid in the development of interventions targeted to those areas to improve long-term outcomes among critically ill children. We thus aimed to evaluate deterioration between baseline and postdischarge HRQL status in the individual components of a common HRQL measure in pediatric survivors of critical illness and to explore how patient and illness characteristics were associated with the most commonly affected components.

METHODS

Study Design and Participants

This was a retrospective cohort study among patients 1 month to 18 years admitted to the Seattle Children's Hospital (SCH) PICU and cardiac ICU who had been enrolled in the SCH Outcomes Assessment Program (OAP), a quality improvement program conducted between December 1, 2011, and February 05, 2017, to collect HRQL data on a sample of SCH inpatients. The OAP collected complete baseline and follow-up assessments on 736 ICU patients. See **eText 1** (http://links.lww.com/CCM/G698) for details of the OAP and inclusion/exclusion criteria. The study was approved by the SCH Institutional Review Board (STUDY00001153).

HRQL Instruments

HRQL was measured using the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales (22) and the PedsQL Infant Scales (Mapi Research Trust, Lyon, France) (23). Children with preexisting severe developmental or functional disabilities were assessed using the Functional Status II-Revised (24) and were not included in this analysis (*n* = 197).

The PedsQL measures HRQL in patients less than or equal to 18 years, with different versions by patient age. All versions are available for parent proxy-report. The Generic Core Scales for patients greater than or equal to 2 years consist of 23 items assessing physical, emotional, social, and school functioning with comparable content across age-based versions. The Infant Scales for patients less than 2 years consist of 36 items for infants 0–12 months and 45 items for children 13–24 months assessing physical symptoms and physical, emotional, social, and cognitive functioning, with 36 items common across the two versions (23, 25).

The PedsQL has demonstrated reliability and consistency of parent proxy-reporting across all ages (26). Multiple studies have established the use of recall to determine patients' baseline HRQL status (27–29). The PedsQL has been frequently used in the PICU setting (7, 8) and demonstrates responsiveness to changes in patients' clinical status during and after PICU admission (19).

HRQL Collection

Within 72 hours of admission, parents/guardians scored their child's HRQL for the month prior to admission, excluding the current illness, to estimate baseline HRQL. Families were contacted electronically or via telephone 4–6 weeks following hospital discharge to complete a follow-up survey. OAP staff attempted to contact families for up to 8 weeks following the initial attempt. Fewer than 5% of patients completed an admission self-report due to young age, neurocognitive status, illness severity, and/or presence of sedating medications, and thus, child self-report data were excluded from this analysis.

HRQL Scoring

Respondents were asked to report how frequently the child experienced problems for each item in the month prior for the baseline assessment and in the 7 days prior for the follow-up assessment. Each item is scored from 0 ("never") to 4 ("almost always"). The total score ranges from 0 to 100, with higher scores indicating better HRQL. A decrease of greater than or equal to 4.5 points between scores on the PedsQL is considered the minimal clinically important difference that patients would perceive to be detrimental (25).

Exposures

We queried the OAP database for patient age, sex, race/ethnicity, language, parent age and education, and Pediatric Medical Complexity Algorithm (PMCA) category (30), and the local Virtual Pediatric Systems (VPS) (31) database for baseline Pediatric Overall

Performance Category (POPC) and Pediatric Cerebral Performance Category (PCPC) scores (32), primary admitting diagnosis, Pediatric Risk of Mortality-III (PRISM) score (33), and ICU and hospital length of stay (LOS) as recorded by VPS registrars. PMCA classifies baseline comorbidity status by categorizing patients as having no chronic illness, noncomplex chronic illness (single-organ system, e.g., asthma or diabetes), or complex chronic illness (progressive or affecting multiple organ systems, e.g., cancer). POPC and PCPC scores classify patients' degree of overall and cognitive disabilities, respectively, ranging from 1 (normal) to 6 (death).

Outcomes

Overall HRQL decline was defined as a decrease of greater than or equal to 4.5 points on the total PedsQL score from baseline to follow-up. For the individual PedsQL items that are on a 5-point scale, we assessed for decline in score by both greater than or equal to 1 point (any change) and by greater than or equal to 2 points (substantial change) from baseline to follow-up. To compare items across survey versions, we grouped items common to both the Infant Scales and the Generic Core Scales into seven thematic categories (activity, sleep, energy, pain, fear, anger, and sadness) that appeared in all six age-based PedsQL versions (**eTable 1**, http://links.lww.com/CCM/G698). Items not represented across all six versions were not grouped into categories (e.g., questions about school).

Statistical Analyses

We determined the percentage of patients who declined by greater than or equal to 4.5 points from their baseline HRQL status at follow-up and the percentage of patients with decline for each survey item. Among patients who declined by greater than or equal to 1 point and greater than or equal to 2 points for each item, we calculated the mean total PedsQL score change and the percentage with overall decline by greater than or equal to 4.5 points. We used chi-square tests to compare the proportion of patients with any decline from baseline to follow-up within each of the seven thematic categories across strata of patient age, PMCA category, diagnosis category, PRISM score, and ICU LOS. We estimated the risk of any decline in each thematic category using multivariable generalized linear Poisson regression with robust standard errors adjusted for time to follow-up. We conducted all analyses using Stata/SE 14.2 (StataCorp LP, College Station, TX).

RESULTS

Population Characteristics

The study cohort included 539 patients, of whom nearly half had complex chronic conditions (**eTable 2**, http://links.lww.com/CCM/G698). Study patients were slightly younger and more commonly had normal baseline POPC and PCPC scores than nonstudy ICU survivors, and were more likely to be admitted postoperatively. PRISM scores and ICU LOS were slightly lower among study patients. Median time to follow-up was 42.4 days after hospital discharge (interquartile range, 31.5–57.6).

Decline by greater than or equal to 4.5 points from baseline HRQL at follow-up occurred in 22.5% of patients (*n* = 121). Patients with HRQL decline had a median baseline score of 90.3 (79.3–96.7) and a median follow-up score of 74.1 (58.1–84.0), representing a median decline of nearly four times the minimal clinically important difference.

Survey Items Associated With Overall HRQL Decline

Among patients less than 2 years with overall clinically important HRQL decline, the individual items most commonly affected were emotional domain items including 1) feeling cranky (75.0% of patients with decline), 2) difficulty self-soothing (67.5%), 3) difficulty falling asleep (65.0%), 4) difficulty sleeping at night (62.5%), and 5) crying a lot (53.9%) (**Fig. 1**). Among all patients less than 2 years in the cohort, item declines were most common for crying or fussing when left alone (28.1%) and difficulty sleeping at night (25.3%) (**eFig. 1**, http://links.lww.com/CCM/G698).

Among patients greater than or equal to 2 years with overall clinically important HRQL decline, patients most commonly experienced declines in physical functioning including problems with: 1) participating in active play or exercise (67.1%), 2) lifting something heavy (64.5%), 3) hurting or aching (55.8%), 4) running (55.6%), and 5) being unable to do things other children their age can do (55.4%). Emotional domain items of feeling sad or blue (50.7%), worrying (48.1%),

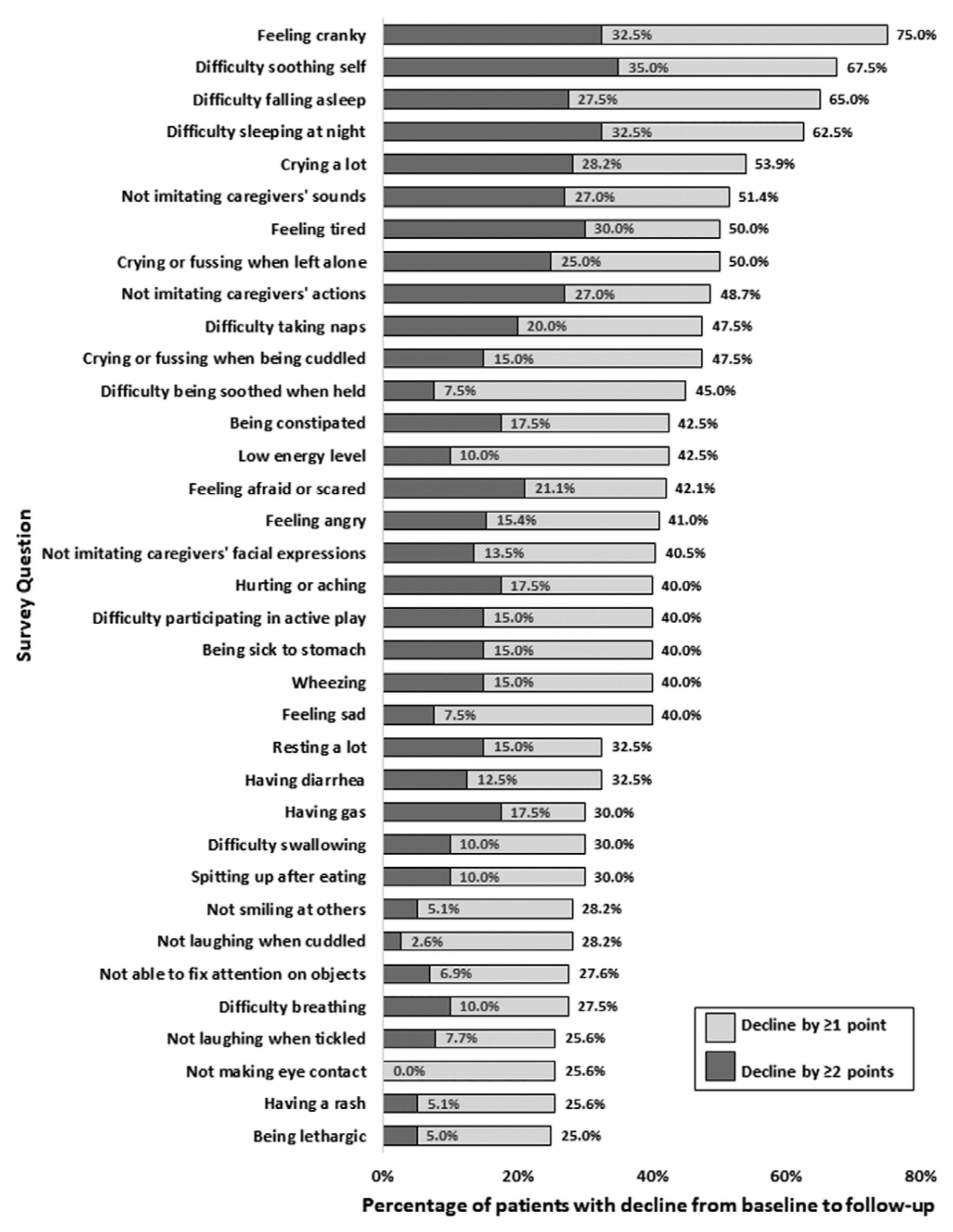

Figure 1. Percentage of patients with clinically important decline (≥ 4.5 points) on the Pediatric Quality of Life Inventory Infant Scales (< 2 yr old) with decline from baseline to follow-up in each survey item.

and feeling angry (46.1%) were also commonly affected (**Fig. 2**). Among all patients greater than or equal to 2 years in the cohort, item declines were most common for participating in active play or exercise (26.8%) and hurting or aching (26.1%) (**eFig. 2**, http://links.lww.com/CCM/G698).

Overall HRQL Decline by Individual Items

Patients less than 2 years with a decline by greater than or equal to 1 point in "laughing when tickled" experienced the greatest mean decline in total PedsQL score (−13.3 points), with 71.4% experiencing a clinically important decline in overall HRQL (**eTable 3**, http://links.lww.com/CCM/G698). For item decline by greater than or equal to 2 points, "laughing when cuddled" was associated with the greatest mean PedsQL score change of −16.6 points, and "imitating caregivers' sounds" was associated with the largest proportion of patients with clinically important decline in overall HRQL (90.9%).

Patients greater than or equal to 2 years with a decline by greater than or equal to 1 point in walking ability experienced the greatest mean decline in total PedsQL score (−17.5 points), with 87.1% experiencing a clinically important decline in overall HRQL (**Table 1**). For item decline by greater than or equal to 2 points, "feeling sad or blue" was associated with the greatest mean PedsQL score change of −25.2 points with 90.9% experiencing a clinically important decline in total score.

Decline by Thematic Category

We grouped items common to both the Infant Scales and Generic Core Scales into seven categories (eTable 1, http://links.lww.com/CCM/G698). Across the entire cohort, worsening energy was most commonly endorsed (31.5%), followed by worsening activity (31.0%), sleep (28.0%), fear (24.7%), pain (21.3%), anger (19.7%), and sadness (16.3%). Worsening activity and pain were most common in older age groups, whereas worsening sleep was most common among infants and worsening fear and anger were

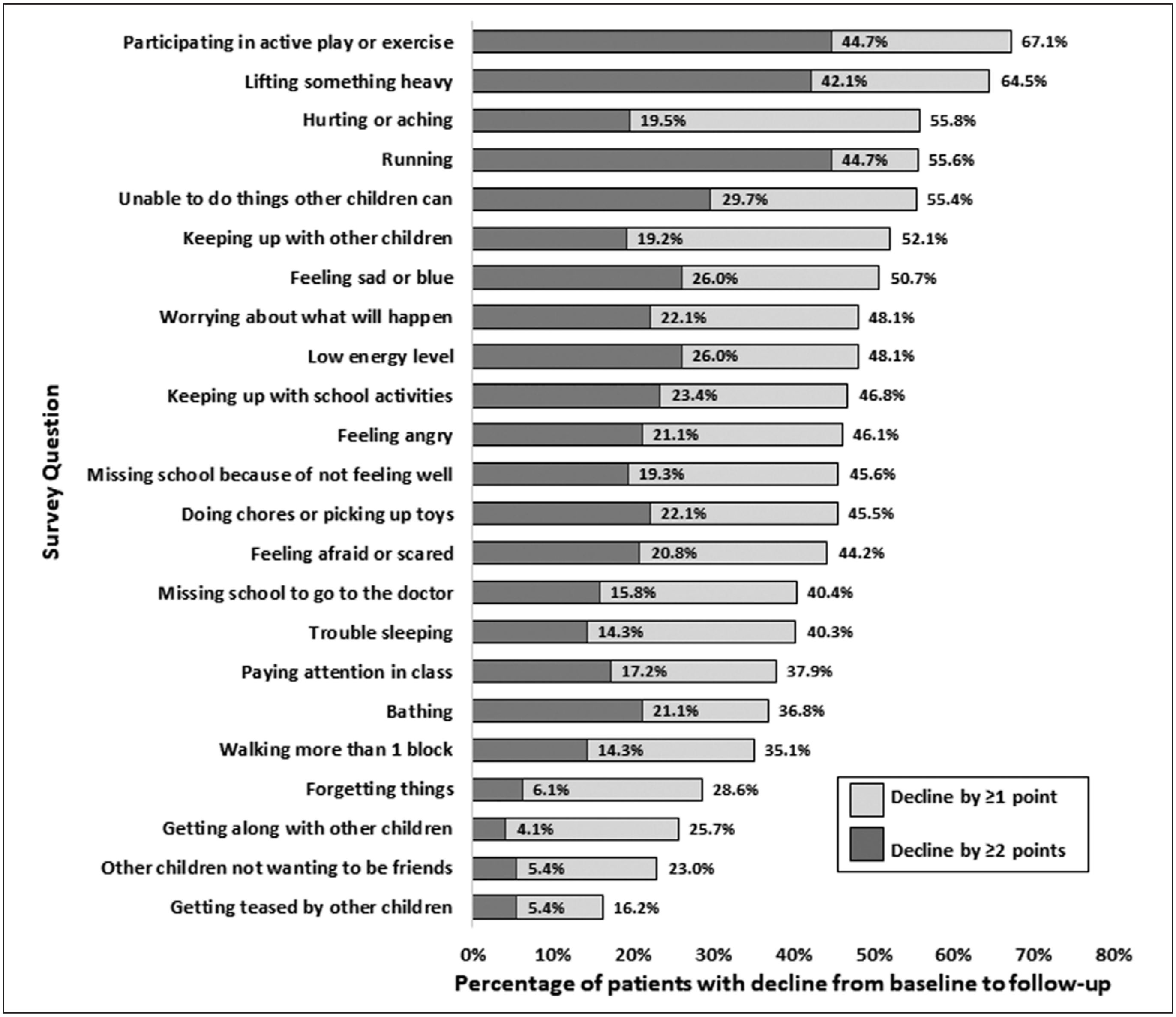

Figure 2. Percentage of patients with clinically important decline (≥ 4.5 points) on the Pediatric Quality of Life Inventory Generic Core Scales (2–18 yr old) with decline from baseline to follow-up in each survey item.

most common among 1–4-year olds (**Fig. 3**). When stratified by baseline medical complexity, patients with complex chronic disease more commonly experienced declines in activity after hospitalization, whereas patients without chronic disease more commonly experienced worsening fear. Minimal variation was observed when stratified by diagnosis category, PRISM score, or ICU LOS (**eFig. 3**, http://links.lww.com/CCM/G698).

On multivariable analyses, all age groups were associated with greater risk of activity decline relative to infants, with the greatest risk for patients' ages 5–12 and 13–18 years; shorter time to follow-up was also associated with activity decline (**Table 2**). Younger age was the only factor associated with worsening sleep. Older age and shorter time to follow-up were associated with greater risk of worsening pain. Worsening fear was associated with the largest number of risk factors on multivariable analysis, with highest risk among patients ages 1–4 years, those without chronic health conditions, those undergoing cardiac surgery, and those with shorter time to follow-up. The only identified risk factor for worsening anger was age 1–4 years, whereas risk of sadness was greatest among patients age 5–12 years and those with longer hospital stays.

TABLE 1.

Decline in Overall Pediatric Quality of Life Inventory Score Among Patients With Decline in Each Individual Pediatric Quality of Life Inventory Generic Core Scales Item

PedsQL Generic Core Scales Item	Mean Overall PedsQL Score Change (Proportion With Decline by ≥ 4.5 Points), *n* (%): Item Decline by ≥ 1 Point	Mean Overall PedsQL Score Change (Proportion With Decline by ≥ 4.5 Points), *n* (%): Item Decline by ≥ 2 Points
Walking more than one block	−17.5 (87.1)	−19.4 (78.6)
Running	−16.8 (80.0)	−22.1 (89.5)
Doing chores or picking up toys	−14.4 (71.4)	−15.8 (70.8)
Bathing	−14.3 (79.6)	−16.0 (80.0)
Paying attention in class	−12.6 (66.7)	−14.4 (71.4)
Low energy level	−12.4 (57.8)	−22.6 (80.0)
Getting along with other children	−12.1 (63.3)	−10.4 (60.0)
Feeling sad or blue	−11.9 (66.1)	−25.2 (90.9)
Participating in active play or exercise	−11.7 (67.1)	−15.5 (70.8)
Keeping up with school activities	−11.3 (61.1)	−15.6 (73.3)
Missing school to go to the doctor	−10.4 (63.9)	−18.1 (75.0)
Lifting something heavy	−9.7 (67.1)	−14.8 (78.1)
Worrying about what will happen	−9.6 (64.9)	−15.7 (77.3)
Keeping up with other children	−9.6 (61.3)	−17.5 (73.7)
Feeling afraid or scared	−9.3 (61.8)	−16.5 (72.7)
Unable to do things other children can	−9.2 (59.4)	−14.5 (68.8)
Hurting or aching	−9.1 (57.3)	−13.3 (65.2)
Missing school because of not feeling well	−8.6 (60.5)	−14.9 (64.7)
Forgetting things	−8.3 (56.0)	−16.6 (50.0)
Feeling angry	−8.2 (51.5)	−14.7 (64.0)
Trouble sleeping	−8.0 (53.5)	−11.3 (52.4)
Other children not wanting to be friends	−7.4 (65.4)	−4.6 (57.1)
Getting teased by other children	−4.6 (52.2)	−4.6 (57.1)

PedsQL = Pediatric Quality of Life Inventory.

DISCUSSION

In this 5-year cohort study of 539 critically ill children, we, for the first time, disaggregated a common HRQL measure into the individual items to identify and quantify how specific PedsQL score components contribute to declines in children's overall HRQL status after intensive care. Despite relatively low illness severity and short ICU LOS, nearly one-quarter of patients experienced a clinically important decline in HRQL from their preadmission baseline to postdischarge follow-up with a median decline nearly four times the minimal clinically important difference. Among patients with overall HRQL decline, young children most commonly experienced deterioration in emotional functioning, whereas older children and teens were most commonly affected by declines in physical functioning. Across all patients, declines were most common in energy and physical activity.

Our evaluation offers important insights into the domains of HRQL most affected across different age groups, baseline health statuses, and diagnoses. Although one of the advantages of using HRQL to measure health outcomes is that it is a comprehensive

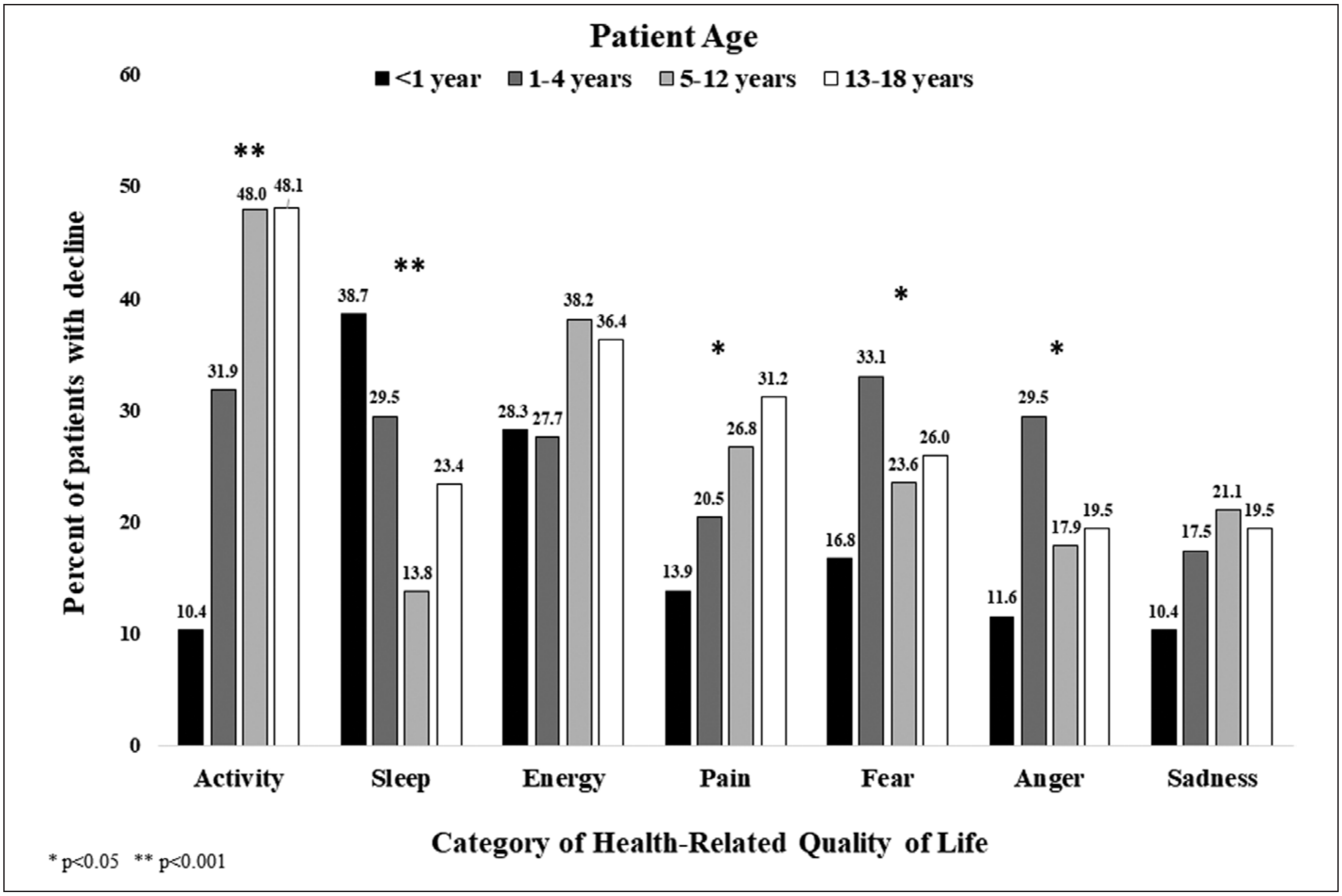

Figure 3. Percentage of all patients with decline from baseline to follow-up in each of seven thematic categories of Pediatric Quality of Life Inventory items, stratified by age group.

measure that incorporates many elements of a patient's physical and psychosocial function, improved understanding of the specific drivers of HRQL changes in different patient populations is crucial to support the development of targeted interventions to optimize patient recovery after critical illness.

Importantly, patients with medical diagnoses as well as surgical patients experienced high prevalence of physical impairment after discharge. Although acute loss of skeletal muscle mass is common among adult survivors of critical illness and contributes to ongoing physical disability, critical illness myopathy is rare in children, and much less attention has been paid to physical recovery in children (34, 35). Early and more aggressive physical therapy in the ICU may address both surgical and nonsurgical mechanisms of persistent physical impairment by reducing ICU-acquired weakness and other musculoskeletal complications (36, 37) while also optimizing recovery from surgery. Early mobilization programs are feasible to implement in PICU settings (38), although not commonly employed (39); larger scale studies are evaluating the impact of such programs.

Pain was among the most commonly reported problems among older children and was frequently experienced by patients with medical as well as surgical diagnoses. Pain may also be underrecognized in infants; although pain was not commonly reported to be a problem, infants had high frequency of worsening fussiness, crankiness, difficulty soothing, and crying, which could be manifestations of pain in this age group. Previous studies demonstrated that patients with prolonged pain or agitation while in the ICU had higher rates of adverse postdischarge outcomes (20), and ongoing pain after discharge may have a similar effect.

Sleep disturbances were common across all ages and diagnosis categories. Although sleep is known to be severely disturbed in the hospital, postdischarge sleep quality has not been well described. Other emotional symptoms, including difficulties with self-soothing and fussiness in infants and anger and sadness in older children, were also common. It is possible that sleep

TABLE 2.

Multivariable Analyses of Associations Between Risk Factors and Declines in Each of Seven Thematic Categories on the Pediatric Quality of Life Inventory

Patient Characteristic	Thematic Category Adjusted Relative Risk (95% CI)						
	Activity	**Sleep**	**Energy**	**Pain**	**Fear**	**Anger**	**Sadness**
Age group							
< 1 yr	Ref	Ref	Ref	Ref	Ref	Ref	Ref
1–4 yr	**3.04** **(1.85–5.01)**	0.74 (0.55–1.01)	0.94 (0.66–1.33)	1.37 (0.85–2.23)	**2.12** **(1.43–3.14)**	**2.47** **(1.54–3.97)**	1.67 (0.95–2.94)
5–12 yr	**4.61** **(2.83–7.50)**	**0.35** **(0.21–0.58)**	1.35 (0.96–1.89)	**1.90** **(1.17–3.08)**	**1.61** **(1.01–2.56)**	1.51 (0.86–2.66)	**2.12** **(1.17–3.83)**
13–18 yr	**4.13** **(2.47–6.92)**	**0.59** **(0.37–0.95)**	1.22 (0.82–1.80)	**2.05** **(1.20–3.48)**	**1.69** **(1.01–2.82)**	1.64 (0.86–3.11)	1.80 (0.95–3.43)
Pediatric Medical Complexity Algorithm category							
Complex chronic	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Noncomplex chronic	0.79 (0.58–1.06)	0.97 (0.71–1.33)	0.93 (0.69–1.24)	0.75 (0.51–1.12)	1.23 (0.86–1.75)	1.04 (0.70–1.54)	1.01 (0.63–1.60)
Nonchronic	0.87 (0.57–1.32)	1.14 (0.75–1.73)	0.79 (0.52–1.20)	0.93 (0.56–1.53)	**2.03** **(1.34–3.06)**	0.95 (0.54–1.68)	1.05 (0.58–1.92)
Diagnosis category							
Medical	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Scheduled surgical	1.26 (0.92–1.70)	1.01 (0.72–1.42)	0.88 (0.65–1.20)	0.81 (0.54–1.22)	1.28 (0.84–1.95)	0.89 (0.56–1.41)	0.93 (0.56–1.56)
Acute surgical	0.77 (0.36–1.65)	0.84 (0.38–1.83)	0.75 (0.37–1.54)	0.76 (0.35–1.65)	1.32 (0.70–2.46)	1.19 (0.56–2.54)	1.43 (0.63–3.21)
Cardiac surgery	1.21 (0.85–1.73)	1.23 (0.85–1.79)	0.79 (0.54–1.15)	0.71 (0.43–1.17)	**1.92** **(1.30–2.83)**	0.83 (0.51–1.36)	0.83 (0.45–1.51)
Pediatric Risk of Mortality III score	1.01 (0.98–1.04)	1.01 (0.98–1.05)	1.01 (0.97–1.04)	1.01 (0.97–1.05)	1.01 (0.97–1.05)	1.01 (0.97–1.06)	1.02 (0.97–1.07)
ICU length of stay (d)	1.01 (0.97–1.04)	0.98 (0.95–1.02)	1.01 (0.98–1.04)	0.99 (0.94–1.04)	1.02 (0.99–1.05)	1.00 (0.95–1.06)	**1.02** **(1.00–1.05)**
Time to follow-up (wk)	**0.93** **(0.89–0.98)**	0.98 (0.92–1.03)	0.95 (0.90–1.00)	**0.92** **(0.86–0.99)**	**0.93** **(0.88–0.99)**	0.99 (0.93–1.06)	0.94 (0.87–1.02)

Ref = reference category.

Boldface values indicate coefficients demonstrating a statistically significant association.

disturbances either contributed to greater emotional lability in patients or that difficulty with sleep was a manifestation of emotional and psychiatric sequelae of the ICU stay. Previous literature demonstrated that nearly one-third of children surviving critical illness report delusional memories, which are associated with an increased risk of post-traumatic stress disorder (40). Interventions that improve sleep quality may reduce cognitive and psychiatric sequelae of ICU care (41, 42).

Fear was another domain that was commonly experienced across different age groups and diagnoses. Children who are younger, more severely ill, and who experience more invasive procedures have more medical fear and post-traumatic stress (43). Fear was especially common among patients in our cohort admitted for cardiac surgery, supporting the possibility that fear may be associated with exposure to invasive procedures. Patients without chronic illness were also more likely to feel afraid relative to patients with complex chronic conditions, which may be due to these patients having less familiarity with healthcare settings.

There were several limitations to this study. This was a single-center study in a large academic center, which may limit generalizability to other settings. Only a sample of SCH ICU patients was enrolled in the OAP as this was a hospital-funded, pilot quality improvement effort without the resources to enroll larger numbers of patients. This is also reflected in a low follow-up response rate; poor follow-up has also been a challenge in other post-PICU studies (21) and warrants reconsideration of optimal practices for maximizing retention (44). Our cohort had relatively low illness severity and short LOS and were not fully representative of the general population of ICU patients, in part reflecting that patients with severe developmental or functional disabilities were not assessed using the PedsQL. This also limited our ability to compare outcomes across the range of PRISM score and LOS.

Assessment of patients' baseline HRQL status was based on parent recall, which is inherently subject to bias. The direction of recall bias in this situation is unknown and likely variable; some families may recall their child to have had better prior HRQL than they actually did (45), whereas others may recall their child's baseline status as worse than it actually was. Although studies have demonstrated validity of the PedsQL for evaluating baseline HRQL based on recall (27–29), this has not been prospectively studied. As is commonly the case for PICU populations (8), HRQL was assessed based on parent proxy-report rather than child self-report; future work should emphasize collection of follow-up data from PICU survivors even if baseline self-report data are not available to provide better comparison with parent proxy-reports. Finally, follow-up was relatively short term.

CONCLUSIONS

By assessing how each specific item of a HRQL measure changes from baseline to postdischarge follow-up among critically ill children, this study provides the first description of how the individual components of HRQL contribute to overall declines, thus identifying the most important targets for interventions. Physical impairments, persistent pain, poor sleep, and ongoing fear were the most commonly affected items on the PedsQL, even among children with low illness severity and short ICU stays. Minimizing deconditioning, adequately managing pain, improving sleep quality, and addressing fear while in the ICU and after discharge should be prioritized in research, clinical, and quality improvement efforts to help optimize HRQL recovery for all children experiencing ICU care.

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