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## Predicting healthcare utilization for children with respiratory insufficiency using parent-proxy ratings of children's health-related quality of life

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### Abstract

**Introduction**—Children with chronic respiratory insufficiency and mechanical ventilation often experience acute illnesses requiring unscheduled hospitalizations. Health-related quality of life (HRQL) may predict future healthcare utilization.

**Methods**—Participants were 30 days–22 years old with chronic respiratory insufficiency (n=120). Parent-proxies completed global HRQL and general health measures. Outcomes were total healthcare (emergency department, outpatient, inpatient) and inpatient days over six months. Adjusted negative binomial regression estimated the effects of global HRQL and general health on utilization.

**Results**—Three-quarters of children had any utilization; 32% had hospitalizations. Children with poor/fair global HRQL had 3.7 times more healthcare days than very good/excellent global

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HRQL. Children with poor/fair global HRQL had 6.3 times more inpatient days than very good/excellent global HRQL. Similar relationships existed between general health and utilization.

**Discussion**—HRQL was associated with healthcare and inpatient days. Clinical teams can use HRQL as a marker for utilization risk, enabling potentially earlier intervention, better outcomes, and lower costs.

### Keywords

Health-related quality of life; healthcare utilization; pediatrics; chronic respiratory insufficiency

Chronic respiratory insufficiency and need for intermittent or continuous mechanical ventilation can occur in association with a variety of pediatric medical conditions, including intrinsic lung disease, neuromuscular disorders (e.g., muscular dystrophy, spinal muscular atrophy [SMA]), skeletal dysplasias, and spinal cord injury. Recent technological innovations allow many children with these conditions to receive home-based care in their communities (Sterni et al., 2016). Despite this shift to home-based care, including mechanical ventilation, children requiring technology assistance are significantly more likely to develop a severe acute illness resulting in unscheduled and costly hospitalizations with care delivered in the intensive care unit (ICU) (Dosa, Boeing, & Kanter, 2001; Edwards, Rivanis, Kun, Caughey, & Keens, 2011). Identifying patients at risk for acute clinical events, and associated healthcare utilization, would help to optimize health outcomes, reduce costs, and improve the child's and family's care experience, aligning with national calls for the "triple aim" of healthcare improvement efforts (Berwick, Nolan, & Whittington, 2008).

Health-related quality of life (HRQL) assessments provide valuable information about clinical outcomes and healthcare quality. In addition, prior studies have demonstrated HRQL can serve as a predictor of future outcomes, such as prognosis and survival (Coates et al., 2000; Eton et al., 2003; Gotay, Kawamoto, Bottomley, & Efficace, 2008; Kaplan et al., 2007; Kephart & Asada, 2009; Lima & Kopec, 2005; Parkerson Jr, Harrell Jr, Hammond, & Wang, 2001; Ryan et al., 2013; Seid, Varni, Segall, & Kurtin, 2004; Terrin, Rodday, & Parsons, 2015; Wherry, Burns, & Leininger, 2014). Limited studies have shown that HRQL scores also predict healthcare utilization (Kephart & Asada, 2009; Lima & Kopec, 2005; Parkerson et al., 2001; Ryan et al., 2013; Seid et al., 2004; Wherry, et al., 2014); even fewer studies have focused on pediatric populations. A study of 317 children aged 2–18 years enrolled in a Medicaid managed care plan found that parent-proxy reported HRQL explained more variation in healthcare costs after 6, 12, and 24 months than chronic condition status alone (Seid et al., 2004). Furthermore, these investigators identified a high-risk group of children with increased healthcare cost by combining information from HRQL and chronic condition status, suggesting that these children would be candidates for additional care coordination. A study of children with inflammatory bowel disease found that child and parent-proxy reported HRQL predicted the number of disease-related hospital admissions, gastroenterology clinic visits, ED visits, psychology clinic visits, phone contacts, and pain management referrals over the next 12 months, controlling for demographic and disease parameters (Ryan et al., 2013). These findings imply that clinical factors alone do not fully explain healthcare utilization and that HRQL assessments add nuances to the patient

experience that provide differentiation beyond clinical factors. Therefore, HRQL assessment may help predict clinical events and healthcare utilization and serve as a marker to intervene and preempt high-cost acute care.

The objective of the current study was to determine whether brief parent-proxy reports of their child's HRQL were associated with future healthcare utilization in a population of children with chronic respiratory insufficiency. The secondary objective was to understand if parent-proxy report of their child's HRQL provided additional information above and beyond physician-rated clinical severity in predicting healthcare utilization. This cohort of children is at high risk for urgent and unplanned healthcare utilization, making it a highly relevant group in which to examine potentially avoidable high-cost healthcare utilization.

## Method

### Sample Selection

Data come from a longitudinal HRQL study of families of patients receiving care through the Critical Care, Anesthesia, Perioperative Extension (CAPE) and Home Ventilation Program at Boston Children's Hospital, previously described (Graham, Rodday, & Parsons, 2014). Briefly, the CAPE Program provides integrated, home-based care to pediatric patients with chronic respiratory insufficiency. Eligible participants were receiving ongoing care from the CAPE Program, not living in a residential facility, and aged 30 days to 22 years, representing the full range of age eligibility in the clinical program. Parent caregivers were 18 years old, actively participating in their child's care, and able to complete measures in English or Spanish. In families with more than one eligible child, parents only participated on behalf of one. Of the 196 patients eligible between February 2012 and March 2013, 140 (71%) were enrolled in the HRQL study. This study received human subjects' approval from the Institutional Review Boards at Boston Children's Hospital and Tufts Medical Center; participating parents provided informed consent.

### Measures

**Child Health Ratings Inventories (CHRIs)**—The CHRIs (Parsons et al., 2006; Parsons et al., 2005; Rodday, Terrin, & Parsons, 2013), a validated and reliable HRQL instrument with child and parent versions, was used to collect parent-proxy report of the child's HRQL. Parent-proxy report was used because of developmental, cognitive, and functional limitations of many children in this sample. The current analysis included parent-proxy reports of both the 5-item child global HRQL scale and a single item on the child's general health. The global HRQL contains items on physical health, mental health, family life, free time or fun, and life enjoyment (Rodday et al., 2013). The general health item asks the parent about how the child's overall health, which has been used extensively in clinical practice and research (Bowling, 2005). Items were scored from 1–5; scale scores were transformed to 0–100, where higher scores indicate higher HRQL or better health. The global HRQL and general health scores were both categorized into three levels based on the distribution of responses in this sample and to ease interpretability: <50 points (poor/fair), 50 to <75 points (good), and ≥75 points (very good/excellent).

While parents completed measures about their child's HRQL every six months for up to 18 months depending on enrollment date into the HRQL study, this analysis focused on HRQL assessments collected at study entry only. Participants could complete measures either on paper or online via StudyTRAX (Macon, GA), a web-based data collection platform. (<http://www.studytrax.com/>).

**Demographic and Clinical Variables**—Parents reported on child and family demographic characteristics, including child and parent gender and age. The clinical report provided information on race/ethnicity, insurance status, diagnosis, respiratory support status, and physician-rated clinical severity. Respiratory support status was categorized as artificial (tracheostomy), artificial + ventilator (tracheostomy and ventilator), non-invasive (continuous positive airway pressure [CPAP] or bi-level positive airway pressure [BiPAP]), or none. This latter category commonly reflected the family's choice to limit mechanical support, recognizing potential health and longevity implications. Those without respiratory support could still require supplemental oxygen. Physician-rated clinical severity (1=least severe, 10=most severe) was collected using a single item severity measure from the National Survey of Children with Special Health Care Needs (U.S. Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau, 2004). This item was categorized into three levels based on the distribution of responses in this sample and to ease interpretability: 5 points (least severe), >5 and 7 points (moderately severe), and >7 points (most severe).

**Healthcare Utilization**—Healthcare utilization was measured as the number of documented emergency department (ED), outpatient, and inpatient days on which the patient had contact with the healthcare system over the six months following the HRQL assessment. The source of healthcare utilization was billing data from Boston Children's Hospital. Participants who did not have available billing data for at least five months following their HRQL assessment were excluded from this analysis. This ensured that all participants had a comparable timeframe in which to experience healthcare utilization. The number of ED, outpatient, and inpatient days were summed to create a "total healthcare days" variable. If multiple visits occurred on a given day, such as an ED visit and an inpatient admission, or multiple outpatient specialty visits, only one was counted. A separate variable that only included inpatient days was also created. Two binary variables were then created for any healthcare utilization or any hospitalization during the 6-month window. The variable for any healthcare utilization was defined as "yes" if the patient had at least one ED, outpatient, or inpatient day, and was defined as "no" if they had none. The variable for any hospitalization was defined as "yes" if the patient had at least one inpatient day, and was defined as "no" if they had none. The primary outcome was total healthcare days within six months following the HRQL assessment. The secondary outcome was inpatient days during the same window.

## Data Analysis

Demographic and clinical variables, HRQL scores, and healthcare utilization were summarized using means (SDs), medians (25<sup>th</sup>–75<sup>th</sup> percentiles), or frequencies and percentages. For days of healthcare utilization, median values excluding children with no

utilization were also calculated (“non-zero median”). Demographic and clinical variables were described overall and by whether the patient had higher HRQL (defined as good, very good, or excellent on both the global HRQL and general health) or lower HRQL (defined as poor or fair on global HRQL or general health). Healthcare utilization was described by the previously-defined three categories of global HRQL, general health, and clinical severity.

To assess for differences in respondents and non-respondents, child age, child gender, clinical severity, diagnosis, and respiratory support among those eligible to participate in the HRQL study (n=196) were compared by enrollment status and inclusion in this analysis. This was done using the two-sample t-test, Wilcoxon rank sum test, or chi-square test.

Generalized linear models (PROC GENMOD in SAS) with a negative binomial distribution and log link were used to assess the relationship between HRQL and days of healthcare utilization. The negative binomial distribution was used to account for overdispersion (i.e., more variability than expected) observed with the Poisson distribution. Separate models were built for categorical global HRQL and categorical general health. The first set of models was unadjusted, while the second set adjusted for categorical clinical severity, and the third set adjusted for categorical clinical severity, years enrolled in the CAPE Program, and child age. Rate ratios and 95% confidence intervals were reported. Linearity was assessed for continuous variables using Pearson residuals plots. Child age was categorized as 0–4, 5–10, and 11+ years, based on graphical displays, to account for non-linearity. Continuous years enrolled in the CAPE Program met linearity assumptions. Continuous forms of global HRQL, general health, and clinical severity were considered, but general health and clinical severity did not meet linearity assumptions.

The type I error rate was set to 0.05 and analyses were conducted in SAS Version 9.4 (SAS Institute, Inc., Cary, NC).

## Results

HRQL measures were completed by 120 parents. Median child age was 7 years and 46% were female (Table 1). More than half of children (58%) had both private and public insurance. The most common diagnosis was SMA type 2 (22%) and 43% of children had artificial respiratory and ventilator support. Median clinical severity was 6.5 (possible range: 1–10). The mean parent age was 40 years and most were mothers (82%). Those with higher HRQL tended to have dystrophies and were more likely to have SMA type 2 than those with lower HRQL. They were also more likely to have no respiratory support. There were no differences in child age, child gender, clinical severity, diagnosis, or respiratory support between respondents and non-respondents. The median global HRQL score was 65 (25<sup>th</sup>–75<sup>th</sup> percentile: 45, 80) and the median general health score was 50 (25<sup>th</sup>–75<sup>th</sup> percentile: 25, 50).

### Healthcare Utilization

Twelve children, eight of whom died, were not eligible for utilization for at least 5 of 6 months in the hospital billing data following their HRQL assessment, so were excluded from healthcare utilization analyses. In the 6 months following the HRQL assessment, 75% of

patients had any healthcare utilization and 32% had any hospitalization. The median number of total healthcare days was 2.5 (25<sup>th</sup> to 75<sup>th</sup> percentile: 0.5, 8) (Table 2).

Table 3 summarizes healthcare utilization by categorical global HRQL, general health and clinical severity. In nearly all cases, those with worse global HRQL, general health, and clinical severity had higher proportions of any healthcare utilization and any hospitalization. Similarly, the number of total healthcare days and inpatient days were generally higher in categories defined by worse global HRQL, general health, and clinical severity.

**Modeling Total Healthcare Days**—Unadjusted results indicated that global HRQL, general health, and clinical severity were associated with total healthcare days (Table 4). In the model including both global HRQL and clinical severity, the effect of global HRQL remained, while the effect of clinical severity was attenuated. After further adjusting for years enrolled in the CAPE Program and child age, the effect of global HRQL strengthened, while there was no change in the effect of clinical severity. Having poor/fair global HRQL was associated with 3.7 (95% CI: 1.9, 7.2) times more total healthcare days compared with having very good/excellent global HRQL ( $p<0.001$ ).

In the model including general health and clinical severity, the effect of general health remained, while the effect of clinical severity was slightly attenuated, but still significant. Adjusting for years enrolled in the CAPE Program and child age did not change the results. Having poor/fair general health was associated with 3.3 (95% CI: 1.7, 6.6) times more total healthcare days compared with having very good/excellent general health ( $p<0.001$ ). Compared with those with the lowest clinical severity, those with moderate clinical severity had 1.8 (95% CI: 1.0, 3.2) times more total healthcare days ( $p=0.05$ ).

**Modeling Inpatient Days**—Unadjusted results indicated that global HRQL, general health, and clinical severity were associated with inpatient days (Table 5). In the model including global HRQL and clinical severity, the effects of both were slightly attenuated. Further adjustment for years enrolled in the CAPE Program and child age resulted in a larger effect of global HRQL. Those with poor/fair global HRQL had 6.3 (95% CI: 1.5, 27.2) times more inpatient days than those with very good/excellent global HRQL ( $p=0.01$ ).

In the model including general health and clinical severity, the effects of both were slightly attenuated. Adjusting for years enrolled in the CAPE Program and child age strengthened the relationship between general health and inpatient days. Those with poor/fair general health had 7.9 (95% CI: 1.9, 32.3) times more inpatient days than those with very good/excellent general health ( $p=0.004$ ).

## Discussion

This study demonstrated that parent-proxy report of child global HRQL and general health were associated with future healthcare utilization, including total healthcare days and inpatient days, among children with chronic respiratory insufficiency. These relationships remained after adjusting for clinical severity, years enrolled in the CAPE Program, and child age. The extent of outpatient and inpatient resource utilization in this cohort relative to the

general pediatric population illustrates the need to predict and intervene in order to optimize health outcomes, improve quality, and reduce healthcare costs. A brief measure of HRQL, such as the 5-item CHRIs global HRQL scale or the single item general health item, is minimally burdensome to families and may be a valuable screening tool for the clinical team to incorporate into routine practice.

In addition to its usefulness as a patient-reported outcome, HRQL assessments provide can serve as predictors of future outcomes, such as prognosis and survival (Coates et al., 2000; Gotay et al., 2008; Hsu, Speers, Kennecke, & Cheung, 2017; Kaplan et al., 2007; Khoulou et al., 2011; Terrin et al., 2015). However, evidence linking HRQL to future healthcare utilization, particularly in pediatric populations, has been limited (Kephart & Asada, 2009; Lima & Kopec, 2005; Parkerson et al., 2001; Ryan et al., 2013; Seid et al., 2004; Wherry, et al., 2014). As examples of existing evidence, a study among children enrolled in a managed care plan (Seid et al., 2004) and a study among children with inflammatory bowel disease (Ryan et al., 2013) both found that HRQL predicted healthcare utilization, independent of demographic and clinical factors. Our results similarly found that parent-proxy report of child HRQL can predict future healthcare utilization.

In addition to examining the relationship between parent-proxy reported HRQL and healthcare utilization, the relationship between physician-rated clinical severity and healthcare utilization was explored. As expected, those with higher clinical severity had more healthcare utilization in unadjusted analyses. However, the effects of clinical severity were attenuated after adjustment for HRQL, time enrolled in the CAPE Program, and child age. In contrast, the effects of HRQL remained after adjustment for the other factors, demonstrating that HRQL may be a better predictor of future healthcare utilization than clinical severity. Further, parent-proxy report has the advantage of not requiring ongoing clinician involvement, so HRQL assessments could be completed during a clinical encounter or remotely between visits, and HRQL assessments could be repeated at appropriate intervals as part of regular clinical care (Feeny, 2013).

A primary goal of identifying patients at risk for acute events would be to augment lower cost services designed to keep the child at home with stable functioning, and shift care away from costly services, such as ED visits or unplanned, acute care hospital admissions. Formal care coordination through medical homes or similar models, such as care provided by the CAPE Program, may be one method for improving health outcomes and decreasing unnecessary or preventable healthcare utilization (Homer et al., 2008; Jackson et al., 2013; Mosquera et al., 2014). A randomized trial of an enhanced medical home for high-risk children with chronic illnesses showed that comprehensive care decreased serious illnesses, ED visits, hospitalizations, ICU admissions, and hospital days (Mosquera et al., 2014). This enhanced medical home provided coordinated and comprehensive care that included 24-hour access to primary care clinicians, easy access to subspecialists, and timely follow-up care.

The population of children enrolled in the CAPE Program and participating in this study was already receiving care as part of an integrated, home-based care program. However, the use of a prediction model that includes a marker, such as HRQL, could help identify families in need of interventions to improve child functioning and limit costlier healthcare utilization.

This is clearly a high-risk group, as illustrated by the percentage with any hospitalizations (32%) and the mortality rate (6%) over a 6-month period. Routine screening with HRQL measures could identify low scores or decreasing score over time, prompting program staff to intervene with a home visit or clinic visit to troubleshoot before the child requires an unscheduled ED visit or hospitalization. The pediatric home nursing team could also use HRQL scores to better manage the child's care. For example, the awareness of low scores may assist the nurse in advocating for reassessment and improvement of home nursing care and management plans. Further, regularly assessing the child's HRQL facilitates ongoing communication between the family, program staff, and home nursing team to better monitor needs, trends, and improvements. This proactive HRQL evaluation would, ideally, shift healthcare utilization away from the inpatient setting to the outpatient or home setting, while also decreasing the angst and cost associated with a reactive, acute care encounter.

Given that the parent is usually the driver of the healthcare utilization in severely ill children, parent-proxy report was used for predicting future healthcare utilization. When collecting HRQL on pediatric populations, it is often recommended that both child and parent-proxy raters be included as each may have different perspectives (Parsons, Fairclough, Wang, & Hinds, 2012; Parsons, Tighiouart, & Terrin, 2013), referred to as information variance. However, the children in this study were distinct as their underlying illnesses often require constant care or monitoring. Parents serving as around-the-clock caregivers may have greater insight into their child's HRQL than parents of healthy children who become more independent with age. This distinction from healthy children also justifies the inclusion of the wide age range of children in this study (30 days to 22 years). In addition, developmental, cognitive, and functional limitations of many of the children in the current study precluded the use of child report.

This study is not without limitations. Healthcare utilization was captured from a single institution resulting in possible underestimation. However, given the complexity of these patients, and the fact that they were enrolled in an integrated, home-based care program at Boston Children's Hospital, the majority of their utilization occurred at this facility as confirmed by a review of claims data from two of the larger payers (*unpublished*). Further, while enrollment rates in the study were high, some CAPE Program families did not choose to participate in the HRQL study. Although there were no differences in child age, child gender, clinical severity, diagnosis, or respiratory support by participation status, there could be differences across other factors that would impact generalizability.

Children with chronic respiratory insufficiency are at risk for developing severe acute illnesses that can result in unscheduled and costly services, such as inpatient stays that typically require ICU-level care. This study showed that parent-proxy HRQL scores were associated with future healthcare utilization among these children, including total healthcare days and inpatient days. Future research should explore longitudinal HRQL scores, including changes over time, and whether change scores are better at predicting future healthcare utilization than cross-sectional HRQL scores. Based on the results of the current study, the use of HRQL in clinical practice, alone or in combination with clinical severity, may help to identify children and families who would be appropriate targets for earlier intervention, thereby improving outcomes, patient and family experience, and shifting care



to less costly services. A minimally burdensome screener has a higher likelihood of completion in families with significant care demands, and may reveal additional social, emotional, and access issues that represent drivers of healthcare utilization.

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## Abbreviations

<b>BiPAP</b>	bi-level positive airway pressure
<b>CAPE</b>	Critical Care, Anesthesia, Perioperative Extension
<b>CHRI</b> s	Child Health Ratings Inventories
<b>CPAP</b>	continuous positive airway pressure
<b>ED</b>	emergency department
<b>HRQL</b>	health-related quality of life
<b>ICU</b>	intensive care unit
<b>SMA</b>	spinal muscular atrophy

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**Table 1**

## Baseline child, disease, and family characteristics

	<i>M (SD), median (25<sup>th</sup>–75<sup>th</sup> percentile) or n (%)</i>		
	Overall, n=120	Higher HRQL, n=70 <sup>a</sup>	Lower HRQL, n=50 <sup>b</sup>
<b>Child Characteristics</b>			
Child age, median (25 <sup>th</sup> –75 <sup>th</sup> percentile)	7 (3, 13)	6 (3, 12)	7.5 (3,14)
Child female, <i>n</i> (%)	55 (45.8%)	34 (48.6%)	21 (42.0%)
Race/ethnicity, <i>n</i> (%)			
Asian	7 (5.8%)	3 (4.3%)	4 (8.0%)
Non-Hispanic black	6 (5.0%)	2 (2.9%)	4 (8.0%)
Hispanic	5 (4.2%)	3 (4.3%)	2 (4.0%)
Non-Hispanic white	93 (77.5%)	56 (80.0%)	37 (74.0%)
Other/Unknown	9 (7.5%)	6 (8.6%)	3 (6.0%)
Insurance status, <i>n</i> (%)			
Private and public	70 (58.3%)	37 (52.9%)	33 (66.0%)
Private only	21 (17.5%)	15 (21.4%)	6 (12.0%)
Public only	29 (24.2%)	18 (25.7%)	11 (22.0%)
<b>Disease Characteristics</b>			
Diagnostic category, <i>n</i> (%)			
Acquired injury	14 (11.7%)	5 (7.1%)	9 (18.0%)
Anomalies	11 (9.2%)	5 (7.1%)	6 (12.0%)
Chronic lung disease	14 (11.7%)	8 (11.4%)	6 (12.0%)
Congenital heart disease	8 (6.7%)	3 (4.3%)	5 (10.0%)
Dystrophies	17 (14.2%)	12 (17.1%)	5 (10.0%)
SMA type 1	8 (6.7%)	4 (5.7%)	4 (8.0%)
SMA type 2	26 (21.7%)	21 (30.0%)	5 (10.0%)
SMA type 3	6 (5.0%)	5 (7.1%)	1 (2.0%)
Other	16 (13.3%)	7 (10.0%)	9 (18.0%)
Respiratory support, <i>n</i> (%)			
Artificial	6 (5.0%)	3 (4.3%)	3 (6.0%)
Artificial + ventilator	51 (42.5%)	28 (40.0%)	23 (46.0%)
Non-invasive	32 (26.7%)	17 (24.3%)	15 (30.0%)
None	31 (25.8%)	22 (31.4%)	9 (18.0%)
Physician-rated clinical severity, median (25 <sup>th</sup> –75 <sup>th</sup> percentile)	6.5 (4, 7)	6 (3, 7)	7 (6, 8)
<b>Family Characteristics</b>			
Parent female, <i>n</i> (%)	97 (81.5%)	61 (88.4%)	36 (72.0%)
Parent age, <i>M (SD)</i>	40.3 (8.4)	39.5 (8.8)	41.3 (7.8)
Parent education, <i>n</i> (%)			
<High school	4 (3.6%)	4 (6.4%)	0 (0.0%)

	<i>M (SD), median (25<sup>th</sup>–75<sup>th</sup> percentile) or n (%)</i>		
	<b>Overall, n=120</b>	<b>Higher HRQL, n=70<sup>a</sup></b>	<b>Lower HRQL, n=50<sup>b</sup></b>
High school graduate	17 (15.2%)	9 (14.3%)	8 (16.3%)
Some college	29 (25.9%)	14 (22.2%)	15 (30.6%)
College graduate	62 (55.4%)	36 (57.1%)	26 (53.1%)

<sup>a</sup>Higher HRQL defined as having good/very good/excellent Global HRQL and good/very good/excellent general health

<sup>b</sup>Lower HRQL defined as having poor/fair Global HRQL or poor/fair general health

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**Table 2**Summary of days of healthcare utilization, n=108<sup>a</sup>

	Median (25 <sup>th</sup> -75 <sup>th</sup> percentile)	Non-0 Median (25 <sup>th</sup> -75 <sup>th</sup> percentile)	Min	Max
Outpatient/ED days	2 (0, 4)	3 (2, 5)	0	27
Inpatient days	0 (0, 2.5)	4 (3, 11)	0	53
Total days	2.5 (0.5, 8)	5 (2, 9)	0	55

<sup>a</sup>Restricted to those with HRQL data and eligible for utilization within billing data for at least 5 months.

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**Table 3**

Healthcare utilization by categories of HRQL and clinical severity, n=108<sup>a</sup>

	n	Any Utilization, n (%)	Total Days		Any Hospitalization, n (%)	Inpatient Days	
			Median (25-75 <sup>th</sup> percentile)	Non-0 Median (25-75 <sup>th</sup> percentile)		Median (25-75 <sup>th</sup> percentile)	Non-0 Median (25-75 <sup>th</sup> percentile)
Global HRQL <sup>b</sup>							
Poor/fair	29	25 (86.2%)	9 (2, 17)	10 (3, 17)	15 (51.7%)	1 (0, 11)	11 (4, 13)
Good	37	30 (81.1%)	2 (1, 5)	3.5 (2, 6)	8 (21.6%)	0 (0, 0)	2.5 (2, 12.5)
V good/excellent	42	26 (61.9%)	1 (0, 7)	5 (2, 8)	12 (28.6%)	0 (0, 2)	4 (2.5, 7)
General health <sup>b</sup>							
Poor/fair	34	27 (79.4%)	8 (2, 16)	10 (4, 17)	15 (44.1%)	0 (0, 11)	11 (4, 18)
Good	46	35 (76.1%)	2 (1, 7)	3 (2, 8)	15 (32.6%)	0 (0, 2)	3 (2, 7)
V good/excellent	28	19 (67.9%)	1 (0, 3.5)	2 (1, 6)	5 (17.9%)	0 (0, 0)	3 (2, 4)
Clinical severity <sup>c</sup>							
Most	21	16 (76.2%)	5 (1, 9)	5.5 (2.5, 10)	10 (47.6%)	0 (0, 4)	5.5 (2, 11)
Moderately	44	32 (72.3%)	3 (1, 9)	6.5 (2, 10)	14 (31.8%)	0 (0, 3.5)	7.5 (4, 20)
Least	43	31 (72.1%)	2 (0, 6)	3 (1, 8)	11 (25.6%)	0 (0, 1)	4 (2, 9)

<sup>a</sup>Restricted to those with HRQL data and eligible for utilization within billing data for at least 5 months.

<sup>b</sup>Poor/fair <50 points; good 50 and <75 points; very (v) good/excellent 75 points.

<sup>c</sup>Least severe 5 points; moderately severe >5 and 7 points; most severe >7 points.

**Table 4**

Global HRQL and general health models for total healthcare days

	Unadjusted model		Adjusted model 1 <sup>a</sup>		Adjusted model 2 <sup>b</sup>	
	Rate Ratio (95% CI)	p	Rate Ratio (95% CI)	p	Rate Ratio (95% CI)	p
Global HRQL model <sup>c</sup>						
Global HRQL						
Poor/fair	3.5 (1.9, 6.4)	<0.001	3.1 (1.7, 5.8)	<0.001	3.7 (1.9, 7.2)	<0.001
Good	1.5 (0.8, 2.6)	0.21	1.4 (0.8, 2.5)	0.26	1.6 (0.9, 2.8)	0.15
V good/excellent (ref)						
Clinical severity						
Most	1.5 (0.7, 3.1)	0.27	1.1 (0.6, 2.3)	0.75	1.1 (0.5, 2.1)	0.89
Moderately	2.5 (1.4, 4.5)	0.001	1.6 (1.0, 2.9)	0.08	1.6 (0.9, 2.8)	0.12
Least (ref)						
General health model <sup>c</sup>						
General health						
Poor/fair	3.4 (1.8, 6.6)	<0.001	3.4 (1.7, 6.5)	<0.001	3.3 (1.7, 6.6)	<0.001
Good	1.4 (0.7, 2.6)	0.34	1.5 (0.8, 2.9)	0.19	1.5 (0.8, 2.9)	0.19
V good/excellent (ref)						
Clinical severity						
Most	1.5 (0.7, 3.1)	0.27	1.2 (0.6, 2.5)	0.54	1.2 (0.6, 2.3)	0.67
Moderately	2.5 (1.4, 4.5)	0.001	1.9 (1.1, 3.4)	0.02	1.8 (1.0, 3.2)	0.05
Least (ref)						

<sup>a</sup> Adjusted model 1 adjusts for physician-rated clinical severity.

<sup>b</sup> Adjusted model 2 adjusts for physician-rated clinical severity, years enrolled in the CAPE Program, and child age

<sup>c</sup> Poor/fair <50 points; good 50 and <75 points; very (v) good/excellent 75 point. Least severe 5 points; moderately severe >5 and 7 points; most severe >7 points.



**Table 5**

Global HRQL and general health models for inpatient days

	Unadjusted model		Adjusted model 1 <sup>a</sup>		Adjusted model 2 <sup>b</sup>	
	Rate Ratio (95% CI)	p	Rate Ratio (95% CI)	p	Rate Ratio (95% CI)	p
Global HRQL model <sup>c</sup>						
Global HRQL						
Poor/fair	4.9 (1.4, 16.9)	0.01	4.0 (1.1, 13.9)	0.03	6.3 (1.5, 27.0)	0.01
Good	1.5 (0.5, 4.7)	0.53	1.2 (0.4, 4.0)	0.76	1.8 (0.5, 6.7)	0.37
V good/excellent (ref)						
Clinical severity						
Most	2.2 (0.5, 9.1)	0.28	1.5 (0.4, 6.1)	0.56	1.2 (0.3, 5.3)	0.79
Moderately	4.1 (1.3, 12.6)	0.01	2.4 (0.8, 7.2)	0.14	2.0 (0.6, 7.4)	0.29
Least (ref)						
General health model <sup>c</sup>						
General health						
Poor/fair	8.3 (2.2, 31.4)	0.002	7.1 (1.9, 27.0)	0.004	7.9 (1.9, 32.3)	0.004
Good	2.4 (0.7, 8.5)	0.18	2.4 (0.7, 8.5)	0.18	2.3 (0.6, 8.3)	0.22
V good/excellent (ref)						
Clinical severity						
Most	2.2 (0.5, 9.1)	0.28	1.8 (0.4, 7.0)	0.42	1.7 (0.4, 6.5)	0.47
Moderately	4.1 (1.3, 12.6)	0.01	2.7 (0.9, 8.0)	0.09	2.4 (0.7, 8.0)	0.14
Least (ref)						

<sup>a</sup>Adjusted model 1 adjusts for physician-rated clinical severity

<sup>b</sup>Adjusted model 2 adjusts for physician-rated clinical severity, years enrolled in the CAPE Program, and child age

<sup>c</sup>Poor/fair <50 points; good 50 and <75 points; very (v) good/excellent 75 point. Least severe 5 points; moderately severe >5 and 7 points; most severe >7 points.