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The Impact of Bronchopulmonary Dysplasia on Caregiver Health Related Quality of Life during the First Two Years of Life

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Abstract

Objectives—Preterm children with bronchopulmonary dysplasia (BPD) frequently require complex home medical regimens and re-hospitalization during the first two years of life. The burden of caring for these medically complex children may negatively affect caregiver health related quality of life (HRQoL). The objectives of this study were to measure caregiver HRQoL of children with BPD and to identify factors that impact caregiver HRQoL during the first two years of life.

Methods—Children (n=186) were recruited from the Johns Hopkins BPD Outpatient Clinic between January 2008 and July 2011. Caregiver HRQoL was measured using The PedsQL™ Family Impact Module. Respiratory symptoms and morbidities were assessed using questionnaires.

Results—Among caregivers of BPD children, significant improvement in physical, worry and daily domains improved longitudinally as children aged. An association was found between lower total HRQoL scores and caregivers of BPD children who reported more respiratory symptoms and acute care usage. No difference in total HRQoL scores was found between caregivers of BPD children requiring respiratory/enteral support and caregivers of children who did not. Caregiver income and educational level did not predict total HRQoL score, but Non-White race and public insurance was associated with a higher total HRQoL score at the first outpatient visit.

Conclusion—An association was found between lower HRQoL scores and caregivers of BPD children with frequent respiratory symptoms and acute care usage. Screening for low HRQoL in caregivers of BPD children with frequent respiratory illnesses should be considered to identify those who may benefit from additional support and intervention.

Keywords

Prematurity; Bronchopulmonary Dysplasia; Caregivers; Health Related Quality of Life

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INTRODUCTION

Prematurity (less than 37 weeks gestation) is a significant problem in the United States with up to 12.2% of live births per year classified as premature. [1] Low birth weight infants (<1500 grams) are at particular risk for developing bronchopulmonary dysplasia (BPD). [2] BPD occurs most frequently in preterm infants with underdeveloped lungs, poor systemic growth and a need for respiratory support during the neonatal period. [3] Following discharge from the hospital, children with BPD often have chronic respiratory symptoms and difficulty growing. [45] Treatment can involve complex and expensive medical regimens including respiratory and nutritional support, especially during the first two years of life. [67]Although studies have reported increased psychological distress and anxiety in caregivers of children with chronic health conditions, little is known about HRQoL among caregivers of children with BPD. [8, 9]

Several studies have examined the quality of life and stress levels of caregivers of preterm infants. Rogers and colleagues found that prolonged mechanical ventilation in the neonatal intensive care unit (NICU) was associated with increased maternal depression at the time of discharge. However, they also found that increased anxiety was common in many mothers of very preterm infants (<30 weeks gestation) and recommended universal NICU screening. [10]

In this study we were interested in identifying factors that influenced HRQoL among caregivers of children who were born premature and who went on to develop BPD. We chose to examine the HRQoL of caregivers of children who were two years of age and younger, since children with BPD are generally at highest risk for respiratory complications during these early years. Indeed, it has been reported that up to one-half of children with BPD, less than two years of age, are re-admitted to the hospital for respiratory illnesses. [3] In addition, many preterm children with BPD require supplemental oxygen, careful monitoring and frequent healthcare visits during this time period. They may also need supplemental enteral feeds to maintain growth and multiple daily medications to control respiratory symptoms. Fortunately, as children with BPD age, most will have improvement in their respiratory symptoms, although some will continue to have significant respiratory symptoms throughout childhood with up to one- fourth having respiratory problems into young adulthood. [11, 1213]

Caring for a preterm child with BPD can be challenging; particularly for caregivers of children who require complex medical regimens. Furthermore, to limit exposure of their child to respiratory viruses and minimize respiratory illnesses, caregivers of young BPD children will often isolate themselves and their child from family and friends.[14]

Since little is known regarding HRQoL of caregivers of children with BPD during the first two years of life, identifying caregivers with HRQoL impairment could help direct resources to those who may benefit most from additional support. In this study we hypothesized that HRQoL of caregivers of children with BPD would improve as their children aged. This was addressed using longitudinal and cross-sectional analyses. We also predicted that caregivers of children who had more acute respiratory problems and caregivers of children who required chronic oxygen and/or enteral supplementation in the home setting would have lower HRQoL. Using cross-sectional analyses we were able to identify factors associated with lower HRQoL among caregivers of children with BPD.

METHODS

Study Population

All subjects (n=186) were recruited from the Johns Hopkins Bronchopulmonary Dysplasia (BPD) Clinic between January 2008 and July 2011. Approximately 98% of caregivers of children attending the BPD clinic agreed to participate in the study. Consent was obtained from a parent or legal guardian and the study was approved by the Johns Hopkins University Institutional Review Board. Inclusion criteria included (1) a diagnosis of BPD by the staffing pediatric pulmonologist and (2) born at ≤34 weeks of gestation. Caregivers of subjects were asked to complete questionnaires at every clinic visit up to 2 years of age.

Demographics

Birth weight percentile was derived from published U.S. norms.[15] Insurance coverage (private vs. public) was obtained from billing records. Race/ethnicity and primary caregiver education level was obtained via questionnaire. Median household income was derived from 2000 U.S. Census Tract Data.

Health Related Quality of Life Measures (HRQoL)

Owing to the absence of validated HRQoL measures for parents of infants, HRQoL was assessed using The Quality of Life PedsQL™ Family Impact Module, which has been shown to be reliable and valid for parents of medically fragile children aged 2–18 years of age.[16–18] This construct assesses primary caregiver self-reported functioning (physical, emotional, social, and cognitive functioning, communication, and worry) and family functioning (daily activities and family relationships). Each of the 36 questions has a 5 point response scale and scores are derived such that higher scores indicate higher functioning (Range: 0–100). Caregivers were given the The PedsQL™ Family Impact Module at each clinic visit. The entire study population (n=186) had completed a total of 408 forms prior to 2 years of age and all of these forms were used for cross-sectional analysis by age groups. Caregivers of 102 subjects had completed PedsQL™ forms at 2 or more separate time points prior to 2 years of age, and these were used for longitudinal analysis.

Respiratory Morbidities

Selected morbidities were assessed through the use of questionnaires at clinic visits at the same time HRQoL was assessed. Questions about acute care use for respiratory symptoms included, emergency department visits, hospitalizations, systemic steroid use, and antibiotic use since the last clinic visit. Questions also asked about symptoms within the past week, including trouble breathing, rescue β-agonist use, activity limitations, and nighttime respiratory symptoms.

Statistical Methods

The relationship between cross-sectional measures and age was assessed using linear regression clustered by subject using Generalized Estimating Equations (GEE) methodology [19] to account for the multiple clinical forms completed per subject (Table 2). A longitudinal comparison of HRQoL scores over time was conducted by comparing descriptive frequencies of individual domains of functioning and total PedsQL scores via *t* tests between first and last form completed before two years of age (Table 3). Descriptive frequencies of individual domains and total scores were compared between different demographic groups using *t* tests (Tables 4 and 5). The relationship between respiratory morbidities and quality of life, which are based on multiple clinical encounters per subject, was assessed by multivariate regression adjusted for potential confounders in the population (age, race/ethnicity, and insurance status) and clustered by subject using GEE (Table 6). STATA IC 11 (StataCorp LP, College Station, TX) was used for all statistical analyses. *P*-values <0.05 were considered statistically significant.

RESULTS

Demographics

The mean gestational age of children with BPD that were recruited from the outpatient BPD clinic was 26.4 ± 2.3 weeks (Table 1). The mean birth weight was 872 ± 345 grams with a mean birth weight percentile of 41 ± 23%. The mean age of children at their first visit was 6.7 ± 3.2 months. Almost 40% required respiratory support at their first visit and 19.4% had gastric tubes for nutritional supplementation. The 72 subjects receiving respiratory support at home include 69 on supplemental oxygen via nasal cannula and 3 on home mechanical ventilation. By self-report, 65.1% of children were Black, 29.6% were White, and 5.3% were either Asian, Hispanic, or of mixed ancestry. Although over 50% of children were covered through public insurance, the mean household income exceeded the U.S. median household income. Most caregivers had at least a high school education.

Health Related Quality of Life Measurements of Caregivers over Time

To determine if there were any significant changes in caregiver HRQoL over child age groups, we examined both cross-sectional and longitudinal measures of HRQoL. Regression analysis of cross-sectional HRQoL scores that stratified all caregiver responses by the age of the child demonstrated that primary caregivers of older children had significantly higher physical (p=0.03; n=406) and daily (p=0.04; n=379) domains than primary caregivers of younger children (Table 2). Bias may arise in the cross-sectional analysis as a subject may not be represented in every age group. Thus, HRQoL scores from the 102 subjects who had data from more than one clinic visit were examined using *t* tests to determine if HRQoL scores improved longitudinally. Among caregivers, significant improvement was found in physical (p=0.02), worry (p<0.01), and daily (p=0.01) HRQoL domains between the first and last visit before two years of age (Table 3).

Predictors of HRQoL in Caregivers of Children with BPD less than two years of age

As we wished to determine whether any characteristics of subjects were predictive of HRQoL for their caregivers, we examined total HRQoL scores between caregivers of children based on demographic, clinical, and socio-economic factors using *t* tests. We found no difference in HRQoL measures at the first clinic visit by sex, birthweight, respiratory support, gastrostomy tubes, household income, or caregiver education level (Table 4). However, at the first clinic visit we found that Non-White race/ethnicity (p=0.01) and public insurance (p=0.01) were predictors of higher total HRQoL scores among caregivers of BPD children. As Non-White race/ethnicity and being covered by public insurance are associated within our study population (chi square p=0.004), we performed multivariate regression adjusted for age at the time of form completion to determine which of these demographic factors were independent predictors of total HRQoL score. We found that both race/ethnicity and insurance status were independent predictors of total HRQoL score (n = 186; regression p=0.008). Public insurance was associated with a 5.5 point higher total quality of life score (co-efficient p=0.021) and Non-White race/ethnicity was associated with a 5.1 point higher total score (co-efficient p=0.048). However, an interaction term between race/ethnicity and insurance type was not significant (p=0.99). Post-hoc analyses of domains of functioning found that HRQoL scores were higher in Non-White caregivers for physical, emotional, social functioning, communication, daily, and family scores compared to white caregivers and that HRQoL scores were higher families with public insurance for physical, emotional, social functioning, cognitive, daily, and family scores compared to those with private insurance (Table 5).

Influence of respiratory symptoms and acute care usage on caregiver HRQoL scores

To assess among caregivers of children with BPD whether increased respiratory symptoms and/or utilization of acute care adversely affected HRQoL in caregivers, we performed clustered multivariate regression adjusted for predictors of total HRQoL score in our population, namely age, race/ethnicity, and insurance status. We found that emergency department visits, hospitalizations, and the use of systemic steroids for respiratory symptoms in children with BPD were associated with lower total HRQoL scores in caregivers (Table 6). Similarly, any difficulty breathing, rescue β-agonist use, activity limitations, or nighttime symptoms in the week prior to the clinic visit also was associated with a lower total HRQoL score. There was a trend towards higher HRQoL scores in caregivers who felt their children were gaining weight appropriately (p=0.053).

DISCUSSION

This study was undertaken to measure caregiver HRQoL of children with BPD and to identify factors that impact caregiver HRQoL during the first two years of life. We found that caregiver physical, worry and daily HRQoL domains improved as their children aged. We also found an association between lower caregiver total HRQoL scores and caregivers who reported more respiratory symptoms and acute care usage in their children.

Lower HRQoL has been reported in caregivers of children with chronic diseases compared to the general population. [2021] Indeed, Hatzmann and colleagues found that caregivers of children with chronic diseases had a 45% risk for HRQoL impairment compared to 25% of the general population.[20] Furthermore, the type of chronic disease or disability has been shown to influence caregiver HRQoL. Kim and colleagues found that mothers of children with mitochondrial disorders had lower HRQoL compared to mothers of children with intractable epilepsy. [22] Increased demands required of caregivers of children with chronic diseases may also influence caregiver HRQoL. In Canada, Brehaut and colleagues found that caregivers of children with cerebral palsy reported more physical and psychological health problems than caregivers of other children. [23]

In our study, we found that caregiver physical, worry and daily HRQoL domains improved as children aged. Our findings are somewhat similar to those of Holditch-Davis and colleagues. In their study African American mothers of preterm infants were categorized into four groups (low distress, extreme distress, high stress and high depressive) using questionnaires that measured stress, depression, anxiety, post-traumatic stress and daily hassle. [24] They found that although groups tended to have their own trajectory, most groups had improved scores in all areas during the first two years of life. In contrast, Singer and colleagues still observed higher psychological stress in mothers of preterm children with BPD at two years of age compared to term infants and preterm infants without BPD.[25] Responses of mothers for these infants born between 1989 and 1991 were obtained by Singer *et al.* using the Brief Symptom Inventory, The Parenting Stress Index, The Impact on Family Scale and the Family Inventory of Life Events and Changes. Another study by Donohue and colleagues, using a cross-sectional analysis of QOL outcomes in caregivers of very low birth weight infants and term infants between 12 and 18 months of age, found no differences in QOL between the caregivers. However they did not distinguish between high risk infants with BPD and low risk infants without BPD. [26] In our study, we speculate that improvement in HRQoL among caregivers of BPD children during the first two years of life is likely due to a combination of factors including improved respiratory health in the child and improved coping skills in the caregiver. Recognizing caregivers with low HRQoL at the initial clinic visit or those who fail to show improved HRQoL scores over time may help identify caregivers who would benefit most from additional support. Other studies have shown that mastery of caregiver skills and less passive coping correlated with higher well-being in caregivers of survivors of traumatic brain injury or respiratory distress syndrome. [27,28] Results from these studies support caregiver interventions that would help improve mastery of skills and teach coping strategies along with more social support and respite. These interventions may also help improve HRQoL in caregivers of children with BPD.

Our study was the first to identify factors that can influence caregiver HRQoL in young children with BPD. Interestingly, the caregivers who had lower total HRQoL scores were caregivers who reported that their children had more respiratory symptoms and more acute care usage between clinic visits. We found that increased frequency of emergency department visits, hospitalizations, use of systemic steroids and respiratory symptoms correlated with lower total HRQoL scores of caregivers of children with BPD. Interestingly, no differences in HRQoL were found between caregivers of children who required supplemental oxygen/ventilatory support and/or enteral nutrition and caregivers of children who did not, suggesting that caregiver HRQoL of children with BPD is influenced more by acute respiratory symptoms and acute care usage rather than a need for chronic respiratory and nutritional support.

In our study we also found that Non-White caregivers had significantly higher total HRQoL scores at their first outpatient BPD visit compared to White caregivers. Since recruitment was based on clinic attendance[28], this difference in HRQoL at the first visit may represent a bias towards Non-White caregivers who can more easily access an outpatient BPD clinic. For instance Non-White caregivers with lower HRQoL may have greater difficulties in attending this clinic compared to White or Non-White caregivers with higher HRQoL. In a study of longitudinal assessment of HRQoL in a cohort of cystic fibrosis (CF) patients, Sawicki and colleagues reported that Black race in parents of CF children was associated with a decrease in vitality.[29] Nevertheless, there is little data on race as a factor in caregiver HRQoL of young children with BPD and our findings may suggest that Non-White caregivers may more easily cope or adapt to their child’s condition at the initial outpatient visit. In our study public insurance, independent of race, was also associated with a higher total HRQoL score at the first clinic visit. Although this was surprising, it has been shown that public programs can lessen the impact of poverty on children through food, healthcare and housing assistance.[30] This assistance, which children on private insurance are unlikely to receive, may be particularly beneficial for caregivers of preterm children with BPD since prematurity has been shown to be associated with high direct and indirect economic costs with substantial parental burden occurring after discharge from the hospital.[31]

Our study has several limitations. Our results may not be generalizable to other areas or centers since the majority of our subjects were Non-White, received public insurance and were from an urban area. Furthermore, our study focused on caregivers and their children who were able to attend a disease specific clinic that focused on preterm infants with BPD. This clinic may inadvertently select for caregivers that have the financial means and time to attend a specialty clinic in addition to their regular healthcare provider. In addition, the income and educational level of the urban caregivers in our study were relatively high such that our study responses may not be representative of other areas that include rural areas with low income and less educated populations. Furthermore, there may be a longitudinal bias in our population as children with more severe lung disease are more likely to be followed through 2 years of age; however we have adjusted for age in our analyses where appropriate. Lastly, the presence of respiratory morbidities was assessed using questionnaires, which may be subject to recall bias.

In summary, we found that physical, worry and daily HRQoL domains of caregivers of children with BPD improved as their children aged during the first two years life. We also found an association between lower total caregiver HRQoL scores and caregivers who reported more frequent respiratory symptoms and acute care usage in their children between clinic visits. Screening of caregivers of children with BPD, particularly those who report frequent acute respiratory symptoms and acute care usage should be considered to help identify caregivers who may be at increased risk for lower HRQoL and who may benefit from additional support and intervention.

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Table 1

Study Sample Demographics

			Study Sample Mean (± SD) [Range]
	n		186
Demographics	**Sex** (% male)		58.6
	Gestational Age (weeks)		26.4 ± 2.3 [23.0 – 34.0]
	Birth Weight (grams)		872 ± 345 [390 – 2510] (n = 182)
	Birth Weight Percentile (%)		41 ± 23 [1 – 93] (n = 182)
	Race/Ethnicity (% white)		29.6
Clinical Characteristics	**Age at Initial Discharge from NICU** (months)		4.2 ± 2.4 [0.4 – 17.1] (n = 184)
	Age at First Pulmonary Clinic Visit (months)		6.7 ± 3.2 [1.9 – 18.3]
	Respiratory Support (% Yes)[*]		38.7
	Gastrostomy Tube (% Yes)		19.4
Socio economic - Characteristics	**Public Insurance** (% Yes)		54.3
	Estimated Household Income ($)[**]		46,337 ± 18,344 [11,119 – 101,358]
	Primary Caregiver Education Level (%)	Less than High School	4.9
		High School Graduate	20.3
		Some College	38.5
		College Degree	18.9
		Any Post-graduate Education	17.5 (n=143)

[*] Supplemental oxygen and/or mechanical ventilation at home.

[**] U.S. median household income is $41,994.

Table 2

Cross-sectional Comparison of Health Related Quality of Life Measurements

	0–6 Months Mean (± SD) [Range]	**6–12 Months Mean (± SD) [Range]**	**12–18 Months Mean (± SD) [Range]**	**18–24 Months Mean (± SD) [Range]**	**Regression with Age[*] Coefficient**
n	69	174	107	58	408
Age at Assessment (months)	4.7 ± 0.9 [2.0 – 5.95]	8.7 ± 1.7 [6.0 – 11.99]	14.9 ± 1.7 [12.0 – 17.94]	20.8 ± 1.7 [18.2 – 23.98]	-
Physical Score	71 ± 21 [8 – 100]	76 ± 22 [0 – 100] (n = 173)	77 ± 21 [17 – 100] (n = 106)	80 ± 21 [17 – 100]	**0.45** ***p* = 0.030 (n = 406)**
Emotional Score	84 ± 18 [25 – 100] (n = 67)	85 ± 19 [0 – 100] (n = 172)	87 ± 16 [45 – 100] (n = 106)	86 ± 17 [35 – 100]	0.18 *p* = 0.26 (n = 403)
Social Functioning Score	81 ± 21 [25 – 100] (n = 68)	82 ± 21 [19 – 100] (n = 171)	82 ± 24 [0 – 100] (n = 103)	84 ± 23 [13 – 100] (n = 57)	0.22 *p* = 0.34 (n = 399)
Cognitive Score	88 ± 15 [50 – 100] (n = 68)	86 ± 19 [25 – 100] (n = 171)	88 ± 18 [20 – 100] (n = 103)	92 ± 14 [40 – 100] (n = 56)	0.25 *p* = 0.14 (n = 398)
Communication Score	84 ± 19 [17 – 100] (n = 67)	86 ± 20 [17 – 100] (n = 162)	86 ± 19 [0 – 100] (n = 98)	87 ± 20 [8 – 100] (n = 52)	0.11 *p* = 0.57 (n = 379)
Worry Score	75 ± 21 [15 – 100] (n = 67)	77 ± 19 [20 – 100] (n = 163)	77 ± 21 [30 – 100] (n = 100)	82 ± 20 [40 – 100] (n = 53)	0.35 *p* = 0.08 (n = 383)
Daily Score	67 ± 29 [0 – 100] (n = 67)	74 ± 28 [0 – 100] (n = 162)	73 ± 27 [0 – 100] (n = 99)	81 ± 23 [25 – 100] (n = 51)	**0.59** ***p* = 0.040 (n = 379)**
Family Score	84 ± 21 [25 – 100] (n = 67)	88 ± 17 [20 – 100] (n = 162)	87 ± 18 [15 – 100] (n = 99)	89 ± 18 [6 – 100] (n = 52)	0.20 *p* = 0.29 (n = 380)
Total Score	79 ± 16 [44 –100]	82 ± 17 [26 – 100]	82 ± 16 [36 – 100]	85 ± 16 [48 – 100]	0.31 *p* = 0.051

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[*] Regressions were constructed with the quality of life measurement as the outcome (dependent) variable and age in months as the predictor (independent) variable. Regressions were clustered by subject as a subject may be represented more than once.

Table 3

Longitudinal Comparison of Health Related Quality of Life Measurements

	N	**1st Visit Mean (± SD) [Range]**	**2nd Visit* Mean (± SD) [Range]**	***p* value**
Age at Assessment (months)	102	7.3 ± 3.4 [2 – 17.5]	14.6 ± 5.4 [4.3 – 22.9]	**<0.001**
Physical Score	101	72 ± 20 [8 – 100]	78 ± 22 [0 – 100]	**0.017**
Emotional Score	99	86 ± 17 [25 – 100]	86 ± 19 [0 – 100]	0.70
Social Functioning Score	97	83 ± 18 [38 – 100]	83 ± 23 [13 – 100]	0.86
Cognitive Score	97	89 ± 17 [25 – 100]	87 ± 19 [25 – 100]	0.30
Communication Score	85	88 ± 15 [33 – 100]	87 ± 21 [8 – 100]	0.62
Worry Score	87	74 ± 20 [15 – 100]	83 ± 19 [30 – 100]	**<0.001**
Daily Score	87	69 ± 28 [0 – 100]	77 ± 26 [0 – 100]	**0.006**
Family Score	86	87 ± 17 [35 – 100]	89 ± 17 [6 – 100]	0.39
Total Score	102	81 ± 14 [45 – 100]	83 ± 18 [26 – 100]	0.44

*Second visit was the most recent questionnaire completed provided the subject was still <2yo at the time of questionnaire completion.

Table 4

Predictors for Health Related Quality of Life at First Clinic Visit

	Predictors		**Total HRQoL Score Mean ± SD (n total = 186)**	**T-test *p* Value**
Demographic	**Sex**	Male	82 ± 16 (n = 109)	0.43
		Female	81 ± 16 (n = 77)	
	Birth Weight	≥ 1000 grams	80 ± 17 (n = 43)	0.40
		< 1000 grams	82 ± 16 (n = 139)	
	Birth Weight Percentile	> 10th	81 ± 16 (n = 163)	0.45
		≤ 10th	84 ± 14 (n = 19)	
	Race/Ethnicity	White	77 ± 16 (n = 55)	**0.012**
		Non-White	84 ± 15 (n = 131)	
Clinical	**Respiratory Support**	Absent	81 ± 16 (n = 114)	0.44
		Present	83 ± 15 (n = 72)	
	GT	Absent	81 ± 16 (n = 150)	0.31
		Present	84 ± 15 (n = 36)	
Socio-Economic	**Insurance Status**	Private	78 ± 17 (n = 85)	**0.005**
		Public	85 ± 14 (n = 101)	
	Estimated Income	Above U.S. Median	82 ± 16 (n = 107)	0.66
		Below U.S. Median	81 ± 17 (n = 79)	
	Education	>High school	80 ± 17 (n = 107)	0.13
		≤High school	85 ± 13 (n = 36)	

Table 5

Race/Ethnicity and Insurance Status as Predictors of Health Related Quality of Life at First Clinic Visit

	White Mean (± SD) [Range]	**Non-White Mean (± SD) [Range]**	**T-test *p* value**	**Private Insurance Mean (± SD) [Range]**	**Public Insurance Mean (± SD) [Range]**	**T-test *p* value**
n	55	131	-	85	101	-
Age at Assessment (months)	8.4 ± 4.6 [2 – 23.9]	9.3 ± 5.3 [2.5 – 23.6]	0.25	8.5 ± 5.3 [2 – 23.9]	9.5 ± 4.9 [3.3 – 23.6]	0.18
Physical Score	68 ± 23 [8 – 100] (n = 54)	77 ± 19 [21 – 100] (n = 130)	**0.004**	70 ± 21 [17 – 100] (n = 84)	78 ± 20 [8 – 100] (n = 100)	**0.008**
Emotional Score	80 ± 17 [45 – 100] (n = 54)	89 ± 16 [25 – 100] (n = 128)	**0.002**	82 ± 19 [45 – 100] (n = 83)	90 ± 15 [25 – 100] (n = 99)	**0.004**
Social Functioning Score	76 ± 20 [25 – 100] (n = 54)	86 ± 20 [13 – 100] (n = 126)	**0.003**	79 ± 21 [25 – 100] (n = 82)	86 ± 20 [13 – 100] (n = 98)	**0.016**
Cognitive Score	84 ± 20 [25 – 100] (n = 54)	90 ± 16 [20 – 100] (n = 125)	0.06	83 ± 21 [20 – 100] (n = 80)	92 ± 13 [50 – 100] (n = 99)	**0.001**
Communication Score	82 ± 18 [33 – 100] (n = 52)	89 ± 19 [0 – 100] (n = 120)	**0.022**	84 ± 20 [0 – 100] (n = 77)	88 ± 18 [17 – 100] (n = 95)	0.18
Worry Score	75 ± 20 [15 – 100] (n = 53)	77 ± 20 [15 – 100] (n = 123)	0.55	75 ± 20 [15 – 100] (n = 79)	77 ± 20 [15 – 100] (n = 97)	0.50
Daily Score	64 ± 27 [0 – 100] (n = 53)	76 ± 28 [0 – 100] (n = 120)	**0.012**	66 ± 29 [0 – 100] (n = 77)	78 ± 27 [0 – 100] (n = 96)	**0.007**
Family Score	83 ± 20 [25 – 100] (n = 53)	90 ± 16 [35 – 100] (n = 122)	**0.028**	85 ± 19 [25 – 100] (n = 79)	90 ± 16 [35 – 100] (n = 96)	**0.040**
Total Score	77 ± 16 [42 – 100]	84 ± 15 [36 – 100]	**0.012**	78 ± 17 [44 – 100]	85 ± 14 [36 – 100]	**0.005**

Table 6

The Effect of Respiratory Morbidities on Health Related Quality of Life

Morbidity Category	**Respiratory Morbidity**	**Number of Subjects [Number of Forms]**	**Effect on Quality of Life Regression Coefficient[*] [95% CI]**	***P* value**
Respiratory acute care since last clinic visit (or since discharge from NICU for first clinic visit)	Emergency Department Visit	177 (355 forms)	−9.9 [−15.4, −4.2]	**0.001**
	Hospitalization	178 (354 forms)	−7.5 [−14.9, −0.1]	**0.048**
	Systemic Steroid Use	176 (350 forms)	−5.0 [−9.8, −0.3]	**0.036**
	Antibiotic Use	178 (355 forms)	−1.9 [−6.1, 2.4]	0.38
Symptoms since within the past week	Any Difficulty Breathing	172 (336 forms)	−9.1 [−14.0, −4.3]	**<0.001**
	Rescue β-agonist Use	172 (337 forms)	−8.7 [−14.1, −3.3]	**0.002**
	Activity Limitations	167 (326 forms)	−15.9 [−22.5, −9.3]	**<0.001**
	Nighttime Symptoms	169 (336 forms)	−12.6 [−18.9, −6.2]	**<0.001**
Since last clinic visit (or since discharge from NICU for first clinic visit)	Weight Gain	170 (330 forms)	6.0 [−0.7, 12.1]	**0.053**

[*] Regressions were constructed with the quality of life measurement as the outcome (dependent) variable and a particular morbidity as the predictor (independent) variable. All regressions were adjusted for race/ethnicity, insurance status, and age of the subject of the time of form completion. Regressions were clustered by subject as a subject may be represented more than once.