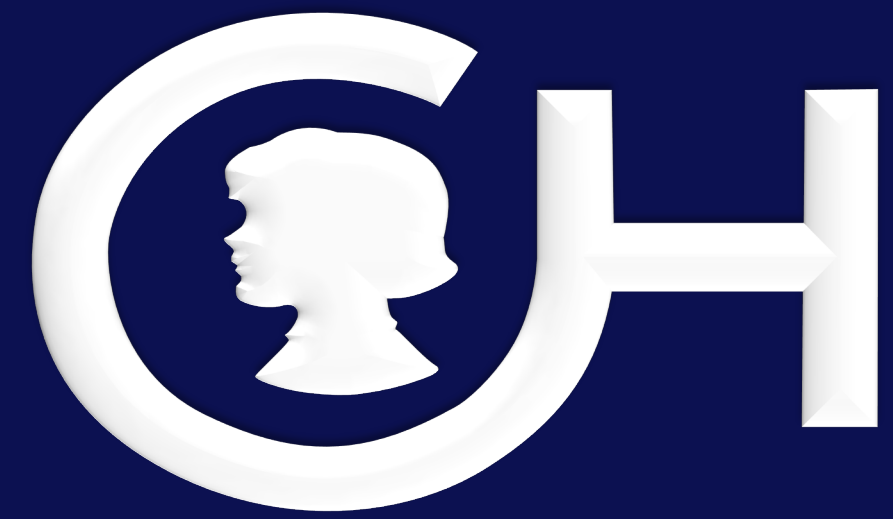


Health Related Quality of Life Among Parents of 3-7 Year Old Children with Severe Bronchopulmonary Dysplasia

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BACKGROUND

Bronchopulmonary dysplasia (BPD) is the most common morbidity of prematurity. Studies have shown that in the first two years of BPD patients' lives, increased respiratory symptoms and acute care usage were associated with lower parental health related quality of life (HRQoL) (McGrath-Morrow et al.). However, little is known about how a parent's general perception of their child's health relates to the parent's own HRQoL and to measures of the child's health utilization at early school age in children with severe BPD.

OBJECTIVES

1. To report associations between parental general report of their child's health and parents' self-reported HRQoL.
2. To investigate relationships between child's health service utilization and parents' self-reported HRQoL.

DESIGN/METHODS

- Ongoing, prospective observational study done through phone interview
- Inclusion criteria:
 - Child was cared for by the Chronic Lung Disease Program at Children's Hospital of Philadelphia
 - Discharged alive between 4/1/2010-4/2/2020
 - Were aged 3-7 years old at the time the questionnaire was administered
- Instruments used:
 - PedsQL v. 2.0 Family Impact Module (FIM) measured parental HRQoL
 - Medical history
- Traditional statistics were used to describe the cohort
- Unadjusted and adjusted linear regression was used to evaluate associations between measures of health utilization and parental HRQoL

Table 1: Characteristics of Cohort n = 76

Perinatal Characteristics	
Gestational age (weeks)	25.9 +/-2.6
Birth weight (grams)	844 (+/- 495)
Female	39%
Race*	
• White	44%
• Black or African American	27%
• Asian	4%
• Other	25%
Ethnicity*	
• Not Hispanic or Latino	87%
• Hispanic or Latino	13%
Length of hospital stay (wks)	36.6 +/- 16.5
Tracheostomy	43%

* = 1 declined

Table 2: Status at Follow up n = 76

Respondent	
• Mother	87%
• Father	9%
• Other	4%
Rehospitalizations since discharge, median [IQR]	3 [1,7]
Current number of medications used, median [IQR]	2 [1,3]
Medications to treat pulmonary disease	79%
Home nursing (in past year)	42%
Therapies in the past year, median [IQR]	3 [2,4]

RESULTS

Table 3: Parental Description of Child's General Health vs. Average PedsQL FIM Total Score

Response: In general, how would you describe your child's health?	Percent	Average PedsQL FIM total score
Excellent	24	83.5 +/- 16.2
Very good	34	77.9 +/- 17.2
Good	33	71.5 +/- 17.7
Fair	8	53.6 +/- 19.1
Unknown	1	26.4

Table 4: Health Status vs. HRQoL (PedsQL FIM Total Score)

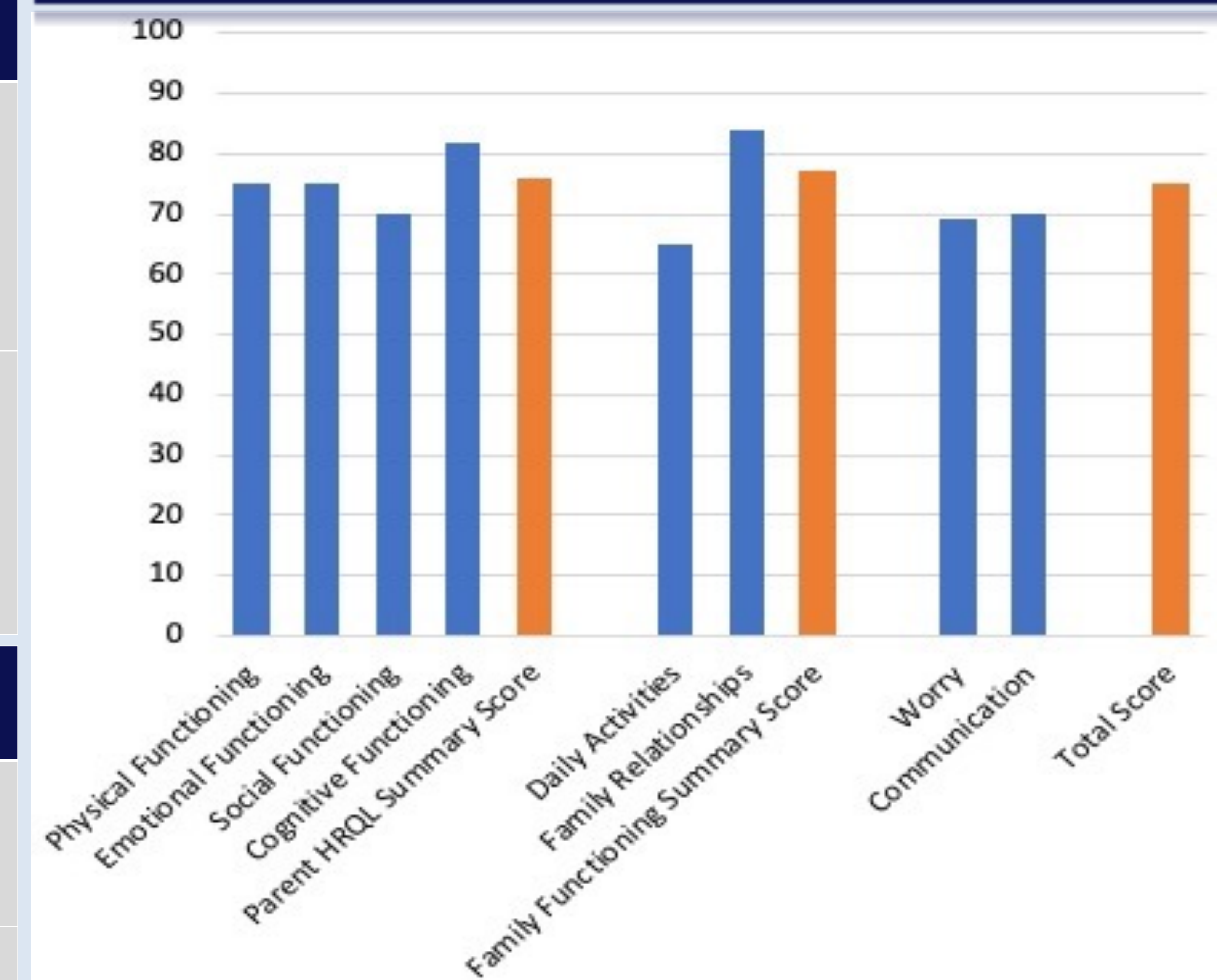
Health Status Indicators	Change in PedsQL FIM Total Score	p-value
Medication (per 1 medication increase)	-3.2 +/- 1.3	0.015
Therapies (per 1 therapy increase)	-5.2 +/- 1.3	<0.001
Rehospitalizations (per 1 event increase)	-3.6 +/- 0.8	<0.001
Tracheostomy	-13.5 +/- 5.4	0.014
Home Nursing	-11.7 +/- 4.3	0.008

References and Acknowledgments

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McGrath-Morrow, S. A., Ryan, T., Riekert, K., Lefton-Greif, M. A., Eakin, N., & Collaco, J. M. (2012). The Impact of Bronchopulmonary Dysplasia on Caregiver Health Related Quality of Life During the First 2 Years of Life. *Pediatric Pulmonology*, 48(6), 570-586.

Figure 1: PedsQL Family Impact Module (FIM) Scores



CONCLUSIONS

This study demonstrates a significant association between the health of children with severe BPD and their parents' quality of life. For each unit change in the parental rating of their child's general health, the PedsQL FIM decreased by 8 +/- 2 points (p<0.001). In unadjusted comparisons, all indicators of the child's health status used were associated with significant decrease in the PedsQL FIM score (Table 4). Our results confirm the relationship between acute care usage and parental HRQoL, while also showing other highly associated factors (Table 4). Further, we demonstrate that that a positive view of their child's health is a strong indicator of a high HRQoL for the parent, despite having medically complicated children. Knowledge of factors that predict HRQoL for parent's caring for children with BPD is important in identifying families that would benefit from additional support.