



# Family-Centered Assessment and Function for Children With Chronic Mechanical Respiratory Support

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## ABSTRACT

**Introduction:** The purpose of this study was to assess health-related quality of life (HRQL) when managing severe, chronic respiratory insufficiency (CRI) at home.

**Methods:** Families enrolled in a comprehensive program for CRI completed the Child Health Ratings Inventories with (a)

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parent-proxy ratings of the child's HRQL and (b) the parent's *own* HRQL. Psychometrics and known groups comparisons were reported. Linear regressions models assessed the effect of the parent's HRQL on proxy ratings.

**Results:** Eighty-six parents (67%) completed the measures. The child global HRQL score was low (63.1,  $SD = 24.9$ ), although ratings of "family life" were higher (73.8,  $SD = 26.5$ ). The parent global HRQL and emotional functioning (EF) scores were low, despite preserved physical and role function. Having a child with a congenital versus an acquired disability was associated with higher parental EF ( $p = .004$ ). Higher parental EF correlated with a higher global child HRQL ( $p < .001$ ).

**Discussion:** Families of children with CRI experience reduced HRQL. The Child Health Ratings Inventories is a valid tool for this assessment, identifying emotional distress and potential gaps in support. *J Pediatr Health Care.* (2014) 28, 295-304.

## KEY WORDS

Quality of life, respiratory insufficiency, chronic disease management, disabilities, family

Chronic respiratory insufficiency requiring assisted ventilation is one of the most serious health-related complications faced by children with physical and developmental disabilities. The estimated prevalence of mechanical ventilator dependence among children in the United States is 6 per 100,000 (Gowans, Keenan, & Bratton, 2007). Historically, these children were cared for in hospitals or long-term care facilities.

Innovations in medical technology, coupled with a growing appreciation of the societal contributions

of children and adults with disabilities, have allowed children with chronic respiratory failure support to remain at home and be integrated into their communities (George, 2010). The 2005 Massachusetts census demonstrated a threefold increase in community-based cases of children receiving chronic ventilator support during the prior decade (Graham, Fleegler, & Robinson, 2007). Despite efforts to support these children and their families, care coordination for this vulnerable group of children remains suboptimal (Dybwik, Tollali, Nielsen, & Brinchmann, 2011; Graham, Pemstein, & Palfrey, 2008; McPherson, Lairson, Smith, Brody, & Jefferson, 2002; Zorc et al., 2003). The Chronic Care Model with its interrelated components of self-management support, clinical information systems, delivery system redesign, decision support, health care organization, and community resources has not been readily implemented (Bodenheimer, Wagner, & Grumbach, 2002).

At the center of home-based care are the children and young adults and their parent caregivers. The latter serve as a conduit of information between hospital- and community-based providers. Parents are responsible for care coordination, early detection of emerging problems, and mastery of the medical equipment. The all-consuming care needs of the child and the unpredictability of the clinical course, characterized by unexpected acute decompensations, even in cases of chronic conditions (Serwint & Nellis, 2005), may produce hypervigilance and fear, as well as distrust of other caregivers, emotional and physical exhaustion, and severe disruption of social health (Carnevale, Alexander, Davis, Rennick, & Troini, 2006). The Caregiver Action Network (2012) estimates that the growing number of adults involved in caregiving activities across the age continuum exceeds 50 million in the United States. Given the pivotal roles of parent caregivers in care management, delivery, and coordination, it is essential to capture their experiences with a valid and reliable measurement of comprehensive health-related quality of life (HRQL). Such understanding is integral to the successful implementation and refinement of the Chronic Care Model, which targets self-management support, decision support, and community resources among its other components.

This study assessed parent's self-ratings of HRQL and parent-proxy ratings of their children's HRQL in families providing home-based, chronic-care management of respiratory insufficiency. HRQL is a multidimensional construct, incorporating physical, emotional, and role (family, community, and societal) functioning. We first conducted psychometric analysis and known groups comparisons for the HRQL measures. We then sought to identify demographic and clinical factors associated with parental self-report and parental-proxy report of HRQL. We anticipated finding appreciably lower scores across

HRQL domains when compared with other pediatric populations. Additional understanding of HRQL considerations will guide providers and families in shared decision making (Fiks, Mayne, Localio, Alessandrini, & Guevara, 2012) and in the development of timely interventions designed to optimize provider-parent partnerships and improve patient-related outcomes.

## METHODS

### Participant Selection and Recruitment

The Critical Care, Anesthesia, Perioperative Extension (CAPE) and Home Ventilation Program was established in June 2007 at Boston Children's Hospital to care for children who are dependent on respiratory technology. Underlying diagnoses represented known patterns of disease (Graham et al., 2007; Odetola, Gebremariam, & Davis, 2010), including a small proportion of intrinsic lung disease and a predominance of neuromuscular conditions with secondary respiratory insufficiency (e.g., spinal muscular atrophy, muscular dystrophies, spinal cord injury, and complex conditions related to hypoxic ischemic encephalopathy or epilepsy syndromes). Program objectives were to provide comprehensive, longitudinal service through individualized care including home visits, liaison with rehabilitation programs and outpatient clinics, school in-service sessions, inpatient consultation, and 24-hour-a-day response for remote acute-care management.

Participants eligible for initial screening included parents of children aged 30 days to 22 years who began receiving ongoing care as part of the CAPE program prior to February 1, 2012 ( $N = 129$ ). Some program participants were ineligible because of their age (i.e.,  $> 22$  years;  $n = 60$ ), because they had single consultations ( $n = 38$ ), because they lived in a residential facility ( $n = 12$ ), or for medical/other reasons ( $n = 2$ ; Figure 1). All potentially eligible participants received an Institutional Review Board-approved information letter describing the study and inviting them to participate. A prepaid, addressed study opt-out card was included to be returned within 2 weeks; 13 parents opted out. All remaining parents ( $n = 116$ ) were contacted by telephone to further assess study eligibility and obtain consent. Parent caregivers had to be at least 18 years of age and have regular contact with and participate in the ongoing care of the child enrolled in the CAPE program. They also needed a working knowledge of English and the ability to provide consent for their own participation. Among the 129 eligible parents, 106 (82%) consented to participate and were enrolled in this study; 90 (70%) completed the baseline assessment, but four Spanish speakers were excluded because the HRQL measures used in the current analysis were only available in English.

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