



Original Research

Chronic respiratory failure: Utilization of a pediatric specialty integrated care program



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ABSTRACT

Objective: Describe utilization and satisfaction in a specialty integrated care program for children with severe, chronic respiratory insufficiency (CRI).

Subjects: Enrollees of the Critical Care, Anesthesia, Perioperative Extension (CAPE) and Home Ventilation Program.

Methods: Children with CRI received home visits, care coordination, and “on-demand” 24/7 access to physicians. Program activity and outcomes were recorded for 3 years using an adapted Care Coordination Measurement Tool© version. Parents completed the Consumer Assessment of Healthcare Providers and Systems (CAHPS). Patient characteristics, program activity, clinical outcomes, utilization, and satisfaction were summarized using descriptive statistics.

Results: CAPE provided care for 320 patients from 2012 to 2014 with a median of 7 encounters per year. Neuromuscular (n = 132, 41%), chronic lung disease (n = 37, 12%), and congenital heart disease (n = 13, 4%) represented the majority of underlying conditions. Services included 905 home, 504 clinic, and 3633 telephone encounters, of which 43.6% included a care coordination activity. CAHPS (n = 102) revealed that 92.1% (n = 93) of children had at least one non-urgent (i.e., routine) visit and nearly two-thirds (64.7%, n = 66) reported the need for urgent or emergency care. Overall, parents were highly satisfied with CAPE, with a mean satisfaction rating of 9.3 (± 1.3) out of 10. Most parents reported that the CAPE team understood the child's (96.0%, n = 95) and family's day-to-day life (86.9%, n = 86).

Conclusions: When given open access to an integrated care program, children in our highly complex population required a median of 7 encounters per year. We believe that this experience is scalable and may inform other organizations contemplating similar services.

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1. Introduction

Chronic respiratory insufficiency (CRI) requiring assisted ventilation is one of the most serious health-related complications faced by children with physical and developmental disabilities. Historically, these children were cared for in hospitals or long-

term care facilities, separated from their families. Technologic innovation, coupled with a growing appreciation of the broader social contributions of individuals with disabilities, have allowed children with CRI to remain at home and integrate into their communities with life-sustaining mechanical support¹.

The need for intensive supports (e.g., transtracheal or non-invasive ventilation, assisted cough, home nursing, parenteral and assisted enteral nutrition, and continuous monitoring) reflects a range of underlying conditions, including neuromuscular disorders, spinal cord injuries, parenchymal pulmonary diseases, and respiratory dysfunction (e.g., central hypoventilation), as well as a burgeoning population of children with complex congenital heart disease.¹ Approximately 6/100,000 children in Utah in 2004 require transtracheal mechanical ventilator assistance²; authors extrapolated that an estimated 4000–6000 children receive ventilator support at home throughout the US. A study from

Abbreviations: CAHPS, Consumer Assessment of Healthcare Providers and Systems survey; CAPE, Critical Care, Anesthesia, Perioperative Extension and Home Ventilation Program; CCMT, Care Coordination Measurement Tool; CRI, chronic respiratory insufficiency; ED, emergency department; SD, standard deviation; SE, standard error; VACHP, The Pennsylvania Ventilator Assisted Children's Home Program

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Massachusetts identified a threefold increase ventilator support in the community over the decade from the mid 1990 to early 2000 s.³ Despite complex needs, affected children may experience better developmental outcomes if cared for in a home setting⁴ and home-based care can be appreciably less expensive than institutional care.^{5–7}

Efforts to support children with CRI at home are extensive, but coordination for this vulnerable group of children remains suboptimal.^{8,9} Most often, the homecare team is led by parent caregivers^{10,11} with virtual intensive care units (ICUs) constructed at home and parents “on-duty” all of the time. As a result, Herculean efforts are required to maintain this care and any semblance of normal family life.^{12–14} Predictably, such demands result in parental emotional distress and diminished global health-related quality of life (HRQL) for both child and parent.^{15–19}

Meanwhile, care systems are fragmented, episodic, inconsistent and, often, inadequate in critical areas such as home nursing, respite, psychosocial support, health education, and marital counseling. Parents frequently experience poor community acceptance with diminished social and employment opportunities.¹⁷ Professional perspectives on children’s true needs and HRQL also often differ from those of their families.^{20–28} For children with CRI, this discrepancy between provider understanding and family experience is potentiated and demands a more family-centered approach.^{16, 29–38}

Even medical support of this vulnerable group of children remains suboptimal. Extensive costs are incurred by families and payers related to preventable hospital-based care.^{8,39,40} Nationally, children with any degree of technology dependence have a nearly 400-fold greater risk of requiring an ICU admission during the course of a year compared to a previously healthy child.⁴¹ A study of ICU admissions between 1997 and 2006 found an increasing proportion of children with comorbid conditions (35% to 41%) and a consistent two-fold increase in charges when compared to children without prior conditions.⁴² Higher illness severity, longer ICU stays, and longer hospital admissions are predictive of decreased adherence to outpatient appointments independent of socioeconomic or demographic risk-factors.⁴³

An opportunity exists, therefore, to improve HRQL while decreasing total medical expenses. Traditional models of care separate routine health maintenance in the community and acute, episodic, hospital-based care. More recent models of integrated care or “enhanced medical homes” merge services for children with a range of chronic illness, reducing serious illnesses and costs.⁴⁴ The challenge remains accessing the appropriate services at the appropriate time, whether community or hospital-based, and empowering families. Hence, we developed a program to test the feasibility of an open access provision of “on demand” care coordination and specialty physician services for families of children with CRI and complex medical needs. Here we report our three-year experience with that program and family perception of the program.

2. Methods

2.1. Program and patient cohort description

The Critical Care, Anesthesia, and Perioperative Extension (CAPE) Program was established in June 2007 at Boston Children’s Hospital (BCH) to care for children with respiratory technology dependence. Program objectives were to provide comprehensive, longitudinal service through individually tailored care with home visits, and to liaise with acute care inpatient services, rehabilitation programs and outpatient clinics, school programs, and community services, including homecare nursing, early intervention

programs, and therapists. A critical feature of the program was provision of continuous (24-h per day/7-days per week), family-driven access to critical care physicians and other professionals. Patients were referred from inpatient ICU services, primary care, family self-referral, and specialized care teams (e.g., cardiology, transplant, pulmonary, neurology). There were no exclusions. All patients identified a primary care pediatrician; the objective of the CAPE Program was to partner with community providers for routine health maintenance while addressing gaps in care related to the child’s underlying complex condition and needs. The CAPE Program was provided in lieu of a traditional, hospital-based pulmonary / respiratory clinic program.

Patients enrolled in the CAPE Program received scheduled home and clinic visits at regular intervals with unrestricted family-driven program utilization. Routine immunizations and evaluations were provided through the primary care, except for rare instances when seasonal Influenza vaccination was provided in the home. Primary care or CAPE providers (for acute, subacute, or care coordination issues) were engaged at the families’ discretion. Primary care could also contact CAPE directly and partnership was bidirectional. The original CAPE Program was staffed by a part-time ICU physician (MD) and full-time respiratory therapist (RT). In 2011, BCH internal grant support permitted expansion to include a nurse practitioner (NP), social worker (SW), and program administrator. The experience reported here is that of the full-service multidisciplinary program. As part of the 2011 program expansion, parents of age-eligible children (30 days–22 years) were invited to participate in a formal evaluation of the CAPE Program, including a serial assessment of patient-and family-centered outcomes, and parent satisfaction. Results of HRQL assessments are reported elsewhere.¹⁵

2.2. Demographic and clinical characteristics

Demographic and clinical information was extracted from the medical chart for all enrollees, including child age and gender, clinical severity⁴ (1=least severe, 10=most severe), respiratory support needs (i.e., “artificial airway” tracheostomy alone, “artificial+ventilator” for those on transtracheal supports, “non-invasive” for those on CPAP or BiPAP, and “none” for those with burgeoning needs or symptom management alone chosen by the family), primary and secondary insurance type, driving distance from BCH, and diagnostic category. Diagnostic categories included acquired injury, congenital anomalies, chronic lung disease, congenital heart disease, muscular dystrophies and spinal muscular atrophy (i.e., congenital neuromuscular), and other. This categorization schema is consistent with those used in previous studies for children with tracheotomy.^{3,42,45} Patients who received only a single consultative service were excluded from the reporting and analysis. Service for enrolled patients was retrospectively identified as respiratory (primarily involving management of ventilation, pulmonary, and aerodigestive issues), specialty (inclusive of respiratory but extended to comprehensive care and care coordination), or residential (primarily respiratory consultative role for those living at a long-term care facility).

2.3. Specialty integrated care program utilization and evaluation

The Care Coordination Measurement Tool© (CCMT) is among a limited panel of validated quality metrics for healthcare delivery.^{46–48} Developed for pediatric primary care practices, it serves to 1) quantify and characterize care-coordination activities, 2) assess the relationship between this activity and outcomes related to resource utilization, and 3) inform resource allocation and personnel needs.⁴⁸ The CCMT was modified to track CAPE Program-specific activity, encounter characteristics, and outcomes

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