

The Pediatric Aerodigestive Center as a Tertiary Care-Based Medical Home: A Proposed Model

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Children with special healthcare needs have been identified nationally as a population whose health care is associated with unmet needs; increased morbidity; fragmentation of care and medical errors; caregiver dissatisfaction; and disproportionately high costs. A subset of these children are medically fragile, with medical complexity that requires a reliance on tertiary care-based services—including subspecialty appointments, surgical procedures, and care coordination resources. For medically complex patients affected by upper and lower respiratory tract and gastrointestinal disorders,

multidisciplinary aerodigestive centers have emerged at tertiary care centers across the United States to facilitate coordinated, high-quality, and high value care. We propose that the aerodigestive center is an effective vehicle for a tertiary care-based medical home. Within this model, the integration of a general pediatrician will help promote holistic, patient-centered care, and the general pediatrician can serve to both support and provide continuity with the primary care medical home.

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On a recent afternoon in our program's aerodigestive center clinic, a 28-month-old male* was brought in by his parents for a coordinated follow-up evaluation. He was scheduled to be seen in succession by his otolaryngologist, pulmonologist, gastroenterologist, and speech therapist as part of a multidisciplinary care model that has emerged at tertiary care centers across the United States.¹⁻⁶

The child was born at 26 weeks gestational age and is followed at our aerodigestive center for consequences related to his prematurity. These include severe bronchopulmonary dysplasia (BPD); tracheostomy dependence due to chronic respiratory failure and acquired subglottic stenosis; cerebral palsy; mild global developmental delays; gastroesophageal reflux disease; and poor weight gain requiring gastrostomy tube placement to support growth and nutrition. More recently, his airway status has improved; and pending further evaluation by bronchoscopy, he may be a candidate

for decannulation. Despite this improvement in his respiratory status, his other medical problems continue to require intensive therapies and care coordination. His developmental delay will require on-going support from occupational therapy, speech therapy, and physical therapy, and he will continue to receive regular botulinum toxin injections from his physiatrist to help manage spasticity. He was also referred to a neurologist this month to evaluate for seizures after his parents witnessed several staring episodes.

This patient's development and chronic medical problems were previously monitored by a neonatology follow-up program, but he has since 'graduated' from their clinic. Despite the family's excellent adherence to aerodigestive center appointments, visits to the patient's community pediatrician for routine primary care have been infrequent. This is due, in part, to the burden of numerous recurring specialty care appointments, which has led to difficulties maintaining a care plan across different medical teams, whose care communication is often limited to written health records and may require a substantial time commitment for his pediatrician to review. And while the aerodigestive center has provided care coordination for their son's airway, respiratory and gastrointestinal problems, the parents voice a desire that his other chronic medical problems could be afforded similar resources.

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Identifying Medically Complex Patients

Providing high value, high quality medical care for patients like this has been the subject of much research, policy and legislative attention across the last several decades. Beginning in the 1970s, studies in child health epidemiology revealed increases in the number and proportion of children with chronic conditions and disabilities.⁷ Medical and technological advances in high-risk obstetrics and neonatal intensive care have helped drive this trend through significant improvements in the survival rates of the smallest and youngest of premature infants. And while these advances have overall improved infant mortality, the morbidity of infants who survive to discharge remains significant, with moderate to severe disability found in up to 50% of infants born at 23–26 weeks gestation.^{8,9} Moreover, common medical conditions associated with prematurity—including BPD and feeding difficulties—are not only associated with increased risk of re-hospitalization within the first year of life,¹⁰ but they also have lasting impacts on neurodevelopment.^{9,11–13}

With this increasing number and proportion of children with chronic conditions and disabilities, children with special healthcare needs (CSHCN) have emerged as a population in need of national resources and dedicated study. Beginning with the federal Omnibus Budget Reconciliation Act of 1989 and continuing with the Supreme Court of the United States' decision in the 1990 case of *Sullivan v Zebley*—both of which served to broaden the scope of access for CSHCN^{7,14}—policy makers have paid significant attention to serving this population. Indeed, in 2001, the Institute of Medicine highlighted CSHCN as a priority population.¹⁵

Defining this population has been a challenge, however, and health policy researchers and experts in the field have published extensively on establishing a

means of identifying CSHCN.^{7,16–33} The federal Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs established the current consensus definition: as defined by a working group of experts, and since cited extensively in the literature, CSHCN are “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”⁷

This definition, while broad, has allowed for dedicated study of CSHCN, with research revealing a significantly disproportionate amount of healthcare spending in this population. Indeed, while some data suggest CSHCN comprise between 15% and 18% of all children, they account for more than 80% of the cost of health care

for children in the United States.^{26,28} However, despite increased spending, this population is differentially affected by unmet healthcare needs¹⁵; hospitalization for acute illnesses, with increasing rates noted over time³⁴; and unscheduled admissions to the intensive care unit. Of these admissions, 32% are potentially preventable, owing to deficiencies in care coordination and other care systems.³⁵ Furthermore, CSHCN are more likely to be victims of medical errors, thought to

reflect the complexity of their care.^{15,36,37} Perhaps as a result of these disproportionate care burdens, data has shown that families of CSHCN are less likely to be satisfied with their care,³⁸ and they are subject to significant psychosocial stressors³⁹—some of which may result in hospitalization for their child.⁴⁰

Galvanized by these data, health policy researchers have

begun targeting for study the most medically vulnerable subset of CSHCN, citing the heterogeneity of the CSHCN definition as a limitation to understanding and improving care.¹⁵ This subset of children with complex medical care needs has been described in the literature using various terminologies, including “medically

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complex children;”¹⁵ “medically fragile children;”⁴¹ and children with “complex chronic conditions.”²⁰ Herein, we shall refer to the population of “medically complex children” (MCC) to describe the subset of CSHCN who have complex medical care needs. This population encompasses children like the male infant cited above, who are affected by multi-system diseases requiring multiple medications and sub-specialists; who may have frequent admissions; who may be technology dependent; and for whom care coordination in the inpatient and outpatient settings is critical.¹⁵ ‘Aerodigestive’ patients, by this definition, thus represent a unique subset of the MCC population whose chronic medical problems include—but are not limited to—complex congenital or acquired disorders affecting breathing, swallowing and growth to various degrees.¹

The Medical Home

Policy leaders have looked at changes in care delivery design to guide improvements in care for MCC. As described by Berwick et al., efforts to improve quality of health care have largely centered on the six domains identified by the Institute of Medicine: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity.⁴² The ultimate goal of targeted interventions is to provide a care model that meets the ‘triple aim’ proposed by the Institute for Healthcare Improvement, in that an intervention should help improve the experience of care; that it should improve the health of the population; and that it should help reduce the per capita costs of healthcare.⁴²

The concept of the medical home emerged in the late 20th century as a model for delivering the highly integrated, coordinated care necessary to ensure quality and value needs are met for the MCC population. As described by the American Academy of Pediatrics (AAP), a medical home should not only provide family-centered, longitudinal care, but it should also make provisions for information sharing and sub-specialty care coordination.^{43–45} And in their more recent revisions to the consensus definition of the medical home, the AAP emphasizes care

coordination as a particularly critical element of care for families with MCC, citing the needs identified by patients and providers.^{45,46} The goals of care coordination should be to (1) develop an anticipatory/proactive plan for appropriate services for the child and family, integrating the recommendations of multiple professionals and service systems; (2) assist the family in accessing needed services and resources; (3) facilitate communication among multiple professions; (4) avoid duplications of services and unnecessary costs; (5) optimize the physical and emotional health and well-being of the child; and (6) improve the child’s and family’s quality of life.⁴⁶

These core principles of the medical home model may be applied across different care settings. And while traditional derivations of the medical home have been based in the patient’s primary care community, the tertiary care center has recently emerged as a site for application of the medical home. Indeed, tertiary care health systems across both adult and pediatric populations have increasingly evolved applications of the medical home in an effort to address the needs of the high-risk patients requiring specialty care.

With these evolving applications, the effect of the medical home in improving quality and cost of healthcare has become a focus of study for health researchers. In adult populations and in single disease care models, for example, enrollment in a medical home that provides multidisciplinary, coordinated disease management has been associated with both decreased mortality^{47,48} and decreased healthcare costs.⁴⁹ Applying the medical home model in the care of MCC reveals similar trends, with several studies in the literature demonstrating

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improvements in quality and cost of care for MCC enrolled in a medical home. For example, in a randomized control trial of high risk patients with chronic illness, Mosquera et al. found that enrollment in a primary care-based comprehensive care program reduced serious illnesses, emergency department visits, hospitalizations, pediatric ICU admissions, and length of stay for hospital admission, with an associated reduction in both Medicaid payments and total hospital and clinic costs.⁵⁰ Gordon et al. reported similar

results, also finding that enrollment of MCC in a tertiary care-based medical home reduced the study population's number of hospitalizations and number of hospital days, with a shift from inpatient to outpatient costs.⁵¹

This trend was recapitulated in a study by Casey et al, who reported that enrollment in a tertiary care-based medical home resulted in a net decrease in Medicaid spending per patient, with a similar shift noted in costs from the inpatient to the outpatient setting.⁵² It is worth mentioning, however, that one study of MCC enrolled in a tertiary care-based medical home only revealed an associated decrease in length of stay for non-intensive care without any net benefit in cost reduction; rather, there was a shift from costs incurred from inpatient to outpatient services. Notably, this study was limited by its dual enrollment of medically fragile patients and their healthy siblings.⁵³

The Aerodigestive Care Model

Applying the model of the medical home to aerodigestive patients poses a unique opportunity for health care improvements; for while the burden of pediatric aerodigestive disorders is unknown,⁴ this subgroup of MCC has several unique features that pose significant challenges. Specifically, the population of aerodigestive patients, as defined herein, is affected by multi-systemic diseases that necessitate the care of multiple subspecialists. This population also has a heavy reliance on technology and surgical procedures. As a result, health care for aerodigestive patients has the potential to be both fragmented and costly. To address these needs, a growing number of tertiary care centers across the country have established multidisciplinary aerodigestive programs capable of providing continuous, patient-centered, highly integrated and coordinated multidisciplinary care,¹⁻⁵ thus meeting several of the criteria for a medical home as defined by the AAP.⁴⁴⁻⁴⁶

With the institutionalization of these multidisciplinary programs, a small but growing body of literature has been published analyzing the effect of program enrollment on aerodigestive patient outcomes and costs. Intriguingly, researchers have identified that the aerodigestive model results in similar effects to a

more traditional medical home. In a landmark study, Appachi et al. analyzed outcomes and health care costs before and after patient enrollment in a tertiary care-

based, multidisciplinary aerodigestive clinic and found that, while the number of admissions per year per child did not significantly change after enrollment, there was a significant decrease in hospital days for all admissions in the post-enrollment period,

with a 70% reduction in hospital days for aerodigestive admissions (e.g., pulmonary, gastroenterology, or otolaryngology-related issues). As a result, there was a large estimated reduction in costs, with an extrapolated reduction of \$1.9 million per year in hospital costs.³ A similar study by Collaco et al. examining the impact of enrollment in a tertiary care-based, multidisciplinary aerodigestive program found evidence of reduction in anesthetic episodes and associated charges, with non-tangible benefits reported in coordination of care and caregiver satisfaction.⁴ Similar cost trends were published by Skinner et al., who analyzed costs before and after enrollment in a tertiary-care, multidisciplinary aerodigestive care program. These authors found a shift in patient costs from inpatient to outpatient services, with an overall 20% reduction in patient charges after enrollment.⁶

These data, while limited to date, are highly promising for the efficacy of an aerodigestive care model in addressing the goals of the 'triple aim,' by improving the experience of care and the health of the aerodigestive patient population while also helping reduce the per capita costs of healthcare. Moreover, the services embedded within the aerodigestive care model in concert with these outcomes data suggest that, for this specific subset of MCC with aerodigestive problems, the aerodigestive center has the potential to serve as a medical home.

Proposing the Aerodigestive Center as a Tertiary Care-Based Medical Home, With a Role for General Pediatricians

Indeed, the aerodigestive care model described above is founded on the core principles of the medical home,^{1-5,44-46} including provisions of patient-centric,

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longitudinal care that spans care settings (e.g., inpatient and outpatient); utilizes a central medical record (within the tertiary care system); and provides families with care coordination resources. However, in order to truly fulfill the role of the medical home, the aerodigestive care model needs to include a general practitioner who can take a holistic view of the patient as well as provide expertise and management for co-morbid medical problems. At present, the vast majority of aerodigestive centers do not incorporate a general pediatrician into their care design: Boesch and colleagues queried 33 specialists from 11 well-established aerodigestive programs across the country using the Delphi method—an iterative, questionnaire-based method of obtaining consensus on a topic—and found that only two participating programs incorporate a general pediatrician in their clinical team.²

We believe this reflects a missed opportunity in providing a comprehensive medical home to aerodigestive patients. Like our own patient described above, a subset of aerodigestive patients have significant medical complexity, with a diversity of comorbid medical problems that may not be sufficiently addressed by multidisciplinary aerodigestive teams. In the example of our patient, he is concurrently followed by several other sub-specialty teams, including neurology, physical medicine & rehabilitation, as well as occupational and physical therapy. And while he is followed by a gastroenterologist as part of his comprehensive aerodigestive care, the scope of his medical complexity would likely benefit from the addition of a nutritionist to his team of care providers.

These specialists do not necessarily need to be incorporated into the aerodigestive center. Rather, a general pediatrician can serve to reflect these specialists' interests, helping the family navigate medication management, care plans, and appointments through the aid of the multidisciplinary team—which may include providers from social work, case management, and clinical nursing backgrounds. With this model, the patient and family benefit from a cohort of providers who are not only embedded within the electronic record and tertiary care system of the patient's sub-specialists, but who also have the resources to provide

effective care coordination—an area that, as defined by the AAP⁴⁶ and the Agency for Healthcare Research and Quality (AHRQ),⁵⁴ is not only costly and challenging for primary care pediatricians,⁵⁵ but that is also often done poorly for MCC across both inpatient and outpatient settings.⁵⁶

In addition to medical management of comorbidities and enhanced care coordination, a general pediatrician can also provide additional support for the aerodigestive population's development needs. These patients, either as a consequence of prematurity or chronic illness, often have issues related to global development. They will often see a speech and language pathologist within the context of the aerodigestive center^{1,2} to help address issues related to swallowing function, but they may also require occupational and physical therapy. The general pediatrician can help identify these needs and facilitate referrals to early intervention services. And for families of school-age children, the pediatrician can provide counseling regarding educational support services, such as those outlined in individualized education programs.

As a part of the aerodigestive medical home, the general pediatrician's role would serve to support, but not supplant, the patient's primary care pediatrician. Indeed, in a majority of the medical home studies refer-

enced above, the focus is on a partnership between the tertiary care-based medical home and the patient's community-based primary care practice. We propose a similar model in which the general pediatrician serves as an interface between the tertiary care-based aerodigestive medical home and the patient's community pediatrician, with the scope of this interaction to potentially include warm hand-offs in the event of admissions to the hospital, major procedures, or changes to the care plan.

Much work is necessary to successfully implement this medical home design within the aerodigestive paradigm, and further research is needed into the longitudinal effectiveness of the aerodigestive care model as a whole. We also recognize that the addition of a general pediatrician in the aerodigestive care model requires a breadth of knowledge of MCC with which some general practitioners may be neither familiar nor comfortable. The proposed addition also

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requires available funding for such a provider. As such, this change of practice will require both educational and fiscal investment by the health system. However, given the encouraging data published to date regarding the effectiveness of the aerodigestive care model in improving health outcomes and costs, we look forward to future studies of the impact of an aerodigestive medical home on this unique population.

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