

# Interaction with Pediatric Healthcare Providers Prior to Admission for Pediatric Critical Illness Due to Respiratory Failure

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## Research Article

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# Abstract

**Objective:** To describe pre-hospital healthcare provider contact and the impact of a child's medical complexity on patterns of contact in the 7 days prior to admission for pediatric critical illness due to respiratory failure.

**Study Design:** Retrospective analysis of data on patients  $\leq 18$  years with respiratory failure admitted to a quaternary pediatric intensive care unit between January 1, 2013 and December 31, 2014. Pre-hospitalization provider contact was compared to the child's medical complexity using Chi square and Kruskal-Wallis tests for categorical and continuous data, respectively.

**Results:** Of 163 patients, the median age was 2.1 years, 59.5% were male, and 33.1% had medical complexity. In the 7 days prior to hospitalization, 68 families (41.7%) had 71 encounters with providers including primary care provider telephone call/office visit (66.2%), telephone contact/office visit with a specialist provider (31%), or urgent care visit (2.8%). Children without medical complexity were more likely than children with medical complexity to have a primary care provider telephone call/ office visit (36.7% vs 13.0%,  $p=0.004$ ). In contrast, children with medical complexity were more likely to have a telephone call or office visit with a specialist (29.6% vs 5.5%,  $p<0.001$ ).

**Conclusions:** In the 7 days before hospitalization for pediatric respiratory failure, nearly 1 in 2 families contacted a healthcare provider with illness-related concerns. During acute medical crisis, children without medical complexity were more likely to contact their primary care provider, while children with medical complexity were more likely to contact a specialist. These findings have important implications for pediatric care delivery.

## Introduction

The medical home is the predominant model for providing comprehensive healthcare to pediatric patients. The medical home is noted by the American Academy of Pediatrics to be accessible, continuous, comprehensive, family-centered, and culturally effective healthcare delivered by a well-trained physician who provides primary care and facilitates all aspects of pediatric care.<sup>1</sup> This role includes providing care to children with acute illnesses in the outpatient setting and helping families assess when they should seek a higher level of care.<sup>1</sup> Further, the medical home is tasked with being the central healthcare provider that coordinates care among a child's specialty care providers.<sup>1</sup> This role is especially important for children with medical complexity. Children with medical complexity are children who have chronic conditions with substantial functional limitations and high healthcare needs.<sup>2,3</sup> These children are often technology dependent and at high risk for hospitalization.<sup>2,4-6</sup> Outside the in-hospital setting, medical homes are an integral part of the care delivery model for both children with and without medical complexity.<sup>1,7-10</sup>

Despite the medical home's key role in prehospital care, little is known about how the medical home is utilized by parents prior to a pediatric intensive care unit (PICU) admission. Specifically, there is a lack of data on how often parents contact their child's medical home or other healthcare providers prior to a PICU admission. Further, the impact of a child's medical complexity on the type of healthcare provider a parent contact remains unknown. Understanding which healthcare providers parents contact during an acute illness will help improve care delivery for children prior to a hospitalization.

In this study, we sought to examine the role the primary care provider, as a proxy for the medical home, and specialty care providers, played in an acute illness and how this varied by a child's medical complexity. To do this, we examined parent-initiated contact with healthcare providers in the seven days prior to a PICU admission. The objective of this study is to describe in the seven days prior to a child's PICU hospitalization for pediatric respiratory failure: (1) frequency and type of healthcare provider contacted by parents; and (2) how a child's medical complexity impacts patterns of parent contact with healthcare providers.

## **Materials And Methods**

### **Study Population**

We conducted a retrospective analysis on data from children 18 years or less admitted to a quaternary PICU with respiratory failure secondary to an intrapulmonary process between January 1, 2013 and December 31, 2014. Respiratory failure was defined as the receipt of invasive or noninvasive positive pressure ventilation due to an intrapulmonary process from disease such as asthma, pneumonia, bronchiolitis, or from acute lung injury. Excluded from our analysis were patients born during the hospitalization, those whose airway was intubated only for airway protection, and patients transferred to another institution. Children were considered medically complex if on PICU admission they had a tracheostomy, home ventilator (via tracheostomy tube or mask interface), and/or a gastrostomy tube, in line with the most commonly used definition that children with medical complexity (CMC) are often technology dependent.<sup>2</sup> The Institutional Review Board of the University of Michigan Medical School approved the study with a waiver of informed consent.

### **Data Collection**

Patient-level data (demographics, comorbid conditions, and hospitalizations characteristics) were obtained through a query of an institutional Virtual PICU System database. Review of electronic medical records was done to collect data on pre-hospitalization healthcare provider contact, functional status, and medical complexity.

### **Study Variables**

Variables collected included: demographics, pre-hospital health status (comorbidities, pre-hospital baseline functional status, and medical complexity), pre-hospitalization healthcare provider contact, and hospitalization characteristics. Demographics included age and sex. Pre-hospital health status included comorbidities, functional status, and medical complexity. Comorbidities were determined using the International Classification of Diseases, 9th revision, clinical modification (ICD-9-CM diagnosis codes).<sup>11</sup> Pre-hospital baseline functional status was determined with the Functional Status Scale (FSS), a validated instrument assessing a child's functional status in 6 domains. Total scores ranged from 6 to 30 with higher scores indicative of worse function.<sup>12</sup> In this study, children were considered medically complex if they had a tracheostomy, home ventilator (via tracheostomy tube or mask interface), and/or a gastrostomy tube, in-line with the most commonly used definition that CMC are often technology dependent.<sup>2</sup>

Pre-hospitalization healthcare provider contact, which included interaction with primary and specialty healthcare providers within the 7 days prior to hospitalization, were identified by review of documentation in the electronic medical record (EMR). The documents reviewed included admission history and physical examination notes, telephone encounter notes, and primary care / specialist office visit notes. Primary care encounters were further coded as community-based primary care or quaternary care affiliated primary care. Community-based primary care providers were any providers not at the quaternary care center, where as quaternary care affiliated primary care providers were primary care providers affiliated with the quaternary care center where the child's subsequent PICU admission occurred.

Hospitalization characteristics included severity of illness measured using the Pediatric Risk of Mortality (PRISM) version III score-derived probability of mortality<sup>13</sup>, type and duration of positive pressure ventilation, use of therapies such as vasoactive medications, extracorporeal membrane oxygenation (ECMO), continuous renal replacement therapy (CRRT), and length of stay in the PICU and hospital.

## Statistical Analysis

Categorical data are presented as frequencies with percentages and continuous data as median values with their interquartile range (IQR). Bivariate comparisons were conducted using chi-square test for categorical variables and Kruskal-Wallis test for continuous variables.

Four separate analyses were performed:

1. Descriptive statistics summarized data for all patients regarding demographics, pre-hospital health status, pre-hospitalization healthcare provider contact, hospitalization characteristics, and type of healthcare provider.
2. Bivariate comparison was performed of demographics, pre-hospital health status, pre-hospitalization healthcare provider contact, hospitalization characteristics, and primary care provider characteristics between children with and without medical complexity.

3. Bivariate comparisons were performed to assess the impact of medical complexity on the type of provider (primary care vs specialist) contacted by a parent.
4. Multivariate logistic regression models were fit to assess for the independent association between the child's medical complexity and the type of provider contacted, controlling for child's age, gender, and comorbidities.

All statistical analyses were performed using STATA for Windows (Stata Corp.; College Station, Texas) version 14.

## Results

### Patient & Hospitalization Characteristics

There were 163 patients included in the data analysis. The patient characteristics are summarized in Table 1. The median age was 2.1 years (IQR, 0.6–10.9 year) and 59.5% of the population were male. Fifty four (33.1%) children were medically complex and 61 (37.4%) had a comorbidity.

When comparing children according to their medical complexity status, children with medical complexity were older (median of 4.6 years vs 1.3 years,  $p < 0.005$ ), were more likely to have a comorbidity (59.2% vs 26.6%,  $p < 0.001$ ), and had worse functional status at hospital admission (median 12.5 vs 6,  $p < 0.001$ ).

Hospitalization characteristics between children with and without medical complexity were similar except that children without medical complexity were more likely to have received vasoactive medications (42.2% vs 24.1%,  $p = 0.023$ ) and ECMO (11.0% vs. 1.9%,  $p = 0.042$ ).

### Pre-hospital Healthcare Provider Contact

In the seven days prior to hospitalization, 68 of 163 families (41.7%) had a total 71 encounters with healthcare providers. Of these encounters, 2 (2.8%) were urgent care visits, 47 (66.2%) were primary care provider telephone call or office visits, and 22 (31%) were telephone calls or office visits with a specialist provider, as displayed in Fig. 1. Among encounters with specialists, pulmonologists were contacted most often ( $n = 15$ , 68.2%). Of those with pre-hospitalization healthcare contact, 26 (36.6%) had a medication dose changed or a new medication prescribed.

### Pre-hospital Healthcare Provider Contact By Child's Medical Complexity

Children without medical complexity were more likely to have a primary care provider telephone call or office visit (36.7% vs 13.0%,  $p = 0.002$ ) in comparison to children with medical complexity (Fig. 2). In contrast, children with medical complexity were more likely to have a telephone call or office visit with a

specialist (29.6% vs 5.5%,  $p < 0.001$ ) than children without medical complexity (Fig. 2). More than 2 out of 3 children (68.5%) with medical complexity had a primary care provider at an institution separate from the quaternary center of study. Importantly, children with medical complexity were more likely than children without medical complexity to have a quaternary care-affiliated primary care provider (31.5% vs. 17.4%,  $p = 0.042$ ) (Fig. 3).

In multivariable analysis controlling for age, gender, and comorbidity, caregivers of children with medical complexity compared to children without medical complexity had a lower odds of calling or visiting with a primary care provider (OR 0.25, CI 0.10–0.65,  $p = 0.004$ ). The model predicted probabilities of a child without medical complexity and a child with medical complexity either having a phone call or visit with a primary care provider was 36.5% and 13.0%, respectively. Also, caregivers of children with medical complexity compared to children without medical complexity had higher odds of calling a specialist (OR 6.06, CI 2.06–17.76,  $p = 0.001$ ). The model predicted probabilities of a child with medical complexity and a child without medical complexity either having a phone call or visit with a specialist was 26.7% and 5.9%, respectively.

## Discussion

Our study findings demonstrate that in the seven days prior to hospitalization for management of pediatric respiratory failure, nearly 1 in 2 families contacted a healthcare provider with illness-related concerns. Additionally, during acute medical crisis, children without medical complexity were more likely to contact their primary care provider, whereas parents of children with medical complexity were more likely to contact a specialist provider. These findings have important implications for care delivery for both children without medical complexity and children with medical complexity.

We hypothesize that the influence of medical complexity on the type of provider contacted by parents occurred due to the different logistics of medical care in these patient populations. Most children without medical complexity visit their primary care provider once a year for a well-child examination and the occasional sick visit.<sup>7</sup> When children without medical complexity become ill, parents logically reach out to their child's primary care provider given their established relationship.<sup>7</sup> In contrast, children with medical complexity are often followed by several specialists along with a medical home or primary care provider.<sup>2,14</sup> Despite the care model that suggests the medical home should be the first contact for all medical concerns, the numerous healthcare providers involved in the care of a CMC could make this less clear for parents. Many children with medical complexity have a prominent chronic system of dysfunction, such as respiratory disease or cardiac disease. As such, these children may follow-up with a specific specialty provider more frequently than their primary care provider. When acute illness concerns occur in that primary area of dysfunction, contacting that specialist could be the most logical provider for a parent to contact. Further, parents may feel that the primary care provider cannot adequately address their concerns about their child's current illness given their medical complexity.<sup>14</sup>

Less than half the parents of children without medical complexity contacted a provider prior to hospitalization for severe illness. Several studies have indicated that early contact with a primary care provider is associated with reduced ambulatory care-sensitive admissions.<sup>15-17</sup> Ambulatory care-sensitive conditions are conditions where a hospitalization could be prevented when primary care is used appropriately.<sup>15-17</sup> While we did not specifically evaluate ambulatory care-sensitive conditions, our data suggests that patients and families could benefit from education on when and how to contact their primary care provider during an acute illness.

With regard to children with medical complexity, it remains uncertain which providers, (primary care or specialists) parents should contact with serious acute illness concerns. In our study, more than 2 out of 3 children with medical complexity had a community-based primary care provider. Due to challenges accessing specialty records or receiving updated documentation from specialists, community-based primary care providers could lack key information to provide medical advice during an acute illness. In contrast, a specialty provider may be unfamiliar with all the varied facets of a child's complex medical history, which also could impair their ability to provide medical advice during an acute illness. Additionally, specialists may be difficult to contact by phone and may not have clinic availability to evaluate patients on an urgent basis. Nevertheless, as we found that only 50% of families with CMC contacted a healthcare provider, we would encourage families with CMC to reach out to a healthcare provider with acute illness concerns. Based on our findings, we would recommend that children with medical complexity have an acute illness plan as part of a larger comprehensive care plan. Comprehensive care plans, developed by the medical home or primary care provider, have been reported to be significantly helpful in the delivery of care to CMC by helping to ensure coordinated and comprehensive patient care across specialties, institutions, and hospitals.<sup>18,19</sup> Specifically, our findings stress the importance of a well-established emergency care plan component to this comprehensive care plan. These plans would detail which symptoms parents should monitor and which health care provider they should call for each specific symptoms. Similar emergency care plans used in children with asthma, Asthma Action Plans, have been well studied and could be helpful in structuring these care plans.<sup>20,21</sup>

Further research examining whether pre-hospitalization provider contact could prevent hospitalizations or reduce illness severity on hospital presentation is needed. While hospitalization for children with medical complexity may be difficult to prevent due to medical fragility, further investigation could elucidate if emergency care plans and/or optimal pre-hospitalization provider contact reduced the severity of illness on hospital admission and morbidity associated with the hospitalization.

This study had several limitations, including the single-center design, its retrospective nature, and the limited 2-year study period. Additionally, data collection was limited to the EMR which reduces the ability to evaluate health care delivery and resource use patterns not documented in the EMR. In this study, children with medical complexity were defined as those with technology dependence. While technology dependence is a component of the generally accepted definition for children with medical complexity,<sup>2</sup> we did not include other components of this definition (congenital or acquired multisystem disease or a

severe neurological condition with marked functional impairment) in our definition. Furthermore, this study did not identify social or economic factors that might alter interactions with healthcare providers prior to hospitalization.

## Conclusions

In the seven days before hospitalization for pediatric respiratory failure, nearly 1 in 2 families contacted healthcare providers with illness-related concerns. Children with medical complexity are more likely to contact a specialist than a primary care provider. These findings highlight the importance of improved education for the role of primary care providers in acute illness care for children without medical complexity and the need for an acute illness crisis plan for children with medical complexity; both could improve care delivery and efficacy in the prehospital setting.

## Declarations

Ethics approval and consent to participate: All experiment protocol for involving human data was in accordance with the guidelines The Institutional Review Board of the University of Michigan Medical School. The Institutional Review Board of the University of Michigan Medical School classified the study as expedited and approved this study with a waiver of informed consent.

Consent for publication: Not Applicable

Availability of data and materials: Data presented in manuscript

Competing interests: Not Applicable

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Authors' contributions: Dr. Pfarr conceptualized and designed the study, drafted the initial manuscript, and reviewed and revised the manuscript. Dr. Yagiela assisted in designing the study, designed the data collection instruments, carried out initial analyses, and reviewed and revised the manuscript. Dr. Odetola coordinated and supervised the data collection and critically reviewed the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of work.

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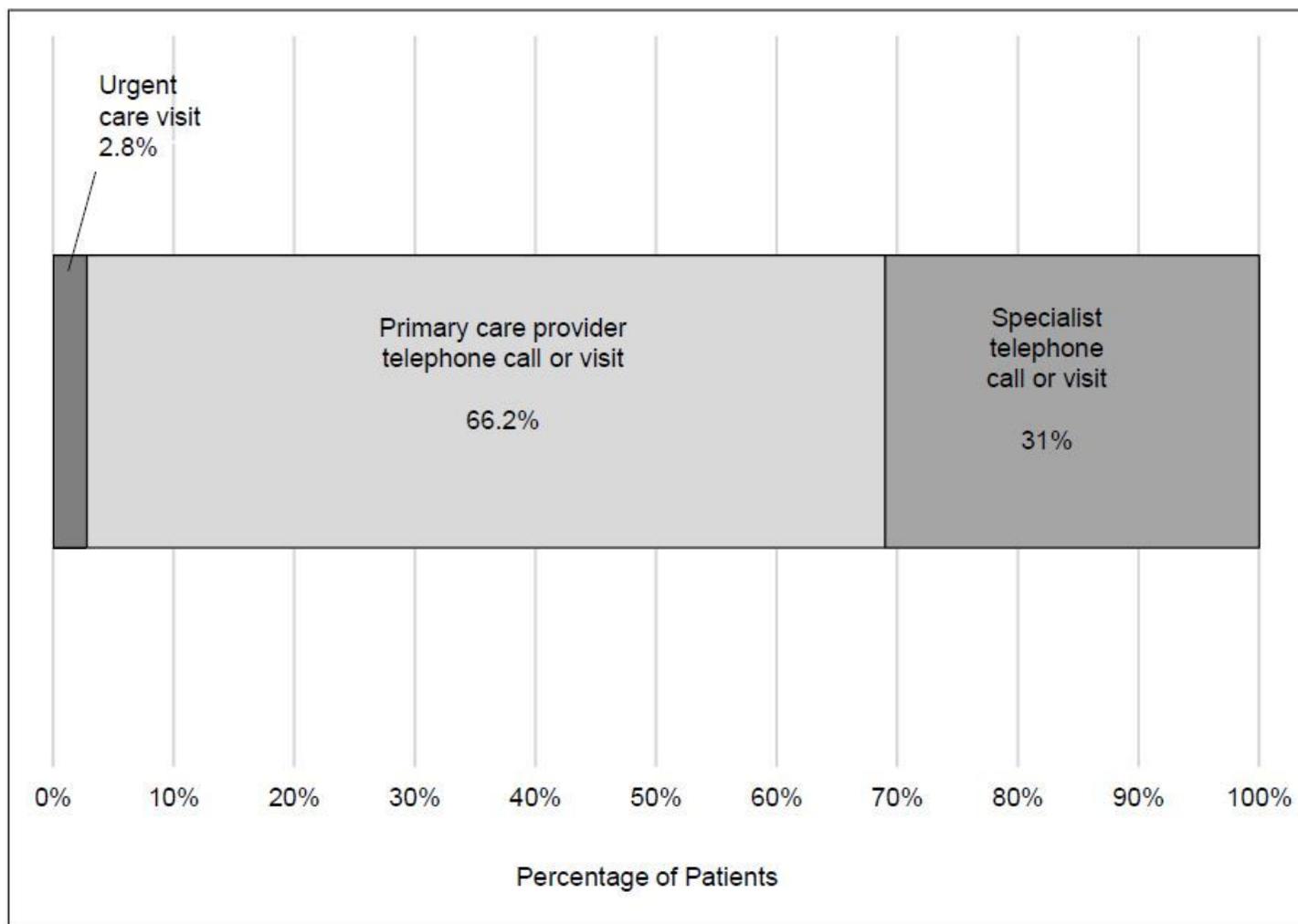
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## Tables

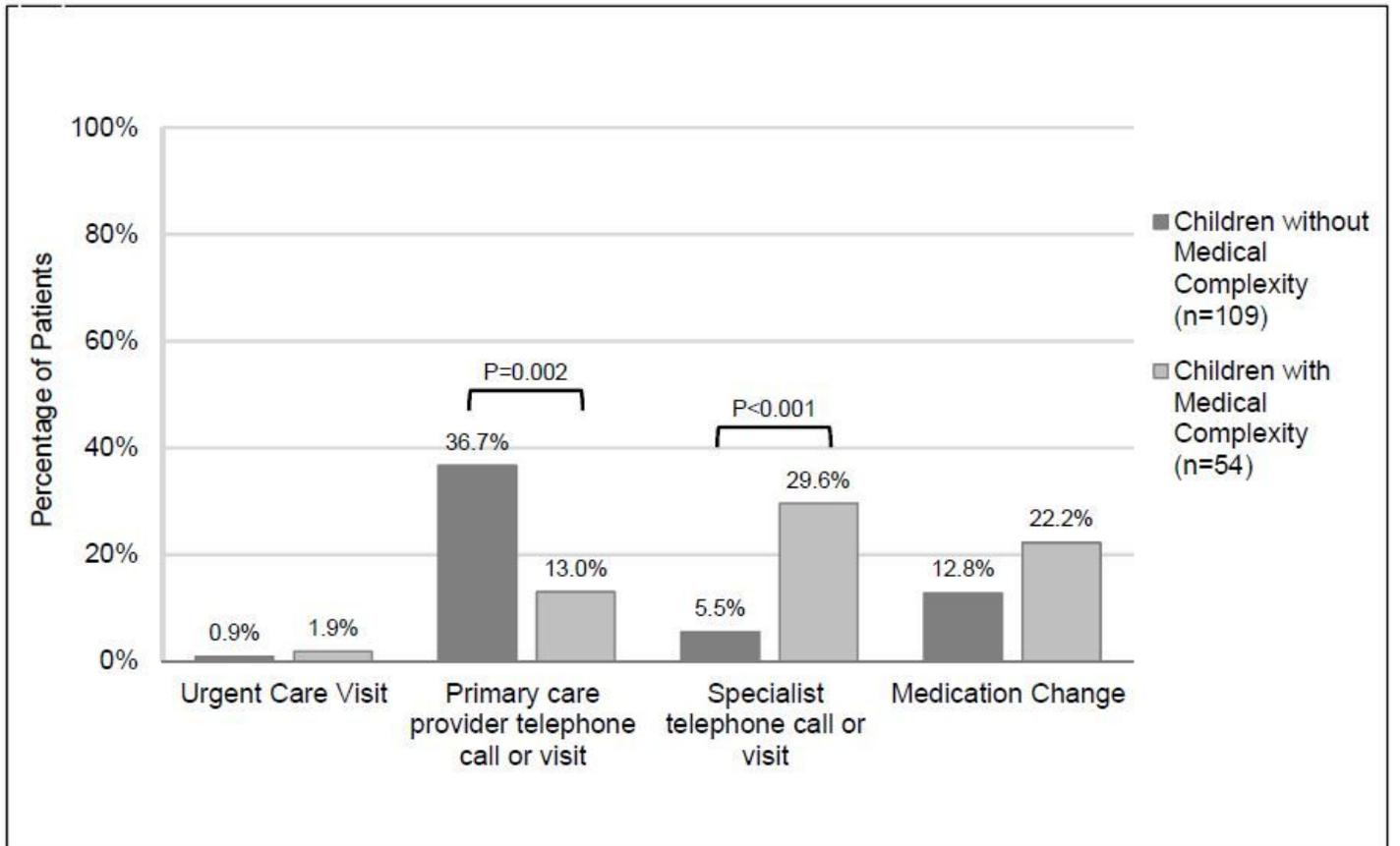
Due to technical limitations, table 1 is only available as a download in the Supplemental Files section.

## Figures



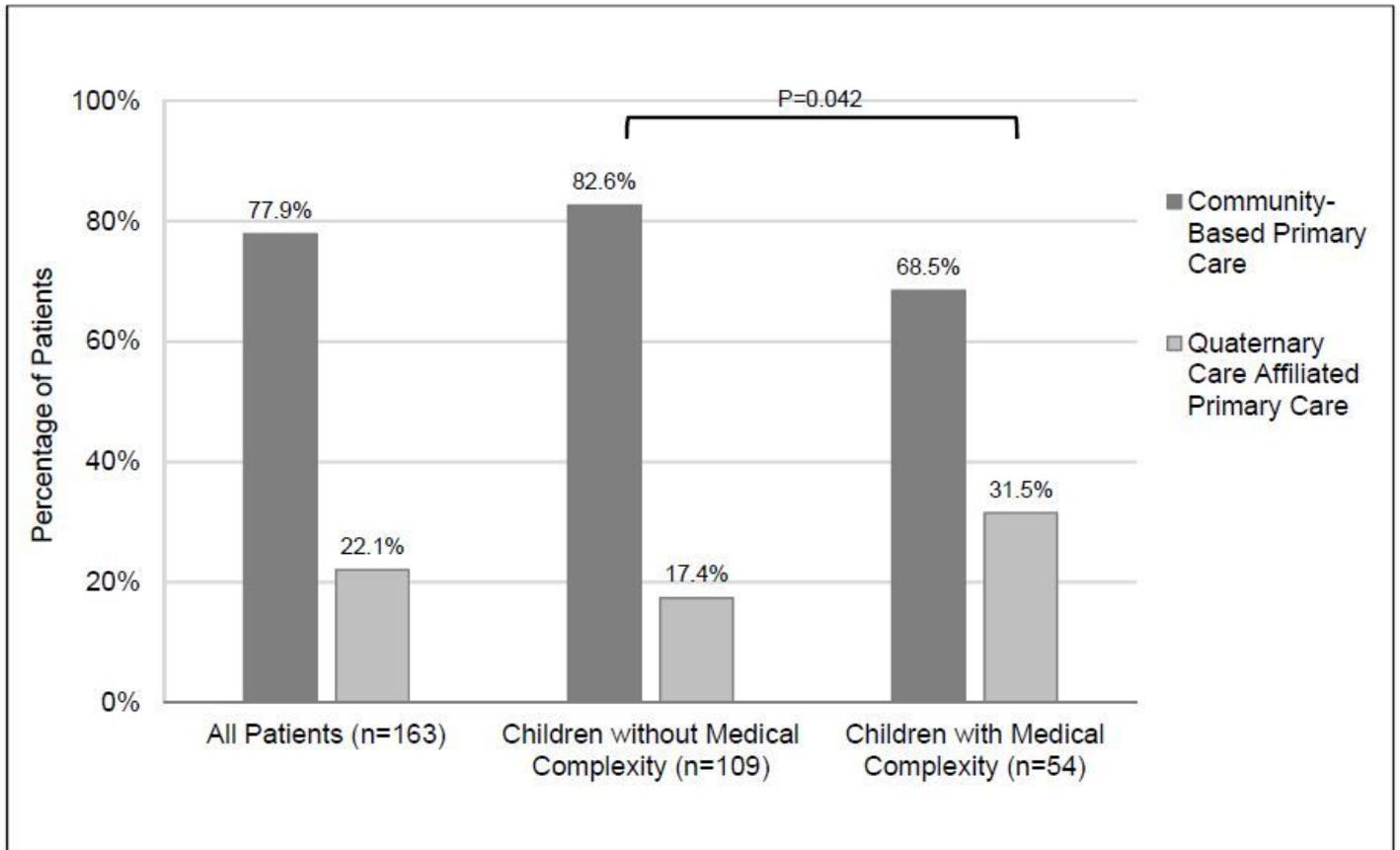
**Figure 1**

Types of Pre-Hospitalization Provider Contact.



**Figure 2**

Pre-Hospitalization Provider Contact by Medical Complexity. Children without medical complexity were more likely than children with medical complexity patients to have a PCP telephone call or office visit (36.7% vs 13.0%,  $p=0.002$ ). In contrast, children with medical complexity were more likely to have a telephone call or office visit with a specialist (29.6% vs 5.5%,  $p<0.001$ ).



**Figure 3**

Primary-Care Provider Characteristics by Medical Complexity.

## Supplementary Files

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- [PfarretalTable1.pdf](#)