Pediatrician Exposure to Neuromuscular Patients

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ABSTRACT

Background: Primary care providers (PCPs) provide general care to patients, including those who are followed by specialists. In the field of rare diseases, there is growing research that the primary care needs of these patients are unique to their individual disease state. The purpose of this study is to determine the prevalence of patients with pediatric neuromuscular diseases among a subset of pediatric practices in Southeastern Wisconsin.

Methods: A retrospective review of all patients with neuromuscular diseases seen at Children's Hospital of Wisconsin (CW) was conducted from January 1, 2016 through September 30, 2018. All patients who were seen by Children's Medical Group (CMG) providers were included, with a division of patients by provider.

Results: Eight hundred eleven (811) unique pediatric neuromuscular patients were identified; 188 patients were included in the study cohort. The median number of patients per provider was 2.5, mean number of patients was 2.68, and mode number of patients was 1.74; 51% of pediatricians within CMG did not care for a pediatric neuromuscular patient.

Discussion: The prevalence of patients with neuromuscular diseases followed by an individual CMG provider is low, with over half of the CMG providers not caring for any patients with neuromuscular diseases. Given the specific primary care knowledge needed to care for these patients, this suggests the need for a novel method of help support these providers.

BACKGROUND

The role of primary care providers (PCP) is to "provide definitive care to the undifferentiated patient at the point of first contact" and to refer to specialists for conditions that are beyond a PCP's scope of practice.[1] However, many PCPs continue to take "responsibility for providing the patient's comprehensive care."[1] While studies have shown that specialists contribute considerable time to primary care issues,[2] PCPs report delivering 88% of the primary care received by their patients.[3] For PCPs to provide general care alongside specialists, they need to have a basic understanding of the various conditions and diseases. The American Board of Pediatrics requires maintenance of certification, which includes continuing medical education credits for PCPs to stay up to date on current literature and practice guidelines. For patients with common conditions, PCPs can access and apply their knowledge and skills on a frequent basis so that they can maintain their competence in caring for those patients. However, this becomes more challenging for rare diseases, especially in fields that are rapidly changing.

One definition of a rare disease based on the Orphan Drug Act of 1993 is any disease or condition that affects less than 200,000 people in the United States.[4] Most pediatric neuromuscular diseases—diseases that affect the peripheral nerve, neuromuscular junction, muscle, or associated connective tissue—fall into this definition. While these diseases are rare, there are over 100 different types—all with unique pathology and treatment considerations. For example, the incidence of Duchenne muscular dystrophy is 1.51 to 2.05 per 10,000 boys and spinal muscular atrophy is 1 in 12,000 people.[5,6] Given this, our hypothesis is that pediatricians likely care for very few, if any, patients with neuromuscular diseases.

The purpose of this study is to evaluate the distribution of

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patients with neuromuscular diseases among a subset of pediatricians in Southeastern Wisconsin to assess the prevalence of patients with neuromuscular diseases per provider.

METHODS

Using the Insight Data Search Portal, a data query collected the name and primary care provider of all unique patients seen in the Pediatric Neuromuscular Clinic at Children's Wisconsin-Milwaukee campus from January 1, 2016 through September 30, 2018. The patients were selected if they were seen in the "CHW Neuromuscular" "Department" of the EPIC electronic health record (Epic Systems Corporation). This method of data inquiry captured all patients with neuromuscular diseases seen at this site while excluding those from the remote clinic in Neenah, Wisconsin. Only patients with completed visits were included; those who were scheduled but never seen in the clinic were excluded. All patient appointments in the symptom-specific "Hypotonia Clinic" within the Pediatric Neuromuscular Clinic were then excluded, as patients seen in that clinic are often diagnosed with non-neuromuscular diseases.

The number of patient visits and unique patients was collected in aggregate and by year or partial year for 2018. Each patient's PCP was identified, but patients were only included in the data analysis if their pediatricians were within the Children's Medical Group (CMG), where individual provider information was easily accessible. This data were analyzed using descriptive statistics.

RESULTS

A total of 1,790 patient encounters occurred within the time frame of this study for 811 unique patients. Of these, 188 patients had an identified pediatrician within the CMG. These patients were seen by 70 different pediatricians in 22 different practice locations (Table). The median number of patients per provider was 2.5, mean number of patients was 2.68, and mode number of patients was 1. Of the 144 pediatricians who comprised CMG, 74 (51.3%) did not have a pediatric neuromuscular patient in their patient panel. The highest number of patients seen by an individual pediatrician was 7.

Table. Prevalence of Pediatric Neuromuscular (NM) Patients in a Pediatrician's Practice

	n (%)
Number of neuromuscular patients	811
Number of pediatricians	144
Number of pediatricians with a NM patient in their practice	70 (49%)
Numberof pediatricians without a NM patient in their practice	74 (51%)
Maximum number of NM patients in a pediatrician's practice	7
Median number of NM patients in a pediatrician's practice	2.5
Mean number of NM patients in a pediatrician's practice	2.68
Mode number of NM patients in a pediatrician's practice	1

DISCUSSION

This study demonstrates that the prevalence of patients with neuromuscular diseases followed by an individual pediatrician is low, with most pediatricians having no identified patients under their care. Those who did typically cared for only 1 patient. This suggests there is not a clustering of patients to certain providers.

These results confirm that for pediatric neuromuscular diseases, pediatricians do not have a high frequency of exposure and experience. And with a field rapidly changing with new diagnostic tests, new treatments, and ongoing clinical trials, a pediatrician cannot be expected to be maintain up-to-date knowledge of the changing recommendations. For example, with Duchenne's muscular dystrophy, the disease-specific standard growth curves published in 2013 are rapidly becoming outdated due to changing treatment algorithms and, thus, no longer accurately reflect the disease-specific percentiles of weights and lengths.[7]

There is literature indicating that better coordinated care can improve outcomes, such as emergency hospital admissions,[8] therefore, maintaining an up-to-date understanding of these diseases is important. Given limited specialists able to education pediatricians, and using results from this study, we addressed this need by developing a neuromuscular pediatrician who specializes in the general pediatric aspects of care for patients with neuromuscular diseases. The neuromuscular pediatrician role is similar to that of a complex care specialist: to act as a resource and answer questions from community providers, provide care for issues between the scopes of practice of PCPs and specialists, and to help manage general pediatric issues during routine multidisciplinary clinic visits.[9] Additionally, the neuromuscular pediatrician can assist with care during hospitalizations and help to coordinate transitions of care after discharge.

This study is limited due to the data collection method. Patients who are not seen at CW-Milwaukee campus were excluded from this study, although the excluded number is small. Analysis also was limited to pediatricians within CMG, which does not include all PCPs in Southeastern Wisconsin. Of note, a benefit of our methodology, compared to using ICD-10 or ICD-9 codes, is that the data was not affected by potential errors in diagnostic coding. As well, we were able to automatically exclude any patient who was not seen by the neuromuscular practice but was seen for other reasons in the institution.

CONCLUSION

In Southeastern Wisconsin, the prevalence of patients with neuromuscular diseases for individual pediatricians within the Children's Medical Group is low. Resources need to be developed to better support PCPs and general care for patients with neuromuscular diseases. Developing a neuromuscular pediatrician role was the model that our neuromuscular program implemented.

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Next steps are to evaluate the efficacy and utilization of this role by patients and their PCPs.

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