

MEDICAL RESOURCE UTILIZATION OF OUTPATIENT CARE FOR CHILDREN WITH NEUROFIBROMATOSIS TYPE 1

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INTRODUCTION

Neurofibromatosis Type 1 (NF1) is an autosomal dominant tumor predisposition syndrome with equal prevalence across all races and genders. It is the most common heritable disease affecting the nervous system with a prevalence between 1:3000 and 1:3500. Manifestations of NF1 can affect the central nervous system (CNS), peripheral nervous system (due to plexiform neurofibromas), musculoskeletal system, and cognitive/behavioral function. While most research focuses on the incidence, symptoms, treatment, and outcomes of specific NF1 manifestations, the magnitude of medical resource utilization for each manifestation is unknown.

AIM

The current study sought to identify which manifestations of NF1 utilize the most healthcare resources and to validate the accuracy of using ICD-9 diagnostic codes to identify patients with NF1.

METHODS

The electronic health record at The Children's Hospital of Philadelphia was queried to identify patients with the ICD-9 code for NF1 (237.71) who were evaluated between January 2011 and December 2015. Patients were excluded if the diagnosis of NF1 could not be confirmed. The frequency of MRI scans, specialty provider visits, and treatment type over the five-year study period were compared across disease manifestations. The positive predictive value (PPV) of identifying patients using the ICD-9 code was calculated.

RESULTS

Table 1. Demographic information of children diagnosed with NF1

	Subject (N=911)
Age, years (mean/median)	13.52/12.94
Range	(.74 – 69.59) 62
Female sex, n (%)	461 (50.6%)
Race, n (%)	
White/Caucasian	606 (66.5%)
Black/African American	156 (17.1%)
Multiracial	16 (1.7%)
Asian	30 (3.2%)
Other	101 (11.0%)
Refused	1 (.1%)
Unknown	1 (.1%)
Ethnicity, n (%)	
Non-Hispanic	780 (85.6%)
Hispanic	78 (8.5%)
Unknown	50 (5.4%)
Refused	3 (.3%)

RESULTS

Figure 1. Clinical characteristics of children diagnosed with NF1

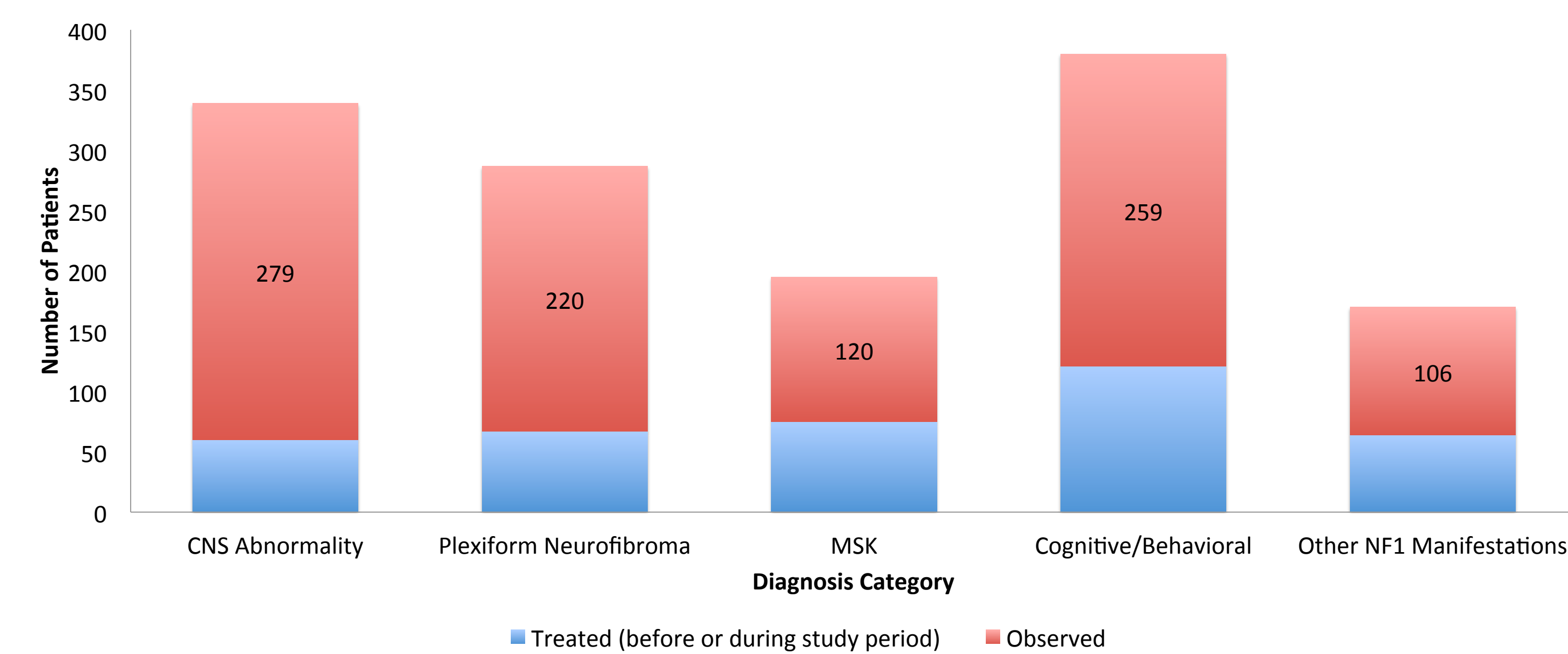
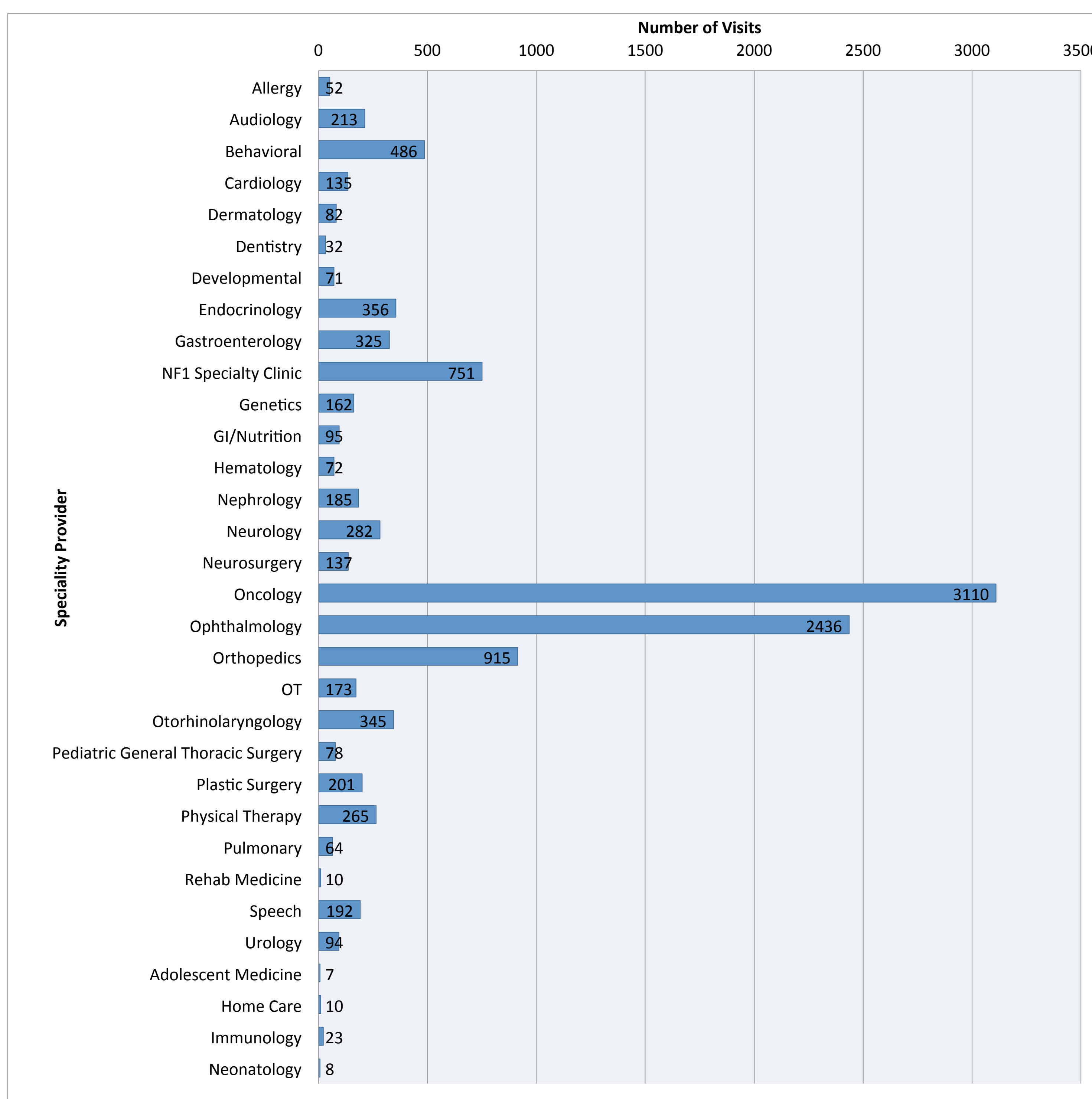


Table 2. Treatment type based on clinical diagnosis category

	Treatment			
	Chemo	Rx	Surgery	Other
CNS Abnormality	35	14	11	0
Plexiform Neurofibroma	12	13	42	0
Musculoskeletal	0	4	35	36
Cognitive/Behavioral	0	121	0	0
Other NF1 Manifestations	1	52	6	5

Figure 2. Frequency of specialty visits by children diagnosed with NF1



RESULTS

Figure 3. Frequency of MRI scans in children diagnosed with NF1

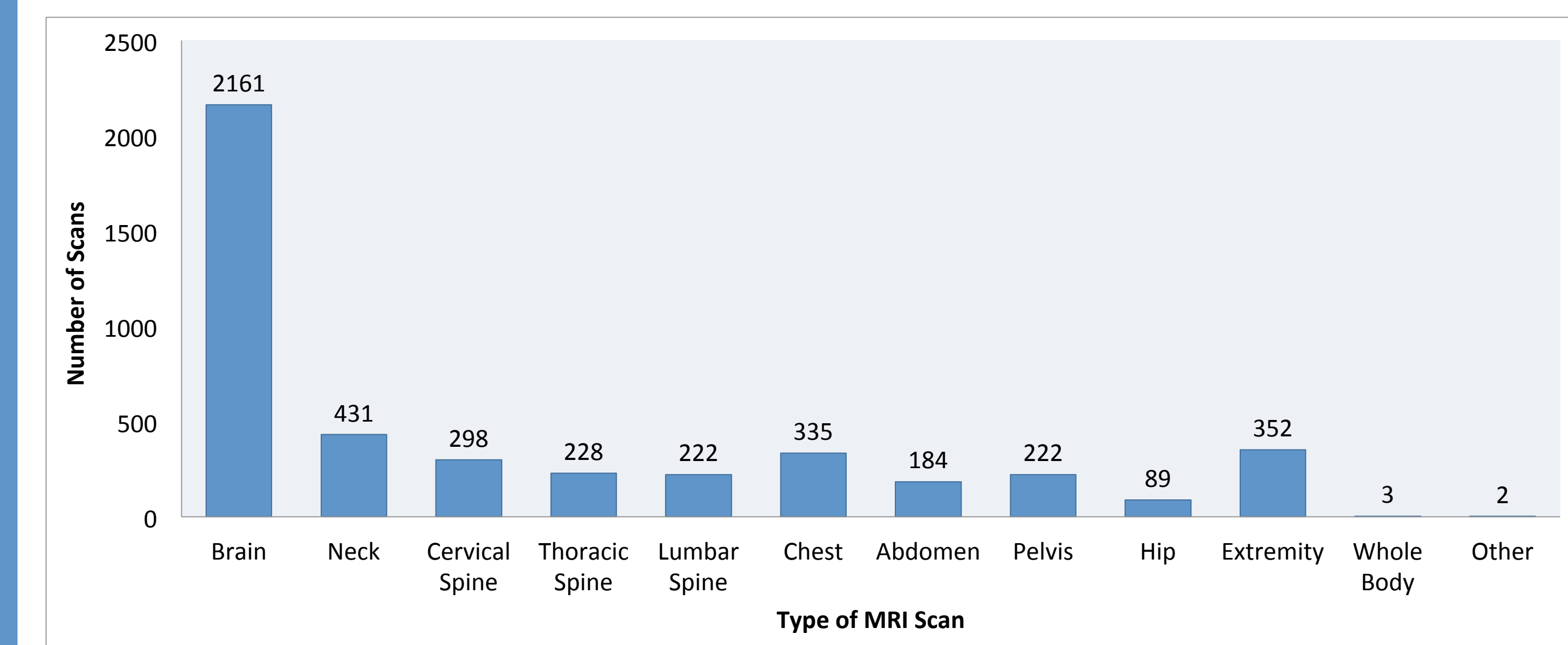


Table 3. Frequency of Primary Care Provider (PCP) visits, specialist visits, and MRI scans with/without sedation based on clinical diagnosis category

	PCP Visits	Specialist Visits	MRI Scans	
			Sedation	No Sedation
All Patients (N=911)	3014	10629	2836	1691
CNS Abnormality	827	6535	1999	1039
Plexiform Neurofibroma	755	4276	1676	1144
Musculoskeletal	697	3159	870	457
Cognitive/Behavioral	1365	5726	1651	783
Other NF1 Manifestations	625	2819	747	383

Table 4. PPV of identifying patients with confirmed diagnosis of NF1 using the ICD-9 code 237.71

Number of Visits Coded with 237.71	NF1 diagnosis confirmed in chart	NF1 diagnosis NOT confirmed	Calculated PPV
1	911	54	94.4%
2	693	13	98.2%

DISCUSSION

CNS manifestations of NF1 demonstrated the greatest utilization of resources (combined MRI acquisitions and specialty visits). The ICD-9 code 237.71 accurately identified patients with NF1. Understanding the costs associated with the frequency and type of resources utilized (i.e., diagnostic imaging and specialty visits) may encourage academic/industrial development of novel therapeutics and creation of algorithms to optimize clinical care. Future studies involve using the ICD-9 code 237.71 to analyze data from adult patient claims to highlight similarities and differences in the morbidity experienced during childhood and adulthood.

FUNDING/SUPPORT

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