# Characteristics of Neonatal Abstinence Syndrome in a Rural Clinic Population: Using Electronic Medical Health Records for Tracking

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## Abstract

**Purpose:** The impact of intrauterine exposure of opioids and other addictive substances on pediatric patients is concerning for health care providers in rural WV. NAS patients must be identified, screened, and treated during the pediatric years to facilitate improved outcomes. The purpose of this research was to evaluate the ability of rural providers to use EHRs to identify, describe, and monitor aspects of NAS across the pediatric health span.

**Methods**: The research team used de-identified data of patients that had the NAS diagnosis from a rural clinic. One hundred fifty-five charts were evaluated. Demographics, clinical characteristics, and developmental milestone status were extracted from charts.

**Results**: There were differences in characteristics across age groups. Reported secondhand smoke was higher among the 0-3 year olds. Normal BMI percentile was highest among 4-5 year olds. The

Ages and Stages Developmental screening was abnormal more in those aged 6-19 years. Foster care was highest among the ages 0-3 years. The 4-12 age groups highest amount of no show visits. Respiratory illness was the most frequent diagnosis and was highest in the 4-5 age group. Eye and ear diagnosis were noted as a recurrent diagnosis in the 4-5 year old group. Diagnosis related to mental health were highest in the 6-18 age group.

**Discussion:** The EHR can be used to describe and track special populations such as NAS in rural areas. Tagging and tacking patients with NAS can help primary care providers manage care and anticipate age related health care needs. Tracking high risk populations assures that the patient care is maintained. Tracking no show rates assists providers in assuring that patient's caregivers are compliant in necessary treatments and referrals. Child Protection can also be involved if medical neglect is noted. EHRs are useful in identifying high risk populations such as NAS to facilitate treatments and continuity of care.

*Keywords*: Neonatal Abstinence Syndrome, electronic medical health records, NAS Characteristics, tracking pediatric NAS

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### Introduction/Problem Statement

Infants regularly exposed to addictive substances in utero may exhibit neonatal abstinence syndrome (NAS). NAS is usually observed in the newborn nursery within the first few days of life. The symptoms include tremors, irritability, poor feeding, high-pitched cry, and multiple other symptoms depending on the substance used by the mother during pregnancy (McQueen & Murphy-Oikonen, 2016).

The incidence of NAS continues to rise in the United States. There was a five-fold increase in the proportion of babies born with NAS from 2000 to 2012 (Sanlorenzo et al., 2018). According to the Health Care Cost and Utilization Project (HCUP, 2016), the occurrence of prolonged hospital stays for newborns diagnosed with NAS increased from 1:1000 to 48:1000 nationally. The proportion of infants diagnosed with NAS who were from rural counties increased from 12.9% in 2003/2004 to 21.2% in 2012/2013 (Villapiano, et al., 2017). West Virginia (WV) increased from 7.4 per 1,000 in 2007 (Stabler et al., 2017) to 50.6 per 1000 live births per year in 2017 (Umer et al., 2018). This has caused an enormous burden on the WV foster care system (McCormick, 2017).

Nurse practitioners in rural areas have multiple obstacles in providing care to special high-risk populations such as infants with NAS. Patients in rural areas face many barriers in health care services related to limited public and person transportation and distance to health care facilities (Warshaw, 2017). The difficulty is compounded by shortages of allied health services and specialty care (MacDowell et al., 2010).

The impact of intrauterine exposure to addictive substances on pediatric patients is a concern for health care providers in WV. Rural clinics often lack resources to manage care of high-risk children. Poor growth and development (Bier et al., 2015; Lamy et al., 2015), cognitive issues (Jaeger, et al., 2015), and risk for abuse (Weberlinget al., 2003) are only a few of the complications that providers must diagnose and treat. NAS patients must be identified, screened, and treated during the pediatric years to facilitate improved outcomes (Knopf, 2016; Lee et al., 2015). The impact of maternal drug use and drugs to prevent withdrawal complications is yet to be fully realized. The purpose of this study is to utilize data obtained from electronic medical records

(EHR) to identify patients with a diagnosis of NAS and describe other clinical and demographic characteristics of this population in a rural clinic.

## Methodology

Administration of Robert C. Byrd Clinic approved use of data for the study. Robert C. Byrd Clinic is a nonprofit rural health clinic providing primary care to a three-county area in southern WV. The clinic is staffed with over 40 medical staff members including physicians, nurse practitioners, and interns. Services provided by the clinic include family practice, osteopathic manipulative medicine, pediatrics, and psychology services. The clinic is in Greenbrier County and designated as a Health Professional Shortage Area (HPSA) in primary care and mental health. Greenbrier County is considered 69.74% rural (Am I rural? – Report - 24901, WV).

This project was submitted to the Institutional Review Board of West Virginia School of Osteopathic Medicine for expedited review procedures and given approval to proceed (IRB# 2018-4). A De-Identified Data Sharing Agreement was obtained for this project from Robert C. Byrd Clinic. In January 2018, the needed demographic and clinical data were abstracted from the EHR using system-provided data abstraction tools. These data abstractions were completed by trained informatics consultants and clinical staff to help ensure data quality and completeness. The clinic provided the research team with de-identified and validated data of pediatric patients (ages birth - 21 years of age) that had NAS diagnosis in ICD 9 (code 779.5) and ICD 10 codes (P 96.1; 96.2) (WHO ICD-10 online versions). HIPPA compliance was maintained.

From the NAS data set, demographic data were extracted from the EHR including age, gender, last three digits of the zip code, insurance payer, and ethnic status. We also extracted clinical characteristics including additional diagnosis, chronic medications, referrals to outside

agencies or providers, immunization status, attritional rate or current patients standing, time of last visit, record of foster care, weight for length or body mass index (BMI) percentile, developmental milestone status ( Squires et al., 2009), secondhand smoke exposure, and appointment history. Data were analyzed with SPSS to assess frequency, counts, and means.

## Results

To evaluate the population of patients diagnosed with NAS, 155 charts with the required ICD 9 and ICD 10 codes for NAS diagnosis were identified and analyzed. The extracted data were entered into the Research Electronic Data Capture (REDCap) which is a secure data management system hosted at West Virginia University. REDCap is a web-based software platform designed to support data capture for research studies. From REDCap, data were imported into SPSS. Of the 155 chart audits, 45% (n=70) were females and 55% (n=85) were male. Ninety-two percent were Caucasian (n=142). The majority of patients (57%) used state insured payers (West Virginia Medicaid, Unicare, Children's Health Insurance Program), 43% had private insurance, and <1% were self-pay. Most of the population were children in the 4-5-year-old age group (Figure 1). Most of the charts had a zip code within four miles of the clinic (Figure 2).

**Figure 1**

*Age Groups*

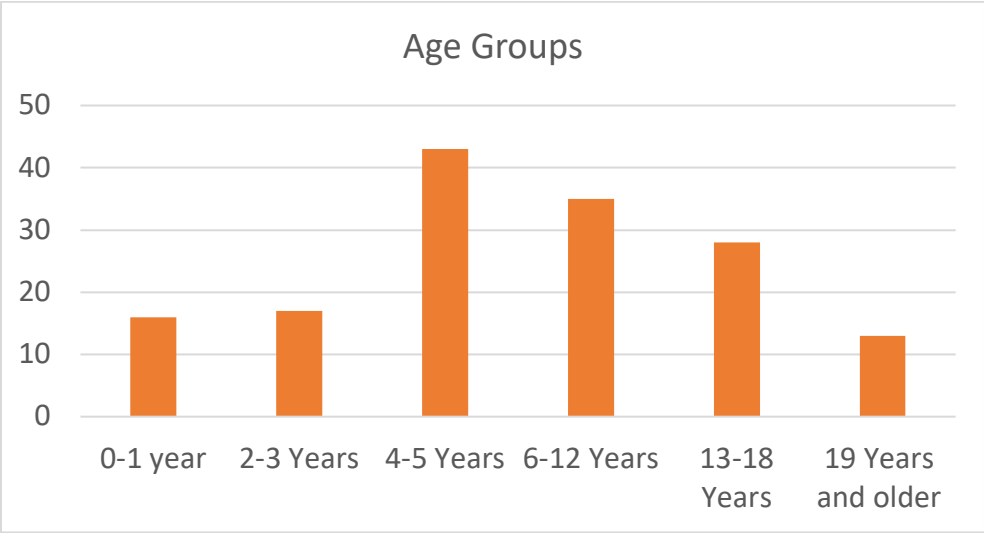
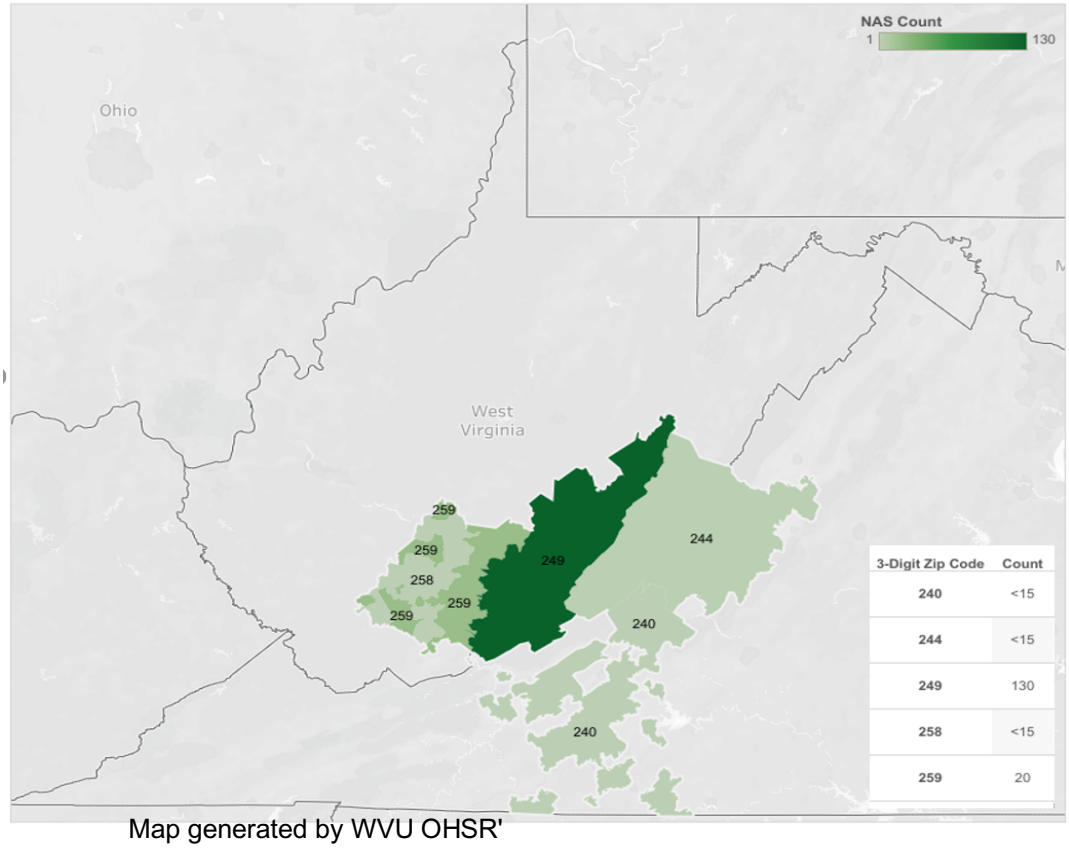


**Figure 2**

*Robert C. Byrd Neonatal Abstinence Syndrome population per 3-digit zip codes*




Contextual factors were assessed within age group in order to understand the potential developmental trajectory of children diagnosed with NAS. Secondhand smoke exposure was highest among the 0-1- and 2-3-year-old groups with each group reporting 60% as having secondhand smoke exposure. Child Protective Services (CPS) involvement or foster care was reported in 22% of the total charts with the 2-3-year-old group of children having the higher percent of reports per age group (58%). Children in the 4-5-year-old group had the highest number of normal BMI Percentile (Figure 3). Ages and Stages Developmental (Squires et al., 2009) screen was noted as “abnormal” more in the age groups of 6-12, 13-18, and 19-21-year (Figure 4). No-

show rates or missing one or more scheduled appointments were highest in the 2-3 (64%) and 4-5 (77 %) year-old groups.

**Figure 3**

*Body Mass Index (BMI) Percentiles for Age Groups*

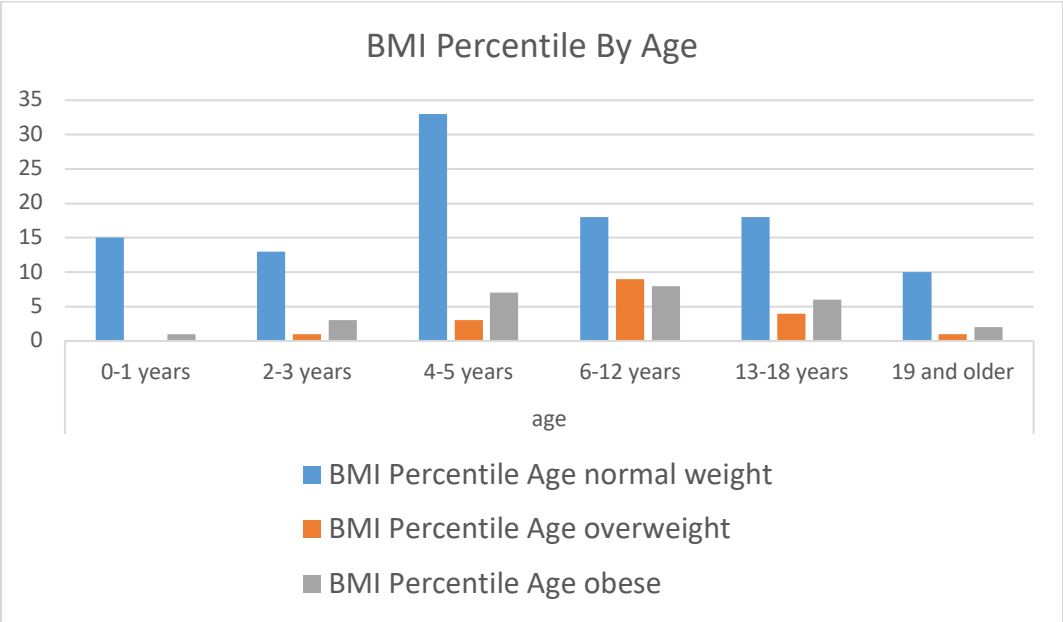
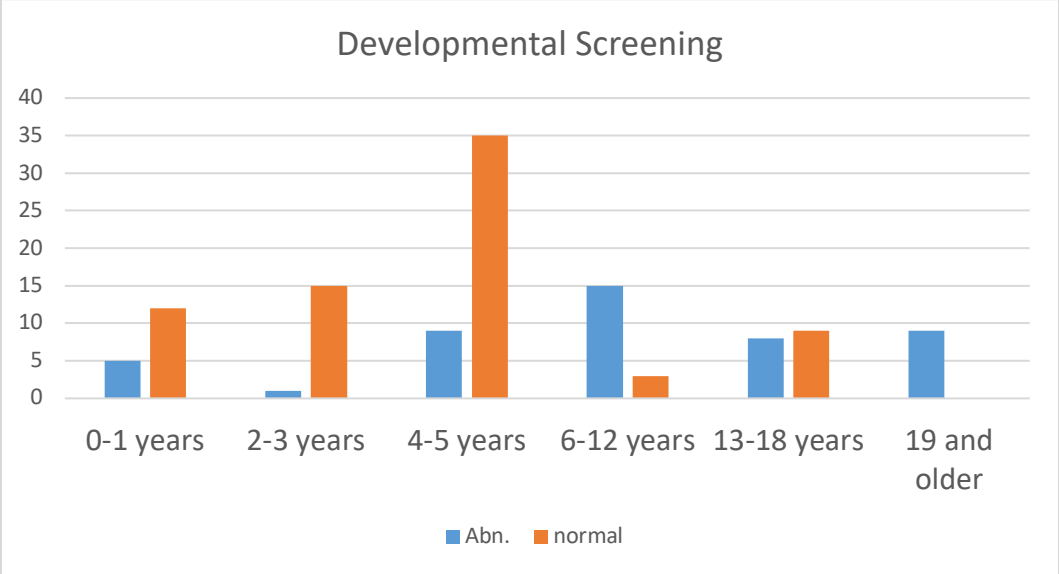


**Figure 4**

*Results for Ages and Stages Screening Tool*




Medical history was analyzed relating to additional diagnosis and medication history. The diagnosis of "well visits" was distributed equally among the ages. Respiratory illness was the next most frequent diagnosis with highest number in the 4-5-year-old group. Disorders of the eyes and ears were noted as a recurrent diagnosis in the 4-5-year-old group (Figure 5). Diagnosis related to mental health were highest in the 6-18-year-old group (Figure 6).

**Figure 5**

*Diagnosis within Age Groups 0-5 years of Age*

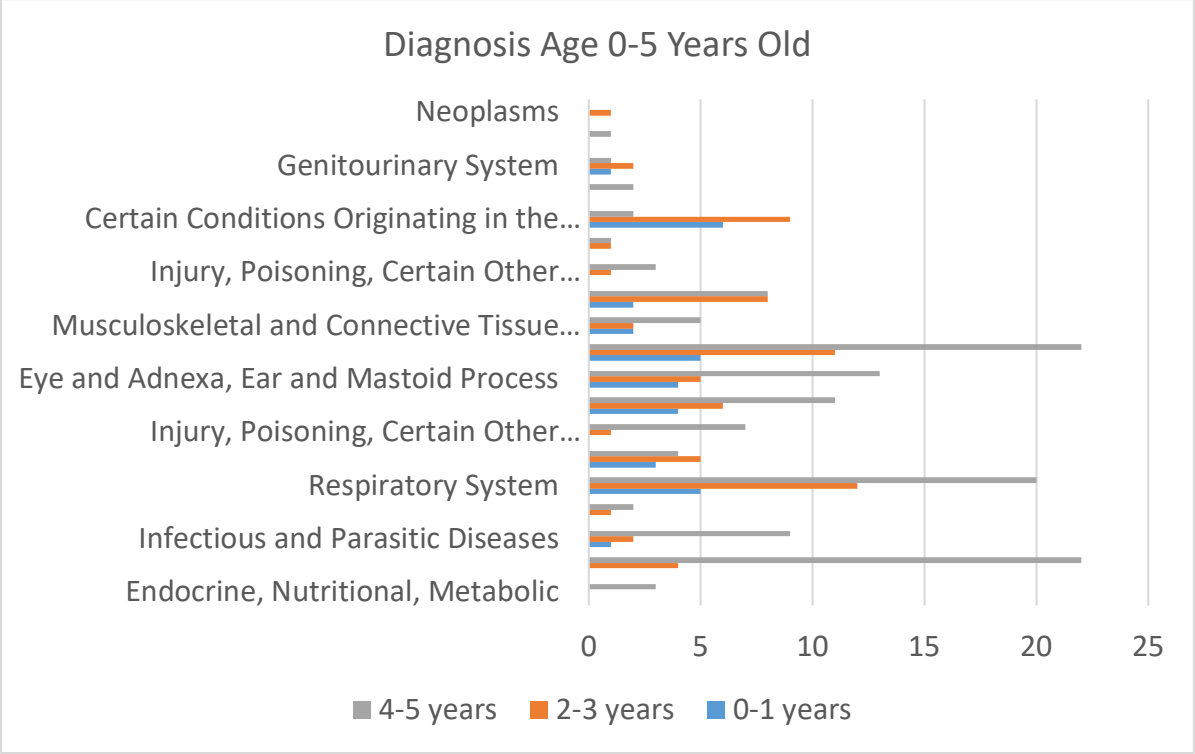
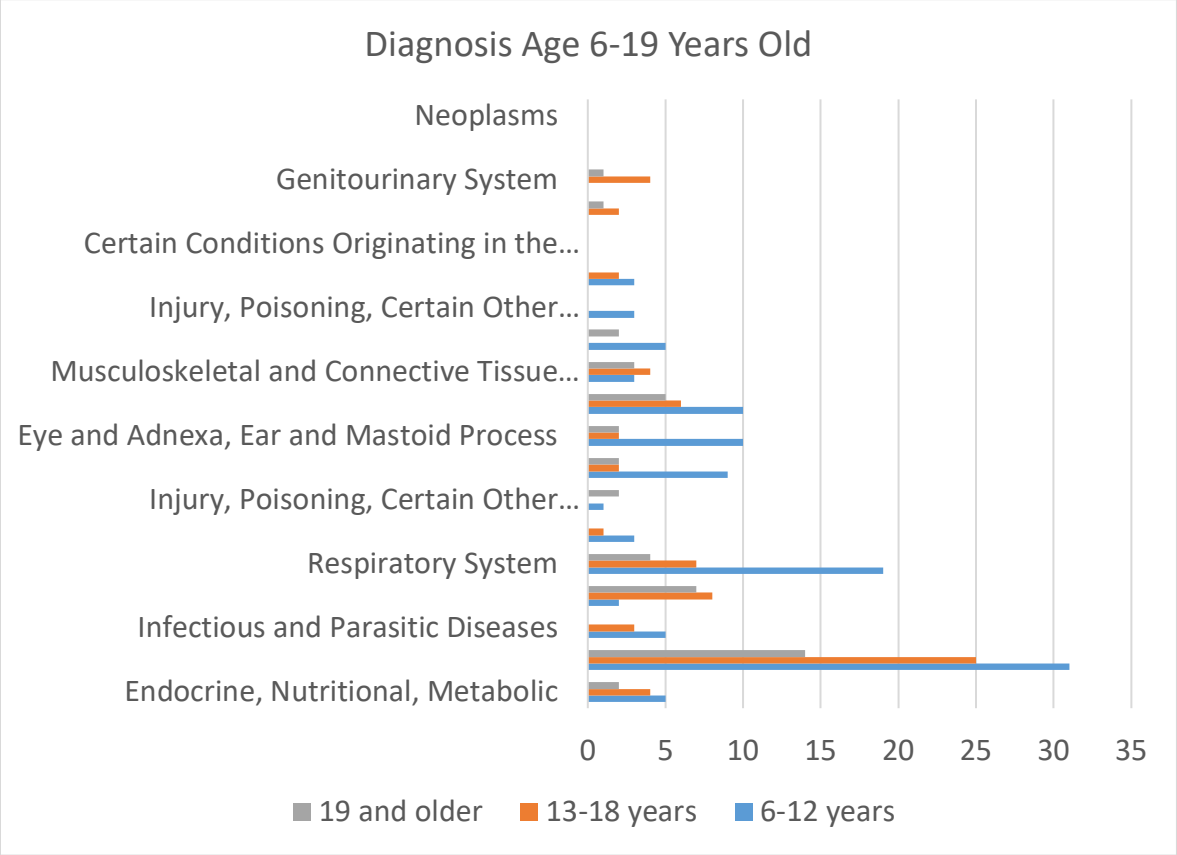


**Figure 6**

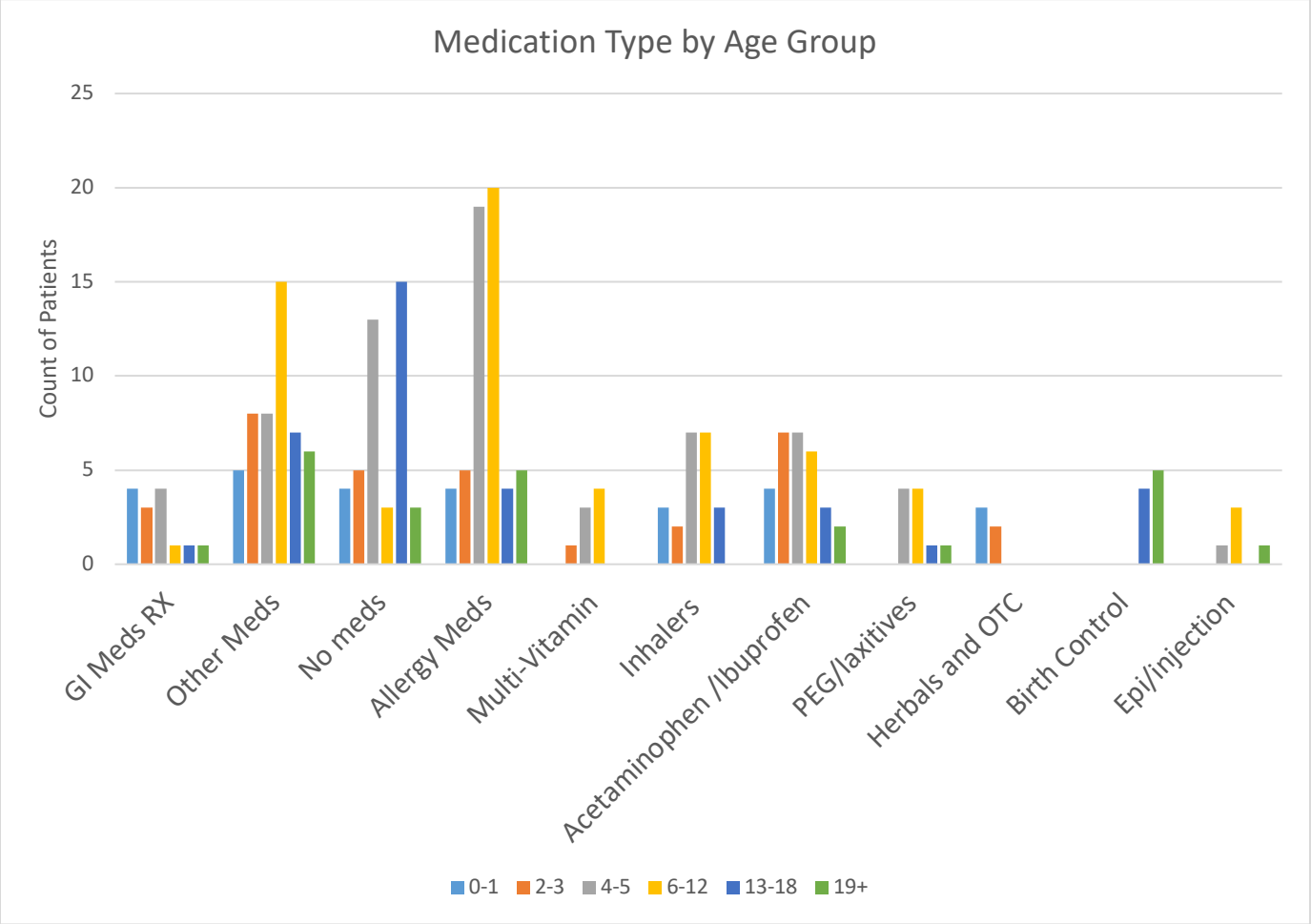
*Diagnosis within Age Groups 6-19 years of Age*




The medication prescribed with the highest frequency was allergy type medications in the 4-5 and 6-12-year-old groups. Other medications not categorized was next highest in the 6-12-year-old group (Figure 7). Patient groups reporting no regular medications were highest in the 4-5 and 13-18-year-old groups.

**Figure 7**

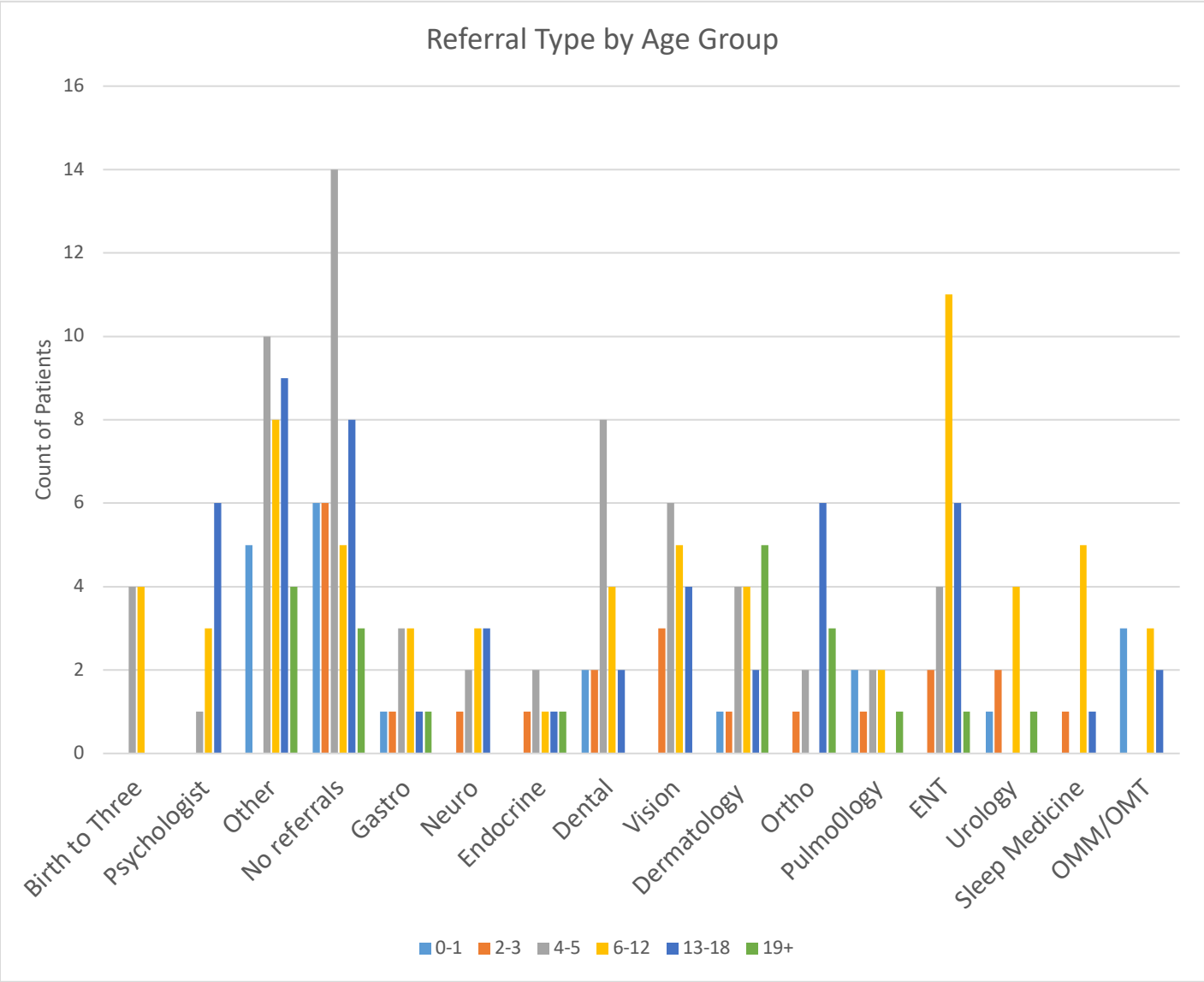
*Reported Medication per Age Groups*




Referrals to outside specialists were grouped by age and specialty as well as miscellaneous and no outside referrals. The majority of those with no referrals noted were in the 4-5-year-old group. Referrals to ear, nose and throat specialists were highest in the 6-12 age group. Of the dental referrals, the 4-5 age group had the most referrals with ages 6-12-year-old group second highest. Of the referrals made to the "in-house" psychologist, the 13-18-year-old group had the greatest number of patients. The 4-5 and 6-12-year-old groups had more referrals than the other groups (Figure 8).

**Figure 8**

*Referral Type by Age Group*




## Discussion

The EHR can assist in describing the NAS population in a rural primary care center. While many of the results align with the usual pediatric population, several important points are noted.

Foster care is highest in the younger population. This could be related to the enormous amount of care any infant requires, especially those with intrauterine exposure to illicit drugs and medications for withdrawal. Since infants with NAS are usually fussier than infants who do not have NAS (Finnegan, 1985; McQueen & Murphy-Oikonen, 2016), they are at a higher risk for abuse (Oldbury & Adams, 2015). The decrease of foster care in older children (McCormick, (2017) could be related to the fact that they are placed with a family member or foster care parent that may adopt them if parental rights are terminated. Another possible explanation is that the biological family stabilized.

Current literature (Fill et al., 2018) supports the premise that children with NAS have a higher risk for issues in school (15.3%) as compared to children without the diagnosis of NAS (11.4%). Attention deficit disorder/hyperactivity disorder, behavior issues, and learning disabilities may surface in this age group as scholastic challenges are encountered (Fill et al., 2018; Jaegeret al., 2015; Morgan & Wang, 2019). In this study the majority of mental health diagnosis started at age 6 years. This may be related to the age required to diagnose attention deficit type disorders. Prior to that age, developmental delays may be noted and treated, but not with a specific diagnosis label. Pediatric providers can alert families to observe children for any academic issues to provide timely intervention. Earlier interventions in school have a higher rate of long-term improvement (Majnemer, 1998).

Patients diagnosed with NAS can be identified in the EHR to promote better follow-up and surveillance of care. Referrals for specialty care made outside of the clinic can be assessed, however, the EHR does not have a method to note patient/family compliance for the visit. Detecting "no show" rates for visits with-in the clinic will alert providers of gaps in medical care.

At that point, the office can contact the family and attempt to facilitate adherence to the medical plan. If they have left the practice, providers can contact the Department of Health and Human Resources (DHHR) and alert them that the patient is no longer in the practice. If a record release has not been requested, DHHR can inform the new health care providers of former medical care and expedite record release. CPS can also be involved if medical neglect is noted.

Demographic data, such as Zip codes, can be used to identify geographical areas that have a higher percentage of NAS children. Regions recognized with a higher prevalence of NAS can be prepared for upcoming needs in academic support. Documentation of NAS prevalence can also empower communities to seek additional grants and funding to provide programs for children and families impacted by NAS.

## Conclusion

Rural health care providers are in uncharted territories when caring for exposed NAS infants as they progress through the pediatric lifespan toward adulthood. Lack of specialty resources and patient/family compliance add to the burden of care. Identifying high-risk patients promotes continuity of care and improved oversight. More work is needed to evaluate the ability of replicating the process in a new EHR system in the clinic. Although this is the first data pull of the diagnosis of NAS, more data over longer periods of time are needed to see the effectiveness of identifying and following the patients with NAS as they age through the system.

## Acknowledgements

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