

Rett Syndrome (RTT)

Rare and complex neurodevelopmental disorder

No studies have examined the associated healthcare resource utilization (HCRU) using commercially available claims data



Methods

Using claims data, the HCRU and costs were compared between children with RTT and children without RTT



Outcomes

The RTT cohort had elevated all-cause HCRU and costs compared with the non-RTT cohort



Elevated Healthcare Resource Utilization and Costs Among Individuals Diagnosed With Rett Syndrome

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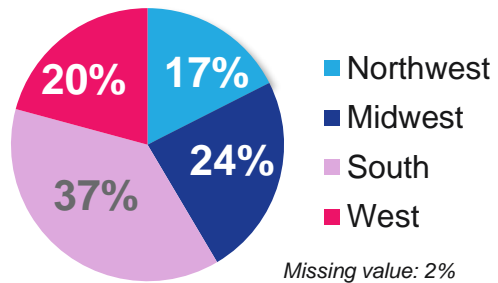
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RTT and non-RTT Cohort Population Characteristics

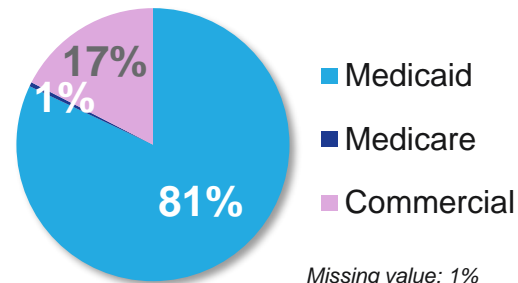
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RTT cohort
Predominantly female
Mean age: 7.2 years

Region



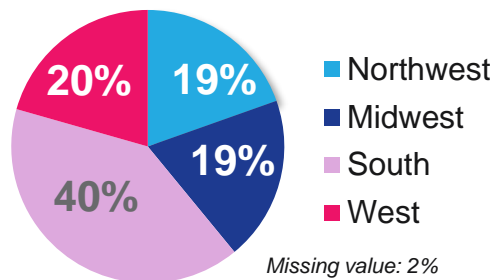
Insurance



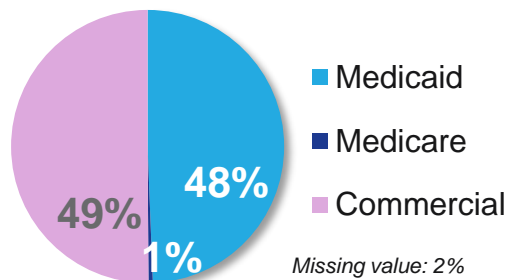
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Non-RTT cohort
Equal gender distribution
Mean age: 5.6 years

Region



Insurance



HCRU and Cost

Compared with the non-RTT cohort, the HCRU for the RTT cohort was:



Significantly greater for medical devices
Significantly higher for all other healthcare resources



Enteral feeding supply kits and enteral nutrition were the most used medical devices by the RTT cohort

Compared with the non-RTT cohort, the RTT cohort's costs were:

10x greater for **inpatient hospital visits**

3.5x greater for **outpatient visits**

3x greater for **emergency department visits**

The top 10 most frequently used medical devices contributed to total costs roughly equally

INTRODUCTION

- Rett syndrome (RTT) is a rare, complex, and progressive neurodevelopmental disorder¹.
- Management of the disorder often involves addressing symptoms through a multidisciplinary team–based approach².
- To date, this may be the first study to use a commercially available claims data set to examine the healthcare resource utilization (HCRU) and costs of individuals diagnosed with RTT.

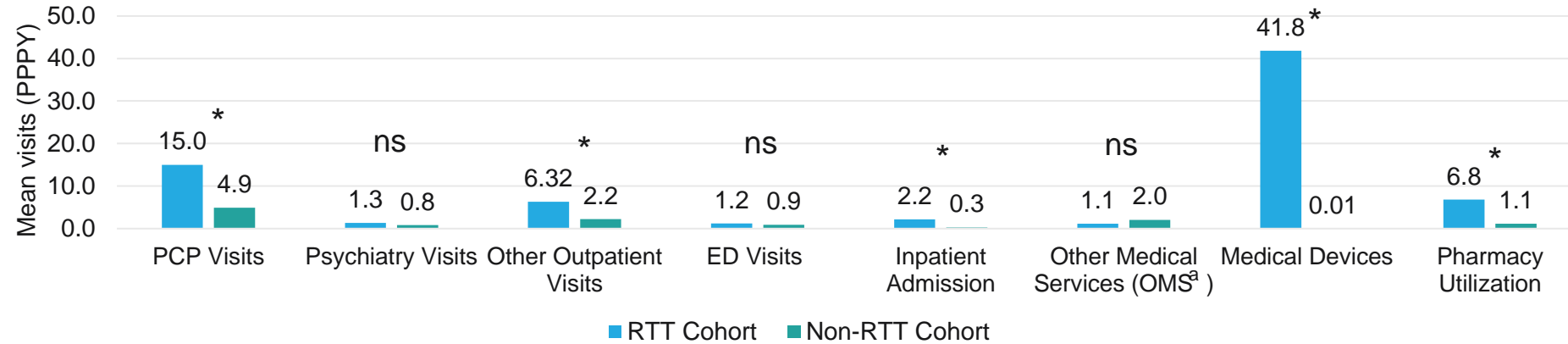
OBJECTIVES

- Compare individuals with and without RTT on HCRU and medical costs.

METHODS

- Study Design
 - A retrospective cohort study using integrated medical claims from Clarivate’s real-world data repository³
- Study Period
 - The study data represent years 2017 to 2022; the case-finding period was from June 1, 2018, to June 5, 2021.
 - The baseline period was 12 months prior to the index date, and the follow-up period was 12 months after the index date.
 - The index date was defined as the date of the first medical claim with a diagnosis of RTT (RTT cohort) or the date of the first medical claim (non-RTT cohort) during the case-finding period.
- Summary of Analytical Methods
 - Chi-square tests and t-tests were used to assess statistical differences for categorical and continuous variables, respectively, between the RTT and non-RTT cohorts. The alpha level for statistical significance was set at $p < 0.05$.
- Summary/List of Outcomes
 - Outcomes included HCRU and costs (per patient per year [PPPY]).

Figure 1. Comparison of HCRU



^a Predominantly diagnostic lab tests; * indicates statistically significant difference (p<0.05); ns, not significant
 ED, emergency department; HCRU, healthcare resource utilization; OMS, other medical services; PCP, primary care physician; PPPY, per person per year; RTT, Rett syndrome

Figure 2. Most Frequently Used Medical Devices

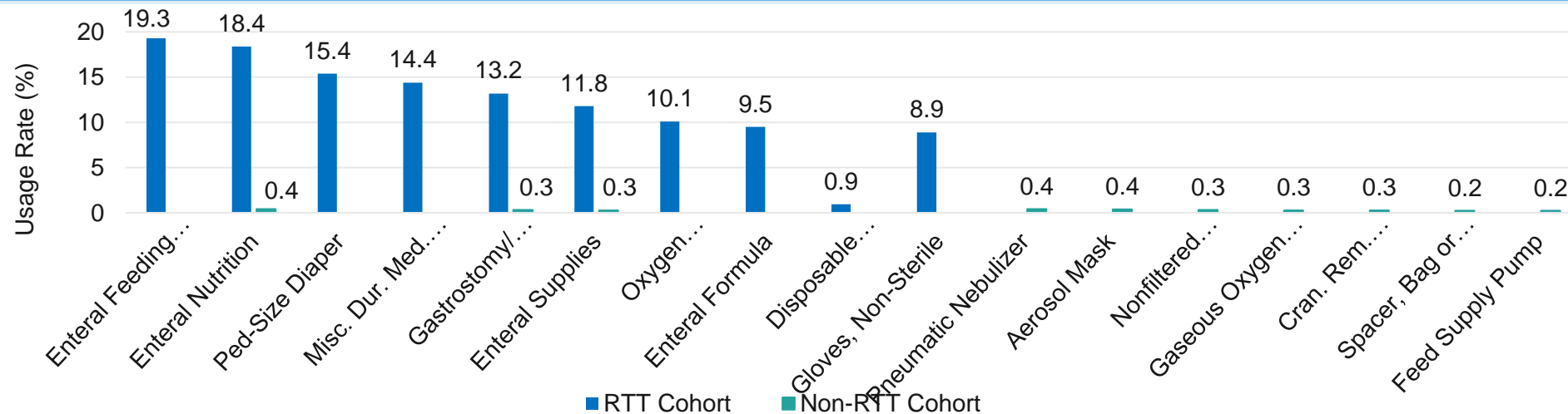
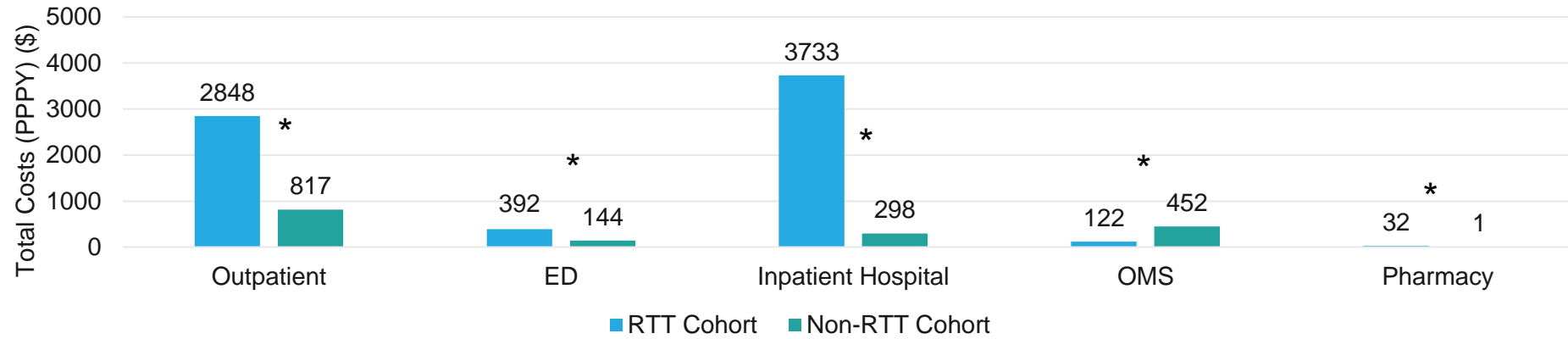


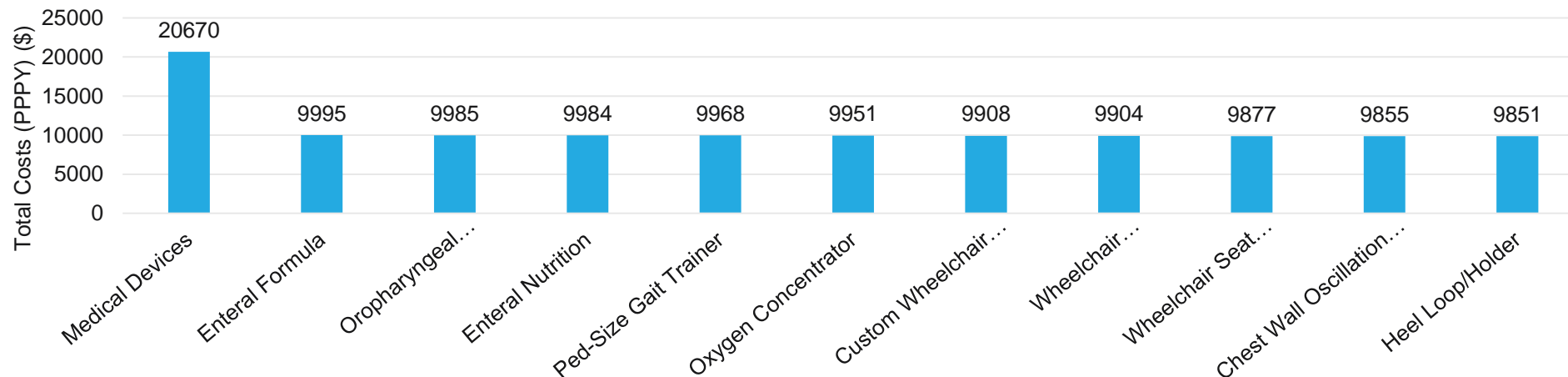
Figure 3. Comparison of All-Cause Healthcare Costs



* indicates statistically significant difference (p≤0.05)

ED, emergency department; OMS, other medical services; PPPY, per person per year; RTT, Rett syndrome

Figure 4. Costs for Medical Devices in the RTT Cohort



Patients could be using more than one device at a time
 PPPY, per person per year; RTT, Rett syndrome

CONCLUSIONS

- Individuals with RTT required significantly more care from physicians and allied health professionals.
- The RTT cohort utilized more medical devices, resulting in significantly higher costs compared to the non-RTT cohort.
- The RTT cohort had elevated all-cause service utilization compared to the non-RTT cohort, which may result in considerable financial burden for payers, parents, and caregivers.
- The RTT cohort elevated service costs were primarily driven by emergency department visits, outpatient visits, and inpatient hospital stays which were 3, 3.5 and 10 times (respectively) greater than the non-RTT cohort.

LIMITATIONS

- The results are subject to the challenges routinely reported with the use of administrative claims data, such as the lack of information about disease severity, whether individuals met supportive criteria for a RTT diagnosis, or whether they were tested for a genetic mutation.
- This study used Clarivate's real-world data repository; as such, the results are not entirely generalizable due to limitations on the representativeness of the claimants.

REFERENCES

1. The National Institute of Neurological Disorders and Stroke. Rett Syndrome Fact Sheet. <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Rett-Syndrome-Fact-Sheet>. Accessed January 15, 2021.
2. Mayo Clinic. Rett syndrome. <https://www.mayoclinic.org/diseases-conditions/rett-syndrome/symptoms-causes/syc-20377227>. Accessed January 15, 2021.
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