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

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EXECUTIVE SUMMARY

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

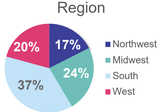
The RTT cohort had elevated all-cause HCRU and costs compared with the non-RTT cohort

RTT and non-RTT Cohort Population Characteristics

1046

RTT cohort
Predominantly female
Mean age: 7.2 years

Region



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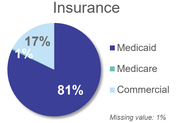

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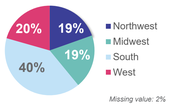
2157

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

Region



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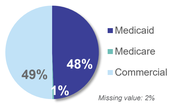

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HCRU and Cost

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*

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

10✖ ***greater** for **inpatient hospital visits***

3.5✖ ***greater** for **outpatient visits***

3✖ ***greater** for **emergency department visits***

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

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 disorder[1]
- Management of the disorder often involves addressing symptoms through a multidisciplinary team–based approach[2]
- To date, this may be the first study to examine the healthcare resource utilization (HCRU) and costs of individuals diagnosed with RTT using a commercially available claims data set

OBJECTIVES

- Compare the HCRU and medical costs between individuals with and without RTT

METHODS

Study Design

- A retrospective cohort study using integrated medical claims from Clarivate's real-world data repository[3]

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 $p \leq 0.05$

Summary/List of Outcomes

- Outcomes included HCRU and costs (per patient per year [PPPY])

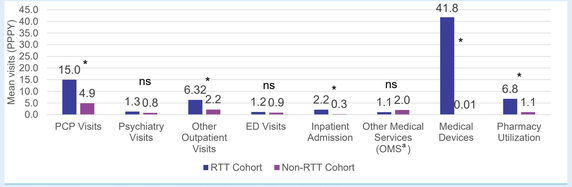
Table 1. Comorbid conditions of the RTT and non-RTT cohorts

	RTT cohort (n = 1046)		Non-RTT cohort (n = 2157)	
	n	%	n	%
Incontinence	435	41.6	29	1.3
Dysphagia	356	34.0	29	1.3
Speech language disorders	356	34.0	183	8.5
Epilepsy/convulsions	338	32.3	35	1.6
Scoliosis	335	32.0	5	0.2
Convulsions	299	28.6	34	1.6
Constipation	296	28.3	123	5.7
Sleep disorders	269	25.7	70	3.2
GERD	191	18.3	54	2.5
Muscle weakness	142	13.6	13	0.6
Epilepsy	73	7.0	4	0.2
Dyspnea	69	6.6	44	2.0
Extrapyramidal movement	61	5.8	1	0.0
Anxiety	28	2.7	50	2.3
Long QT syndrome	26	2.5	0	0.0
Restlessness and agitation	20	1.9	9	0.4
Anemia	16	1.5	51	2.4
Depression	2	0.2	5	0.2

Diagnoses were counted during the 12-month period following the index date.
GERD, gastroesophageal reflux disease; RTT, Rett syndrome

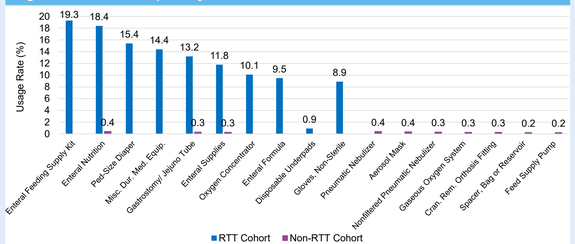
RESULTS

Figure 1. Comparison of HCRU



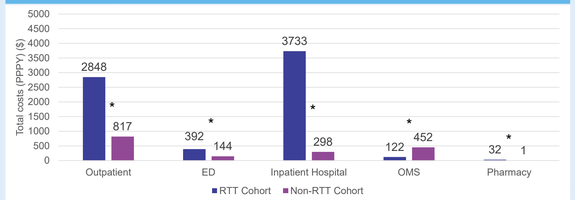
*Predominantly diagnostic lab tests; * indicates statistically significant difference (ps0.05); ns, not significant
ED, emergency department; HCRU, healthcare resource utilization; OMS, other medical services; PCP, primary care physician; PPPY, per person per year; RTT, Rett syndrome

Figure 2. Most Frequently Used Medical Devices



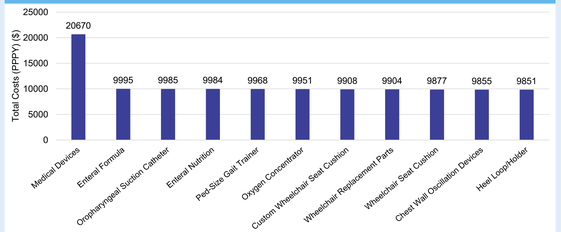
RTT, Rett syndrome

Figure 3. Comparison of All-Cause Healthcare Costs



* indicates statistically significant difference (ps0.05)
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 various 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 and medical service utilization compared to the non-RTT cohort, which may result in considerable financial burden for payers, parents, and caregivers
- When individuals with RTT used healthcare resources, they had significantly higher costs compared to those who did not have RTT: service costs for the RTT cohort were 3 times (emergency department visits), 3.5 times (outpatient visits), and 10 times (inpatient hospital stays) greater than the non-RTT cohort

LIMITATIONS

- The results are subject to the challenges routinely reported with the use of commercial 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 only used Clarivate's real-world data repository; as such, the results are not entirely generalizable due to using only one source of commercial claims data

REFERENCES

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2. Mayo Clinic. Rett syndrome. https://www.mayoclinic.org/diseases-conditions/rett-syndrome/symptoms-causes/syc-20377227. Accessed January 15, 2021.
3. Clarivate. Real World Data. https://clarivate.com/products/real-world-data/. Accessed January 15, 2021.

ACKNOWLEDGMENTS

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DISCLOSURES

Dr. May is an employee of Acadia Pharmaceuticals, Inc. which sponsored the study. Drs. Tigwa, Parab, and Ruetsch are employees of Health Analytics, LLC which was funded to conduct the stud.

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