

# Capturing the Burden of Prader-Willi Syndrome on Patients and the Healthcare System: A Real-World Analysis of United States Claims Data

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## INTRODUCTION

Prader-Willi syndrome (PWS) is a rare multi-system genetic disorder characterized by hyperphagia, behavioral/psychological complications, and a range of medical comorbidities. The observed median age at death was 23 years (IQR 6-36) per a recent analysis of US IQVIA Health Plan Claims Data<sup>1</sup>.

Chronic, life-threatening hyperphagia beginning in early childhood is associated with food seeking behaviors, high rates of choking, accidents, gastrointestinal perforation, and temper outbursts<sup>2,3</sup>. Uncontrolled hyperphagia was a leading cause of death, contributing to approximately one-third of all reported deaths and half of all deaths in children in a cause of death analysis<sup>2</sup>. Though PWS' health economic burden has been described previously<sup>4</sup>, specific services driving that burden were not documented.

This analysis aims to describe the healthcare services that drive some of this heightened utilization and morbidity burden by examining ambulance-related and palliative services used by this population, as documented in a US administrative claims data set.

## MATERIALS & METHODS

- Observational retrospective analysis was performed on a de-identified U.S. closed-claims dataset (2021-2023).
- Patients with ≥2 claims with a diagnosis of PWS (Q87.11) >2 weeks apart were included in the study.
- Diagnoses and services codes occurring during this three-year period were documented but all utilization metrics were annualized.
- Annual averages of ambulance (HCPCS A codes) and palliative services were stratified by age groups (< 12, 12-23, 24-35, 36-47, 48-59 years).

## RESULTS

- A total of 3685 patients were included in the study.
- Though the proportion of patients decreases as function of age, the use of ambulance services increases up to the 24-35 age stratum, it remains constant thereafter (Figure 1).
- Palliative services mostly increase with age, but this utilization is much higher than in the overall population (2022: 0.5%<sup>5</sup>).



### Ambulance Use Services

- The annual average of ambulance service codes remain constant across all age strata.
- Patients with at least one service tend to have many services, suggesting that some patients carry a greater burden than others (Figure 2).



### Palliative Use Services

- The rate of palliative service codes is relatively high given that the majority of palliative services in US are provided to a population age 65+<sup>5</sup>.
- Patients with at least one service tend to have many services, again suggesting that some patients carry a greater burden than others (Figure 3).

Figure 1. Percentage of PWS Patients with Services

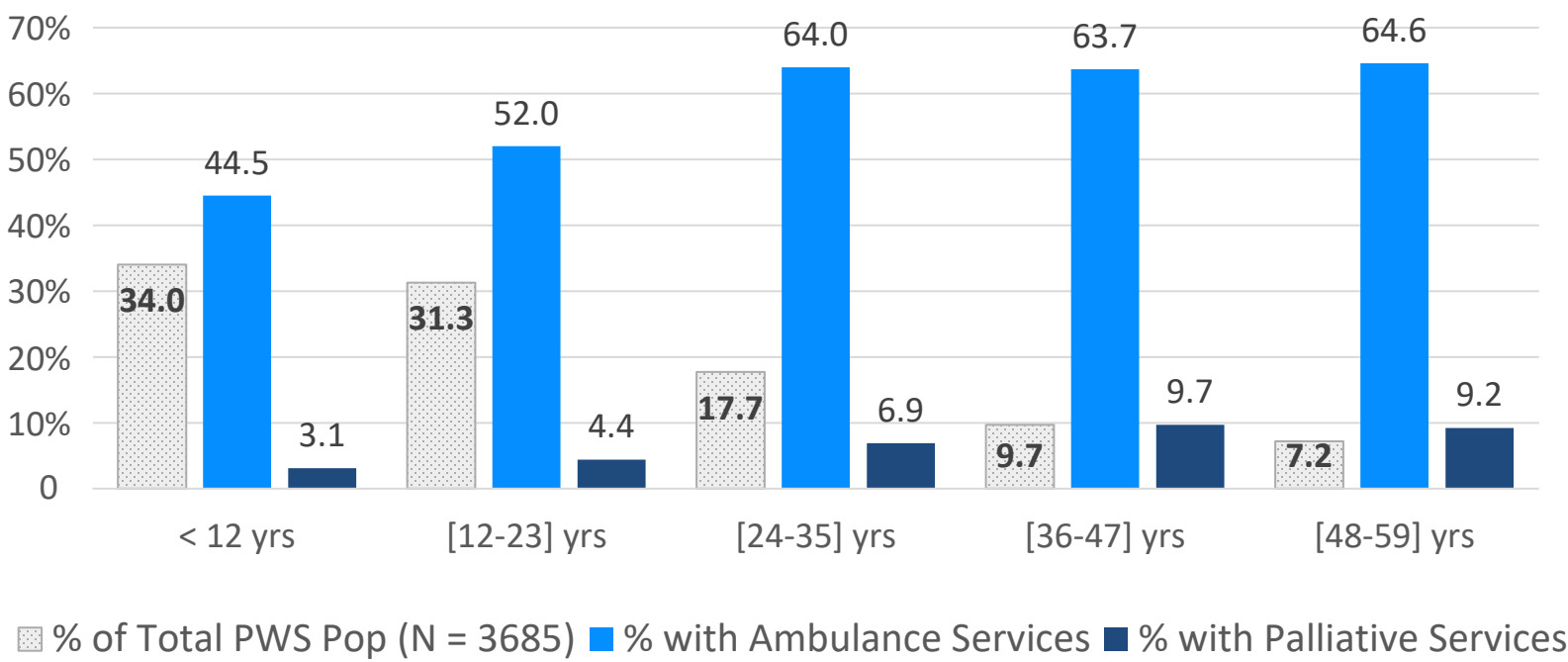


Figure 2. Annual Number of Ambulance Services for PWS Patients

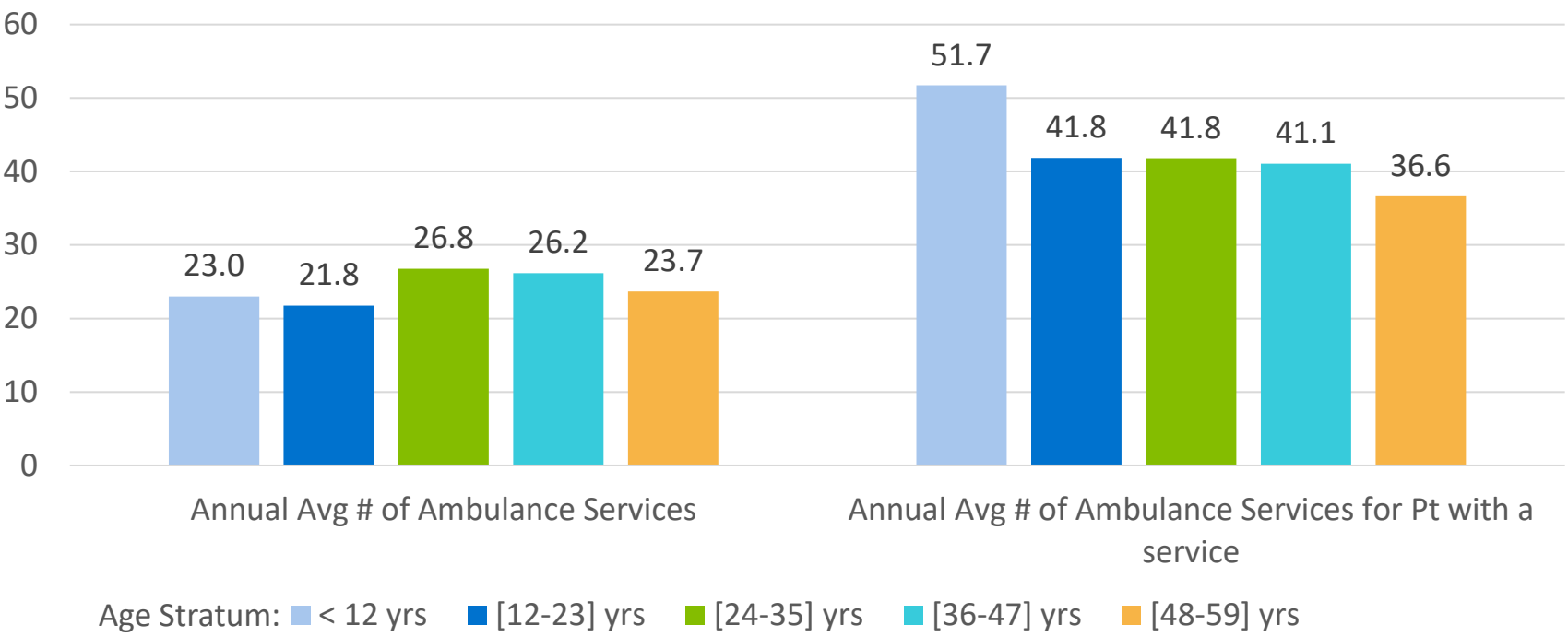
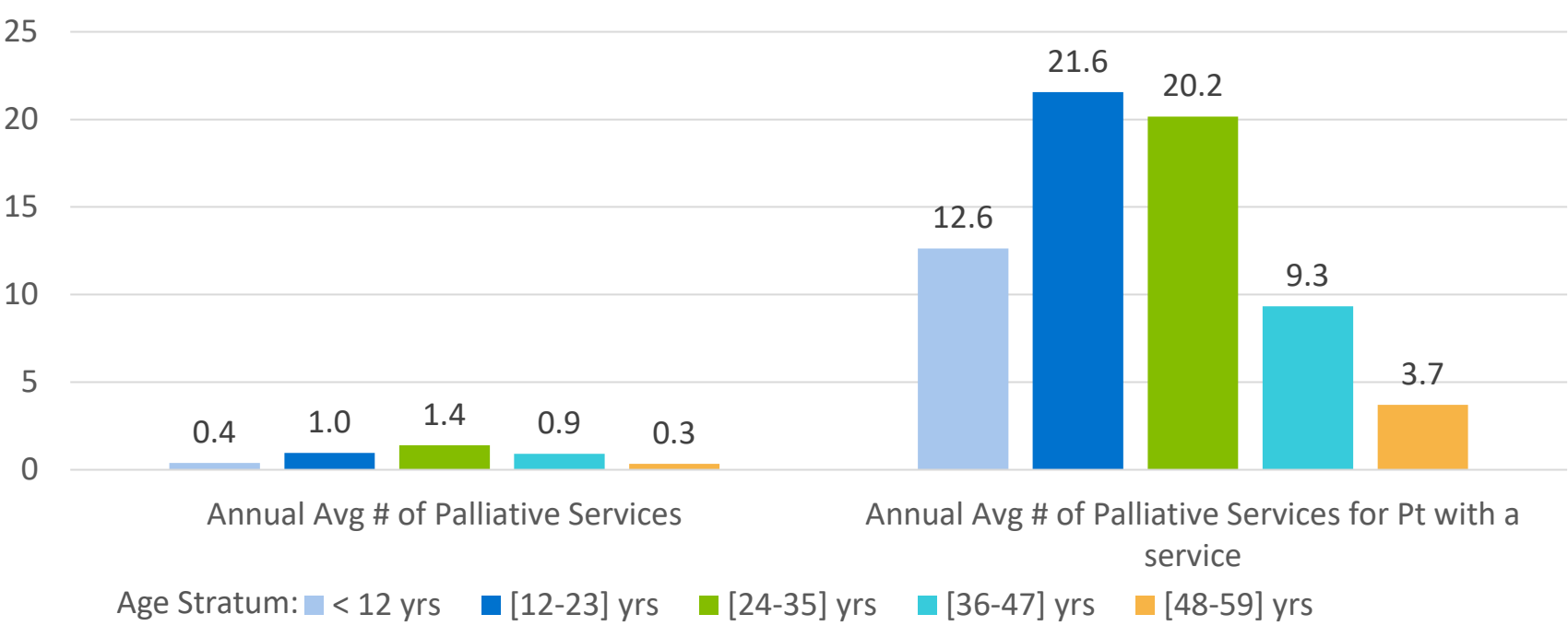


Figure 3. Annual Number of Palliative Services for PWS Patients



## CONCLUSIONS

- Ambulance and palliative services are a novel way to assess burden in real world data.
- Disease burden greatest in younger patients, but remains similar with age, despite diminishing population size.
- Utilization of ambulance and palliative services in this population provides insight into the burden associated with heightened PWS mortality.
- This real-world analysis reinforces existing PWS literature, validating published evidence from US claims data on the considerable burden and mortality of individuals with PWS and the US healthcare system.

## ACKNOWLEDGEMENTS

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Abbreviations: PWS, Prader-Willi syndrome; Pop, population; Avg, average; Pt, patient.

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