

**BACKGROUND**

Data from the OptumHealth reporting and insights employer-based claims database were used to conduct this retrospective cohort study among individuals enrolled in a large population-based insurance plan for children from birth to 18 years of age. The study cohort included beneficiaries who were identified as having Down syndrome (DS) and their matched controls through their employers, including primary subscribers, secondary subscribers, and dependents. The database covers the period from the first quarter of 1999 through the fourth quarter of 2013.

Patients were assigned to one or more age categories based on their date of birth and were then randomly assigned to the DS case group or control group using a matching algorithm. The first continuous enrollment period was used in the analysis for patients without a diagnosis for any of the conditions listed below (ICD-9-CM codes: 758.xx).

**METHODS**

Baseline characteristics, outcomes, and statistical analysis

- **Patient matching:** Patients within each age category in the DS case cohort were matched to control patients in the same age category in a 1:4 ratio using a greedy matching algorithm.
- **Analysis:** Outpatient and inpatient annual health care utilization costs were obtained from the database for each age group.
- **Analyzes:** All health care utilization costs were compared between the two cohorts using Wilcoxon signed-rank tests.

**RESULTS**

Baseline characteristics post-matching

- **Out-of-pocket costs:** Patients of DS did not have significantly higher average annual out-of-pocket costs compared to their matched controls in each age group and cost component.
- **Total annual cost:** The greatest incremental out-of-pocket costs were inpatient costs during the first year of life (between $2,506 and $3,415) and last year of life (between $2,506 and $3,415).
- **Control group:** Between the two cohorts using Wilcoxon signed-rank tests.

**DISCUSSION**

- **In addition, non-economic factors such as emotional considerations are important to the overall cost of care.** Small differences between the DS case group and control group that meet statistical significance through these differences are unlikely to be clinically meaningful.
- **Conclusion:** This study focuses only on out-of-pocket health care costs to parents of children with DS, which is only one of many costs associated with having a child with DS. Many costs associated with having a child with DS may include medical expenses, non-medical expenses, or other expenses for services DS may need.

**LIMITATIONS**

- **Parents of children with DS pay on average $384 per month in out-of-pocket medical expenses, on average, when costs are estimated over a 15-year period.** Parents of children with DS pay on average $384 per month in out-of-pocket medical expenses, on average, when costs are estimated over a 15-year period. This estimate does not consider the costs associated with non-medical expenses or other expenses for services DS may need. Costs associated with non-medical expenses or other expenses for services DS may need.

**CONCLUSION**

- **Patients with DS pay on average $384 per month in out-of-pocket medical expenses, on average, when costs are estimated over a 15-year period.** Patients with DS pay on average $384 per month in out-of-pocket medical expenses, on average, when costs are estimated over a 15-year period. This estimate does not consider the costs associated with non-medical expenses or other expenses for services DS may need. Costs associated with non-medical expenses or other expenses for services DS may need.