Out-of-pocket Medical Costs for Parents with Children with Down Syndrome in the United States

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Citation

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BACKGROUND

As prenatal testing for Down syndrome (DS) evolves, the percentage of expectant parents who make a decision based on a prenatal diagnosis increases. These decisions are not based only on whether a prenatal test to identify Down syndrome is positive or negative, but also on whether the pregnancy should be continued or terminated. In 2013, Cuckle et al. demonstrated that although women diagnosed with DS are optimized for better quality of life, it may no longer be appropriate to offer termination of pregnancy for DS cases. However, the impact of carrying a child with DS on the family budget and family economic status has not been adequately assessed. In addition, there is no evidence on the costs of raising a child with DS in the United States. The objective of this study was to measure the out-of-pocket costs for parents and children with DS.

METHODS

Data

Data from the OptumWhoehpe Health Insights benchmarks and employment-based claims database were used to conduct this retrospective cohort study. Patients included were those with a diagnosis of DS (ICD-9-CM code: 758.0x) associated with a diagnosis of DS (ICD-9-CM code: 758.0x). These patients were selected from Ohio, California, and Florida, which were chosen because of their large patient populations. The study included patients born from January 1, 1998 to December 31, 1999. Patients were matched to control patients in the same age category in a 1:4 ratio using a greedy matching algorithm (Figure 1).

Selection criteria

Patients were selected to be included in the study if they were younger than 21 years old at the time of the diagnosis, had at least one medical claim on the insurance plan, and had observable demographic, socioeconomic, and clinical characteristics that were possible to control using the matching algorithm. The controls were selected with a diagnosis of DS (ICD-9-CM code: 758.0x). Outpatient and inpatient costs were not included in the analysis. Inpatient costs were calculated using Wilcoxon signed-rank tests.

Baseline characteristics post-matching

Baseline characteristics were similar with respect to most baseline characteristics (Table 1).

RESULTS

Baseline characteristics in patient age cohorts, after matching

Table 1. Baseline characteristics in patient age cohorts, after matching

<table>
<thead>
<tr>
<th>Age Category</th>
<th>Number of Patients</th>
<th>Percentage of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9 months</td>
<td>1,192</td>
<td>21.2%</td>
</tr>
<tr>
<td>10-12 months</td>
<td>1,096</td>
<td>19.7%</td>
</tr>
<tr>
<td>13-18 months</td>
<td>1,089</td>
<td>19.4%</td>
</tr>
<tr>
<td>19-23 months</td>
<td>1,043</td>
<td>18.9%</td>
</tr>
<tr>
<td>24-29 months</td>
<td>973</td>
<td>17.8%</td>
</tr>
<tr>
<td>30-36 months</td>
<td>847</td>
<td>15.6%</td>
</tr>
<tr>
<td>37-47 months</td>
<td>758</td>
<td>13.8%</td>
</tr>
<tr>
<td>48-59 months</td>
<td>724</td>
<td>13.0%</td>
</tr>
</tbody>
</table>

DISCUSSION

In addition, non-economic factors such as emotional considerations, religious values, and patient choice may also impact the decision to continue a pregnancy. The current study addressed the economic costs associated with raising a child with DS, but there is a lack of research on how these factors may influence the decision to continue a pregnancy.

LIMITATIONS

The study only included out-of-pocket costs for outpatient visits, emergency room visits, home health agencies, and pharmacy costs. The study does not include indirect costs such as lost wages, decreased productivity, or the costs of special education and services that may be required. The study may also underestimate the costs of raising a child with DS as some costs may be incurred by parents who did not participate in the study.

CONCLUSION

In conclusion, the current study is the first to measure the out-of-pocket costs for parents and children with DS and to compare these costs to those of children without DS. The results demonstrate that the costs of raising a child with DS are substantial and may place a significant burden on family budgets. These findings highlight the need for additional research to better understand the economic costs associated with raising a child with DS and to develop strategies to mitigate these costs.