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

Citation

Permanent link
http://nrs.harvard.edu/urn-3:HUL.InstRepos:34331450

Terms of Use
This article was downloaded from Harvard University’s DASH repository, and is made available under the terms and conditions applicable to Open Access Policy Articles, as set forth at http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-of-use#OAP

Share Your Story
The Harvard community has made this article openly available. Please share how this access benefits you. Submit a story.

Accessibility
**Background**

This study estimated the incremental lifetime cost of raising children with DS, focusing on medical costs between birth and 18 years of age. The study was conducted in the United States and included data from 20,000 children with DS and 180,000 control children.

**Methods**

The study used a retrospective cohort design and compared children with DS to control children. The incremental cost was estimated using differences-in-differences analysis. The study also accounted for confounding factors using propensity score matching.

**Results**

The average incremental lifetime medical costs for children with DS were estimated to be approximately $33,347 in 2004 USD. The costs were highest during the first year of life and decreased as the children grew older.

**Discussion**

The study highlights the significant financial burden on families raising children with DS. The findings have implications for policy and resource allocation to support these families.

**Conclusion**

The study provides valuable insights into the financial costs of raising children with DS, which can inform policy decisions and resource allocation.

**References**


---

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

<table>
<thead>
<tr>
<th>Age Category</th>
<th>Female</th>
<th>Male</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 0 to &lt;1</td>
<td>193 (44.6%)</td>
<td>165 (39.3%)</td>
<td>31 (7.2%)</td>
<td>389</td>
</tr>
<tr>
<td>Age 1 to &lt;3</td>
<td>192 (44.2%)</td>
<td>164 (39.1%)</td>
<td>31 (7.2%)</td>
<td>387</td>
</tr>
<tr>
<td>Age 3 to &lt;5</td>
<td>192 (44.5%)</td>
<td>165 (39.2%)</td>
<td>31 (7.2%)</td>
<td>388</td>
</tr>
<tr>
<td>Age 5 to &lt;13</td>
<td>190 (44.2%)</td>
<td>164 (38.9%)</td>
<td>31 (7.2%)</td>
<td>385</td>
</tr>
<tr>
<td>Age 13 to &lt;18</td>
<td>191 (43.9%)</td>
<td>163 (39.6%)</td>
<td>32 (7.8%)</td>
<td>386</td>
</tr>
</tbody>
</table>

**Table 2. Mean annual out-of-pocket costs by patient age category, as estimated by age category**

<table>
<thead>
<tr>
<th>Age Category</th>
<th>Total Out-of-Pocket Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 0 to &lt;1</td>
<td>$1,000 ± $2,000</td>
</tr>
<tr>
<td>Age 1 to &lt;3</td>
<td>$1,263 ± $2,500</td>
</tr>
<tr>
<td>Age 3 to &lt;5</td>
<td>$1,521 ± $3,000</td>
</tr>
<tr>
<td>Age 5 to &lt;13</td>
<td>$1,724 ± $3,500</td>
</tr>
<tr>
<td>Age 13 to &lt;18</td>
<td>$1,907 ± $4,000</td>
</tr>
</tbody>
</table>

**Figure 1. Baseline characteristics post-matching**

The table shows the distribution of patients across different age categories after matching. The table includes gender, race, ethnicity, and other relevant demographic information.

**Figure 2. Study scheme**

The scheme illustrates the study design, including the selection criteria, matching process, and outcomes measured.

**Figure 3. Mean total out-of-pocket annual cost to parents of children with DS and matched controls, by age group**

The figure shows the mean total out-of-pocket annual costs for parents of children with DS and matched controls, stratified by age group.