Socioeconomic impact of preterm birth in Germany and Austria: A parental perspective

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Background and objective: In Europe, the prevalence rate of premature birth ranges from 5.5 to 11.4% - an average of 7.1% of all live births. Preterm birth poses a growing risk to health and well-being of many Europeans and increasing costs to society in terms of lifelong need for support. Our objective was to measure the socioeconomic burden of preterm birth on their parents and the society in Germany and Austria.

Methods: A novel web-based technology was constructed to perform a survey of parents of preterm infants. It was developed in collaboration with parents, pediatricians and socioeconomic researchers. Main focus were morbidity, social status, direct and indirect costs. Parents were invited to participate to this online-questionnaire from information letter sent out to pediatricians and therapists and from websites targeting parents of preterm birth. Data were collected between September 2007 and March 2008 in Germany and Austria.

Results: Parents of 588 preterm birth children responded. The detailed characterisation of the parental perspective on the impact of preterm birth is represented below:

- 43% were born less than 32 weeks
- 39% were born between 32 and 36 6/7 weeks
- 7% were born after 37 weeks
- 1% were born before 28 weeks
- 23% were born before 28 weeks
- 37% were born before 28 weeks

Fig. 1. 80% of the infants were less than 5 years old

Fig. 2. 76% of the infants were born less than 32 weeks of gestation

Tab. 1: Characteristics of hospitalisation, need for additional therapies and adjuvants, Parents perspective on their infants neurocognitive development. Neurological problems were most often diagnosed within the first year of life (70%). They decrease with increasing gestational age. The incidence of most school related problems (data not shown) is independent of gestational age.

<table>
<thead>
<tr>
<th>Hospitalisation</th>
<th>≤ 28 wks (n=228)</th>
<th>28 - 31 6/7 wks (n=220)</th>
<th>&gt; 32 wks (n=138)</th>
</tr>
</thead>
<tbody>
<tr>
<td>length of stay in hospital/days (average)</td>
<td>116</td>
<td>71</td>
<td>28</td>
</tr>
<tr>
<td>readmission after discharge (%)</td>
<td>65</td>
<td>54</td>
<td>42</td>
</tr>
<tr>
<td>outpatient examinations/days/year</td>
<td>7.3</td>
<td>4.1</td>
<td>2.5</td>
</tr>
</tbody>
</table>

Parent’s perspective on neurocognitive development

1Type of difficulty

- overall developmental delay, n (%) | 58 | 42 | 35 |
- vision, n (%) | 46 | 32 | 21 |
- hearing, n (%) | 8 | 10 | 5 |
- language, n (%) | 35 | 24 | 20 |
- neuromotor, n (%) | 38 | 28 | 16 |
- feeding difficulties, n (%) | 41 | 30 | 23 |

Additional therapies

- physical therapy, n (%) | 86 | 62 | 58 |
- occupational therapy, n (%) | 47 | 32 | 26 |
- speech therapy, n (%) | 42 | 24 | 20 |
- others (e.g. massage, ophthalmology, animal or music therapy), n (%) | 86 | 69 | 26 |

Adjuvants

- inhaler, n (%) | 61 | 35 | 21 |
- apnea monitor, n (%) | 63 | 33 | 12 |
- nursing auxiliary, n (%) | 9 | 2 | 3 |
- others (e.g. glasses, orthoses, wheelchair), n (%) | 134 | 61 | 35 |

Parents economic impact:

- Travel expenses
- Accommodation
- Missing working hours, loss of income
- Costs for child care
- Costs for private lessons
- Non-covered costs by insurance for
  - therapies
  - adjuvants
  - drugs

Fig3: Overall socioeconomic impact of preterm birth on the health system and the parents

<table>
<thead>
<tr>
<th>Financial impact of health system</th>
<th>Hospital stay</th>
<th>Re-admission</th>
<th>Follow up examination</th>
<th>Therapies</th>
<th>Adjuvants</th>
<th>Drugs</th>
<th>School performance difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Km costs</td>
<td>€ infant/5 years</td>
<td>€/infant/year</td>
<td>Overall costs in Germany (with 15.000 preterm delivery &gt; 32 wks), in €/year</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation costs for hospital visits</td>
<td>5.300</td>
<td>1993</td>
<td>399</td>
<td>5.978.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation cost for follow-up visits</td>
<td>990</td>
<td>372</td>
<td>74</td>
<td>1.117.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation costs for ambulant treatment</td>
<td>1100</td>
<td>414</td>
<td>83</td>
<td>1.241.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation costs to therapists</td>
<td>4.560</td>
<td>1715</td>
<td>343</td>
<td>5.144.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costs for therapies</td>
<td>1180</td>
<td>236</td>
<td>4550.000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costs for drugs</td>
<td>410</td>
<td>82</td>
<td>1.230.000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costs for child care</td>
<td>360</td>
<td>72</td>
<td>1.080.000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount</td>
<td>6613</td>
<td>1323</td>
<td>19.840.000</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Conclusions: This survey is a novel approach to assess the social and economic burden on parents of preterm infants. Moreover, it helps to measure the impact of preterm birth also to the society.

Work place challenges for the parents: due to missing working days a family can anticipate a loss of income for 460€ for a mother and 1200 € for a father (per what / year ?

Tab. 2: Socioeconomic impact of preterm birth on parents and estimated for the society in Germany