Current medical care of children and adolescents with disorders of sex development in Switzerland

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Introduction and objectives
In Switzerland, persons with DSD asked for better care. It is unclear how many persons are diagnosed with DSD each year in Switzerland and whether medical care meets current international guidelines for DSD.
We aimed to estimate how many children and adolescents have a DSD diagnosis according to Chicago consensus [1] and to describe the current medical care of DSD.

Methods
In Fall 2017, we sent a questionnaire to pediatric endocrinologists of 8 Swiss children’s hospitals asking them:
- To estimate numbers of treated DSD patients
- To indicate specialists involved in DSD care and
- To report research activities.

Results
The 8 children’s hospitals cover >85% of newborns in Switzerland and treat ~750 children with DSD (Table 1). Each year, ~24 newborns and 24 patients aged 1-17 years were diagnosed with complex DSD (ambiguous genitalia). Most hospitals used international guidelines [2] and had interdisciplinary DSD teams (Fig.1). Transition to adult medicine was between 16-25 years, but adult physicians specialized on DSD were lacking. All hospitals participate in the new Swiss DSD cohort study.

Table 1: Estimated number of children with DSD [1], aged <17 years and treated in 8 participating children’s hospitals.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>N per clinic (mean)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total DSD diagnoses</td>
<td>748</td>
<td>94</td>
<td>23-200</td>
</tr>
<tr>
<td>Complex DSD</td>
<td>90</td>
<td>11</td>
<td>3-23</td>
</tr>
<tr>
<td>Congenital adrenal hyperplasia</td>
<td>127</td>
<td>16</td>
<td>4-35</td>
</tr>
<tr>
<td>Ullrich-Turner Syndrome</td>
<td>134</td>
<td>17</td>
<td>9-35</td>
</tr>
<tr>
<td>Other DSD diagnoses, incl. Klinefelter Syndrome</td>
<td>397</td>
<td>50</td>
<td>0-174</td>
</tr>
</tbody>
</table>

Fig.1: Number of specialists per medical speciality in 8 participating children’s hospitals.

Conclusion
Incidence and prevalence of DSD are unknown in Switzerland. Most children’s hospitals had established interdisciplinary DSD teams, which treat children with DSD and their families according to international guidelines, but specialized DSD psychologists and adult DSD specialists were lacking. The new Swiss DSD cohort study will allow to assess reliable data of DSD, facilitate communication among physicians and with advocacy groups, and provide a basis for research.

References:

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