**INTRODUCTION**

Severe epileptic encephalopathies (EEs) of childhood are pharmacoresistant and result in developmental delays, neurocognitive impairment, and motor deficiencies. Caregivers experience substantial humanistic and economic burdens due to the comprehensive care requirements evident with EEs.

Concerns about the emotional impact on siblings of a brother/sister with an EE were reported by 74% (71/98) of caregivers responding to a recent survey.

Qualify of life of the entire family is affected, especially for siblings.

Impact on sibling mental health and social development may be under-recognized by the medical community.

**PURPOSE**

The Sibling Voices Survey evaluated the psychosocial impact of growing up with a sibling affected by Dravet syndrome (DS), Lennox-Gastaut syndrome (LGS), or other severe EEs.

**METHODS**

Survey Development and Recruitment

- Four online surveys were developed in consultation with DS and LGS patient communities and healthcare professionals (www.siblingstudy.com).
- Questions were refined based on beta testing in small groups of parents and siblings.
- Cohort-specific questions were designed for siblings 9-12 years old (y/o), 13-17 y/o, and ≥18 y/o and for parents (siblings 21 y/o and parents not reported here).
- Study protocol was approved by Western IRB (Puyallup, WA) on July 14, 2017.
- Survey responses were solicited between July 19, 2017 and December 31, 2017 (5.5 months).

Survey Design and Analysis

- Survey questions were designed to evaluate psychosocial parameters (Figure 1).
- Quantitative analysis was by visual analog scores (VASE).

**RESULTS**

**Sibling Voices Survey Respondents**

- N=248 survey respondents: siblings <18 y/o (n=44) are shown in Figure 2.

Figure 2. Respondents <18 y/o

**Respondent Demographics**

- Sibling <18 y/o respondents (Table 1)
  - 9-12 y/o (n=24), including 2 sets of twins and 1 set of triplets
  - 13-17 y/o (n=17)
- Patients with epilepsy corresponding to sibling respondents
  - 75% (9-12 y/o cohort) and 46% (13-17 y/o cohort) of siblings with EE had Dravet syndrome

**Table 1. Demographic Characteristics of Sibling Survey Respondents <18 y/o (n=44)**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>9-12 y/o (n=24)</th>
<th>13-17 y/o (n=17)</th>
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<tbody>
<tr>
<td>Sex, % (n)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12 (50)</td>
<td>11 (65)</td>
</tr>
<tr>
<td>Female</td>
<td>12 (50)</td>
<td>6 (35)</td>
</tr>
<tr>
<td>Age, mean (range)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9-12 y/o</td>
<td>10 (9-11)</td>
<td>14 (13-15)</td>
</tr>
<tr>
<td>13-17 y/o</td>
<td>11 (10-12)</td>
<td>15 (14-16)</td>
</tr>
<tr>
<td>Special needs</td>
<td>% (n)</td>
<td></td>
</tr>
<tr>
<td>9-12 y/o</td>
<td>9 (37)</td>
<td>6 (35)</td>
</tr>
<tr>
<td>13-17 y/o</td>
<td>8 (47)</td>
<td>8 (46)</td>
</tr>
<tr>
<td>Family size, mean (range)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9-12 y/o</td>
<td>4 (3-6)</td>
<td>4 (3-6)</td>
</tr>
<tr>
<td>13-17 y/o</td>
<td>4 (3-6)</td>
<td>4 (3-6)</td>
</tr>
</tbody>
</table>

**Figure 3. Most Difficult Aspects Experienced by Siblings of Patients With Epilepsy**

- The most difficult aspects of having a sibling with an EE differed among cohorts (Figure 3A).
  - Top concerns: 9-12 y/o: worried/scared; less parental attention; activities disrupted.
  - Top concerns: 13-17 y/o: parental stress; worried/scared; more responsibilities of home; embarrassing behaviors.

**Figure 4. Most Difficult Aspects Experienced by Siblings of Patients With Epilepsy**

- The most frequent emotional impacts reported by 9-12 y/o: easily startled, unhappiness, grumpiness (Figure 4A).
- The most frequent emotional impacts reported by 13-17 y/o: immaturity, unhappiness, bad dreams (Figure 4A).
- Greater degree of sadness and lower degree of anger than worry/fear or stress over sibling’s diagnosis in both cohorts (median [IQR] on a 0-10 visual analog scale).

**Figure 5. Support Networks Described by Siblings**

- Emotional self-reports: 9-12 y/o (n=24), 13-17 y/o (n=17)

**DISCUSSION**

- The Sibling Voices Survey identified sibling-specific concerns about growing up with a brother/sister with epilepsy.
- These results confirm and extend previously reported findings specifically concerning CS/LGS with EE or other severe EE adversely affects the entire family unit.
- Supportive services for families with a child who has epilepsy could improve family psychosocial dynamics and functioning by addressing areas such as:
  - Stresses at home, school, and socially.
  - Effects on emotional health such as insistent moodiness and fears or changes in mood.
  - Social support networks most likely to be helpful.

**REFERENCES**


**ACKNOWLEDGMENTS**

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