Siblings of Epileptic Encephalopathy Patients Are at Risk for Depression and Anxiety: Results From the Sibling Voices Survey

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Funding and Conflict of Interest

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• Laurie D. Bailey is an employee of, and owns stock in, Zogenix, Inc.
Introduction

- Dravet syndrome (DS), Lennox-Gastaut syndrome (LGS), and other severe childhood epileptic encephalopathies (EEs) require comprehensive care

- Burden of care
  - Emotional impact on immediate caregivers affects the quality of life of the entire family unit\textsuperscript{1-2}

- Impact on the siblings of EE patients
  - 74\% (114/154) of caregivers reported concern for sibling well-being\textsuperscript{3}

Knowledge gap in the impact of severe epilepsy on siblings

Recent parent survey about siblings recognized “risk of psychosocial problems”¹

Objective

• The Sibling Voices Survey was developed to assess the emotional impact of growing up with a sibling with DS, LGS, or other severe childhood EE
  – This study assessed emotions and symptoms suggestive of depression and anxiety
Methods – Survey Development

• Online, age- and role-specific surveys
  — Siblings 9-12 years
  — Siblings 13-17 years
  — Adult siblings ≥18 years
  — Parents (not reported here)

• Developed in consultation with DS and LGS patient communities and healthcare professionals and approved by Western IRB (Puyallup, WA)

• Participants recruited through patient advocacy websites, social media, medical meetings, and patient community events
  — Obtained subject or caregiver consent

• Open for responses July 19 – December 31, 2017
Methods – Survey Design

• Metrics for identifying risk factors for depression and anxiety
• Questions designed to assess depressed mood
  – 4 questions, 0-3 scale
  – 1 question, 0-10 scale
• Questions designed to assess anxiety symptoms
  – 2 questions, 0-3 scale
  – 1 question, 0-10 scale
• Adult siblings answered retrospectively (about while growing up) and currently
• Free-form responses
Results – Sibling Voices Survey Respondents

- All respondents (N=248)
  - Parents (n=128)
  - Patients with epilepsy (n=115)
  - Siblings 9-12 y/o (n=24)
  - Siblings 13-17 y/o (n=17)
  - Adult siblings ≥18 y/o (n=79)
  - Total sibling respondents (n=120)

- Patients with epilepsy (n=107)
  - 1 sibling respondent (n=96)
  - 2 sibling respondents (n=9)
  - 3 sibling respondents (n=2)

y/o, years old.
# Demographic Characteristics of Respondents

*Excludes a set of 3 triplets who responded “no” to “twin sibling.”

NA, not applicable.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Age Group</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9-12 y/o</td>
<td>13-17 y/o</td>
</tr>
<tr>
<td>n</td>
<td>24</td>
<td>17</td>
</tr>
<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>Twin sibling, n (%)</td>
<td>2 (8)*</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Age, years, mean (range)</td>
<td>10 (9-12)</td>
<td>14 (13-15)</td>
</tr>
<tr>
<td>School grade, mean (range)</td>
<td>5 (3-7)</td>
<td>9 (8-11)</td>
</tr>
<tr>
<td>Family size, mean (range)</td>
<td>5 (4-8)</td>
<td>5 (4-10)</td>
</tr>
<tr>
<td>No. of children/family, mean (range)</td>
<td>4 (2-6)</td>
<td>4 (2-8)</td>
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## Demographic Characteristics of Patients With Epilepsy

<table>
<thead>
<tr>
<th>Characteristic</th>
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<tbody>
<tr>
<td>n</td>
<td>107</td>
</tr>
<tr>
<td>Patient age, years, mean (range)</td>
<td>16 (1-61)</td>
</tr>
<tr>
<td>Patient sex, n (%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>44 (41)</td>
</tr>
<tr>
<td>Female</td>
<td>63 (59)</td>
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<tr>
<td>Epilepsy diagnosis, n (%)</td>
<td></td>
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<tr>
<td>Dravet syndrome</td>
<td>41 (38)</td>
</tr>
<tr>
<td>Lennox-Gastaut syndrome</td>
<td>13 (12)</td>
</tr>
<tr>
<td>Other epileptic encephalopathy</td>
<td>53 (50)</td>
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</table>
Potential Symptoms of Depressed Mood

- ≥50% of most sibling cohorts reported feeling unhappiness or irritability
- More adult than 9-12 or 13-17 y/o siblings reported feelings of tiredness or not enjoying things
- Reported depressed mood symptoms increased with age
- 35% (28/72) of adult siblings reported treatment for clinical depression
A substantial proportion of sibling respondents reported sadness over their sibling’s diagnosis.

Feelings of sadness were greater than anger in 9-12 y/o and 13-17 y/o siblings.

Adult siblings were not asked these questions.
<table>
<thead>
<tr>
<th>Age Group</th>
<th>Response</th>
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<tbody>
<tr>
<td>13-17 y/o</td>
<td>“When I think about it sometimes I start to cry and it makes me upset.”</td>
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<td></td>
<td>“I feel guilty because I am the older sibling for him and a role model but I don’t think I’m doing a good job.”</td>
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<tr>
<td>Adult Siblings</td>
<td>“[My sister with epilepsy] severely impacted my youngest sister (now 18), who developed depression and anxiety. It got so bad she began cutting herself.”</td>
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<td>“There is a lot of negative energy constantly in our family.”</td>
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<td>“...makes me feel guilty and also angry that I have to feel like this.”</td>
</tr>
</tbody>
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Potential Symptoms of Anxious Mood

- ≥50% of 9-12 y/o and adult siblings reported being easily startled
- About one third to one half of all siblings reported having nightmares
All siblings reported substantial worry/fear and stress over their sibling’s diagnosis.

Adult siblings reported the highest degrees of worry/fear and stress.
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<tr>
<td>13-17 y/o</td>
<td>“I try to spend some time reading or listening to music to calm me down.”</td>
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<td></td>
<td>“I love doing sports to get my mind away from all the drama at home.”</td>
</tr>
<tr>
<td>Adult Siblings</td>
<td>“It scared me and caused me a lot of stress that I did not believe I should share with others. I kept it to myself and it made me shut people out.”</td>
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<td></td>
<td>“Their stress and frustration are contagious and it sits like a dark cloud above our heads.”</td>
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Conclusions

• Siblings of children with DS, LGS, and other EEs may warrant assessment of anxiety and depressed mood symptoms by healthcare providers

• Siblings reported sadness and stress over brother/sister’s epilepsy
  — 35% (28/72) of adult siblings reported treatment for clinical depression

• Confirms and extends previous reports suggesting that caring for children with DS, LGS, and EEs adversely affects family unit as a whole\(^1,\!^2\)

Clinical Significance

• Siblings of patients with epilepsy can be at risk for depression and anxiety
• Clinicians should discuss potential symptoms of sibling depressed mood and anxiety with parents, especially unhappiness, irritability, and stress
• Further research should consider how to identify signs of depression and/or anxiety in siblings and the role of supportive services in intervention strategies
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