



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

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

- 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 unit¹⁻²
- Impact on the siblings of EE patients
 - 74% (114/154) of caregivers reported concern for sibling well-being³

1. Jensen MP, et al. *Epilepsy Behav.* 2017;74:135-43.
2. Campbell JD, et al. *Epilepsy Behav.* 2018;80:152-6.
3. Villas N, et al. *Epilepsy Behav.* 2017;74:81-6.

- Knowledge gap in the impact of severe epilepsy on siblings
 - Recent parent survey about siblings recognized “risk of psychosocial problems”¹

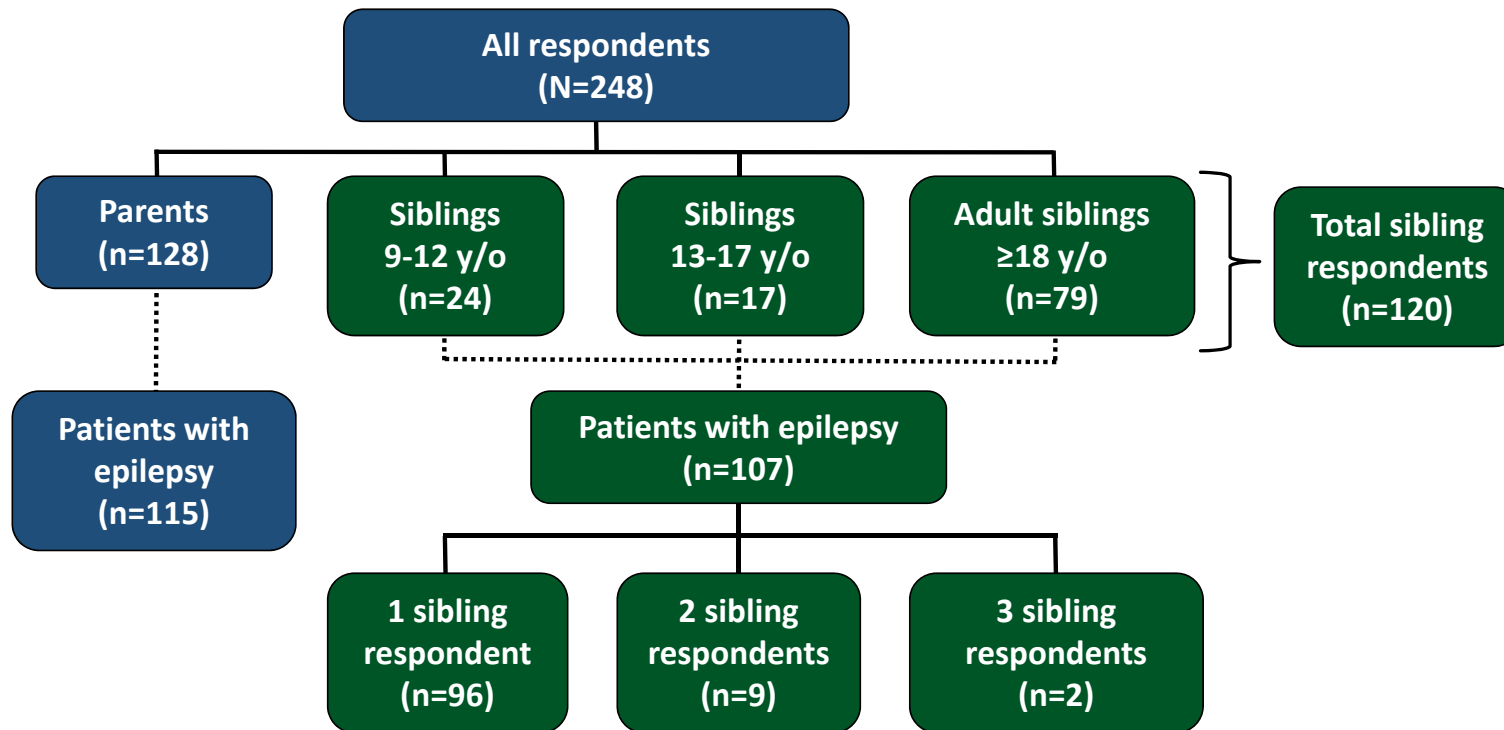
1. Kroner B, et al. *J Pediatr Health Care*. 2018;32:348-55.

- 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

- 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

- 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



y/o, years old.

Demographic Characteristics of Respondents

Characteristic	Age Group			All
	9-12 y/o	13-17 y/o	Adult Siblings	
n	24	17	79	120
Sex, n (%)				
Male	12 (50)	11 (65)	23 (29)	46 (38)
Female	12 (50)	6 (35)	56 (71)	74 (62)
Twin sibling, n (%)	2 (8)*	0 (0)	1 (1)	3 (3)
Age, years, mean (range)	10 (9-12)	14 (13-15)	24 (18-63)	21 (9-63)
School grade, mean (range)	5 (3-7)	9 (8-11)	NA	NA
Family size, mean (range)	5 (4-8)	5 (4-10)	4 (1-30)	4 (1-30)
No. of children/family, mean (range)	4 (2-6)	4 (2-8)	3 (0-10)	3 (0-13)

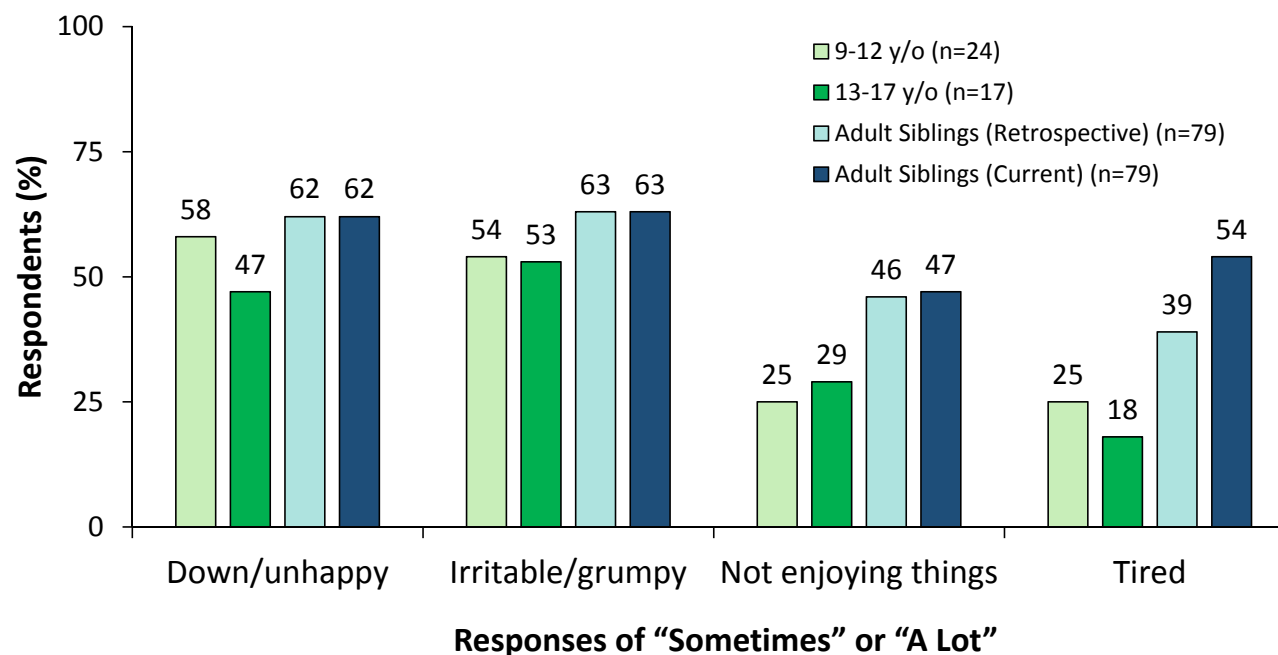
*Excludes a set of 3 triplets who responded “no” to “twin sibling.”

NA, not applicable.

Demographic Characteristics of Patients With Epilepsy

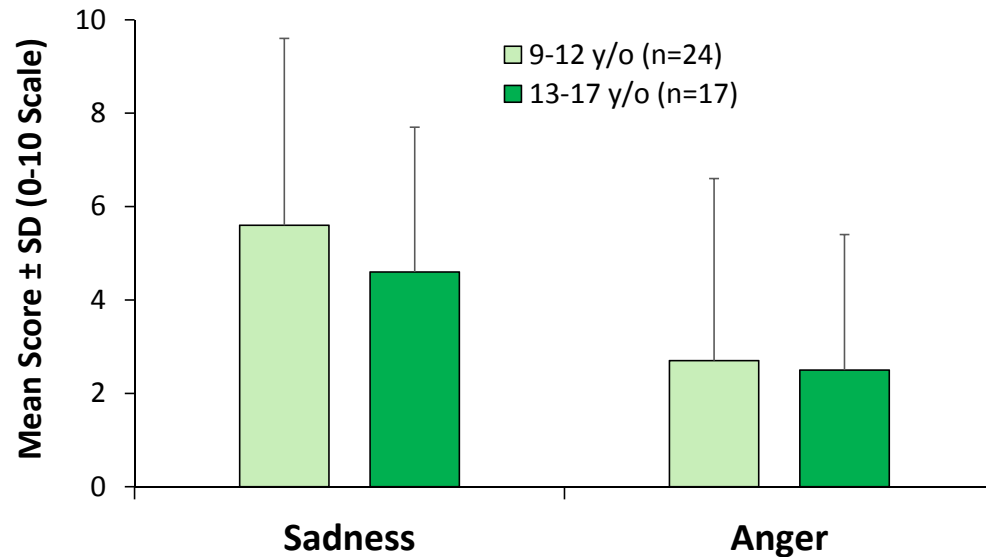
Characteristic	
n	107
Patient age, years, mean (range)	16 (1-61)
Patient sex, n (%)	
Male	44 (41)
Female	63 (59)
Epilepsy diagnosis, n (%)	
Dravet syndrome	41 (38)
Lennox-Gastaut syndrome	13 (12)
Other epileptic encephalopathy	53 (50)

Potential Symptoms of Depressed Mood



- $\geq 50\%$ 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

Degree of Sadness or Anger Reported Over Sibling's Diagnosis



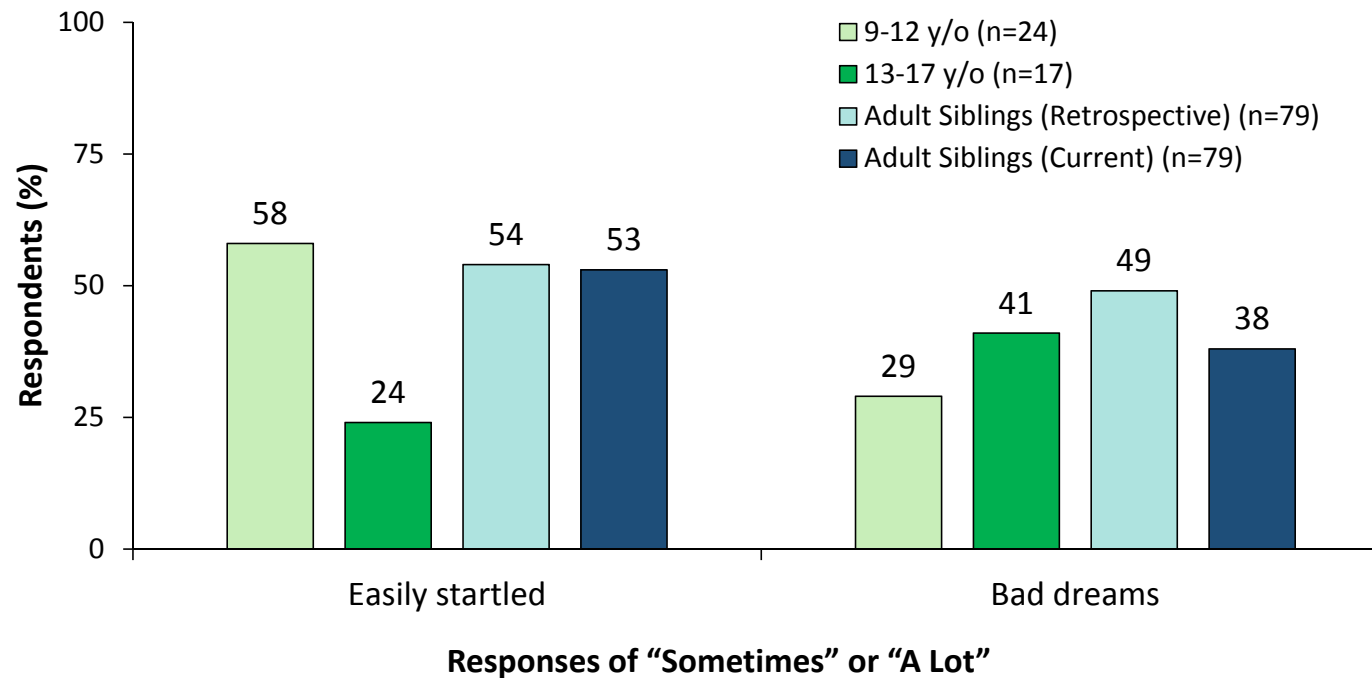
Adult siblings were not asked these questions.

- 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

Free-Form Responses Suggestive of Depressed Mood

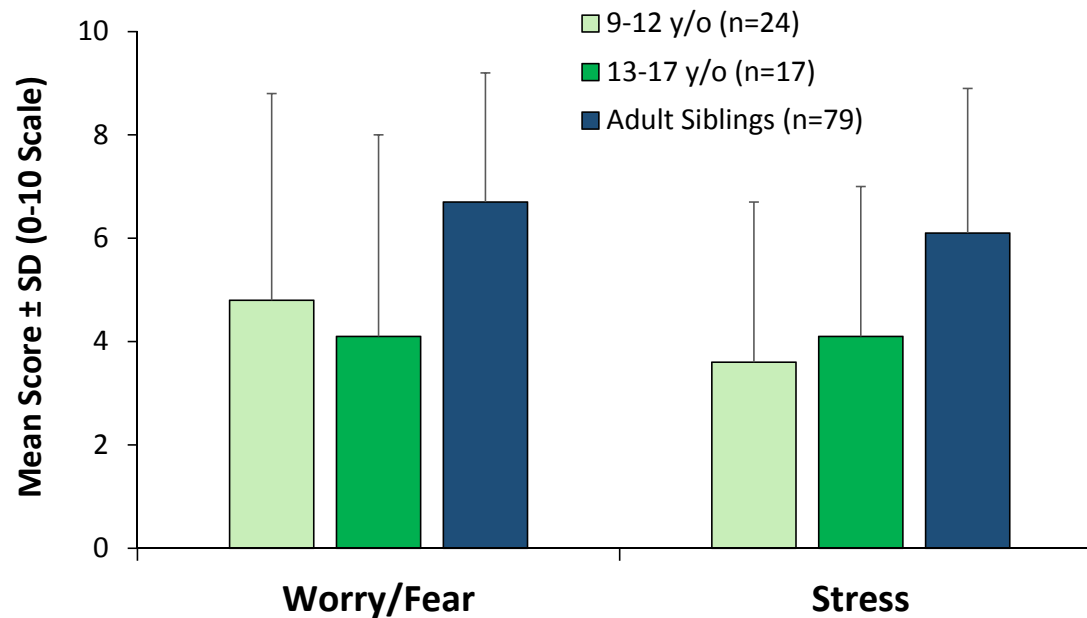
Age Group	Response
13-17 y/o	“When I think about it sometimes I start to cry and it makes me upset.”
	“I feel guilty because I am the older sibling for him and a role model but I don’t think I’m doing a good job.”
Adult Siblings	“[My sister with epilepsy] severely impacted my youngest sister (now 18),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

Potential Symptoms of Anxious Mood



- $\geq 50\%$ of 9-12 y/o and adult siblings reported being easily startled
- About one third to one half of all siblings reported having nightmares

Degree of Worry or Stress Reported Over Sibling's Diagnosis



- All siblings reported substantial worry/fear and stress over their sibling's diagnosis
- Adult siblings reported the highest degrees of worry/fear and stress

Free-Form Responses Suggestive of Anxiety

Age Group	Response
13-17 y/o	"I try to spend some time reading or listening to music to calm me down."
	"I love doing sports to get my mind away from all the drama at home."
Adult Siblings	"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."
	"Their stress and frustration are contagious and it sits like a dark cloud above our heads."

- 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}

1. Jensen MP, et al. *Epilepsy Behav.* 2017;74:135-43.

2. Campbell JD, et al. *Epilepsy Behav.* 2018;80:152-6.

- 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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