

How does caring for a child with severe, refractory epilepsy affect lives of caregivers?

Results from focus groups and interviews with caregivers

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INTRODUCTION

- Caregiving for children with epileptic encephalopathies (EE) affects caregivers' lives in multiple ways
- To better quantify this impact we need psychometrically sound measures that ask about life domains most important to caregivers
- We conducted focus groups and interviews to better understand what areas of impact are most important to caregivers

PURPOSE

Obtain information from caregivers of children with EE about both positive and negative impacts of caregiving



PARTICIPANTS & METHODS

- Caregivers were required to be over 18, speak English, and care for a child under 18 years of age with Dravet Syndrome or other EE
- All focus groups and interviews were conducted by phone
- Focus groups involved small group discussions; interviews were conducted one on one with a researcher
- Discussions were audiotaped and used to generate summaries
- Summaries were analyzed used qualitative software Dedoose (dedoose.com) to identify themes

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RESULTS

PARTICIPANT CHARACTERISTICS

- 19 caregivers participated in small group discussions (n=12) or in one-on-one interviews (n=7)
- Approximately one-third of participating live in Europe
- Average age of the caregivers was 42 years, 88% were female, 85% were white, 79% were married
- 63% of children had Dravet syndrome. Also included: SCN8A, Lennox-Gastaut Syndrome and Intractable Epilepsy
- The mean age of the child with EE was 8 (range: 2-18 years)

THEMES

Caregivers talked about impact of caregiving in four overarching areas:

Physical, Mental, Social & Financial

BENEFITS

- Appreciation of what is important in life
- Learning to be more compassionate
- Becoming better advocates.

CHALLENGES

- Sleep deprivation and physical exhaustion were common
- US caregivers reported more financial difficulties and more difficulties with access to respite care than European participants

“
Finances are a huge part of our life, a huge stress as far as feeling like we're kind of failing him and not being able to give him everything that he needs or everything we want him to have to be able to thrive a little bit more.
”



CONCLUSION

- Caregivers of children with EE reported considerable caregiving burden, especially those living in the US, a finding that suggests the need for more support for US caregivers
- 50 candidate items have been developed using the feedback from caregivers and are being field tested
- The measure of caregiving impact will be publicly available in fall 2017