These patients require constant care and monitoring which can significantly impact the broader patient community. Areas of focus for this analysis were:

- Recent data has begun to quantify the impact on these conditions on the primary caregivers but other information exists on the impact on the entire family unit and specifically on siblings.
- Siblings are often identified and indirectly involved in the care of their affected brothers and sisters.
- Siblings have had no prior recognition for their care provides and the medical community.

To the extent on an sibling living in a family with a child with severe epilepsy has not been well described. The Sibling Voices Survey was developed to evaluate the psychosocial impact on siblings who are the caregiver with severe childhood epilepsy.

METHODS

Data Sources

- A web-based survey (www.babysurvey.com) was conducted in collaboration with the Dravet Syndrome Foundation, Lennox-Gastaut Syndrome Syndrome Patient Community and Healthcare Professionals.

- Questionnaires were further refined following beta testing in a small group of subjects that included parents and siblings from the patient community.

- The survey was conducted and processed on the internet.

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RESULTS

- Figure 1: Schematic representation of the Sibling Voices Survey

- Figure 2: Example of survey questions for siblings 13-17 years used to identify emotions

- Figure 3: Responses to questions designed to identify difficult aspects

- Figure 4: Responses to questions designed to identify the top 3 most difficult aspects

INTRODUCTION

- Intractable intractable childhood-onset syndromes, and other epilepsy syndromes with onset in childhood are typically resistant to treatment and accompanied by neurodevelopmental impairment.

- These patients require constant care and monitoring which may have significant impact.

- Recent data has begun to quantify the impact on these conditions on the primary caregivers but other information exists on the impact on the entire family unit and specifically on siblings.

- Siblings are often identified and indirectly involved in the care of their affected brothers and sisters.

- Siblings have had no prior recognition for their care providers and the medical community.

- The effect on a sibling living in a family with a child with severe epilepsy has not been well described. The Sibling Voices Survey was developed to evaluate the psychosocial impact on siblings who are the caregivers to children with severe childhood epilepsy.

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FIGURES

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