Assessing the Impact of Caring for a Child with Dravet Syndrome: Results of a Caregiver Survey

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INTRODUCTION
Dravet syndrome (DS) is a rare, devastating epileptic encephalopathy characterized by:
- Frequent seizures and multiple seizure types, including status epilepticus
- Neurodevelopmental problems
- Increased rates of sudden unexpected death in epilepsy
- Studies have shown DS places a heavy burden of caregivers who were not employed (n=9), a majority of whom reported a loss of spending time with family and friends (2), as well as a loss of sleep and a significant increase in stress (3).

METHODS
- An electronic survey to describe and quantify the impact of caring for a child with DS on caregivers' health and quality of life was conducted through Research Electronic Data Capture (REDCap), a web-based structured methodology and workflow for providing data management solutions.
- The survey was reviewed and approved by the Colorado Multiple IRB; all participants provided informed consent.
- Survey domains included time spent performing caregiving tasks, health-related QoL, and work-related productivity:
  - Modified Oberst Caregiving Burden Scale (OCBS)
  - 5-item instrument that rates caregiving tasks based on caregiver's planning, organizing, and difficulty of task (1=most difficult, 10=least difficult)
  - EuroQoL-5D (EQ-5D) health-related quality of life survey
  - 5-dimension survey that rates QoL on a 5-point scale (0=death; 1=perfect health).
- 63% of respondents scored between 80 and 100, and 71% scored ≤67.

RESULTS
- The top 5 domains with a moderate or greater time spent performing caregiving tasks, health-related QoL, and work-related productivity were:
  - Personal care (87% flexible time)
  - Arranging for care (73% flexible time)
  - Time spent performing caregiving tasks.
- An EQoL Index was computed using responses to the EQ-5D-3L crosswalk, which was developed to map EQ-5D-3L to EQ-5D-5L.
- Table 3
- Table 4
- Table 5

CONCLUSIONS
- DS caregivers were nearly twice as likely to score <65 on the Modified Oberst Caregiving Burden Scale (OCBS) compared to a normative population (71% vs. 38%).
- DS caregivers were more likely to lose their jobs compared to the general population (43% vs. 30%).
- Increased rates of sudden unexpected death in epilepsy (SUDEP) and hospitalization were also significantly higher in DS compared to the general population (77% vs. 67% and 19% vs. 13%, respectively).

STUDY LIMITATIONS
- Single-center study with small sample size (34 participants) limited the generalizability of our data.
- Survey design was limited to the impressions and recollections of participants, thus making our data subject to various response and recall biases.
- Participants were recruited based on participation in a larger prospective observational study (1)

REFERENCES

DISCLOSURE
- No conflicts to report.

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