DISCUSS Dravet – Key socioeconomic findings from a large multinational survey of Dravet syndrome caregivers

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INTRODUCTION

- Dravet syndrome is a rare, refractory epilepsy typically involving multiple co-morbidities including motor, cognitive and behavioural impairments.1
- The wide scope of co-morbidities combined with frequent, treatment refractory seizures can be expected to result in a high impact on patients and caregivers affecting all aspects of their lives, with many aspects not reported.2

OBJECTIVES

- The Dravet syndrome caregiver survey (DISCUSS) sought to determine the social and financial impact of Dravet syndrome on patients and their caregivers and explore healthcare resource utilisation associated with its current management.

METHODS

DISCUSS was an online, anonymous survey carried out from 23 June - 4 August 2016 comprising 150 questions about

- caregiver household (demographic information), health status of the patient current and past treatment
- experiences of diagnosis
- quality of life, including the standardised EQ-5D-5L instrument.3
- social and financial caregiver impact and
- health services use.

Only fully completed surveys[4] were accepted for submission. Gate questions ensured negative responses were not probed further.

Participants were recruited through email invitations to approximately 1,000 members of patient advocacy groups (PAGs) of different countries associated with the Dravet Syndrome European Federation (DSEF) as well as through internet based sources (Facebook and Twitter).

Survey versions were available in English, Spanish, Latin American Spanish, Portuguese, Brazilian Portuguese, French, German, Italian and Polish (translated from English by specialist translators), and Croatian, Dutch and Romanian (translated by local language PAG members). All language versions were tested by local speakers before survey launch.

For descriptive statistics, patient ages were grouped as infant (<2 years), pre-school (2-5 years, inclusive), middle childhood (6-11 years, inclusive), adolescent (12-17 years, inclusive) and adult (18 years and older). Statistical significance (p<0.05) of differences between frequencies was determined using a two-tailed z-test for two proportions with a 95% confidence interval on the difference between the proportions using XLSTAT in Excel.

RESULTS

Demographics

- 584 fully completed surveys were submitted (mothers 86%, fathers 12.3% and other caregivers 1.6%) of which the majority (92%) lived in Europe.
- 20% of caregivers lived in a single and 77.6% in a household with more than 1 adult.
- The mean patient age was 10 years (median, 9 years).
- The middle childhood group was the largest, most others comprised 25% -15% and infants 6% of total submissions (Figure 1).

Disease severity

- Less than 10% of patients reported no seizures in the previous 3 months. Whereas only 3% of infants were seizure-free, this proportion increased steadily by age, to 14% of adolescents (p<0.05 compared to infants) and 11% of adults (Figure 2).

ACKNOWLEDGEMENTS

The authors would like to thank everyone who took the time to respond to the survey. We would also like to thank DSEF affiliated patient advocacy group members for piloting, proofreading and translations during preparation of the survey and campaign materials. This study was sponsored by Zogenix International Limited.

REFERENCES


[4] with the exception of one question about the cost of non-pharmacological treatments

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Presented at the 12th EPNS Congress in Lyon, France on June 20-24 2017