Unravelling the non-pharmacological therapeutic needs associated with Dravet syndrome


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PURPOSE Dravet syndrome (DS) is characterised by a drug-resistant epilepsy and severe comorbidities.

This study aimed at investigating the non-pharmacological therapies received by DS patients and the economic impact on their caregivers and families.

METHOD In order to examine the non-pharmacological therapeutic needs of DS patients and the socio-economic impact of these therapies on families, we developed an online survey specifically focused on:

- Demographic and clinical data
- Non-pharmacological therapies
- Educational needs

RESULTS 62 participants (37% females)

Median age of 9.5 years (range 9 months-51 years)

Up to 91.9% of the patients surveyed used non-pharmacological therapies, mainly aimed at treating cognitive, sensory and motor impairments. In most of the cases, these therapies are beneficial for the patients. However, they also represent high financial costs which are usually borne entirely by the families.

CONCLUSIONS Supporting DS patients involves both the pharmacological and non-pharmacological treatment, which has a beneficial effect but represent a high economic impact on the life of patients and caregivers.

Our study suggests:

- the inclusion of the costs associated with non-pharmacological interventions in the national health system;
- a better coordination of a multidisciplinary team, including psychologists, occupational and speech therapists, and professionals in special educational.

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