

Interventions for families of children with Dravet Syndrome to improve their quality of life

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SÍNDROME DE DRAVET FUNDACIÓN

1. INTRODUCTION

- DS is a developmental epileptic encephalopathy of genetic origin, with 80% of affected patients having a mutation in the SCN1A gene.
- Although the main manifestation is epilepsy, it is accompanied by various comorbidities, such as language and attention disorders, learning disabilities, behavioral disorders or gait ataxia.
- The regular care required by a person with Dravet Syndrome considerably affects the quality of life of the affected person and family due to the multiple symptoms of the disease.

2. OBJECTIVE

To generate interventions with the knowledge about the aspects and needs of families with DS to improve the quality of life that families yearn for.

4. RESULTS

EARLY DIAGNOSIS



- Early detection allows families to organize their lives based on the knowledge that their children have ongoing problems.
- An earlier diagnosis could improve the cognitive development of these children and opens the prospects for improving prognosis.

NEW TREATMENTS FOR THE MANAGEMENT OF DS THROUGHOUT THEIR LIFE



- There is a need for new treatments to improve the control of DS during the patient's lifetime.
- The research, the development and the approval of new drugs is essential → to reduce the need for hospitalizations.

PERSON-CENTERED CARE SYSTEM

The importance of the generation of health structures facilitate access to therapies that contribute to the comprehensive care of these patients, considering the different dimensions, aspects and comorbidities of the disease.



→ DISEASE CONSCIOUS HEALTH SYSTEM

- Comprehensive patient-centered care is necessary with physician-family cooperation.
- Feasible and comprehensive information about the effects of DS.
- Psychological support or DS support teams should be offered and providing them with helpline contacts as a result of the considerations of caregivers about their child's development and future with periodic screenings of these caregivers searching for signs of depression and anxiety.



→ DIFFERENT TYPES OF SUPPORT

Regular screening, psychological support groups, community education program, trained respite, online Dravet support groups, contact days for children spending more time with their friends and siblings, special outings alone with their parents, emotional and social services and financial support.



→ EMERGENCY PROTOCOL

5. CONCLUSION

The knowledge of interventions to improve the quality of life of families who have children with Dravet Syndrome can be useful when establishing strategies to address the social and health care needs of these caregivers, thus contributing to improving the quality of life of the caregivers and, consequently, of the patients.

3. METHODOLOGY



Narrative review



Pubmed
CINAHL
PsycInfo



"Dravet Syndrome"
AND
Family
AND
Interventions
AND
"Quality of life"



Last 10 years



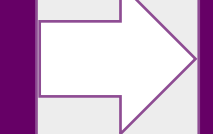
Children
0-18 years-old

Articles identified
(n=46)

Limits, title and abstract
(n=39)

Inclusion and exclusion
criteria
(n=20)

Final Articles
(n=10)



6. BIBLIOGRAPHY

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