Survey: Falls in Patients with Epilepsy

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Introduction. We promoted a simple questionnaire in order to evaluate the impact of ictal falls in the daily life of epileptic patients.

Methodology. An online survey was open from 12th May to 31st October 2017 and was translated in 9 languages. It consisted of 21 questions mainly related to epilepsy type and falls frequency and semiology. The survey was completed by legal representatives of an unselected cohort of epileptic patients, but only those who reported falls were considered. The attendees were recruited by different methods (mail, social networks, posters).

Results. We collected data from 714 patients across 36 countries affected by Dravet syndrome (DS) (361-50.6%), Lennox-Gastaut syndrome (LGS) (93-13.0%), and other epilepsies (260-36.4%). Falls were reported in 648 (90.7%) surveys. Among patients with sudden and violent falls (335), more frequent in LGS (81.7%), 34% had >50 falls/year. Among patients with falls related to convulsive seizures (488), more frequent in DS (81.4%), 20.4% had >50 falls/year.

Conclusions. Although our survey has many methodological limitations, it underlines the burden of ictal falls. The data we collected may be useful to activate initiatives for the search of protection systems aimed at improving the quality of life.
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PURPOSE
- To generate a novel evidence base that enhances the understanding of the incidence of falls in patients with epilepsy.
- We expect this evidence base to help improve data understanding and to bring forth the number of falls in order to activate initiatives for the search of protection systems aimed at improving the quality of life.
- We believe this to be of benefit to all patients with drug resistant epilepsy.

RESULTS - Study Population
- Demographics
  714 fully completed surveys were submitted. Patients came from 36 different countries.
- Epilepsy Type
  361 patients (50.6%) were affected by Dravet Syndrome (DS), 93 (13.0%) by Lennox-Gastaut Syndrome (LGS), 260 (36.4%) by other epilepsies.
- Age
  The population is homogeneously distributed among the different age groups, except in the case of ‘other epilepsy’, where there is a higher proportion of adults.

RESULTS - Falls
- Number of seizure-related falls during a year
  "SUDDEN AND VIOLENT" FALLS (N=324) - "CONVULSIVE SEIZURES" FALLS (N=466)
- Lennox-Gastaut syndrome: 67.1% had >50 drop attacks/year, 50.9% had >50 convulsive seizures with falls/year.
- Dravet syndrome: falls frequency varied with no particular trend.
- Head Protection System
  - The helmet is only used by 17% of patients who reported falls.
  - 75% of the participants had interest in a system such as an AIR-BAG or similar in order to protect the head in case of epileptic falls.

METHODS
- An Online Survey was open from 12th May to 31st October 2017.
- The questionnaire was completed by legal representatives of an unselected cohort of epileptic patients, but only those who reported falls were considered.
- The attendees were recruited by different methods: mail, social networks, posters.
- The survey was translated in 9 languages: English, Spanish, Portuguese, French, German, Italian, Croatian, Romanian, Dutch. All the translations were verified by local operators before the survey launch.

QUESTIONNAIRE
- The questionnaire comprised of 21 questions. Survey questions included demographic information about the patient (country, age), epilepsy type (2 items), falls frequency and semiology (8 items), helmet use (6 items) and interest in having an alternative head protection device (2 items).
- Most of the questions allowed users to select responses from a predetermined list of answers.

STATISTICAL ANALYSIS
- A preliminary statistical analysis was performed, in order to find significant correlations. Differences across groups were evaluated by means of the Pearson’s Chi-squared test.

CONCLUSIONS
- An important limitation of our survey is being self-administered. Data regarding some clinical aspects (i.e. epilepsy diagnosis) are therefore not fully reliable. This notwithstanding, key informations about icct falls are usually referred from the family also during conventional interviews.
- Our survey underlines the burden of icct falls in a large cohort of epileptic patients and the desire to have an innovative head protection device.
- The collected data may be useful to activate initiatives finalized to the search of such a protection system, with the goal of improving epileptic patients’ quality of life.

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