Sudden unexpected death in epilepsy (SUDEP) disclosure in pediatric epilepsy: An Italian survey on “to tell or not to tell”

Galli Federica a,*, Vignoli Aglaia a, b, Canevini Maria Paola a, b, Cerioli Gabriele a, Vegni Elena a, b

a Department of Health Sciences, University of Milan, Milan, Italy
b ASST S. Paolo and S. Carlo Hospital, Via A. Di Rudinì, 8-20142 Milan, Italy

ABSTRACT

Background and objectives: Although there has recently been significant debate regarding the importance of disclosing the risk of SUDEP, professional societies and clinical practice guidelines currently recommend that the risk of SUDEP be disclosed as part of a comprehensive epilepsy education program. Therefore, the primary aim of the present study was to examine whether healthcare providers treating pediatric patients with epilepsy in Italy would disclose the risk of SUDEP to the parents of children with epilepsy.

Methods: The present study assessed data from a questionnaire that collected sociodemographic information and physicians’ attitudes towards SUDEP. The survey was available online from September to December 2015. Chi-square (χ²) tests and multivariate logistic regression analysis were performed when appropriate, and a qualitative content analysis of open-ended questions was performed.

Findings: A total of 114 medical doctors (71 females and 43 males) completed the questionnaire. Of the respondents, 18 (16.2%) stated that all patients should be counseled about SUDEP, 22 (19.8%) thought that the majority should be, 58 (52.3%) said that only a minority should be, and 13 (11.7%) believed none should be. With respect to physicians’ experience in counseling about SUDEP, only 2 (1.8%) counseled all their patients. A univariate logistic regression analysis showed that the factors associated with “not counseling about SUDEP at all” were the low number of patients with epilepsy they took care of (p < 0.01), fewer years of experience (p = 0.03), and the belief that it was safe from a legal point of view (p < 0.001). The main reasons for counseling about SUDEP were refractory course of epilepsy (79%) and if the parent/patient requested information (65%). Additionally, the findings of the qualitative analysis highlighted the emotional difficulties that neuropediatricians encounter when dealing with the disclosure of SUDEP.

Conclusions: The present findings showed that a minority of neuropediatricians in Italy counseled all parents of their patients about SUDEP. Educational training may help physicians better communicate with the patient/parents regarding this difficult issue.
risk of SUDEP by neuropediatricians, and specifically ask for a tailored and well-timed disclosure [14].

To the best of our knowledge, no studies have explored the attitudes of healthcare professionals in Italy towards the disclosure or non-disclosure of the risk of SUDEP to the parents of children with epilepsy. We investigated if cultural differences may influence SUDEP disclosure, as seen in other settings [15]. The aim of the present study was to determine whether or not healthcare providers treating pediatric individuals with epilepsy in Italy would disclose the risk of SUDEP to the parents of children with epilepsy.

2. Materials and methods

We used an anonymous web-based survey to assess the opinions and experience about counseling on risk of SUDEP of Italian medical doctors who take care of pediatric patients with epilepsy. In September 2015, a call to answer the online questionnaire about SUDEP was sent to 556 physicians trained in epileptology and working in Italy, and the survey was available until December 2015. We repeatedly e-mailed the invitation to participate in the survey to neurologists and child neurologists who were member of different neurologic societies, in order to increase the response rate. The questionnaire was structured to assess socio-demographic data and clinicians’ attitudes towards disclosure of the risk of SUDEP, and was composed of 5 closed questions and 1 open question (Table 1). We designed it based on the findings derived from the open questions of a previous Italian survey [12], after adapting the content to detect the attitude of professionals working in the pediatric field, as only one study [8] has focused specifically on pediatric epilepsy, the first contribution on this topic [11]. We used a combined qualitative–quantitative approach as the most effective method to understand a complex phenomenon where subjective experience is a core component [16,17].

2.1. Statistical analysis

We adopted a combined quantitative–qualitative method of analysis. For the quantitative analysis, we analyzed socio-demographic information (sex, age, type of medical specialty, number of pediatric patients seen, years of clinical experience) as categorical independent variables. Clinicians’ attitudes regarding personal beliefs about counseling patients and their parents on SUDEP and beliefs about disclosing the risk of SUDEP directly to children were considered to be independent variables. The decision of a physician “to counsel or not about SUDEP” in their own clinical practice was considered to be the dependent variable. We recorded both the independent variables and the dependent variable in binary terms to allow for their computation in the logistic regression analyses.

For the qualitative data, we conducted a content analysis on the answers (narratives) of the open questions included in the questionnaire (see questions 3, 4, and 6; Table 1). Two researchers (EV and FG) performed the qualitative analysis, independently reading the narratives to familiarize with the entire dataset. Next, the researchers independently coded the narratives by identifying and labeling categories that best captured the issues described by the respondents in their answers. Through a series of joint meetings, they discussed the identified categories during an open-coding phase and then grouped the categories into broader conceptual themes. The researchers manually developed an initial thematic coding framework with a provisional name and definition for each theme. The narratives were then co-coded by the two researchers using this framework to test the adherence of the themes to the data. Coding disagreements were reconciled via discussion until a final consensus was reached and the final themes were determined. Finally, the researchers refined and finalized the labels of each theme, computed the number of narratives containing each specific theme, and selected representative excerpts.

2.2. Statistical procedure

Statistical analyses were performed using IBM SPSS, v. 22. In addition to the descriptive statistics, univariate and multivariate (forward method) logistic regression analyses were conducted to identify predictors of non-disclosure of the risk of SUDEP. Chi-squared (χ²) tests were performed when appropriate. Only variables with a p ≤ 0.05 were included in the multivariate model; an alpha value of 0.05 was considered to indicate statistical significance for all variables.

3. Results

3.1. Descriptive statistics

Of the initial 556 physicians who received the survey, 114 individuals (20.5%; 71 females and 43 males) aged 24–71 years (median age: 46.15 years, standard deviation [SD]: 11.91 years) responded to the questionnaire. Most of them were specialized in child neurology (n = 86, 75.53%) and, of the remaining, 23 (20.17%) were neurologists, 2 (1.75%) were pediatricians, and 1 (0.87%) was a neurophysiologist; 2 doctors (1.75%) did not specify their medical specialty. Four child neurologists had additional postgraduate training in pediatrics, 4 neurologists had various postgraduate training in neurosurgery, neurophysiopathology, or criminology, and 17 (14.9%) were postgraduate students. Of all the respondents, 76% were in a stable couple relationship, while 24% were unmarried; 61% had children while 39% did not. 52.2% (n = 59) usually took care of patients with epilepsy, 38.9% (n = 44) occasionally saw patients with epilepsy, and 8.8% (n = 10) rarely assisted patients with epilepsy; 1 physician didn’t answer. Table 2 describes the clinical activities of the respondents.

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**Table 1**
The questionnaire of the web-based survey.

<table>
<thead>
<tr>
<th>Socio-demographic data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex □ ▄</td>
</tr>
<tr>
<td>Married/Cohabitant □Yes □No</td>
</tr>
<tr>
<td>Age ___</td>
</tr>
<tr>
<td>Specialization □ ongoing □ completed</td>
</tr>
<tr>
<td>Type of specialization</td>
</tr>
</tbody>
</table>

Do you have patients with epilepsy: □ Usually □ Occasionally □ Rarely

Years of clinical experience □ 1–10 □ 11–20 □ 21–30 □ 31–40 □ 41–

If yes: how many patients do you follow? □ 1–10 □ 11–50 □ 51–100 □ >101

If yes: which percentage of pediatric patients do you follow? □ > 25 □ 25 ≤ 50 □ ≤ 51

**Attitude towards SUDEP**

1. I believe that physicians should counsel about SUDEP □ with all patients □ the majority of patients □ the minority of patients □ None

2. When the patients are children, I believe physicians should counsel about SUDEP with □ parents of all □ the majority □ the minority □ None

3. Define the possible advantage of discussing SUDEP with the patients and their parents:

3.1 Because patients have the right to know the truth

3.2 Because the compliance will improve

3.3 Because I feel safer from a legal point of view

3.4 Other (specify) ________________

4. Define the possible hindrance of discussing SUDEP with the patients and their parents:

4.1 Because it is worthless to frighten patients

4.2 Because it is not necessary that patients know all the truth

4.3 Because it is difficult to communicate and I risk being misunderstood

4.4 Other (specify) ________________

5. I have counseled on SUDEP □ (if children, with their parents):

□ with all the patients □ with the majority □ with the minority □ None

Open question

6. If you ever counseled a patient and/ or her/his parents about SUDEP, we ask you to describe that encounter, illustrating how it went, the words that you and the patient/ parent used, the reasons why you talked about SUDEP, the reactions you and the parent had during/after the interview.
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