



Recommendations for risk management and better living with epilepsy. Phenomenological study of the experience of patients, relatives, and bereaved families

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Title Page: Recommendations for risk management and better living with epilepsy.
Phenomenological study of the experience of patients, relatives and bereaved families.

Agnès Oude Engberink ^{a,b}, Marie Faucanié^c, Myriam Boulais^c, Laurence Nègre-Pages^c,
Gérard Bourrel ^{a,b} , Audrey Jaussent ^c, Arielle Crespel ^d, François Carbonnel ^{a,b} , Marie-
Christine Picot ^{c,e}.

^a UA11 Institute Desbrest of Epidemiology and Public Health, INSERM, Univ
Montpellier, Montpellier, France

^b Department of Primary Care, School of Medicine, University of Montpellier, France

^c Clinical research and epidemiology unit (Department of Medical Information), CHU
Montpellier, Univ Montpellier, 34 295 Montpellier Cedex 5, France

^d Epileptology unit, CHU Montpellier, Univ Montpellier, 34 295 Montpellier Cedex 5,
France

^e Centre de Recherche en Épidémiologie et Santé des Populations (CESP), U1018,
INSERM, Univ Paris-Saclay, Villejuif, France

Corresponding author:

Agnès Oude Engberink

Maison de santé Pluriprofessionnelle Universitaire Avicenne

2 rue Ibn Sinai dit Avicenne

66330 Cabestany

agnesisambert@wanadoo.fr

Key Words

epilepsy, epilepsy-related risk, SUDEP, phenomenology, empowerment

Abstract (306 words)

Objective: To understand the lived experience of people with epilepsy (PWE) and their relatives, the risks associated with epilepsy, the information received from healthcare professionals, and the reaction to this information.

Methods: Qualitative phenomenological study conducted between 2016 and 2018. Individual semi-directive in-depth interviews were performed based on a triangulation of sources in three study groups: PWE, relatives of PWE, and bereaved families. Interviews were analyzed continuously, using a semiopragmatic method until data saturation.

Results: Interviews with PWE (N=16), relatives of PWE (N=8), and bereaved families (N=10) led to several observations: (i) The stigmatizing representations of epilepsy and its constraints lead to a feeling of abnormality which determines the behavior of patients and their relatives; (ii) The global uncertainty surrounding epilepsy is an obstacle to the delivery of clear and personalized information by professionals, and, consequently, to empowerment; (iii) The communication skills of the physician have an impact on the lived experiences of patients and relatives; (iv) Better knowledge on direct mortal epilepsy-related risk could influence the perception of danger to oneself, and help find a balance between overprotection and trivialization. The experience of the patients and relatives led them to formulate concrete recommendations: (i) for the general public: to run information campaigns in order to limit

stigmatization; (ii) for caregivers: to provide personalized and detailed information without minimizing the risks, in order to enable patients to "live by setting these risks"; (iii) for patients: to have a trusted person who is informed and trained in seizure management, to join patient associations.

Conclusion: Our study points out that stigma, uncertainty, and lack of clarity of information are all barriers to patient empowerment. In order to provide prompt and personalized information on how to live with epilepsy while managing the risks, physicians need to develop person-centered communication skills. Future research is also required for the development of tools to facilitate this communication.

Key Words: epilepsy, epilepsy-related risk, SUDEP, phenomenology, empowerment

Abbreviations:

BF: Bereaved Families

PWE: People With Epilepsy

RSME: *Réseau Sentinelle Mortalité Epilepsie*

SUDEP: Sudden Unexpected Death in Epilepsy

1. Introduction

People with epilepsy (PWE) face specific risks related to the characteristics, conditions of occurrence, and severity of seizures [1]. The risk of unintentional injuries (from burns, falls, road traffic accidents, or drowning) as well as intentional injuries is particularly high in PWE [2]. Other major causes of excess mortality directly related to epilepsy include status epilepticus and Sudden Unexpected Death in Epilepsy (SUDEP). SUDEP is the most common cause of death directly related to epilepsy. It is estimated to account for about 40% of epilepsy-related deaths in patients with drug-resistant epilepsy [2].

The question of informing patients and their families about the risks, especially the risk of mortality, remains a problematic issue. The National Institute for Health and Care Excellence [3] recommends a SUDEP discussion with PWE and family members. Much work has focused on how physicians discuss the risk of mortality. In a retrospective case note, Waddell et al. [4] reported a documented discussion on SUDEP for only 4% of 345 patients. A study on truth-telling among Italian epileptologists [5] showed that only 9% of 195 respondents discussed SUDEP with all of their patients. Another Italian survey [6] showed that only 2% of 114 physicians counseled all their patients. Strzelczyk et al. [7] examined the predictors and attitudes toward counseling on SUDEP, other epilepsy risk factors, and suicidal ideations among 519 Austrian, German and Swiss neurologists and neuropsychiatrists. Less than 3% reported counseling their patients on SUDEP, while 93% reported counseling all their patients on driving restrictions, and 81.5% on risks in daily-life activities. A web-based survey [8] showed that 59.5% of 1,200 neurologists in the US and Canada reported that negative reactions were the most common response to the SUDEP discussion. This suggests that there may be ways to frame the discussion in order to minimize patient/caregiver distress. Miller et al. [9] reported the procedures of neurologists, pediatric epileptologists and advanced

practice nurses regarding the discussion of SUDEP with their patients: whatever the discipline, there are arguments for and against discussion, the decision remains personal.

In a web-based Norwegian survey [10], at least 90% of PWE (N=1183), family members, or guardians (N=676) wanted information on the risk of epilepsy-related injuries and premature death. In a survey of 67 parents of children with epilepsy, Gayatri et al. [11] revealed that 91% of parents wanted to know about SUDEP, and that 67% wanted to be informed of SUDEP at the time of their child's diagnosis. Ramachandran's qualitative study [12] supports these findings. Xu et al. [13] showed that 89% of 105 adult patients wished to be informed about SUDEP, and that 59% requested detailed information. Using a qualitative study, Tonberg et al. [14] interviewed 27 young adults (18-29 years) who had been told about SUDEP at least 2 weeks before. Even if the received information satisfied them all, their understanding of SUDEP was often limited and incorrect. Twenty-two said that everyone should be told about SUDEP. Most thought that disclosure should take place at the time of diagnosis, or soon after, preferably in a face-to-face consultation. These studies demonstrate that there is a considerable gap between what the patients want regarding information and what they are actually given by their care providers [10]. The 2016 PAME Conference [15], involving bereaved families, focused on the need for (i) better patient education, and (ii) careful consideration of the lived experiences of PWE, relatives, bereaved families, and care providers.

These data leave many questions unclear: How do patients and families experience the disease and epilepsy-related risks? What do patients think about the way doctors inform them and discuss the general risks, the risk of mortality and the issue of death itself? These questions led us to propose a qualitative research study focusing on lived experience, in order to try and provide answers and help develop prevention strategies. The aim of this phenomenological qualitative study was to understand (i) the lived experiences of PWE, (ii)

the associated risks, (iii) the information received from healthcare professionals, and (iv) the reaction to this information. Three groups were included in the study: PWE, relatives of PWE, and bereaved families.

2. Material and Methods

2.1 Study Design:

A qualitative phenomenological study was chosen to describe and understand the experiences of three different groups: PWE, relatives of PWE, and bereaved families.

2.2 Population:

PWE and relatives of PWE were invited to participate by their general practitioners, by private neurologists (from the South of France), or by the epilepsy unit of the university hospital of Montpellier. Bereaved families were identified through the French Sentinel Network of Epilepsy-Related Mortality [16] (*Réseau Sentinelle Mortalité Epilepsie* - RSME). All of the screened patients and relatives of PWE were contacted by phone to schedule a face-to-face interview with the RSME psychologist, after having given their consent to participate in the research study.

Three groups of participants were included: 1/ PWE: Patients with a definite diagnosis of epilepsy - with active epilepsy or in remission, treated or not, aged from 15 to 65 years; 2/ Relatives of PWE: parents or partner or brother/sister of a PWE; and 3/ Bereaved families (BF): Relatives having reported an epilepsy-related death to the RSME, regardless of the cause of death and delay since death.

Patients or relatives with learning difficulties, or patients who refused audio recording were not included.

We used purposive sampling to obtain a diversity of experiences across various individual and clinical characteristics such as sex, age, age of death for bereaved relatives, type and severity of epilepsy, and pharmacoresistant or not.

We applied the principle of data saturation without pre-defining the number of interviews in each group.

2.3 Data Collection:

The collection method consisted of phenomenological semi-structured interviewing that took place face-to-face in order to understand the experiences in depth.

An interview guide was developed by the scientific committee which included an epileptologist, the RSME psychologist, a coordinating doctor and the RSME project manager.

The guide contained phenomenological questions focused on lived experiences (**supplementary data 1**). Two qualitative research methodologists verified the appropriateness and the intelligibility of the questions after completion of the first two test interviews conducted with PWE (included in the analysis).

The same interview guide was used for the PWE and their relatives. The first part concerned the disclosure of the disease. The questions invited participants to relive the moment when they were told about their epilepsy and the related risks, and what happened afterwards. The second part concerned the information they had received about the disease and its risks. The third part explored how the current disease was influencing their way of life (employment, lifestyle, identity). Finally, they were asked about their risk behavior and its representation. For the group of bereaved families, questions about their pre-death experience were added, relating in particular to the circumstances of the death, to specific events in the period preceding the death, and to behaviors or clinical signs that could have alerted them. Interviews were conducted by an RSME psychologist (MB) who had received

phenomenological interview training [17]. Depending on the participants' choice, the interviews were conducted face-to-face at home or at the nearest hospital. The interviewer introduced herself as a psychologist working in the field of epilepsy, and made sure that an atmosphere of confidence was created in order to favor spontaneous and truthful responses. The different conditions of the interviews were reported: time, place, positioning, and context. Participants' individual characteristics were collected from a questionnaire that was filled in before the interview. Clinical characteristics (type of epilepsy, type and frequency of seizures, age of onset, treatment, etiology of epilepsy, comorbidities) were collected from the medical record of the patients. The interviews were digitally recorded and then transcribed word for word, respecting what was heard. Non-verbal data were not analyzed.

2.4 Data analysis:

Semiopragmatic phenomenology is a descriptive method for categorizing lived experiences recorded in interview transcripts. The first steps of this analysis were performed according to a constant comparison process [18] which was used to build the categories. It was completed by a semiopragmatical data interpretation procedure inspired by C.S. Peirce [19].

In this method, the analyst takes into account all semiotic elements (including linguistic and contextual clues) relevant to the research question. Then, those with a resemblance of meaning are assembled and linked together to build empirical categories.

In our study, semiopragmatic analysis allowed the logical ordering of these empirical categories, according to Peirce's hierarchical classes of signs. As a result of this logical ordering, the most dense category (i.e., of the highest level in the hierarchy of signs) determined the meaning of the concluding phenomenon (in this case, understanding life

experience with the disease and its associated risks) [20]. (Steps of this pragmatic phenomenological analysis are available in **supplementary data 2**).

The descriptive statistics on sociodemographic and clinical characteristics were performed using SAS® version 9.1 (SAS Institute, Cary, NC).

2.5 Ethical considerations and Data accessibility

Before the interview, participants were informed that their responses would remain confidential and anonymous. They were asked to sign an informed consent form.

The study was submitted to the ethics committee (Committee for the Protection of Persons (Sud Méditerranée IV) - reference number Q-2016-02-02). It was approved by the French National Commission for Data Protection (*Commission Nationale de l'Informatique et des Libertés*). The trial is registered at ClinicalTrials.gov under the identification number NCT02952456. The data can be made available upon request, with agreement from the research team, and may be provided to researchers with an analysis protocol.

3. Results

3.1 Characteristics of participants

Between June 2016 and July 2018, 16 PWE, 8 relatives, and 10 bereaved families (9 parents, 1 sister) were included. The bereaved were all from independent families. Two of the relatives of PWE were related to 2 interviewed PWE. The main characteristics of the PWE are reported in **supplementary data 3** for each group. No refusal to participate was recorded. One of the patient interviews could not be analyzed due to poor quality of recording.

3.2 Emerging categories of analysis:

The results are presented in the form of phenomenological statements, each sub-category of which being illustrated by verbatim excerpts (tables 1-5). Patients are indicated by the letter P followed by the interview number, relatives by the letter R, and the bereaved by the letter B.

3.2.1 Stigmatizing representations of epilepsy and its constraints transform self-image, by inducing an experience of abnormality, and determine the behavior of patients and relatives.

When the diagnosis of epilepsy is disclosed, patients and relatives report stigmatizing social representations of epilepsy due to a lack of knowledge of the disease. This portrays an image of a shameful and frightening disease, or one that is assimilated to a psychiatric illness (madness). The other representation seems to be related to the constraints of the disease, responsible for the deprivation of freedom throughout life. Some patients and relatives complained that doctors had "told them about the constraints before explaining the disease". These representations have an early impact on self-image, leading to a feeling of abnormality and difference from others, which can result in withdrawal and isolation. The relationship with others is also affected in school or professional settings, where stigmatization is the most difficult issue to endure. This stigmatization or feeling of abnormality determines different behaviors and attitudes among relatives, ranging from trivialization to overprotection.

In two thirds of cases, it leads to overprotection, with parents putting their child in a "bubble". PWE then become withdrawn and secretive, in order to escape overprotection or avoid creating concern. One set of parents even said that their son had "escaped" from the house. For this family, talking about the illness was avoided, so as not to end up in conflict, in a ruptured relationship, or in their son feeling isolated.

Conversely, in the case of trivialization, some families cultivate the illusion of “living like others” by allowing their child to take risks, while others accept the concept of “living with epilepsy by limiting the risks”.

Table 1: Stigmatizing representations of epilepsy.

3.2.2 The uncertainty surrounding epilepsy affects the delivery of clear and personalized information by professionals, and is an obstacle to patient autonomy.

For patients and relatives, multifactorial uncertainty is a source of anxiety. According to the participants, there are several forms: (1) a clinical expression that is "indefinable" by the patients; (2) uncertainty regarding the occurrence of the seizure; (3) etiological uncertainty about the origin of the symptoms experienced (co-morbidity, neurological disease, iatrogeny); and (4) prognostic uncertainty concerning the outcome of PWE.

This uncertainty prevents doctors from providing precise and personalized information. Patients and relatives sense the awkwardness of the doctors, and this hinders their understanding and control of the disease or seizure, as well as their autonomy (empowerment).

Table 2: The global uncertainty surrounding epilepsy

3.2.3 The relational and communication skills of the doctor have an impact on the experience of patients and relatives.

According to participants, physicians should acquire skills in disclosing the diagnosis of epilepsy and providing information on its related risks. A direct and poorly documented disclosure is experienced as a shock by the relatives, whereas a person-centered disclosure explaining the uncertainty facilitates acceptance. They all report the tendency of doctors to minimize and reassure by disclosing the temporary nature of an epilepsy that will disappear in

adolescence, or by emphasizing the protection provided by regular medication. They even downplay the life-threatening risk when discussed: one bereaved relative reports that a neurologist who was shown a SUDEP brochure by a patient stated that "it was very rare and would not happen to him". Finally, participants would like to see an approach that focuses on the patients and their experience, rather than one that often lacks in empathic understanding and listening.

Table 3: The relational and communication skills of the doctor

3.2.4 Personal experiences influence the perception of danger to oneself, which may encourage risk-taking. The lack of awareness of the direct lethal risk contrasts with the near-death experience of some (patients and relatives) during the generalized seizure.

Danger and mortal risk are difficult to perceive for oneself. Lack of awareness of danger may facilitate risk-taking, and depends on previous experiences, frequency of seizures, and perceived triggers.

Regardless of the group of participants, the risk is associated with the direct consequences of an unpredictable "loss of consciousness", and the occurrence of a nocturnal seizure in bed is thought to protect against the risk of death. All but 1 of the patients were unaware of this direct fatal risk, and only 5 relatives said that they had heard of sudden death (SUDEP) or direct death related to the seizure. Of the 6 people informed, only 2 had received information from their neurologist. On the other hand, although they claim to be unaware of the vital risk, some patients report to have personally experienced the sensation of imminent death during the seizure. Some relatives have also imagined this feeling, but without saying so.

Table 4: Risks associated with epilepsy.

3.2.5 The lived experiences of patients and relatives lead them to formulate concrete recommendations.

For the general public, relatives recommend limiting stigmatization and misrepresentation by providing information about the disease via the media. For patients, the main recommendation is to avoid being alone. They recommend being with someone they can trust - someone who is informed and trained in seizure management - especially when with the family or wherever they may go. They advocate written materials for those around them. They also recommend regular consultations with the neurologist, asking the right questions, and insisting on clear information. Relatives claim (i) that they find it difficult to strike a balance between overprotection and trivialization, (ii) that particular attention should be paid to the transition to independence and to changes in status (adolescence, marriage, emancipation), and (iii) that conflicts (a factor of isolation) should be avoided in order to maintain the relationship. They suffer from not being able to share their experience with peers, and therefore advocate personal involvement in associations. Their critical experience with doctors leads them to making recommendations against them. Overall, they want an empathetic approach that takes everyone's experiences into account. Regarding the risks, they propose personalized, progressive, and repeated information. They have no fixed position as to whether, when and how to inform individuals of the life-threatening risk. They advocate not to minimize this risk, and the bereaved are aware of their ambivalence between regret at having ignored it and fear that the ongoing anguish prevented their children from living. Despite this context, they find it necessary to focus the information delivered around a positive message of “living with risk settings”. On the other hand, they suggest that doctors should take into account the warning signs they perceive (physical: sign of severity of seizures; psychological: climate of tension, change in the patient's character, or a mere hunch).

Table 5: Recommendations from the experience of patients and relatives.

4. Discussion

The aim of this study was to understand how patients, relatives, and bereaved families experience epilepsy and its risks, by enabling them to voice their own experiences. In 2016, Ramachandranair [21] felt that the "patient voice on SUDEP had been absent". The phenomenological approach has resulted in essential observations and recommendations from the three groups (PWE, relatives, the bereaved), the main ones of which we will discuss.

First: Fighting against the stigma that determines the feeling of "abnormality" and the inappropriate behavior of patients and relatives. As soon as the diagnosis is confirmed, PWE and their relatives experience a stigma that is twofold. It is both social (referring to the attitude of the population, in particular in the school and professional environment), and personal (taking the form of self-stigmatization linked to representations of deprivation of freedom). This feeling of self-stigmatization is found in patients having undergone epilepsy surgery who, despite obtaining good results, do not return to a "normal life" because they internalize the concept of "abnormality" [22]. According to Cheung and Wirell [23], teenagers consider epilepsy to be the chronic disease with the greatest social impact and stigma. Thus, PWE call for public information campaigns to combat this stigma.

Second: Managing uncertainty in order to facilitate patient autonomy. The uncertainty associated with the disease, whatever its dimensions (clinical, diagnostic, prognostic), seems to prevent doctors from providing clear and personalized information. This restricts the patient's autonomy and leads to a feeling of helplessness for the relatives. According to Corrigan [24], personal empowerment is important, as it is a factor of resilience to self-stigma. This reinforces the importance of providing information that incorporates uncertainty as well as patient education that focuses on rebuilding self-esteem.

Third: Striking a balance between overprotection and trivialization. The way of disclosing the diagnosis and the experience of receiving this disclosure both influence behavior. Relatives

can present two opposite attitudes: (i) "overprotection" of the child, or (ii) "trivialization" of the disease and its risks, with the illusion of "*letting him/her live his/her life like others*". In the first case, there is a risk of the child becoming withdrawn, and conflicts leading to social isolation. The second case may induce greater risk-taking. To avoid finding themselves alone and in difficulty, patients and relatives recommend having an informed and trained "trusted person". This is one of the original results of our study, and represents a prevention perspective that requires development. Recently, Wilson [25] showed that humans develop complex coping systems or 'positive illusions' on living with epilepsy, leading to a better quality of life, and less depression. In 2015, Escoffery et al. [26] showed that these coping systems reduce stigma. Participants advocated striking a balance between these two attitudes by suggesting that doctors focus their information around a positive message of "living normally but controlling the risks". Graber [15] discusses the importance of "tailored risk", giving patients guidelines to assess their risk level and improve communication.

Fourth: Questioning the lived experience and providing information so that patients can assimilate the risks. The major risks expressed by PWE in our study are the direct consequences of an unpredictable loss of consciousness (mainly road accidents, and falls). The participants' responses show that danger is difficult to perceive for oneself and that most people are unaware of the lethal risk, both of which can lead to risk-taking. Their answers depend on their personal views [9] and previous experiences. The attitude of doctors is partly to blame. Strzelczyk et al. [7] show that most doctors address the risks associated with everyday injuries, but not the life-threatening ones. Studies on neurologists [11, 21] show that the majority rarely or never discuss the risk of SUDEP with their patients. They are reluctant to inform the patients because they fear their fear [27,28], especially since the sudden disclosure of the diagnosis without any additional information will have been experienced as a shock and a stressful event (as conveyed in our study).

The work of Long [29] and Cooper [30] shows that PWE and relatives want to be informed about the risks, including the risk of SUDEP. Bereaved families deplore the fact that neurologists do not sufficiently emphasize the risk of nocturnal mortality. They complain that information about SUDEP often only arrives after death [31,32], and that, before death, professionals tend to minimize the risk by talking about a "transient disease that you don't die from". However, they are aware of the fact that knowing this would not necessarily have prevented death, and might have led to the patients living in permanent fear. Phenomenological questioning brings out another paradox: while the participants declare being unaware of the vital risk, several relatives and patients admit to having experienced a sensation of imminent death without ever having discussed it with their doctor. Our results, like those in the literature, question the usefulness of discussing the vital risk with all patients. Would it not be better to provide detailed, progressive, person-centered information, accompanied with empathy, rather than talking about it systematically and sometimes brutally, or than not talking about it at all?

Patient-centered information is information that takes into account the lived experience of the patients and their family members. It enables them to express how they live, and takes into consideration their understanding of the disease, personal history, knowledge of the disease, opinion on risk-taking, what they want, and what they hear about epilepsy and its risks.

In a short review, F. Zahedi [33] explains that sometimes the principles of respect for the patients' autonomy require accepting their refusal to know the truth, provided that a person is designated to receive information and make medical decisions on their behalf. This reinforces the value of an informed and trained trusted person.

The question of how promptly the information is provided is linked to the question of the right moment to disclose the diagnosis: "one must know how to wait in order to reach the goal that one proposes" [34]. The family physician, through knowledge of the history and long-

term follow-up, assimilates all the information in order to help perceive this right moment. Optimizing the coordination between general practitioners and neurologists on the delivery of personalized and progressive information seems to be an interesting perspective.

Finally: Training professionals for a patient-centered approach. Phenomenological questioning facilitates authentic responses as to how participants experience communication with their neurologists. They often sense a lack of listening, support, and empathy, and are forced to look on the internet for missing information [11], or to share their experience in peer associations. The participants would like their neurologists not to evade the questions, and to answer with comprehensive language. Training medical students to deal with announcing bad news in a patient-centered approach is an interesting perspective of our study, and is in line with the recommendations of the Institute of Medicine [35]. This approach stimulates the reflexivity of the patient, who becomes aware of his/her behavior, and can then alter it in a process of empowerment. It could enable patients to learn how to manage the risks in daily life.

Strengths and limitations

This work hypothesized an internal methodological consistency between the objective of the research (lived experience), the appropriate phenomenological approach to data collection, and the data analysis, favoring a logic of emergence [36]. The phenomenological approach made it possible to stimulate the reflexivity of the participants, whose lived experience enabled the development of relevant recommendations for inclusion in risk prevention actions that were not limited to SUDEP. Although the patients involved were predominantly women, the description of the sample shows that the characteristics of the participants were varied. One of the limitations of our study concerns the interview techniques that the investigator did not fully master when addressing the risks associated with epilepsy. Taking on the role of

informant, she sometimes limited the participants' verbalization. Several triangulation procedures guarantee the validity of the data: (i) triangulation of sources (three target groups), and (ii) triangulation of analyses by two experienced researchers who produced a general synthesis after data saturation.

In each step of the analysis process, there was transparency. Semiopragmatic analysis using *a priori* hierarchical classes of signs added precision to the logical constructs of categories of studied phenomenon (by limiting investigator-related interpretation bias).

In France, the lack of coordination of professionals (particularly between general practitioners and neurologists) may have accentuated the participants' feeling with regard to uncertainty and information provided. However, the results may be transferable or may offer research hypotheses in different contexts (facing the same issues).

5. Conclusion

Our study points out that stigma, uncertainty, and lack of clarity of information are all barriers to patient empowerment. Participants want prompt, personalized information about epilepsy and its risks. Physicians need to develop person-centered communication skills. The question is not “Should we talk about SUDEP?” but “What should be said, to whom, when, and how?” Future research is necessary for the development of tools to facilitate this communication.

Declaration of Competing Interests:

None of the authors have any conflicts of interest to disclose.

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TABLES

Table 1: Stigmatizing representations of epilepsy.

Category 1	Subcategories	Verbatims
Stigmatizing representations of epilepsy and its constraints transform self-image and determine the behavior of patients and relatives	Stigmatizing social representations transform—self-image by inducing a feeling of abnormality	<i>"Epilepsy is considered as a shameful disease" R7</i> <i>"For him, the way people looked at him was degrading" B9</i> <i>"I was taken for a madman" P9</i> <i>"I felt very early on that I was different, abnormal" P5, P3</i> <i>"He doesn't consider himself as a sick person but as a disabled person" R9</i>
	Constraints create the awareness of a deprivation of freedom	<i>"The disclosure of the diagnosis is full of things I wanted to do later that I won't be able to do" P7, P1</i> <i>"I feel restricted in my freedom" P3</i> <i>"In adolescence, to be deprived of everything is to be deprived of living" P2</i>
	These representations determine the behavior of:	
	- Parents: between overprotection, trivialization and acceptance of "living with epilepsy"	<i>"I was enclosed in a protective bubble" P12, R1</i> <i>"She was always under surveillance" B5</i> <i>"I always wanted him to be like everyone else" B10</i> <i>"I'm not going to forbid him to live, you have to accept what you are" R5</i>
	- Patients: Attitudes of secrecy and withdrawal, conflicts leading to breakdown	<i>"The main after-effect is that I'm afraid of people" P6</i> <i>"She didn't want to talk about it so that we wouldn't worry" B2, B3, B5</i> <i>"She was in conflict with her mother, we had no more communication" B3, B6</i>
	Difficulties fitting in at school or work	<i>"At the time, children would hit him on the head to provoke seizures" B9</i> <i>"I couldn't get a job because I had epilepsy" P7</i>

Table 2: The global uncertainty surrounding epilepsy

Category 2	Subcategories	Verbatim
The global uncertainty surrounding epilepsy, which affects the delivery of clear and personalized information by professionals, is a source of anxiety and an obstacle to patient autonomy.	Global uncertainty causes anxiety and confusion	
	• The clinical expression of epilepsy and seizure is perceived as an indefinable symptom	<i>"Indefinable symptom" B2</i> <i>"When I don't feel good about myself, and am feeling sluggish, I think of epilepsy" P10, P5, P4, P12, P14</i>
	• Uncertainty as to when the next seizure will occur	<i>"When you can't feel the seizures coming, it's distressing" P2, P10, P11</i>
	• Uncertainty regarding the prognosis	<i>"It's complicated not knowing what's going to happen later, how it's going to end, and what the consequences will be" P7, R8</i>
	• Uncertainty related to comorbidities or to iatrogeny, leading to confusion	<i>"We don't know if it's the disease, my psychological state, or my treatment" P2, R8</i>

Unclear and inadequate information creates uncertainty

• Physicians addressing patients in an awkward manner *"Even the neurologist didn't know what to say, given that I had no predisposing factors" P4, P1*

• Unclear information *"I was told: "she might have others, or no more, or more, or less", it was a total blur" R8*

"Preventing nocturnal seizures wasn't well explained" B3, R4

"the problem is not the actual epilepsy, it's knowing what it is" P5

Uncertainty is an obstacle to the patients' autonomy and to understanding and managing their disease *"Not knowing exactly what it was coming from made it difficult to know what to look out for" R1*
"It's a feeling of helplessness, my husband and I are coping very badly with the situation" R6, P2

Table 3: The relational and communication skills of the doctor

Category 3	Subcategories	Verbatim
The relational and communication skills of the doctor have an impact on the experience of the patients and relatives	A direct and poorly documented disclosure comes as a shock to the relatives,	<i>"I didn't appreciate the direct way the neurologist told me. He said: "your daughter has epilepsy.", He was too concise... it knocked me for one and I didn't ask any questions, it was like a slap in the face" R7, P4</i>
	whereas a person-centered disclosure, taking into account uncertainty and temporality, facilitates acceptance.	<i>"the neurologist told us "we're going to need time to determine the type of epilepsy, its cause and its treatment", putting words where it hurts, so we'll adapt our life - as well as his (hers) - accordingly". R5</i>
	Minimizing and reassuring - rather than explaining - is a common attitude in doctors:	
	-regarding the temporary aspect	<i>"I was led to believe that it would end in adolescence" P6,R2</i>
	-regarding the protection provided by medication	<i>"he said "if you take the treatment properly, you can live with it", he didn't mention any danger, I didn't think the disease was too serious" B3</i>
	-regarding the vital risks when they are addressed.	<i>"she showed us the brochure on SUDEP, saying "you shouldn't really take much notice of this because it's very rare and, in any case, you don't die of epilepsy"" B2</i> <i>"the treatment doesn't prevent all seizures but you don't die from them" B7, B10.</i>
	Use of understandable and appropriate language	<i>"they should learn how to express themselves more simply" P5.</i>

	<i>"he didn't speak of epilepsy, he said convulsion"</i> R5
An empathetic, understanding, attentive, patient-centered approach is expected by the patients and relatives.	<i>"I found that the consultation was not personal enough, it was treated too lightly"</i> B3 <i>"when he saw that I had a list of questions, he left the room"</i> R4 <i>"we're not being listened to"</i> R8

Table 4: Risks associated with epilepsy.

Category 4	Subcategories	Verbatim
Personal experiences influence the perception of danger to oneself, which may encourage risk-taking. The lack of awareness of the direct lethal risk contrasts with the near-death experience of some (patients and relatives) during the generalized seizure.	Perception of danger to oneself is difficult, especially if it is lethal	<i>"I don't see the risks for me"</i> P2, P10 <i>"of course I can have a fit at the wheel, but in the water I'm a pretty good swimmer"</i> P3 <i>"I never thought you could die from an epileptic fit"</i> (said by all except P1). <i>"the Professor had told us about sudden death but we didn't think it could happen to us"</i> B9 <i>"when it comes to driving, I turn a blind eye, but when I prang it (the car), I feel angry (...). It makes me talk about it, as I cut and burn myself quite a lot"</i> P10 <i>"One thing's for sure: when the seizures are spaced out, life is more peaceful"</i> R6 <i>"I dived with them a lot, I went 40 m deep"</i> P12 <i>"be careful not to get too tired, avoid staying up too late, avoid stress, avoid screens"</i> P4, P12, P11, P7, P3, P9
	Risk-taking depends on previous experience, frequency of seizures, and perceived seizure-triggering factors	
	Risk is perceived as a direct consequence of an unpredictable loss of consciousness (from falls, accidents, drowning, and burns to accidental death).	<i>"the fall is more dangerous than the seizure"</i> P7 <i>"when a child loses consciousness, I think of accidental death, not direct death"</i> R5, B2, B5
	Lack of awareness of the risk associated with nocturnal seizures.	<i>"We weren't worried because the seizures were at night, we don't think there's any risk in bed"</i> B3, B4
	The lack of awareness of vital risk contrasts with the near-death experience of generalized seizures (patients and relatives).	<i>"I felt like I was dying. I thought: 'well, this is it, I'm dead' (...), I couldn't breathe"</i> P5 <i>"I'm afraid she'll die of suffocation, that she won't come back"</i> R6, R1 <i>"When I saw it was getting worse, I asked: 'can you die from it?'"</i> B10

Table 5: Recommendations from the experience of patients and relatives.

Target groups	Recommendations	Verbatim
General public	1 Limit stigmatization by providing clear information for the media	<i>"use social media, because epilepsy isn't talked about, unlike breast cancer or heart disease" B1,3</i>
Patients	2 Respect the usual rules of hygiene for PWE	<i>"Take your medication at a set time", "rest, don't drink alcohol or take drugs", "don't spend too long on screens" (all participants)</i>
	3 Have regular consultations, ask doctors the right questions	<i>"see the neurologist more often" B3, R5 "ask the right questions" B10</i>
	4 Avoid being alone, by being with a trusted person who is informed and trained in seizure management	<i>"wherever he went, people were warned" B10 "I think that the people around us should be made aware, have booklets..." B3</i>
	5 Be aware of the night-time risk for seizures	<i>"how to prevent fatal night-time seizures was not well explained or understood" B3</i>
Friends and relatives	6 Strike a balance between overprotection and trivialization	<i>"everything was organized to avoid risks, constantly" B9</i>
	7 Be more attentive to transitions towards independence and to changes in status (adolescence, emancipation, marriage)	<i>"in adolescence, it's more difficult" R4 "when she got married, I stepped back to make room for her husband" R7</i>
	8 Avoid conflicts in order to maintain interpersonal relationships and to prevent isolation	<i>"don't cut ties and communication with the patient so as to avoid leaving him/her alone". B1, B3</i>
	9 Facilitate experience-sharing with peers	<i>"I regretted not having other people to talk to about it" P7, P8</i>
	10 Get involved in passing information on and making a difference	<i>"I had to work hard at doing research on the net about epilepsy" B3 "I distributed lots of brochures so that people could understand" B9, B4</i>
Healthcare professionals	11 Have a patient-centered, empathetic approach	<i>"we didn't feel welcome, we didn't have a listening ear for talking about all this" P8</i>
	12 Take into account the impact of epilepsy on family life and relatives	<i>"we went there to talk about the family's experience" R8 "they don't take any interest in what goes on in your life" B3</i>
	13 Provide personalized information on mortality risks that is progressive and repeated.	<i>"suggest doing it on a case-by-case basis, if the question is asked" R4</i>

	<p><i>"For me, not at first, so as not to alert the patient too much and for him not to dare do anything. You have to go gradually. When it's a good time to talk about it, you go deeper"</i> R7</p> <p><i>"not to receive information unaccompanied"</i> P4</p> <p><i>"the doctor should give us this type of booklet (brochure on the risks of epilepsy) and explain it"</i> P6</p> <p><i>"you have to say everything but know how to say it"</i> B7</p>
14 Take into account the "warning signs" reported by relatives (physical, psychological, hunches)	<p><i>"When he was vomiting, no one took him seriously, but the doctor told me: "you're right, it's because of the severe seizures". I found him getting slower and slower".</i> B10</p> <p><i>"When you see your child in a bad way, you have to insist, put things into perspective, because the doctor is satisfied with just giving medicine".</i> B9</p> <p><i>"in terms of character, she was becoming very, very aggressive".</i> B3</p> <p><i>"Before her death, the atmosphere had become very tense, there was a huge combination of stress, frustration, discontent that probably generated something."</i> B6</p> <p><i>"I don't know, maybe also a hunch"</i> B2, B7</p>
15 Focus information around a positive message	<p><i>"Enjoy life while setting the parameters for risk"</i> B5</p>

SUPPLEMENTARY DATA (SD)

SD 1: Interview guide for PWE

A - Remembering when the diagnosis was disclosed:

"Take some time to think back to the exact moment when you were first told about epilepsy:

Who told you? What words were used? What came to mind at that moment? What did

epilepsy mean to you at that time? How did you perceive epilepsy? How did you feel?"

B - Information received on epilepsy and its risks:

“What information did you receive about epilepsy and its risks? Who gave it to you? How did you hear about the risks in your daily life? About the risks of SUDEP? What advice were you given? Have you personally sought additional information? What kind of information?”

C - Experience with epilepsy today:

"How do you live with this disease today? (If there has been a change in your initial perception or experience, what has influenced this change?)"

D - Experience of the risks associated with epilepsy

"How do you perceive the risks related to this disease? In what situation did you know that you were taking a risk in relation to your disease? What are the risks? What do you allow yourself to do?

What precautions do you take today to reduce the consequences?

In what way do the risks linked to epilepsy influence your relationship with others, your way of looking at life, your behavior, your plans?

What would you say to a person to whom you are informing that they have epilepsy? How would you explain the risks and their prevention?"

SD 2: Steps of a pragmatic phenomenological analysis

Perform a word-by-word transcription of the recordings (verbatim).

Carry out a first reading, followed by a focused reading.

Extract significant units from the text, and group them by themes.

Collate textual and contextual meaningful semiotic elements as well as their semiopragmatic characterization.

Perform a first categorization by regrouping these semiotic elements and the significant units in accordance with the research question.

Develop the categories by continuing the comparison, until theoretical saturation is reached.

Place the emerging categories into logical order.

SD 3: Characteristics of the 3 groups of patients

	PWE N=16	PWE of the relatives group N=8 (8 parents)	Deceased patients of the bereaved families group N= 10 (9 parents, 1 sibling)
Age at death / Age, y: mean (\pm SD)	37.1 (\pm 14.6)	29.5 (\pm 10.9)	28.4 (\pm 9.7)
Gender: Women n (%)	10 (62.5%)	4 (50%)	7 (70%)
Living conditions, n (%)			
Sharing household	14 (87.5%)	6 (75%)	8 (80%)
Living alone	2 (12.5%)	1 (12.5%)	2 (20%)
Medical Institution	-	1 (12.5%)	-
Alcohol dependence, n (%)	0	0	1 (10%)
Cannabis consumption n (%)	1 (6.25%)	1 (12.5%)	3 (30%)
Tobacco, n (%)	4 (25%)	1 (12.5%) ^o	4 (40%)
Car driving, n (%)	6 (37,5%)	3 (37.5%)	3 (30%)
of whom n with active epilepsy:	3	0	3
Age at onset of epilepsy, y: mean (\pm SD)	16.0 (\pm 11.4)	12.1 (\pm 6.5)	11.7 (\pm 6.8)
Duration of epilepsy (y)	21 (\pm 2)	17 (\pm 9.5)	11.7 (\pm 6.8)

Type of epilepsy, n (%)			
Focal	11 (69%)	4 (50%)	6 (60%)
Generalized	5 (31%)	2 (25%)	3 (30%)
Epileptic encephalopathies	0	2 (25%)	1 (10%)
GTCS frequency (during past year), n (%)			
-	-	-	4 (40%)
> 1/month	7 (43.75%)	1 (12.5%)	6 (60%)
1/month - 1/year	1 (6.25%)	1 (12.5%)	-
< 1/year	8 (50%)	4 (25%)	-
None			
AED treatment, n (%)			
Monotherapy	4 (25%)	1 (12.5%)	3 (30%)
Polytherapy	12 (75%)	7 (87.5%)	7 (70%)
Compliance to AED, n (%)			
Good	14 (87.5%)	8 (100%)	5 (50%)
Medium	1 (6.25%)	-	5 (50%)
Poor	1 (6.25%)	-	-
Drug-resistant epilepsy, n (%)	11 (75%)	7 (87.5%)	7 (70%)