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Living safely with epilepsy: a key learning review

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ABSTRACT – This review focusses on counselling to reduce the risks of seizures in epilepsy patients. Risk reduction, whilst maximising the independence of persons with epilepsy, is a core element of epilepsy practice. The importance of the issue is reflected by the inclusion of risk assessment and reduction in the recent International League Against Epilepsy Curriculum for epileptology. This article addresses the key elements of epilepsy risk and provides practical guidance for counselling and risk reduction. A review of key publications was performed focusing on: (1) the risk of injury associated with seizures; (2) safety issues related to seizures and lifestyle; (3) SUDEP risk and avoidance; and (4) assessing individual risks. Risk is common in epilepsy and is multifactorial. Clinicians should be aware of the risk factors associated with different epilepsy features, such as seizure type, as well as those related to lifestyle and common indoor and outdoor activities. In addition, transcultural differences should be considered in risk assessment and counselling, *e.g.* regarding SUDEP or even driving, for which regulations vary across nations. Assessment of individual risk is evolving through a better understanding of risk factors and methodologies which can improve communication and empower patients to help identify and manage their individual risks.

Key words: seizure, safety, risk, management, epilepsy, injury

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Risks in epilepsy patients can be related to seizures, aetiology, and diagnostic or therapeutic interventions, and may imply outcomes associated with physical, psychological or social health (Noe, 2019). The identification of risk factors involved in each setting and for each type of outcome is key to build up evidence-based safety recommendations and to design strategies to decrease the odds of undesirable outcomes.

This narrative review focuses on the direct consequences of seizures on the physical health of persons with epilepsy (PWE); thus, addressing the learning objective *2.2.3 Provide guidance regarding safety issues related to seizures* of the ILAE curriculum for epileptology (Blümcke *et al.*, 2019). The search strategy and inclusion criteria are detailed in *box 1*.

Physical damage related to seizures includes a wide range of events,

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Box 1

This narrative review is intended to provide an updated and evidence-based frame of knowledge for counselling epilepsy patients and their caregivers on safety issues. An extensive literature search was developed: PubMed; limit: Human studies; search terms, each applied to [All Fields] were ("epilepsy" OR "seizures") AND ("risks" OR/AND "injuries"). In a second step, those terms were combined with ("death" OR/AND "SUDEP") and with ("driving" OR "sports"). A first selection of articles that were pertinent to the predefined aims of the review was achieved through abstract review.
Full texts were obtained (language limited to English, Spanish, Italian, French, and Portuguese) for data abstraction. Additional relevant articles were identified through hand searching of references. In some cases, when different sources converged providing similar data, we chose to include reviews with high didactic value as references. Conflicting or insufficient data on some issues were appropriately labelled in the text.

from very mild injuries to death. Although *accidents* are generally understood as events leading to physical damage due to an unexpected, external, non-disease related cause (Beghi *et al*., 2002), the unexpected nature of seizures probably underlies the use of the term in many reports on this topic. On the other hand, including *seizure-related injuries* as accidental injuries, while highlighting their unintentional nature, may have a negative impact, minimizing the potential for prevention.
Seizure-related injuries (SRI) and seizure-related deaths have warranted extensive clinical research, aimed to unveil the incidence and magnitude of the problem, and to identify risk factors that could allow for preventive interventions. However, most available data are supported by retrospective studies (largest series), and sometimes using different operational definitions, with subsequent limitations regarding the generalization of their findings (Beghi, 2009). While many studies applied an implicit concept of "injury"(Sajjan *et al*., 2016), or a very broad one including any symptom or sign secondary to seizures (Nakken and Lossius, 1993; Friedman *et al*., 2010), others used more specific definitions according to predefined aims and methodologies: from ICD codes in studies based on registries (Mahler *et al*., 2018), to lists based on particular types of lesions (Sapna *et al*., 2008; Tiamkao *et al*., 2009; Baca *et al*., 2013; Lagunju, *et al*., 2016;) or restricted to injury severity (Téllez-Zenteno, *et al*., 2008; Camfield and Camfield, 2015). Moreover, criteria for classification of injury severity have led to significant variation among studies.

With this caveat in mind, and aiming to provide a didactic and practical summary of use for both neurologists and primary health care providers, we propose an approach through four specific learning objectives:
– To understand the current evidence on risks of injuries associated with seizures.
– To provide counselling to minimize seizure-related injuries associated with everyday living activities.
– To provide counselling on the risk of death associated with seizures.
– To manage the fundamentals for assessing individual risks.
The main findings of this review are summarized below, according to each of these specific learning objectives, following a logically based stepwise approach; from the available evidence leading to the identification of risk factors to the delineation of recommendations for counselling.

Risk of injuries associated with seizures

The magnitude of the problem

Different studies have shown that PWE have an increased risk of accidental injuries compared to the general population, particularly adult epilepsy patients (RR 3.42) (Asadi-Pooya *et al*., 2012); in children, the risk is non-significant or mildly increased (Kirsch and Wirrell, 2001; Lagunju *et al*., 2016; Sajjan *et al*., 2016). Relative risks in mixed populations have been reported, ranging from 1.1 to 1.7 (Beghi *et al*., 2002; Téllez-Zenteno *et al*., 2008; Mahler *et al*., 2018). When SRI were excluded, the RR decreased from 1.6 to 1.4 (Beghi *et al*., 2002). Many factors probably interact in a complex way to account for the individual risk of injuries in epilepsy patients. This risk is related not only to seizures themselves, but to pharmacological treatment and its adverse effects as well as, sometimes, associated comorbidities. Implementation of more efficient preventive measures requires a detailed analysis of individual features such as sex, age, seizure type, epilepsy duration, antiepileptic treatment and medications for other disorders.
Regarding the specific risk provided by seizures, reports on lifetime prevalence of any SRI vary according to age group and disease duration, from 9-12.6% in children with newly diagnosed epilepsy (Appleton, 2002; Ting and Kwong, 2010) to 27-30% in adults with chronic epilepsy (Neufeld *et al*., 1999; Tiamkao and Shorvon, 2006; Orozco-Hernández *et al*., 2017). The impact of the length of follow-up was nicely summarized by Lawn and colleagues, who found a risk of a first-ever SRI at one year of 5%, increasing gradually to 26.1% at 20 years (Lawn *et al*., 2004). In all age groups, epilepsy severity and neurological or cognitive

comorbidities were associated with a further increase up to 44% in children (Buffo *et al.*, 2008) and 54% in adults (Friedman *et al.*, 2010). The annual SRI risk rate ranges between 5-40/100 patient-years (Neufeld *et al.*, 1999; Beghi *et al.*, 2002; Tiamkao and Shorvon, 2006) in unselected epilepsy patients to 120-180/100 patient-years in institutionalized cases with multiple disabilities (Nakken and Lossius, 1993; Deekollu *et al.*, 2005). In certain subgroups of patients, risks of specific types of injury may be even higher; the risk of head injuries was reported as 278/100 patient-years in one series of institutionalized PWE (Russell-Jones and Shorvon, 1989).

Seizure-related injuries are usually mild (44-61%) (Asadi-Pooya *et al.*, 2012; Lagunju *et al.*, 2016), do not require hospital assistance and include skin and soft tissue bruises and lacerations, mostly affecting the head, mouth, teeth, tongue and upper limbs (Lagunju *et al.*, 2016). Even in events requiring consultation, 33% were mild injuries (Kirby and Sadler, 1995). Severe SRIs that require hospital admission were reported in 0.4-8.8% in different series (Russell-Jones and Shorvon, 1989; Friedman *et al.*, 2010; Asadi-Pooya *et al.*, 2012; Lagunju, *et al.*, 2016), with severe traumatic brain injuries (TBI) being the most dreaded.

Types of injury related to seizures

In adult epilepsy patients, increased risks of soft tissue injuries (RR: 4.3), burns (RR: 3.3), mild head injury (RR: 2.7), oro-facial lesions (RR: 2.6) and fractures (RR: 1.9), compared to controls, were reported in a retrospective study (Asadi-Pooya *et al.*, 2012). In case-control studies on unselected epilepsy patients, a mildly increased risk remains even when SRIs are excluded: RR of 3.2 for fractures (Desai *et al.*, 1996), 1.2-1.9 for soft tissue injuries and 1.4 for TBI (van den Broek *et al.*, 2004).

Regarding the specific risk of different types of lesions associated with seizure occurrence, **soft tissue injuries** are recognized as the most frequent type of SRI, both in children and adults, accounting for 26-44% of all SRIs in the former (Buffo *et al.*, 2008; Lagunju *et al.*, 2016) and were reported to be referred in up to 85% of adults with epilepsy who had presented with an injury (Bellon *et al.*, 2013). These include wounds, lacerations, abrasions, and bruises or superficial haematoma, with varying inclusion criteria and representation in different series. These types of injuries are more frequently located in the craniofacial region, and were shown to be only partially avoided by the use of helmets (Deekollu *et al.*, 2005) in high-risk patients. While some studies excluded oral traumas from their figures, significant tongue injury and teeth loss/fracture have been reported to account for 9-27.2% of SRIs in children and 5-10% in adults in other series (Nakken and Lossius, 1993; Buck *et al.*, 1997; Buffo *et al.*, 2008; Baca *et al.*, 2013; Lagunju *et al.*, 2016; Verboket *et al.*, 2019).

Although the head is the more frequent location of SRIs, not all head lesions qualify as **traumatic brain injuries** (**TBI**), and they are rarely described as severe (Beghi *et al.*, 2002). On the other hand, Neidlinger *et al.* reported that up to 10% of clinically minor head injuries presented with an intracranial haematoma or a skull fracture on CT (Nei and Bagla, 2007). From a different perspective, in large TBI series, those occurring in PWE were associated with falls and were more frequently found to be severe and recurrent (Wilson and Selassie, 2014).

The risk of **bone fractures** in other locations apart from the head is increased 1.3-4.3-fold in epilepsy patients (Wirrell, 2006), and is only partially explained by the occurrence of seizures (Desai *et al.*, 1996). Thirty-four to 43% of fractures in PWE were attributed to seizures (Wirrell, 2006). The incidence of seizure-related fractures has been reported to vary from 6.65-63.8/1,000 person-years, according to the selected population, with hospital-based series showing higher incidence rates (Tan and D'Souza, 2013). In patients aged 16 and older, the risk of a lifetime seizure-related fracture was estimated to be 1.6 per decade (Ahmad *et al.*, 2012). The risk of seizure-related bone fracture is particularly increased for hip fractures (OR: 5.3), as well as forearm (OR: 1.7) and spine (OR: 6.2) locations (Vestergaard, 2005).

Specific estimates on **burns** related to seizures have shown significant variation, from a lifetime prevalence of 3.7% to 10.2% in adults with epilepsy attending tertiary clinics (Spitz *et al.*, 1994; Neufeld *et al.*, 1999) to a rate of 15.9% per year in a population-based study (Buck *et al.*, 1997). On the other hand, Beghi and colleagues found no significant increase in risk of burns in PWE (Beghi *et al.*, 2002; van den Broek *et al.*, 2004). Interestingly, Josty *et al.* reported a significant decrease in the rate of severe seizure-related burns requiring admission to a burn unit, compared to previous series dated from 1956 to 1968 (Josty *et al.*, 2000). Moreover, scalds rather than flame burns were reported as the predominant type of burn, with a mean affected body surface of 2.2% rather than 15%. This difference was considered to be related to new technologies applied to home solutions, as well as changes in some traditional practices, *e.g.* decreasing the use of open fires for domestic heating.

Drowning is included as a type of severe injury, because it is a preventable cause of death in epilepsy patients of all ages, but particularly in children and young adults (Bain *et al.*, 2018). The rates of submersion events in children with epilepsy were reported to be 4 to 13.9 times higher than in controls (Tan and D'Souza, 2013), accounting for 2.9% of severe submersion events in children (Pearn *et al.*, 1978). The risk of drowning in

epilepsy patients was 10-fold higher compared to individuals without epilepsy in a Canadian study including mostly adults (Bain *et al*., 2018) and up to 19-fold higher in a metanalysis of epilepsy cohorts (Bell *et al*., 2008). In the latter, mortality rates due to drowning were higher in adults (SMR 20) compared to children (SMR 7.7), while maximum risks were found in a subpopulation with cognitive disabilities (SMR 25.7) or an institutionalized subpopulation (SMR 96.9). Severe submersion events and drowning include accidents occurring at home, mostly in the bath (44-72%) (Ryan and Dowling, 1993; Bain *et al*., 2018; Cihan *et al*., 2018), as well as those in private or public swimming pools or even open water, the latter being the most frequent setting based on various retrospective series of children with drowning/near-drowning events (Orlowski *et al*., 1982; Pearn *et al*., 1978).

Risk factors for SRIs

Different variables have been associated with either an increased risk of injuries in epilepsy patients and/or specifically seizure-related injuries, considered as a whole or according to specific lesional types. These risk factors may in turn be viewed as modifiable or non-modifiable or preventable, and the strength of the association can range from "well established" (statistically confirmed in a well-designed study and/or in two or more studies) to "probable" based on an association in single studies, but is not supported by multivariate analysis and/or appropriately powered studies; some additional "possible" factors are frequently described, but without currently available evidence-based data.

Taking into account this complexity, the evidence related to different epilepsy and patient's features that can increase the risk of seizure-mediated injuries is summarized below.

Non-modifiable risk factors

– ***Age***: The risk of a SRI slightly increases with age, from a hazard ratio of 1.05 (non-significant) in children under 15 years to 1.55 in those 65 years and older (Mahler *et al*., 2018).

– ***Gender***: Although a mild predominance of direct injuries (head trauma, fractures) as well as drowning was described in males (Medvdovsky *et al*., 2006; Tan and D'Souza, 2013), a statistically significant association was not confirmed, at least in adults (Asadi-Pooya *et al*., 2012). On the other hand, burns were shown to be more frequent in women (Spitz *et al*., 1994; Buck *et al*., 1997), and considered to be related to exposure to different heating devices associated with household tasks, involving, for example, the oven and open fire in the kitchen, iron, *etc*.

– ***Epilepsy type***: Certain epilepsy types or aetiologies have been postulated to increase the risk of injury by some authors, such as generalized epilepsies (Sajjan *et al*., 2016), either symptomatic (Camfield and Camfield, 2015) or not, juvenile myoclonic epilepsy (Wirrell, 2006), or different aetiological categories (Buffo *et al*., 2008), but no consistent associations have been demonstrated to date.

– ***Age at epilepsy onset***: An earlier age at onset was described to be associated with an increased lifetime prevalence of SRIs based on retrospective studies (Neufeld *et al*., 1999; Bellon *et al*., 2013; Orozco-Hernández *et al*., 2017), but the impact of epilepsy duration (Friedman *et al*., 2010) and thus, time of exposure, must be considered for accurate interpretation of these results.

– ***Seizure type***: In most publications on the topic, the seizure classification system used is the ILAE 1981 classification; "generalized tonic-clonic seizures" ("GTCS") are frequently referred to include not only true GTCS but also focal to bilateral tonic-clonic seizures or even those of unknown onset, according to the ILAE 2017 classification system. Other limitations inherent to community-based or retrospective studies based on self-reporting also apply. In this context, clear and reproducible results have shown that seizures triggering falls (Nakken and Russell-Jones and Shorvon, 1989; Lossius, 1993; Lawn *et al*., 2004; Tiamkao S. and Shorvon, 2006; Asadi-Pooya *et al*., 2012; Verboket *et al*., 2019), including atonic (Nakken and Lossius, 1993; Lawn *et al*., 2004; Deekollu *et al*., 2005; Bellon *et al*., 2013) and "GTCS" (Nakken and Lossius, 1993; Buck *et al*., 1997; Neufeld *et al*., 1999; Appleton, 2002; Deekollu *et al*., 2005; Tiamkao *et al*., 2009; Friedman *et al*., 2010; Lees, 2010), are the most consistent and well established risk factors for SRIs for all age groups. Other seizure types that can be considered as probable risk factors for SRI are myoclonic seizures (Appleton, 2002; Bellon *et al*., 2013; Deekollu *et al*., 2005; Neufeld *et al*., 1999) and focal unaware seizures (Appleton, 2002), the latter specifically associated with burns (Jang *et al*., 2006). Impairment of consciousness in absence seizures was associated with a significant risk of injury, more frequently in teenagers than in children, and in the context of juvenile myoclonic epilepsy (Wirrell *et al*., 1996).

Although the type of seizure is dictated by the specific type of epilepsy or location of the epileptogenic zone or network, and thus it would be considered a non-modifiable factor, treatments may be more effective for certain seizure types.

– ***Comorbidities*** (Mahler *et al*., 2018), and particularly neurodevelopmental delay (Asadi-Pooya *et al*., 2012) or cognitive disability (Friedman *et al*., 2010; Orozco-Hernández *et al*., 2017) that may be

associated with certain epilepsy aetiologies, additionally predispose epilepsy patients to injuries and should be taken into account for counselling. Based on a single study, a history of alcohol abuse was proposed as a risk factor for head injury in PWE (Medvdovsky *et al*., 2006).

Modifiable risk factors

– ***Seizure frequency***: As expected, a higher seizure frequency (Beghi *et al*., 2002; Lawn *et al*., 2004; Tiamkao S. and Shorvon, 2006; Camfield and Camfield, 2015), and particularly a higher frequency of seizures with falls (Friedman *et al*., 2010; Asadi-Pooya *et al*., 2012), is related to a higher risk of SRI. The cut-off that has been shown to have a better predictive value in unselected PWE is a mean seizure frequency of 12/year, meaning a higher risk of SRIs in general, particularly related to burns and drowning (Buck *et al*., 1997; Lawn *et al*., 2004; Tiamkao *et al*., 2009).

– ***Seizure severity***: In one study of adults with epilepsy, in which a self-rating scale was applied for seizure severity, severity was found to be independently associated with SRIs, burns and fractures (Buck *et al*., 1997), based on a multivariate analysis.

– ***Antiseizure medication (ASM)*** can facilitate injuries through their adverse effects: unstable gait and somnolence, for example, would predispose to falls, while the potential role of ASM and particularly enzyme inducers in promoting osteoporosis and increasing the risk of fractures is still controversial (Wirrell, 2006). Long-term exposure to ASM is possibly a risk factor for fractures (Ahmad *et al*., 2012). On the other hand, polytherapy, and in particular a higher number of ASMs, was shown to be associated with SRIs and severe SRIs in multiple studies (Lawn *et al*., 2004; Buffo *et al*., 2008; Asadi-Pooya *et al*., 2012; Bellon *et al*., 2013; Orozco-Hernández *et al*., 2017). While in children a cut-off of more than one drug (Lagunju *et al*., 2016) or two ASMs (Sajjan *et al*., 2016) has been proposed, in adults, the most consistent finding was that three or more ASMs independently increased the risk of fractures and drowning (Buck *et al*., 1997).

Antiseizure medication and comorbidities would then underlie the remaining increased risk of injury in epilepsy patients even when SRI are excluded (van den Broek *et al*., 2004).

Counselling on safety issues related to seizures in everyday living activities

Achieving seizure control

Bearing in mind the intrinsic risk of injuries during seizures, particularly with falls, and the aforementioned modifiable risk factors, achieving optimal seizure control would be the main strategy to prevent physical injuries in PWE (Spitz *et al*., 1994; van den Broek *et al*., 2004; Tan and D'Souza, 2013; Camfield and Camfield, 2015;Noe, 2019). In addition to adherence to treatment, everyday living activities that impact the likelihood of seizure occurrence include avoidance of both facilitators (sleep deprivation, drugs, alcohol) and triggering factors. Although seizure triggers are usually syndrome or patient-specific, facilitators are relatively non-specific and affect most PWE, allowing for some general recommendations.

Studies on sleep in temporal lobe epilepsy patients have shown that a 30-minute reduction in sleep duration is associated with a 5% increase in the likelihood of having a seizure (Foldvary-Schaefer, 2014; Carreño and Fernández, 2016), while reduced levels of melatonin were found in refractory cases (Carreño and Fernández, 2016). Naps were found to compensate for a lack of nocturnal sleep (Foldvary-Schaefer, 2014).

In epilepsy patients, the actual risk of alcohol-related seizures is unknown even though restrictions have been largely promoted. In this context, a placebo-controlled study evaluating the impact on EEG and seizures in patients with regular alcohol consumption found no significant differences (Höppener *et al*., 1983). More recently, for seizures associated with acute alcohol consumption, a dose-effect relationship has been shown, and a generalized epilepsy seems to add additional risk (Hamerle *et al*., 2018). Occasional light consumption does not significantly alter seizure frequency in most patients (Hamerle *et al*., 2018), therefore, when a patient wishes to consume alcohol, controlled responsible consumption should be recommended, rather than complete abstinence.

Recommendations for improving seizure control, with a focus on counselling, are summarized in *box 2*.

In some countries, structured patient education programs devoted to improving management of seizures and epilepsies have been developed (*e.g.* MIND-SET, WebEase, PACES, MOSES, Famoses), while other educational resources as well as self-aid groups are offered in different settings. Health care professionals should become familiar with locally or regionally available resources, to encourage their use by epilepsy patients and/or their carers, optimizing efforts to provide appropriate information and counselling.

Decreasing the risk of injury when seizures are recurrent

With the same needs and rights as anyone else, PWE frequently face limitations regarding their

Box 2. To achieve a better seizure control

General recommendations for healthcare providers

- Optimize drug treatment (type of ASM, dose, schedule)
- Use monotherapy as far as possible
- Promote and periodically evaluate adherence to treatment

Counselling PWE and caregivers

- Explain the relevance of treatment adherence and discuss strategies to avoid skipping/forgetting doses, to secure availability of medication, etc.
- Educate to avoid common seizure facilitators
- Evaluate the presence and type of insomnia. Consider anxiety, stress, depression, as these are associated with insomnia in up to 40% of epilepsy patients
- Promote healthy sleep habits. If partial sleep deprivation is unavoidable, recommend compensation with napping
- Discourage excessive alcohol consumption or frequent intake
- Train PWE to identify their individual seizure triggers, and thus, to avoid them

performance of activities in their community. Although the main underlying goal is to protect themselves from injury or death related to a seizure during these activities, these restrictions may significantly compromise the individuals' autonomy, independence, job opportunities and even many activities of daily living.

Activities of daily living

The evidence: Both mild and severe injuries were found to occur at home in more than half of cases (Neufeld *et al*., 1999; Beghi *et al*., 2002; Tiamkao S. and Shorvon, 2006; Lees, 2010) as well as up to 86% of SRIs (Friedman *et al*., 2010); these were reported to occur during daily-living activities, raising the question of whether frequent restrictions imposed on outdoor activities are a real benefit. This predominance was found in all age groups and for all types of injury, and may be explained by the interaction of potentially risky indoor activities and the fact that PWE frequently spend most of their time at home. On the other and, injuries at the workplace, although more common in PWE compared to controls (van den Broek *et al*., 2004), are much less frequent and less severe than it may be anticipated by most employers, accounting for up to 10% of all injuries (Beghi *et al*., 2002; Friedman *et al*., 2010), usually being reportedly minor (Cornaggia *et al*., 2006).

While some authors describe a higher risk for injuries associated with seizures arising out of sleep, both in adults (Sapna *et al*., 2008) and children (Appleton, 2002), daytime seizures were also considered a risk factor for SRIs (Tiamkao *et al*., 2009). In any case, the literature mostly describes indoor SRIs that occur during domestic activities. Bathing using a bathtub or a shower is associated with submersion events, drowning and/or burns, and these events accounted for 11% of all SRIs in a cohort of adult epilepsy patients (Sapna *et al*., 2008). In another study including teenagers and adults, 12% had a seizure during bathing or swimming at home (Buck *et al*., 1997). Based on a series of autopsies, 44-72% of drowning events related to seizures occurred in a bathtub (Bain *et al*., 2018)(Ryan and Dowling, 1993; Cihan *et al*., 2018). Cooking, ironing, dealing with household heating systems and hand-held hair appliances are most frequently associated with burns related to seizures (Spitz *et al*., 1994; Tiamkao and Shorvon, 2006). In addition, burns due to hot tap water and other hot fluids (hot drinks, oils) were reported to occur five to seven times more frequently in PWE (Ansari *et al*., 2008).

In children, the likelihood of having an accident due to a seizure in the bath is reported to be increased in those with neurological comorbidity (Lagunju *et al*., 2016), and is reported to be rare in retrospective series of children with drowning or near-drowning events (Pearn *et al*., 1978; Orlowski *et al*., 1982). Direct injuries were mostly referred if seizures occurred in the kitchen, on the stairs or upon awakening, falling from the bed (Appleton, 2002).

During pregnancy, direct injuries associated with seizures, mostly bilateral tonic clonic seizures (of either generalized or focal onset), may affect not only the patient, but also the foetus intra-uterus, eventually leading to foetal death. Non-adherence, vomiting and pharmacodynamic changes associated with pregnancy are additional issues that must be discussed with the patient in order to decrease the risk of seizures (Sheth *et al*., 2004). During the puerperium, emotional changes and sleep deprivation are additional risk factors for seizure and SRI occurrence. Based on a retrospective audit of SRIs during the first year of life in offspring of mothers with epilepsy, 6.7% had significant events related to maternal seizures, half of which were serious or potentially serious, occurring more frequently during baths or while on stairs (Fox and Betts, 1999).

Recommendations and counselling: Counselling in this domain should consider individually tailored risks and balancing safety and overprotection, in order to foster independent living as far as possible. A careful discussion with the patient and with whom he or she may share common daily activities should

aim to identify risks and the patient's expectations, considering the particular socioeconomic and cultural context. Whenever possible, performance of daily-living activities that pose an increased risk of injury should be deferred to times when other persons are at home. Regarding the assessment of personal choice, the capacity to understand risks should also be evaluated. For example, in individuals with an intellectual disability who may not be aware of some risks, such as drowning while bathing, a more directed, straightforward recommendation to use showers instead of bathtubs should be provided, restricting bathing to times when the patient may be observed directly by a caregiver. General recommendations on safety measures at home are highlighted in *box 3*.

Technical devices are being developed rapidly, which help to preserve independent living for different limitations or disabilities. Patients should be informed about special counselling centres, to learn about equipment, tools, resources or appliances according to their individual needs, and/or the need for a specialized therapist in each case.

Non-modifiable risk factors, such as age, can also guide some aspects of counselling: adaptation of bath supervision from infants to adolescents should be discussed with the parents in order to avoid submersion accidents in older children gaining independence in activities of daily living; on the other hand, the risk of fractures, in particular, must be considered in older adults.

Being able to understand the dynamics of one's own disease, including triggering factors and seizure types (*e.g.* presence of prodromal symptoms and auras) will be of help to follow recommendations in order to avoid SRIs. Sometimes, it may be useful to recreate imagery related to seizures (particularly those with loss of awareness) in simple, lay words or simulations, through a carefully guided interview, to allow each patient to visualize the real risks to which he/she may be exposed during that period of time. In addition, promoting patients' awareness of the circadian rhythm of their seizures will allow for tailored preventive measures (*e.g.* pharmacological) or specific self-protecting behaviours at night.

Specific counselling for safe neonatal care in mothers with epilepsy (Fox and Betts, 1999) includes avoiding heights (feeding and changing at floor level) and carrying the baby in the arms on stairs, in the kitchen, *etc.* A secure means of baby transportation and joint supervision of baths should be established. The need for supervision during different tasks or activities based on safety issues should be carefully discussed, taking into account individual risk factors and availability of family support.

Finally, giving advice on patients' personal development or professional choice or seeking any type of job may be a complex, multifactorial issue in which the health professional is not always invited to contribute; honest discussion on the prospects of employment should be encouraged. In the context of the present risk analysis, information on legal restrictions according to each country should be provided, as well as counselling on suitable or unsuitable employment options, taking into consideration the epilepsy

Box 3. Living with epilepsy: safety measures at home*

Kitchen
- Avoid cooking on a stove
- The use of a microwave oven is preferable, at subscalding temperature
- Use long oven gloves while cooking
- Safety appliances: insulated plastic kettles, self-sealing deep fryers, cooker guards, anti-spill mugs, cooking basket, timers

Bathing
- Avoid being locked in the bathroom
- Avoid shower cubicles with glass enclosures
- Use thermostats to control water temperature (below 43°C)
- Use showers rather than bathtubs
- Use hand-held showering devices with automatic flow cut-off when released
- Use taps that turn instead of those with levers
- Always keep the drain hole open
- Consider direct observation of bathing for patients with ongoing seizures

Electric devices
- Minimize the use of handheld hairdryers, curling irons, electric irons

Heating systems
- Avoid fires; if necessary, consider flame-retardant clothing
- Use fire/radiator guards, securely placed in front

Other recommendations to avoid direct injury
- Avoid high ladders
- Use soft or padded furniture
- Place bed mattress on the floor
- Consider the use of helmets (particularly in children at high risk of frequent falls, although improvements in design are needed for both comfort and efficacy [Deekollu *et al*., 2005])
- Promote regular physical exercise, appropriate sun exposure and standard measures to avoid osteoporosis
- For patients at high risk of hip fracture, consider the use of hip protection pads

*(Spitz, 1998; Ansari *et al*., 2008; Nei and Bagla, 2007; Unglaub *et al*., 2005;Wirrell, 2006; Noe, 2019)

and seizure type, severity, long-term prognosis and comorbidities.

Traffic accidents as a cause of seizure-related injury or death

The evidence: A recent community-based, cohort study, found an increased risk of severe traffic accidents in PWE ranging from a HR of 2.2 for pedestrians, HR of 1.7 for cyclists, and HR of 1.3 for car drivers (Sundelin *et al*., 2018). Interestingly, the only risk that has been consistently studied to date is that associated with driving.

Probably due to legal constraints, few reliable data are available about the prevalence of driving among PWE. It has been estimated that 64-73% of adult epilepsy patients drive some kind of vehicle (Classen *et al*., 2012); 26-28% reported that they had had a car accident, but only 11% of these accidents were seizure-related (Lossius *et al*., 2010). While 31-38% of seizures while driving would precipitate a traffic accident, according to a recent retrospective survey in Japan (Nishida *et al*., 2020), in only up to 5% was some type of physical injury determined. For PWE, traffic accident rates were estimated to be 1.13-2.16-fold higher than that of the general population, but results are conflicting (Classen *et al*., 2012). Moreover, seizure-related fatal car crashes were found to account for only 0.2% of traffic-related deaths (Sheth *et al*., 2004).

Risk factors: Poor seizure control, a past history of seizures while driving, non-adherence to treatment, a history of alcohol abuse, and poor seizure disclosure have been associated with a higher risk of motor vehicle crashes in PWE (Lossius *et al*., 2010).

Conversely, proposed mitigating factors for PWE would be a previous history as a good driver and good adherence to treatment, and in persons with a first seizure, no recurrence after a follow-up period of at least six months with normal EEG and MRI (Kang and Mintzer, 2016).

While GTCS are associated with a higher risk of severe injury in this setting, seizures of any type and duration of loss of awareness can have a variable impact on the ability to drive (Chen *et al*., 2014) and thus, a range of consequences. In theory, having a warning should allow PWE to pull off the road before an impending seizure, assuming motor function is not impaired at the initial stage of the seizure, however, whether auras in general make driving safer is still unclear (Xu *et al*., 2019).

Regarding the reasons underlying driving in persons with active epilepsy, occupational needs and lack/paucity of alternatives for transportation were the most frequently cited, although self-esteem and social and family needs have also been mentioned (Elliott and Long, 2008). Even after counselling, frequent inability to plan and support a change in behaviour was observed as the main barrier, in addition to a lack of concern regarding one's health or a false perception of safety.

Counselling and recommendations: Efforts have been made in many countries and regions to define guidelines to help identify when a PWE should be allowed to drive safely. In some European countries, neurologists are required to declare the diagnosis of epilepsy to the authorities; these measures can be detrimental to the doctor-patient relationship, risking future disclosure of seizure recurrence and compromising compliance with regulations or risk reduction (Classen *et al*., 2012).

Current recommendations to discuss during consultation with all epilepsy patients wishing to drive should focus on:

– the risk of injury or death to the patient or third parties related to traffic accidents, and subsequent legal consequences;
– the relevance of achieving good seizure control;
– compliance with local/national driving restrictions for epilepsy patients (considering local variations if travelling abroad), including:
  • the requirement of seizure-free intervals (usually 6 to 12 months);
  • eventual reinstitution of driving restrictions during major ASM changes, even in seizure-free patients (*e.g.* taking into account recurrence risks after ASM withdrawal according to epilepsy type, or ASM substitution due to adverse events, pregnancy, *etc.*);
  • the legal consequences in case of traffic accidents (seizure related or not) if driving illegally;
– clinical or personal factors that may be considered to provide an individually based risk assessment, *e.g.* only nocturnal or focal aware seizures, consistent auras, *etc.*;
– counselling for driving after a first seizure; available evidence would support shortening the usual one-year seizure-free period required for driving to a six-month follow-up period without recurrence, with normal MRI and EEG (Kang and Mintzer, 2016);
– evaluation of the motives for driving and discussion on alternatives to ensure mobility (walking for short distances, shared transportation to work, help from family/friends, use of public transportation if available);
– the relevance of adhering to good driving practices.

Recommendations for cycling or using other wheel-based or motor vehicles by PWE for transportation on public roads would be based on common sense, as

evidence is lacking. The use of appropriate helmets is highly encouraged for cycling for both children and adults (Wirrell, 2006).

Sports

The evidence: Different studies have shown that PWE are less likely to perform regular physical activity (PA), to be fit and to practice sports, compared to the general population (Allendorfer and Arida, 2018; Johnson *et al*., 2020). Previously, restrictions on sports for PWE have been based on the possibility of exercise-induced seizures and, additionally, on the risk of injury or even death related to seizures occurring during a particular PA. Fear of seizure precipitation by PA has been shown to be a strong barrier, shared by patients, relatives and, not infrequently, by trainers and treating physicians. Although up to 10% of patients perceived a seizure increase during exercise, a clear relationship was found in just 2% of cases (Noe, 2019). On the other hand, regular PA was associated with better seizure control in different retrospective and prospective studies, although these were mostly small series with self-reporting (Pimentel *et al*., 2015). Although, no injuries during different sport activities or cycling were reported in a long-term follow-up cohort of patients with childhood-onset epilepsy (Camfield and Camfield, 2015), an increased risk of injury associated with absence seizures while cycling has been reported (Wirrell *et al*., 1996). Less frequent injuries associated with sport were found in PWE compared to controls (Téllez-Zenteno *et al*., 2008), but the potential impact of a lower level of physical activity in PWE must be taken into account.

Being aware of the risks of severe injury, particularly with regards to some specific sports, counselling should be counterbalanced with the significant physical and emotional benefits of partaking in sporting activity, including improvement in social abilities, mood and self-esteem (Collard and Ellis-Hill, 2017; Allendorfer and Arida, 2018; Johnson *et al*., 2020).

Risk factors for SRIs during sports: Limited data are available regarding which sports are associated with specific risks for individuals suffering from seizures, and how specific risks may vary according to seizure type and frequency. In general, epilepsy factors associated with higher risks are seizure severity and frequency, while anticipating symptoms (auras and prodromes) may play a protective role. Additionally, individual characteristics, such as history of SRIs, adherence to treatment and neurological comorbidities, must be taken into account in order to determine a personal risk profile that should be combined with the evaluation of risks for each particular sport.

According to the intrinsic risks of injuries or even death, sports have been categorized into three main groups (Capovilla *et al.,* 2016) (*table 1*). Controversies remain on the risk allocation for some sports, such as boxing (for which neurology associations had proposed a general ban, although non-specific risks for PWE have been demonstrated) or shooting. Sometimes, the availability of supervision or other environmental features may be decisive for risk stratification. For example, walking outdoors rather than using indoor treadmills, or swimming in a supervised pool rather than in open water.

Counselling and recommendations: Given the extensive benefits of sport and regular exercise, the main message to be delivered is to promote PA for all epilepsy patients. Interventional studies on epilepsy patients showed that a sustained change in behaviour regarding PA was obtained through the participation in a four-week physical training program (Bjørholt *et al.,* 1990), while a program of periodic, individually tailored counselling sessions over a six-month period failed to increase the number of daily steps as a marker of PA in children (Brown *et al*., 2019).

Appropriate counselling requires detailed evaluation of both the patient's clinical risk factors and the risks inherent to the type of PA that is being proposed. According to available data and international recommendations, we provide suggestions (*table 1*) that should be carefully discussed together with the patient and his/her family. However, due to a lack of strong evidence and the fact that most of these points are based on common sense and expert consensus, controversies regarding counselling still remain. For example, some authors do not recommend Group 3 sports for PWE regardless of seizure control status (Pimentel *et al*., 2015), while others propose that they should be allowed only after a seizure-free period of 3-5 years (Smart and Lippmann, 2013). Of course, in any case, PWE should wear appropriate protective gear for each sport; helmets for cycling and riding, personal floating devices for water sports, *etc*.

Swimming deserves a particular mention because it is a prevalent and widely available practice, and the risk of drowning is increased four-fold in PWE. Results on actual risks are conflicting (Pimentel *et al*., 2015), but a conservative behaviour is recommended, including the need for constant supervision by a well-trained adult, the use of personal floating devices and avoidance of swimming in open water where rescue is particularly challenging, regardless of seizure-free status. Scuba diving is strongly discouraged.

For particular sports or activities which are not addressed here, or which may be performed in special settings, advice should be sought from a physical trainer or a specialist in sports medicine, before providing a final recommendation.

Table 1. Recommendations regarding physical activity for epilepsy patients, according to clinical status and sport-related level of risk; based on the ILAE Task Force on Sports and Epilepsy report (Capovilla *et al*., 2016).

Epilepsy: clinical status	**Activity /Sport****	**Recommendation (*always after neurological evaluation and risk/benefit assessment*)**
Acute symptomatic seizures	Group 1	Practice permitted if precipitating condition is resolved
	Group 2, 3	Need for individualized evaluation via counselling
Single, unprovoked seizure	Group 1	Practice permitted, including competitions
	Group 2, 3#	Practice permitted after 12 months of seizure freedom
Recurrent, focal aware seizures	Group 1	Practice permitted, including competitions
	Group 2	Some may be permitted (analyse individually)
	Group 3	Discouraged (if risks do not involve others, may be permitted under informed consent)
Recurrent seizures with impairment of consciousness	Group 1	Practice, including competitions, may be permitted
	Group 2	May be permitted with restrictions. Individual discussion and informed consent is recommended
	Group 3#	Strongly discouraged
Seizure-free for at least 12 months	Group 1, 2, 3#	Practice and competition may be permitted for all sports
Breakthrough seizures under antiseizure medication reduction / programmed withdrawal	Group 1	Practice permitted, including competitions
	Group 2, 3#	Not recommended until after 3 months of seizure freedom under stable conditions of treatment (e.g. previous treatment)
Seizure-free, under antiseizure medication withdrawal	Group 1	Practice permitted, including competitions
	Group 2, 3#	Not recommended after initial medication change, until 6 months of seizure freedom without antiseizure medication
****Main sports included in each risk group:**		
Group 1- without or minimal additional risk for PWE	Soccer, volleyball, basketball, football, baseball, field hockey, cricket, dancing, golf, tennis/other racquet sports, athletics not including swimming or heights, judo	
Group 2- moderate risk for PWE	Karate, most water sports, cycling, horse riding, sports on ice, combined athletics competitions such as biathlon, triathlon, etc., skating or snowboarding	
Group 3- high risk for PWE, companions and/or bystanders	Motorsports, aviation, parachuting, climbing, diving, surfing, solitary sailing, horse racing	

some authors do not recommend Group 3 sports for PWE regardless of seizure control status (Pimentel et al., 2015), while others propose that PWE are allowed after a 3-5-year seizure-free period (Smart and Lippmann, 2013).

Counselling on the risk of seizure-related death

The magnitude of the problem

PWE have a 20-24-fold increased risk of sudden death (Hesdorffer *et al*., 2011;Whitney and Donner, 2019) and an all-cause standardized mortality ratio of 1.8-4.1 compared to the general population, as identified in a review of community-based studies (Tomson *et al*., 2004).

The increased mortality in PWE can be attributed to a complex group of potential events, including severe SRIs such as head trauma or drowning, status

epilepticus, severe ASM adverse reactions, underlying aetiology, suicide, or sudden unexpected death in epilepsy patients (SUDEP) when all other causes are excluded. Being able to alert patients and caregivers on the risk of death related to seizures and help them recognize the risk factors to foster its prevention is clearly a key concept regarding counselling on safety measures in PWE. Mortality associated with SRIs has been reported to account for 1-11% of deaths in PWE, with drowning being the most frequent (Spitz, 1998; Nei and Bagla, 2007; Beghi, 2009; Bowman, *et al*., 2010). Risks and recommendations regarding severe SRIs, including drowning, are discussed above. In this section, we briefly discuss counselling issues aimed to prevent SUDEP, which is reportedly the most frequent cause of seizure-related death (Tomson *et al*., 2004;Shankar *et al*., 2017). Details on SUDEP definition and classification and the current hypotheses on underlying mechanisms have been published elsewhere (Shankar *et al*., 2017).

For SUDEP, an incidence rate of 1/1,000 person-years has been estimated for adults with epilepsy and five-fold lower for children (Harden *et al*., 2017), with an age distribution showing a peak in the 20-40-year range (Tomson *et al*., 2004; Watkins and Shankar, 2018). Similar rates in children have been recently described (Saxena *et al*., 2018), although no specific age range associated with a higher risk could be demonstrated (Hesdorffer *et al*., 2011).

Risk factors:

Non-modifiable risk factors: Male gender (OR: 1.42), epilepsy onset before 16 years (OR: 1.72) and epilepsy duration longer than 15 years (OR: 1.95) were significantly associated with an increased risk of SUDEP (Hesdorffer *et al*., 2011). Proposed factors based on the past medical history are illicit drugs or excessive alcohol consumption, cognitive impairment (either intellectual disability or cognitive decline), and certain comorbidities such as asthma and psychiatric diseases, particularly anxiety and depression, however, no conclusive evidence can be derived from the available studies.

Potentially modifiable factors:

– *Related to features of epilepsy:* "GTCS" are the seizure type usually associated with SUDEP (OR: 10) (Whitney and Donner, 2019). Patients with frequent "GTCS" are at increased risk, and a cut-off of ≥3/year was demonstrated to increase the odds of SUDEP 15-fold (Hesdorffer *et al*., 2011). Patients with predominantly nocturnal seizures would be exposed to an even higher risk (Whitney and Donner, 2019).

– *Related to epilepsy treatment and management*: pharmaco-resistance is one of the most frequently evoked risk factors for SUDEP, as demonstrated by the steady increase in odds ratio for SUDEP based on the combination of seizure frequency and antiepileptic treatment (Hesdorffer *et al*., 2011); ranging from an OR of 4.46 for one to two GTCS/year with no ASM or monotherapy, to an OR of 22.64 with at least three GTCS/year under polytherapy. However, a metanalysis did not confirm this assumption (Harden *et al*., 2017), and this remains controversial. Non-adherence, low plasma levels of ASM, sudden and frequent changes in ASM, but also not adding ASM when patients persist with uncontrolled seizures may also have a detrimental effect, although the level of evidence is low (Harden *et al*., 2017; Watkins and Shankar, 2018). On the other hand, nocturnal supervision and using nocturnal monitoring devices were shown to decrease SUDEP risk, with an OR of 0.4 and 0.1, respectively (Harden *et al*., 2017).

Thus, medical actions to decrease the risk of SUDEP include:

– optimizing treatment and maximizing seizure control, with particular emphasis on supressing or reducing, as much as possible, GTCS or focal seizures with frequent evolution to bilateral tonic-clonic seizures (Evidence Level B) (Harden *et al*., 2017);

– offering regular clinical review and frequent follow-up visits in patients with uncontrolled epilepsy;

– exploring relevant comorbidities and treating them accordingly.

Counselling and recommendations: Available guidelines for counselling on SUDEP (Harden *et al*., 2017) highlight the need for early discussion on this subject, although personal, religious and cultural factors must always be taken into account to achieve effective communication. In general, it is recommended to inform patients, carers and families at the first consultation for a single seizure, on the risks of injuries of varying severity associated with seizures. The risk of SUDEP should then be discussed, at least when the diagnosis of an epilepsy type or aetiology provides more accurate prognostic information.

Counselling on SUDEP (Harden *et al*., 2017; Watkins and Shankar, 2018;Whitney and Donner, 2019) should include:

– a discussion on the risk of SUDEP with patients/carers, particularly for those cases at higher risk (Collazo and Tatum, 2016). In lower-risk cases, a more individualized approach may be assumed, and timing or strategies may vary considering particular idiosyncrasies;

– empowerment of patients to identify their own individual risks using different tools, such as EpSMon (Newman *et al*., 2016);

– chronic monitoring, and particularly nocturnal monitoring, using different tools, which have been

proposed as an additional measure to help decrease the risk of SUDEP. In patients with predominantly nocturnal GTCS, either direct or indirect (remote) supervision during the night is recommended, according to psychosocial and family characteristics (Evidence Level C) (Whitney and Donner, 2019);
– seizure detection tools that vary from audio monitoring systems to new devices which detect physiological events (Watkins and Shankar, 2018); although there is current and increasing research on the topic, conclusive evidence is still lacking (Rugg-Gunn, 2019). Balanced counselling on the availability and usefulness of these devices for supervision and monitoring of PWE, particularly during the night, should therefore be provided. This must include a discussion on the limitations related to both sensitivity (detection is not granted for all seizures/events) and reliability (false alarms) (Hamerle *et al*., 2018);
– support to the parents regarding their decision on nocturnal monitoring systems;
– reinforcement of the relevance of adherence to treatment (regular schedules, avoidance of missing pills, *etc*.);
– stimulation of a healthy lifestyle, with particular emphasis on sleep habits and avoidance of excessive alcohol intake;
– avoidance of the prone position during sleep in patients with GTCS, as most patients with SUDEP during night sleep were found in the prone position, a finding that has been recurrently mentioned in the literature (Liebenthal *et al*., 2015; Collazo and Tatum, 2016). However, there is no conclusive evidence of the prone position as a risk factor for SUDEP, as this would be the terminal position by the end of the seizure, and not necessarily the sleeping position before the seizure (Ryvlin *et al*., 2013). Moreover, as a recommendation, this would not be easy to monitor. Instead, instructing carers to stimulate the patient (tactile, auditory) early during the postictal period, and rolling him/her to a safe lateral position could prevent SUDEP in some cases.

Assessing individual risks and delivering individually tailored counselling

With the main goal of improving the quality of life of PWE through fostering an independent, albeit safe, life, awareness on risks and prevention measures is an additional responsibility and medical challenge. Based on the available evidence, which should be periodically updated, health care providers, and particularly neurologists / epileptologists are strongly recommended to assess the risks associated with epilepsy and seizures on an individual basis. These include epilepsy duration, age, epilepsy and seizure types, antiepileptic medication, and comorbidities, and within the individual socio-cultural and economic context; all this information should be merged in order to assess the different specific situational risks.
Providing guidance and advice on risks and safety issues also requires the ability to apply available general recommendations to the individual patient. Moreover, it focuses on the need to work together with the patient in a process of shared decision making. In addition to an open discussion, different tools have been proposed and are currently being developed to aid in this process.
Tools devoted to help physicians estimate individual risks in PWE include nomograms (Jehi *et al*., 2015) and online risk calculators, while option grids (Seal *et al*., 2014) have been proposed to facilitate the patientĭs active participation, contributing to their empowerment, higher quality decision making and responsible self-management. Again, individual factors such as age, literacy and other sociocultural issues would have to be considered in order to choose the most appropriate tool to approach each topic for each particular patient (Scalia *et al*., 2019).
A *SUDEP and safety checklist* has been developed as an evidence-based tool to support individual risk assessment and ease communication. This tool is available and free in the United Kingdom and Australia. A patient-managed risk tool is currently also available as a mobile app called "EpSMon" (Epilepsy self-monitor – www.epsomon.com) that can be downloaded for free by epilepsy patients in the United Kingdom; patients can then complete an online questionnaire every three months to obtain an updated risk profile. The app also provides counselling on risk reduction as well as recommendations for the need for medical re-evaluation or additional counselling (Newman *et al*., 2016). Other mobile apps are being increasingly offered, many of which are free, and mostly designed to create a seizure, medication and events personal diary in order to improve seizure control and enhance self-management. Although not focused on risks, some of them use monitoring algorithms and alarm systems with localization data to facilitate assistance. Other tools for risk assessment and guidance in different scenarios have also been developed. For a discussion or planning of pregnancy, Option Grid may be used to check epilepsy treatments when considering pregnancy (Option Grid®, ISBN 978-0-9571887-3-0), evaluate AED withdrawal (Lamberink *et al*., 2017) or evaluate the risk of seizure recurrence after epilepsy surgery (Jehi *et al*., 2015).
After counselling, it is highly recommended to document, in the clinical chart, all suggestions and reasons given, not only to identify gaps, doubts or problems to be addressed later, but to account for legal responsibility which may be an issue related to the delivery

(or lack of it) according to legal restrictions in the community.

In the context of both big data management and precision medicine concepts, risk assessment is an area of current development, influenced by fast-evolving technologies. Taking into account environmental, cultural, religious, social and psychological factors is key to provide an individually tailored risk assessment, promoting safety as well as self-knowledge and empowerment. □

Key points

- Epilepsy patients (mostly adults) have an increased risk of injury and death, affecting nearly all domains of everyday life.
- Seizure-related injuries are usually mild and occur most frequently at home.
- Traumatic brain injury, burns and submersion events are the most feared types of injury associated with seizures, and may be life-threatening events.
- The most significant risk factor for injuries and death is the persistency and frequency of GTCS.
- In addition to optimizing treatment, counselling on safety issues for everyday activities must be delivered in the clinic.
- Discussion on risks and preventive measures for sudden unexplained death in epilepsy should be encouraged.
- An individually tailored risk assessment would provide the basis for balanced counselling on safety issues while promoting independence and quality of life.

Supplementary data.
Summary didactic slides are available on the www.epilepticdisorders.com website.

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Further reading

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TEST YOURSELF

(1) What risk factors are associated with traffic accidents in persons with epilepsy?
A. Poor treatment compliance
B. Frequent seizures
C. Alcohol consumption
D. All of the above

(2) What is true regarding the risk of burns in persons with epilepsy?
A. Children are more prone to burns than adults with epilepsy.
B. Women are more prone to burns than men and should be counselled early regarding the possibilities of prevention.
C. Burn injuries due to direct exposure to fire during a seizure currently represent the most common type of burn.
D. Seizure-related burns are almost always related to generalized tonic-clonic seizures.

(3) Which is the most frequent type of seizure-related injury?
A. Burns compromising the face and upper respiratory tract
B. Submersion events and drowning
C. Hip and ankle fractures
D. Soft tissue injuries affecting the head

(4) In which setting do seizure-related injuries most frequently occur?
A. During sports
B. At home
C. At work
D. While driving

(5) What are your recommendations for practicing soccer/basketball for a teenager with a focal, structural epilepsy and normal cognition?
A. Wait until one year of seizure freedom for a contact sport.
B. Practice the sport, but exclude competition, in order to avoid seizures triggered by stress.
C. Practice the sport, including competitions.
D. Practice the sport, including competitions, but wearing a helmet.

(6) What are your recommendations for swimming for a child with well-controlled epilepsy under medication, and moderate neurodevelopmental delay?
A. Avoid swimming, given the high risk of drowning.
B. Allow bathing in private pools only, with constant supervision by relatives in charge.
C. Allow swimming in pools with personal floating devices and constant supervision by trained personnel.
D. Allow swimming in open water, with personal floating device and supervision.

(7) Which of the following behaviours can decrease the risk of SUDEP?
A. Early stimulation in the postictal period
B. Avoiding excessive alcohol intake in the evening
C. Taking benzodiazepines before sleep
D. Following a strict medication schedule to avoid plasma level fluctuations

(8) When should the risk of death be discussed with an epilepsy patient?
A. The increased risk of death associated with epilepsy (injuries and accidents, SUDEP, suicide, aetiology) must be explained during the first consultation.
B. Risks of seizure-related injuries should be discussed early on for all patients with seizures, and SUDEP for all epilepsy patients.
C. The risk of SUDEP should be explained for every patient immediately after the first seizure-like event.
D. As this is a sensitive issue, it should be mentioned only when the patient or relative asks for information on it.

(9) What strategy is preferable for counselling epilepsy patients on epilepsy-associated risks and SUDEP?
A. Brochures and high quality, evidence-based educational material.
B. Promoting self-aid groups and counselling in pairs, with those who will better understand their fears.
C. Web-based self-management tools, to promote self-empowerment.
D. All of the above, after an individually tailored discussion with the treating physician.

Note: Reading the manuscript provides an answer to all questions. Correct answers may be accessed on the website, www.epilepticdisorders.com, under the section "The EpiCentre".