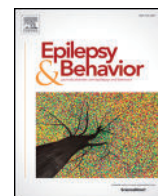




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## Epilepsy &amp; Behavior

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## Editorial

## Applying ethical principles in discussing SUDEP with patients and families

Clinicians continue to struggle with and are ambivalent about whether, how, and when to discuss the risk of sudden unexpected death in epilepsy (SUDEP) with their patients or their families. As neurologists we disclose difficult news to our patients almost daily. However, many of us feel differently when it comes to discussing SUDEP, a condition that will of course never happen to most patients, and for which the current outlook for effective prevention beyond the use of anti-seizure medication is only anecdotal, and not based on firm evidence [1]. Nevertheless, bereaved families – the real experts on the issue of counseling – have very strong views that the information about SUDEP should be discussed with every patient as early as possible, preferably by the treating neurologists; patients, parents of children with epilepsy, and advocacy groups share and endorse this opinion [2, 3]. These overwhelming views were the impetus for the development of professional guidelines in numerous countries that recommend discussing SUDEP with patients and families.

The paper by Nisbet et al. in this issue of *Epilepsy & Behavior* originates in Scotland, where in 2010 a court ruling declared that physicians counsel all patients with epilepsy on SUDEP. Consequently, even if they were not content with this practice, clinicians were now obligated to discuss SUDEP with their patients [4]. This is in contrast to Australia, where doctors are not likely to be found negligent for not discussing SUDEP [5], or other countries, where many physicians do not counsel patients on a regular basis, whether or not there are specific guidelines in place. Of course, guidelines may not be too helpful. Indeed, they are mostly lifeless documents rather than interactive processes that provide the necessary tools for how to analyze difficult clinical situations. Guidelines are often the result of a consensus exercise, and are not always evidence-based. (The late Abba Eben, for many years Israel's top diplomat, once remarked ironically: "A consensus means that everybody agrees to say collectively what no one believes individually".)

The literature implies that there is a significant discrepancy between clinicians' belief in the need to counsel patients and the reality that most of them do not follow this practice [6]. It is unclear whether this discrepancy results from inadequate analytical skills, communicative skills, or both. For example, Galli et al. reported that in their survey of clinicians in Italy, 55% of responders admitted lacking adequate communication skills to discuss SUDEP. Sadly, the authors failed to explore this problem in more detail [6]. Note, however, that both analytical and communication skills can be developed.

My colleagues and I believe that formally recognizing difficult clinical situations as ethical dilemmas, and utilizing ethical principles to address them, can be of tremendous help. Such approaches allow us to recognize opportunities for how to analyze any individual clinical situation and help us to come up with a suitable resolution [7,8]. In these publications, we have moved forward from applying the vague term

of 'art of medicine' to designate the conscious recognition and utilization of grounded ethical principles with the term '*ethical lens*'. Through ethical analysis, the clinician is able to decide which decision(s) would be ethically appropriate by comparing what is good ethical practice in this case versus other cases; in this way decisions made in similar and different cases are compared [9]. Using ethical considerations consciously also calls for trustworthiness, transparency, empathy, and humility, all of which enhance the process of communication.

Beauchamp and Childress have articulated and analyzed the most notable contemporary approach to ethical reasoning to resolve ethical questions in clinical care. The *four principles* of modern biomedical ethics are: *autonomy* (the view that each person is an individual worthy of respect and of having a voice), *beneficence* (doing good), *non-maleficence* (doing no harm) and *justice* (fairness regardless of a person's circumstances). Each of these principles is considered equally important and none trumps another [10].

Take, for example, the principle of *autonomy*. As clinician we are obliged to listen to our patients about their overwhelming wish to be informed about SUDEP. Respecting autonomy means reducing the clinicians' paternalistic attitude for the individual patient, even when we (clinicians) feel responsible to act in what we believe is the patient's best interest [11]. In fact, patients who have already read about SUDEP on the Internet greatly appreciate receiving the information in the context of their own epilepsy even if they do not initiate the discussion. Clinicians who do initiate the discussion from early on in their relationship with their patients tend to develop a more trustful relationship with their patients than those who avoid the disclosure [12].

The concern about causing anxiety unnecessarily should always be on the clinician's mind, and lead them to follow the ethical principle of *doing more good than harm*. However, the literature suggests that this potential anxiety is overrated and most patients and family cope relatively well while receiving the information. The better the clinician knows the patient's and family's narrative, including their personal culture, the more comprehensive will be the analysis of the ethical situation. Understanding the family's narratives, expectations, and concerns has always been helpful in guiding patients and families to make an appropriate management decision. "Clinicians are recommended to start from the assumption that patients and families are able to cope with the facts and reserve any potential nondisclosure to situations where harm is expected to result from telling the truth" [11]. A potential alternative would be to ask the patient and family to complete a brief measure for anxiety and depression before the first consultation, to assess their risk for fearful reactions. To my knowledge, there are no publications so far that have studied this option.

The principle of *justice* can have different facets. For example, Nisbet and colleagues [4] and others [13] reveal that clinicians tend to discuss

SUDEP to motivate patients to adhere to their anti-seizure medications. This approach is not likely to be beneficial, as experience suggests that it rarely improves adherence. One should also counsel patients that commercially-available devices that purport to be able to detect nocturnal seizures have generally not undergone rigorous testing leading to regulatory approval (with the exception of the Brain Sentinel® Seizure Monitoring and Alerting System), nor have any been shown to date to prevent SUDEP. Importantly, “a patient has the indisputable right to receive honest and comprehensive answers asked of their doctor. This includes questions related to SUDEP...” [5].

Reese and Pearl [12] also take an ethical approach in their chapter discussing SUDEP, trying to reconcile the different arguments while recognizing that the ethical dilemma is in a state of flux as new evidence becomes available (keeping in mind that little has changed in the last decade with respect to either robust evidence or clinicians' attitude [5]).

In conclusion, healthcare expertise should be an evolving process; in a rapidly changing era, we as healthcare providers must constantly build on our skills and sustain ourselves in a dynamic and relentless pursuit for improvement. As clinicians we need to devote our attention to fostering novel abilities and skills and show willingness to accept innovative ideas [14]. Analyzing how to provide SUDEP information to a particular patient and family is an acquired skill – one that can be learned, developed, and practiced. Ethical principles provide a useful framework for those of us who seek to improve their ability to analyze difficult situations, come up with a reasonable resolution, and communicate their thought process to the patient.

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