

SUDEP, was considered compliant with medication, and was not informed about her risk. There was no medical record of nonadherence, but evidence at the inquiry was presented that Erin was not picking up her prescriptions and not taking her medication as prescribed.

Had Erin been referred to an epilepsy specialist nurse service (had one existed in Bife) there is, in my view, a real possibility that she would have been provided with more advice and information, informed about the risk of SUDEP and that her seizure frequency and compliance with medication would have been monitored. She might have complied better with taking her medication. Seizures might have been eliminated. She might not have succumbed to SUDEP (Duff 2011).

Both judicial determinations from Scotland recommend that SUDEP should be discussed early on with the vast majority of patients. The judges recognized the importance of clinical discretion to withhold discussion, but the most recent determination recommends that the reason for withholding, such as serious harm to the patient or incapacity, should be recorded (Duff 2011). It is worth noting, however, that no actions for negligence have yet been reported in cases involving SUDEP deaths and, instead, systems for investigation in public interest have been activated by some families affected by SUDEP. The two aforementioned Scottish cases both led to changes in service provision. Following the 2002 Fatal Accident Inquiry, an epilepsy clinic to review patients with epilepsy was established by the general practice and the 2009 Ombudsman's Report makes reference to the creation of a new epilepsy specialist nurse post.

## ARGUMENTS FOR NONDISCLOSURE

The main arguments against disclosure are that (1) telling patients will cause anxiety for no benefit, (2) there is no research on patient wishes in this area and that patients may not want to hear about SUDEP, and (3) a clinician may be successfully sued for denying a patient "the right not to know" the risks associated with a condition.

It is understood that patients vary in personality and coping styles and therefore in their attitude to information and how they use it to navigate health issues (Andrewes et al. 1999; Politi et al. 2007). Some may not want to be involved in aspects of discussion or decision making with their health-care providers. In the SUDEP debate, those who argue for the right not to know highlight differing patient-information-seeking behavior such as active searching (seekers), conscious blocking (avoiders), and a combination of styles (weavers) (Morton et al. 2006; Pinder 1990), expressing concern that where broad requirements to discuss SUDEP with all patients are mandatory preference is therefore given to the needs of seekers above all others.

But this need not be so. Where guidelines do exist, there are options for variation. Patients' wishes are clearly highlighted in ethical literature on information giving, and clinical guidelines are always recognized as being subject to clinical discretion where there is good reason not to follow a guideline. The General Medical Council (2008) advises

doctors to provide patients with appropriate information, which should include an explanation of any risks to which they may attach significance. Doctors must not make assumptions about a patient's understanding of risk or the importance they attach to different outcomes. They should discuss these issues with their patient. A clinician who probed patient wishes on information provision would have good reason not to inform if the patients indicated that they did not want to have full information including risks of seizures; if the issue was regularly revisited; and if there was no material reason to override this, such as nonadherence to treatment. Pinder (1990) investigated information provision using Parkinson's disease as the case study. She found that clinical practice on information giving was rarely determined by an accurate assessment of what the patient wanted, but it was largely dictated by clinician's assumptions as to what patients did or did not want to know. Clinicians were broadly divided into three groups of information-giving style: Closed, open, or changing. Pinder concluded that identifying patient wishes necessitates proactive engagement by a clinician to discover what the patient wants to know, and ought to know, about their condition and its treatment. However, the medical literature suggests that many clinicians have taken specific positions on when to discuss SUDEP, such as only if a patient asks, at the time of prescribing AEDs, or only in cases with (Pinder 1990) recognized risk factors (Morton et al. 2006).

Outside the epilepsy field, there is some evidence in the literature from which to draw, including a systematic review and a meta-analysis that provide some general indication of the relationship between bad news and anxiety. The evidence suggests that anxiety is a common and adaptive initial response to an "at risk" notification, but it usually dissipates within a month (Shaw et al. 1999; Marteau 2008). Psychological theories of self-regulation describe the ways that humans maintain equilibrium while responding to threat (Taylor 1991). Clearly, fear unchecked can become negative and restrictive, but natural anxiety should not be assumed as harmful.

Some authors contributing to the SUDEP debate have put forward the argument for a patient's right not to know (Beran 2006; Black 2005), even suggesting that in some circumstances clinicians could be sued if they tell patients about SUDEP (Beran et al. 2004). Although therapeutic privilege provides a defense to the legal right to know where there is good reason that discussing SUDEP with a patient will cause harm, the concept of a legal right not to know, although recently mooted in the context of routine HIV testing and genetics, is not one that has rooted yet in any established legal concept or legal authority.

A therapeutic privilege exists in medical care to withhold information where it would cause harm to the patient. This concept is recognized by medical law as a defense to a legal action based on failure to disclose a material risk. Therapeutic privilege is normally confined to a psychiatric setting. What is clear from professional guidance and legal precedents is that therapeutic privilege does not mean unfettered discretion to decide one way or another, but instead it is conditional on a process of rational decision making. The General Medical

Council (2008) of the United Kingdom, for example, states that such information should not be withheld and that it is necessary for making decisions unless the clinician believes the patient would be caused serious harm beyond being upset or refusing treatment. Any decision to withhold information should be recorded, justified, and reviewed. The concern about the harm of raising patient anxiety is discussed regularly in the medical literature on SUDEP as the reason for not providing information. Temporary anxiety in a patient is not normally viewed by the courts or ethical bodies as being sufficient to constitute sensible medical grounds for withholding information (*Deriche v. Eastling Hospital NHS Trust* 2003). The only epilepsy-related research on this subject is a survey of neurologists, some of whom report anxiety (Morton et al. 2006). One-third of respondents thought that information about SUDEP caused anxiety; but they were not asked how they assessed this, whether they followed up to check if anxieties were lasting and whether the patient was offered or responded well to further information and support. Interestingly, doctors who discussed SUDEP with the majority of their patients were less likely to report negative reactions, suggesting, as the author recognized, a practice effect. The lack of evidence on patient harm from discussion of SUDEP was highlighted in the recent Scottish investigation. The Scottish Public Services Ombudsman (2009) declared that "much of the evidence in this area is ... at best anecdotal and any reliance on an assumption about patients' reactions must be tempered by the lack of actual hard evidence."

### SUDEP INFORMATION: WHEN AND HOW?

Epilepsy is a burden on all patients, with varied risks and impact depending on the type and control of the condition, associated comorbidity, and how each person manages their unique circumstances and treatment. The impact can be lessened, and it is now recommended practice to give advice tailored to the individual context (Stokes et al. 2004; Miller et al. 2014).

Where the decision is made to inform patients about SUDEP, the timing and method of communication continue to be points of debate with little standardization of approach and few recommendations. The question may arise in a consultation if the patient initiates the discussion, if the professional initiates the discussion, or if the consultation addresses potentially risky behavior such as poor adherence to treatment.

Should the question be answered if the patient asks? The literature on this question supports disclosure should a patient ask a question relevant to SUDEP (Beran et al. 2004; Black 2005; Morton et al. 2006; Brodie and Holmes 2008; So et al. 2009; Miller et al. 2014). However, this approach clearly places the onus of asking on patients, who may not know which questions to frame. Consequently, disclosure is likely to be restricted to those individuals who are already well informed and confident enough to seek information.

Should the question be addressed only in patients at high risk for SUDEP? It is generally agreed that SUDEP information should be provided to high-risk groups, such as those

with poorly controlled seizures, allowing them the opportunity to participate in risk assessment (So 2006; Tomson et al. 2008; Brodie and Holmes 2008). This may include screening for cardiac interventions and discussion of options for supervision (Tomson et al. 2008, 2009; Finsterer and Stollberger 2009). Where patients have epilepsy and learning difficulties, professional guidelines recommend that health professionals be aware of the higher mortality risks and discuss these with the individuals affected, and their families and/or caregivers (Stokes et al. 2004). For people with newly diagnosed or mild epilepsy, the risk may be lower, but SUDEP deaths do occur in this group as noted by the Scottish Fatal Accident Inquiries (Taylor 2002; Duff 2011). Nevertheless, the assumption has prevailed that SUDEP is a risk for only those with intractable epilepsy (Tomson et al. 2008), which, to some extent, ignores "... the larger group of individuals with better but not fully controlled epilepsy who have a lower, but nevertheless real, risk of SUDEP" (Tomson et al. 2008). In the clinical audit of epilepsy-related death in the United Kingdom, a number of SUDEP cases were recorded in patients having only rare seizures. Looking at 158 adult patients who had attended specialist care, 5% were known to have had less than one seizure per year, 3% were people noted to have had a single seizure or the first in many years, and 4% were people considered to be seizure free. It was noted that 25% of the deaths were in people whose records did not record the frequency of seizures, and 22% were in people where the records were not clear. Six percent of the patients who died were not treated with AEDs (Hanna et al. 2002).

There is general agreement that SUDEP discussion should take place if circumstances warrant this. This is particularly important with the nonadherent patient (Black 2005; Morton et al. 2006; So et al. 2009; Miller et al. 2014). The challenge is timely identification of nonadherence. Research in other chronic conditions has shown that it is often difficult for a doctor to know who will comply with treatments as prescribed and why (Wertheimer and Santella 2003; Horne 2006). Further, during the consultation patients often overestimate adherence so as not to disappoint (Horne 2006). Waiting until the patient is known to be nonadherent may be too late, or it may be impossible to change their behavior.

The report of the Fatal Accident Inquiry into the death of Erin Casey is illustrative as the clinical team considered Erin low risk and adherent to treatment. The judge found that Erin, who died only 7 months following diagnosis, did not find her medication straightforward and without any support or effective monitoring was not in fact taking it as prescribed or indeed picking up her repeat prescriptions. She did not give any indication in appointments that she was failing to adhere to her medication regime but did express concerns about tiredness and weight gain and interaction with the contraceptive pill leading to a reduction in dose. The judge concluded there was a real possibility that had Erin been told about the risk of SUDEP she would have managed her condition differently. He recommended that the vast majority of people with epilepsy should be advised of the risk of SUDEP on or shortly after diagnosis unless a particular patient is judged to be at risk of serious harm by the provision of such information.

It may underline the need to comply with the regime of medication and it may reinforce the merit in adopting modes of lifestyle which could reduce the risk of seizure and therefore of succumbing to SUDEP. Finally it would give the clinician, the patient and their family the opportunity to consider issues of night supervision, the use of seizure alarms and the practice of resuscitation techniques all of which, on the evidence which I accepted, might reduce the risk of SUDEP (Duff 2011).

With evidence that maintenance of a stable AED regimen might reduce risk, it would be timely for discussion about risks and benefits of treatment to include the small risk of fatality from a seizure (Cook 2005; Faught et al. 2008; Tomson et al. 2008; Hughes 2009). In the words of a person with epilepsy, "for many, the decision to take medication is a huge one. If they are not aware of the dangers of seizures as well as the side-effects of medication I do not feel that their decisions are truly informed" (Kearton 2005).

### ADHERENCE, SELF-MANAGEMENT, AND SHARED DECISIONS

Nonadherence to prescribed medication regimens in epilepsy is associated with a more than threefold increased risk of mortality (Faught et al. 2008). However, the issue of adherence is not straightforward (Wertheimer and Santella 2003; Horne 2006; Chapman et al. 2014). When attempting to address this problem, it must be remembered that nonadherence is a variable and dynamic behavior and patients may not necessarily be consistently adherent or not adherent.

A guideline for the United Kingdom on shared decision making and medicines adherence suggests that medicine taking is "... a complex human behaviour ..." and that unwanted and unused medicines "... reflect inadequate communication between professionals and patients ..." (Nunes et al. 2009). Health professionals working with epilepsy patients recognize the complexities of risk communication and adherence reflected in a recurring troubling scenario, aspects of which are reflected in the stories of David, Celine, and Peter presented in *Sudden Unexpected Death in Epilepsy: A Global Conversation* (Chapman et al. 2005). A young person dies, and discussions with family and friends reveal the picture of a vibrant individual who did not want to have epilepsy. Seizures were embarrassing and a nuisance, but they believed coping well meant not to fuss and friends were told not to worry. It appears that their doctors may have considered them to be well controlled, adherent, and adequately informed patients. However, these patients and their families did not realize that epilepsy could be fatal and the bereaved families often indicate that adherence was likely to have been spasmodic. Frequently, bereaved families believe that the young adults would have handled their epilepsy differently if they had really understood the risks of their condition, and this possibility continues to haunt them. Driving, employment, and the adverse effects of medication are all issues for young people to navigate. They balance their lives with their epilepsy as they believe best. However, some coping and

self-management styles, while apparently successful, if not adequately informed, may in fact lead to vulnerability.

Self-management of epilepsy (how people live with the condition) is a complex activity that can be measured by exploring various domains including control of seizures, provision and use of information, use of medicines, staying safe, and lifestyle (Dilorio et al. 1994). A study of adherence and self-management showed an association between non-adherence and low self-management scores. Patients at risk through low self-management scores were those people in employment, those living with others, and those with a high level of education (Smithson et al. 2012).

Research across chronic conditions has consistently found that lack of adherence is associated with patients' doubts about their need for medication and concerns about side effects (Horne 2006). Patients with asthma, for example, were significantly more likely to endorse the need for regular medication if they shared the "medical view" of asthma as an "acute or chronic condition" with potentially serious consequences. If, on the other hand, patients saw their condition as chronic only, they were more likely to doubt the need for regular medication. The implications for asthma treatment were that it is not sufficient to advise a patient to take medication but that a clear rationale is needed. A medicines Necessity Concerns Framework has been developed, and this postulates that adherence to treatments is the interplay between patients' belief in their personal need for treatment and their concerns about potential adverse consequences of treatment. Nonadherence is increased when patients express high concerns and low necessity (Horne et al. 2013). This framework was applied to a population with epilepsy, and it has been shown that people with strong concerns about AEDs were more likely to be nonadherent (Chapman et al. 2014).

Behavioral theory might help explain why patients who have a mind-set that seizures are benign may make poor decisions regarding the management of their condition because they are missing important information (Austin 2011). The severity of any potential harm is recognized as a key influence on health behavior and decision making (Weinstein 1999). If patients and caregivers do not appreciate that avoidance of fatality is one reason for treatment, it raises the question of whether this lack of information is significant to patient decisions about adherence and self-management. In people with epilepsy, there is some evidence that a discussion of the risks of the condition (including SUDEP) by specialist nurses can improve adherence (Lewis 2008) and that missed prescriptions are a risk factor in epilepsy death (Ridsdale et al. 2011). The risk of death following a seizure might be significant to some patients in balancing the risks and benefits of their behavior.

Some information on epilepsy routinely imparted to patients may create major disincentives for engagement with treatment. The concern over possible loss of a driver's license, or unpleasant side effects, for example, may inhibit reporting of seizures or attendance at appointments. It is logical to fully inform patients about risks soon after diagnosis when there is possibly the greatest potential to communicate the imperative of aiming for seizure freedom through



appropriate treatment and lifestyle choices. As time passes, if few seizures are experienced with no apparent harmful effects, there is the potential for patients to become blasé about seizures and more concerned about the daily inconvenience of treatment and lifestyle adaptation.

Whether an individual patient is perceived to be at high or low risk for SUDEP, his or her behavior cannot be predicted. Private decisions take place outside the consulting room. Life changes occur, and people with epilepsy will make decisions based on the framework of knowledge that they have been given, with some choices leading to fatal outcomes. For example, when a young woman unexpectedly becomes pregnant she may decide to stop her epilepsy medication without consulting any doctor. National investigations of maternal deaths consistently raise concerns that many pregnant women with epilepsy are concerned about the side effects of medication, and there are a steady number of women who die each year that appear to have stopped medication, with and without the knowledge of their medical team. The importance of preconception counseling for women with epilepsy of childbearing age is a key recommendation of the report into all maternal deaths released in the United Kingdom (Lewis 2007). Because not all pregnancies are planned, it is imperative that such information must be given at the first opportunity, with frank two-way communication underpinning true physician-patient concordance (Horne 2006) and hopefully engendering informed patient adherence.

In the United Kingdom, detailed professional guidance has been developed to mark the shift toward patients and doctors making decisions together and reflects exchange of information between patients and doctors as being central to decision making (Nunes et al. 2009). This should include information on diagnosis, prognosis, and uncertainties, plus information on the potential benefits, risks, and burdens of treatment and of not treating (General Medical Council 2008).

Focusing on comprehensive epilepsy education as the framework for SUDEP discussions is a positive recommendation (So 2009), although models and evaluation of such programs have been limited (Institute of Medicine 2012). Fortunately, in recent years the Managing Epilepsy Well network of the CDC (<http://www.cdc.gov/epilepsy/>) in the United States has begun to provide leadership in the development and testing of innovative self-management programs.

## CONCLUSION

The cause of SUDEP is yet to be discovered; however, the identification of certain risk factors now provides a platform for preventative action. Strong campaigns by community-based epilepsy organizations have increased awareness of epilepsy-related risk in people with epilepsy, the broader community, health and forensic professionals, and policy makers. Guidelines in some countries now address the need for improved patient education regarding risk management as well as high-quality medical management. Unfortunately, many countries are yet to be influenced by these developments, so the future goal must be the development of global strategies through international

networking. Scientific research into SUDEP is increasing, and the establishment of international epilepsy-related death registers will gradually bring together important data to assist in demystifying this tragic phenomenon.

For many years, there has been reluctance by some health professionals to talk openly about SUDEP. However, the weight of opinion is shifting to full disclosure. A call for openness on SUDEP, encouraging early discussion of risk, was backed by an international expert panel and 14 international epilepsy organizations at the 30th International Epilepsy Congress in Montreal during 2013 ([www.sudep.org/article/sudepactionleadscallforopenness2013](http://www.sudep.org/article/sudepactionleadscallforopenness2013)).

In response to calls for disclosure and discussion, many health professionals are unsure of how to respond. This suggests that the philosophy of self-management and informed decision making have not been universally adopted into epilepsy care. If this framework was in place, it would be a short and self-evident step to include SUDEP in usual risk communication. Consequently, the SUDEP debate has injected some urgency into the discussion on how epilepsy education generally should take place, something which is long overdue (Prinjha et al. 2005).

Risk assessment and communication should not stand alone from the general epilepsy information that is integral to patient decision making. We would therefore endorse the vision for optimal education in epilepsy as a foundation for patient self-management recently put forward by the Institute of Medicine.

People who are informed, supported and actively engaged in productive interactions with "prepared, proactive, practice teams" (Wagner et al. 2005) should be at the center of a health care system that is designed to provide access to high-quality epilepsy care. To be consistent with this broad framework for the delivery of health care, appropriate educational programs and resources ought to be readily available to ensure that people with epilepsy (and their families and care-givers) are knowledgeable about the condition and have the requisite skills to engage in productive interactions with their health care team (Institute of Medicine 2012).

With this knowledge, the patient is better able to manage their condition and make informed choices about medicines and personal safety.

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