

EPILEPSY PATIENTS AND THEIR FAMILIES SHOULD ROUTINELY BE TOLD ABOUT THE RISK OF SUDEP- NO: NOT ALL

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A diagnosis of epilepsy to this day carries with it stigma, impacts quality of life, and induces anxiety and fear due to the uncertainty of when the next event could occur. However it is broadly possible to divide patients into two categories those who will be reasonably controlled with one or two medicines (60-70%). And the other 30 % who will not be controlled despite two or more medicines.

Then ensues the possibility of sudden unexplained death in epilepsy (SUDEP) - This entity is not uncommon and patients are detected to have had the same if they are seen to be missing on follow-up. There are several mechanisms which have been proposed for the same. From patient management point of view the question then arises :

Should patients or their caregivers be told of the risk of SUDEP?

There appear to be two considerations. On the one hand, the probability of death is unpredictable and cannot be definitely foretold in one given patient and that many patients and families will worry unnecessarily if they are told about this being one of the outcomes and this itself may impact the quality of life. On the other hand, there are certain risk factors for SUDEP especially when seizures are frequent, of long duration, intractable seizures, greater number of AEDs , sub therapeutic AED levels, generalized tonic-clonic seizures, a young age, male gender, coexisting neurologic deficits, poor compliance with medications etc. As the putative risk factors are know the preventable of these factors - like medication compliance, supervised sleeping arrangements, alarms in case of movements or seizures and aiming towards seizure control by early epilepsy surgery in surgically remediable syndromes should be thought of as preventive measures. The question of discussing the risks of SUDEP presents us with medical, ethical, and possibly legal, implications. If as a clinician we believe after careful consideration that there is a 60 to 70 % chance of being seizure free with so little a risk is it worthwhile scaring the patient unnecessarily ? There are many risks we as individuals face like when crossing the street, or driving independently for the first time after learning driving- these could be lethal but would one be frightened and not do any of these activities at all and get paranoid and anxious over these. However when the patient presents with a profile of high risks it would be worthwhile talking to the patient and caregiver about outcomes and precautions.

There are also very few studies with a high level of evidence that any of these would make a difference and be harmless for the patients quality of life. There is no right or wrong answer each situation be dealt with individually according to perceived risk . A scoring system for the same would be helpful. This then goes to say that talking to all our patients regarding compliance and good seizure control is of paramount importance and as such all patients with epilepsy should be cared for more closely and avoid high risk situations and circumstances.

References:

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