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# Communication and Mental Preparation Issues for the Epilepsy Surgery Patient

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**ABSTRACT:** This paper reviews the importance of adequate communication between the treatment team and the patient and family in epilepsy surgery. Ensuring that patient and family adequately understand the diagnosis, natural history, management alternatives and the risks and outcomes of surgery is a challenge for each epilepsy team. Guidelines as to process and content from the authors' experience and the participants in the workshop are presented.

**RÉSUMÉ:** La communication et la préparation mentale des patients qui doivent subir une chirurgie pour l'épilepsie. Cet article revoit l'importance d'une communication adéquate entre l'équipe soignante et le patient et sa famille dans la chirurgie de l'épilepsie. C'est un défi pour chaque équipe traitant des patients épileptiques, que d'assurer que le patient et sa famille comprennent adéquatement le diagnostic, l'histoire naturelle, les alternatives de traitement et les risques et les résultats de la chirurgie. Des lignes directrices quant au processus et au contenu à partir de l'expérience de l'auteur et des participants à l'atelier de travail sont présentées.

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Communication issues and mental preparation for a patient undergoing surgical intervention for epilepsy are very important. This process must include the patient and their support group of family and friends. There are many general issues of living with epilepsy and specific concerns that arise or are brought into focus at the time of presurgical evaluations for epilepsy treatment.

We present an account of our approach to communication issues in this clinical situation emphasizing practical considerations found useful in the authors' experience and incorporating information from participants at the temporal lobe epilepsy workshop. More detailed considerations of ethical aspects have been presented by Schwager et al.<sup>1</sup> Very useful discussion of patient expectations and related communications is contained in the work of Taylor et al.,<sup>2</sup> and Andermann.<sup>3</sup>

Epilepsy differs from a number of other disorders coming to neurosurgical treatment inasmuch as most patients have experienced disabling seizures for a very significant length of time. Thus it is usually a patient with a chronic illness who is entering an epilepsy unit for consideration of surgery. As a result, the patient and family are experienced with respect to the disabilities involved. The role of the treatment team is thus to explain and explore with the patient and family the relative importance of seizure type, frequency, associated neuropsychological deficits, and the psychosocial consequences of their disease.

To communicate effectively about the surgical options, the treatment team must ensure that the patient understands a number of features of his or her illness. These include: 1) the diagnosis of epilepsy in as much detail as can be usefully assimilated; 2) the natural history and prognosis of the patient's

epileptic condition and its medical management; 3) the nature of surgical treatment(s); 4) the risks common to any surgical treatment and those specific to the proposed diagnostic or surgical procedure; 5) the limitations of surgical treatment; 6) the results expected and; 7) the psychosocial outcomes. It is our experience that surgical consultation at a reasonably early stage of presurgical evaluation, focusing on risk and morbidity versus outcome, clarifies needs and realistic expectations.

The framework for communication will vary from center to center depending on local patterns of expertise and interest and the patient and family needs and competencies. It is preferable to educate generally prior to the presurgical workup and add specific information as it is collected. For this patient population, repetition and gradual introduction of concepts and information appears to work best. Inadequate communication, i.e. poor understanding of risks, benefits and outcomes and unrealistic expectations, may be avoided by consistent, clear statements and communication between team members and the patient and family at each stage.

It is our practice to make several statements to the patient and family before consent to surgery is accepted. These serve to test the patient's resolve and understanding. The types of statements used include: 1) "If you can live with your seizures and they are

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really not interfering with your life, then you should not consider having an operation"; 2) "The surgery is for seizures, it does not change any other problems you may have unless they are related to seizure occurrence"; 3) "This surgery is elective and can be done now or in the future; not doing surgery is an option"; 4) "If you are considering this operation with the view that there is a guarantee that your seizures will be abolished (or your memory or other deficits improved, et cetera), then you should not have the operation."

Some important features to review in individual patients as applicable are:

- 1) The need for invasive monitoring for localization. In this group of patients surgical implantation of electrodes for additional diagnostic information is necessary. These procedures must be explained to a well-informed patient who has a clear understanding of the complexities of the procedures and the risk and benefits. The plan after monitoring should be clearly stated to avoid any misunderstandings, e.g. "This is an operation not just a test. We could go through all this and not be able to offer you anything further."
- 2) In those patients who require awake craniotomy with cortical localization studies, very specific teaching of a surgical "timetable" for the day of operation with expectations for each stage has been found to significantly allay patient anxiety. Depending on local practice, anaesthesiologists, speech language pathologists or neuropsychologists will participate in this education. It is, however, customary and mandatory that the surgeon handle much of this communication personally to establish the type of rapport and control necessary for smooth conduct of the operative procedure. Emphasis on the continued support and communication which will occur in the operating room greatly assists patients' cooperation in these demanding procedures.
- 3) The expectations for the postoperative course should be outlined in detail. The "timetable method" will also usually clarify for the patient and family realistic expectations of pain control, wound care, discharge date, possible neurological and medication morbidities and post hospital care needs. Written schedules for early and frequent postoperative visits seem to reduce postoperative anxiety and promote rapid recovery. This group of patients are seemingly very resilient and easily kept "on track" with clear communication.

In recent years, epilepsy surgery has come more to the public forefront and the general level of information among patients is such that many patients have expectations in their own minds prior to arriving for presurgical investigation. Communication and preparation at all stages is greatly enhanced by information from reliable sources. This includes the treating neurologists who have dealt with the patients for prolonged periods prior to the investigative and surgical phases.

It is becoming increasingly important to consider the alternate and supplementary sources of information available to the patient. Many patients and their families will have diverse sources of information, both reliable and disreputable. Information they collect may be applicable to their situation or may be irrelevant or misleading. It is useful to canvass this topic at one or more points in any presurgical work up. Clear, consistent, reliable and repeated communication from the treatment team is the best avenue to combat misinformation and allay anxiety in the patient and their family.

Some patients and family benefit from discussions with other post surgical patients. The applicability of this varies widely. So long as salesmanship can be avoided by postsurgical patients, it is a useful resource to offer many patients.

Communication among professionals on the treatment team in the epilepsy centre and referring physicians and other caregivers is likewise important, both for the individual patient and family and to promote adequate expectations for the management of epilepsy patients in general. The surgical treatment of epilepsy has the advantage of a well-informed multidisciplinary team and gradual workup and decision-making system to aid and inform the communication process. Despite the complexities of the clinical problems encountered, it is usually possible to communicate adequately and significantly contribute to satisfactory outcome.

#### REFERENCES

1. Schwager H-J, Weinberg G., Kanoti G. A.: Ethical considerations in surgery of epilepsy. In: H. Lüders ed, *Epilepsy Surgery*, Raven Press 1991.
2. Taylor DC, Neville BGR, and Cross JH. New measures of outcome needed for the surgical treatment of epilepsy. *Epilepsia* 1997; 36:625-630.
3. Andermann F. Approaches to patient selection of resective procedures. In: Spencer SS & Spencer DD eds. *Surgery for Epilepsy*. Boston: Blackwell, 1991.