



## Special Communication

## Is epilepsy surgery a threat to a patient's self? A conversation

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Dear Maria,

It is with interest that I have been reading your contribution to *Literature and Medicine* [1]. You have been presenting your analysis concerning issues of epilepsy surgery as deduced from four literary depictions by people involved in concerning their or a family member's candidacy for surgical seizure treatment. Your title was eye-catching during one of my regular literature searches since it stood out of the plethora of new genes and this kind of stuff. I promptly felt the need to find out about *Disembodiment and Identity in Literary Depictions of Epilepsy Surgery*.

Most protagonists in the narrations you analyzed did not undergo brain surgery, and you focused on aspects of (dis)embodiment and identity as an integral part of these decisions and the person's experience. You have been presenting interesting arguments that "...patients manage to incorporate their epilepsy in the construction of their selfhood, [making] epilepsy surgery ... an attack to corporeal unity", as you explain. You argued, that "patients may be unaware of the extent to which epilepsy is part of their identity" and that, in case of brain surgery, "post-operative readjustment requires remarkable changes to a patient's self-concept". With respect to the physicians involved in this decision-making, you concluded that "...epilepsy surgery seems to originate from the wrong assumption that...epilepsy...can be reduced to a material, anatomical lesion" and you named that observation a "depersonalization of patients to the benefit of surgeons" [1].

As a neurologist working in epilepsy care for long years now, I warmly welcome your contribution pointing out really important aspects, which to me also seem underappreciated in clinical epilepsy care. Yes, epilepsy surgery is a threat and hazard to people, neither only to their brains (patients ask me: "Do you really cut into my brain and take a part out?"; "How large is this piece?"; "Doc, will the surgeon really touch my brain?") nor solely defined by direct risks for somatic disabilities like motor, sensory, speech or memory dysfunction (patients said to me: "Will I still be myself afterwards?", one claimed "You will cut out my emotional center, won't you...!"). Psychic, emotional, social and personal implications are deeply rooted in all aspects of this disease: the

patients and families and many doctors' views on epilepsy are very much influenced by individual as well as collective views and opinions about the brain and epilepsy, influenced by centuries [2]. "The brain", as much as "the heart", in our cultural contexts is conceived as a key element of personality, self, emotions, feeling, consciousness, awareness, being – deep down into how we talk. This is one major reason why heart and brain surgery are conceived different to other surgical procedures. In addition, seizures manifest themselves within these spheres of human being by altering these very aspects [3], making epilepsy very special, even if we can explain many phenomena better than in medieval times and before. As epileptologists, we do meet that in every day-work with seizure patients.

In addition, people with epilepsy are very different in their way experiencing the disease, coping with it, living with it. Could it be, that also those differences matter when we discuss epilepsy surgery and the way patients judge this treatment?

I would like to share some of my experiences with epilepsy surgery patients with you and further readership. Intentionally I chose the form of a letter, since this allows for a personal narrative of my experiences as an epilepsy specialist.

### 1. Outline: the principal chances of epilepsy surgery

While two thirds of epilepsy patients achieve seizure freedom by medication, one third experiences continued seizures despite medication, i.e. difficult-to-treat epilepsy. Surgical treatment offers a good overall chance for seizure freedom to those patients: About 50–60% of patients undergoing surgical treatment indeed do achieve seizure freedom, many of them in a stable long term fashion [2]. According to experience since the 1940ies and for general risk-benefit relations, temporal lobe surgery is the most frequent procedure all over the globe. This is followed by lesional surgery in various brain localizations depending on individual surgical risks. Compared to the low rates of seizure freedom of 5 to 10% by continued pharmaceutical treatment including new drugs [2,4], the chances of surgery are 5 to 10 fold higher for many difficult-to-treat patients. The key factor here is appropriate candidate selection. This, in the first place, is a matter of recognizing a pattern of medical signs and facts, to be identified by the medical professional, i.e. the epileptologist [2]: the patient shall present with *focal* (that means localization-related) epilepsy, the seizures shall *continue despite appropriate medications*, the "*focus*" is to be found and shall be "circumscribed" or "singular", and the intervention conceived must *not*

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directly produce a neurological deficit. It's a prerequisite therefore for any patient to undergo a comprehensive investigation including core methods of direct seizure observation/recording (i.e. video-EEG), EEG analysis, neuropsychological exploration and imaging, and to find what we call *concordant signs* there; this is offered in specialist centers. However, no less important is what is called the patients "psychosocial ability for epilepsy surgery", i.e. a patient as well as his/her peers shall understand and be able to stand the process of investigations as well as the treatment in all important aspects in order to reach a real informed consent, since epilepsy surgery is highly elective. Of course this is not a one way process, but rather a way patient and doctor go together - and also the doctor must show psychosocial abilities here.... Since it is difficult to predict the success for an individual patient [5], patient and doctor move into a field where success isn't guaranteed and risks are an integral part [6].

## 2. The way to epilepsy surgery and the specialist's role in it

... shall start early enough before the actual surgery, follow a multi-stage way, and needs several appointments over a longer period not only including the diagnostic steps, but talking with time, a close personal exchange between patient and doctor, getting known to each other, building up confidence, characterizing the options including pro's and con's and especially: clarifying the individual patients expectations towards treatment. Underestimating the latter can lead to major problems.

I like to tell you that concerning epilepsy surgery, initial patient positions are very variable. Some people show actively up with a targeted question for surgery, and it can be hard and disappointing to refuse it in the light of an epilepsy syndrome that cannot be treated surgically - here I sometimes feel overwhelming expectations towards salvation by surgery. Others also actively ask for a surgical cure, but don't have an idea so far, what the process is like. Sometimes the motivation is rather a wish for getting rid of the seizures anyhow in order to achieve something else, e.g. driving license, a partnership, a profession, freedom from medication, to give typical examples. Leaving the stigma is a major factor for many. "The seizures determine my life" is a repeated theme. Again others might have never thought or even heard of epilepsy surgery - here it's a particular challenge for the specialist to introduce the surgical idea to patients who are likely candidates. Patients and their relatives need very individual amounts of time to think it through, ask their questions and find their view. This discussion shall be open. Specialists shall not overburden or even force a patients towards presurgical diagnostics or surgery.

The patient is setting the pace. The patient's position is to be respected. The patient can deny. This principle shall be followed, in my view, even with the most promising constellation pro surgery in the doctor's eyes.

It is valuable here to ask questions like that: Why do you aim for surgery? What do you wish for? What are your plans? Depending on the answers, there can be a need to slow down a patient, to explain that this treatment is not able to fulfill a particular personal wish mentioned. With the years I passed on to tell my patients, even the seemingly best candidates, also in advanced stages of investigations: You don't need to do it. Epilepsy surgery is not "a must", nothing I "recommend". Indeed, I feel that professionals shall avoid using terms like "surgery is highly recommended" also in formal medical documents. I'd prefer to explain: You can choose it based on our findings pointing towards a favorable effect given that your risks are low. Success is not guaranteed and the risks are not zero, and it's you who's facing this choice. This for a patient is a little bit like passing through *Skylla* and *Charybdis*. Moreover I ask: Imagine the situation that you undergo the surgery but you will have a complication with disabling symptoms... imagine that seizures recur after surgery... what would this mean to you? Could you live on? Ask all your questions, sleep it over, and only go for it if you feel quite well about it. And: Don't do it mainly for others also (not for the family, not for the partner, not for the doctor!). We, the professional team, are

asked to introduce our patients to this world, to counsel any patient very elaborate on an individual basis, discussing their questions, prepare them well and accompany them as humans [7]. I'm convinced that a systemic approach to the situation is helpful. It's not only worth but necessary knowing how the patient is like, how he lives, and what his or her life has been like so far [8]. I'm quite convinced that an approach taking into account these personal systemic aspects can help diminishing the occurrence of the phenomena you mentioned (further referred to below).

Having spoken about "good candidates" so far, it's necessary to mention that accepting being no candidate for epilepsy surgery is also a challenge to both the patient and the doctor, too. Some patients show up with the distinct question for surgery, but simply don't have this option. In many others, the step-wise investigations will not lead to a surgical plan. There are so many scenarios where brain surgery is not a reasonable option: the seizures are not focal, the findings do not disclose the epileptogenic zone, the epileptogenic zone is not removable... then, I have to explain that this gate appears closed, but that this does not mean that they cannot expect help.

## 3. The challenges of epilepsy surgery beyond the surgical act

"Alleviation of chronic illness is a complex psychosocial process", you say. A really classic situation faced in epilepsy surgery care indeed is, that seizure freedom after long years of pharmacoresistant seizures causes problems (by the way: this is independent of the way achieved). Patients here not rarely show striking difficulties to cope with the new situation. I have seen patients just helpless what to do now, i.e. the "burden of normality" you mentioned. One man in a personal letter to our team explained: "The seizures for that long have been an integral part of my life...it feels strange to me that their gone". Sometimes it's pressure from outside, expectations towards patients to function normally now that the seizures no longer occur. I have seen relationships break and couples divorce (what at times was regarded a positive, autonomic act also...); and sometimes patients are simply deeply unhappy albeit seizure free, the latter most often when personal expectations targeted on very different issues than seizure freedom [9].

To me, it's not so much most patients plan to "restore the former life" (your "status quo ante"). They rather wish to proceed no longer restricted by the impact the seizures have on their lives. I do like the view promoted by the German epileptologist Dieter Janz in the tradition of Viktor von Weizsäcker, that healing or cure does not mean to reconstitute a patient - in contrast, a patient indeed will not be the same as he was before "after" a disease or therapeutic intervention [10]. Most of them have lived with epilepsy for 10-20 years starting in childhood to adolescence. The average duration of epilepsy before surgery is >20 years all over the globe [20]! This is 20 core years between 10 and 20 to 30-50 years of age accompanied by difficulties, restrictions, and stigma. Important to say that a significant part of restrictions is based on wrong assumptions and incorrect medical counseling. So it's us again, that sometimes aggravate the stigma by recommending to avoid sleep deprivation, drinking alcohol, attending sports, going to cinema or other advices.

Could it be that patients perform your *integration of seizures into the construction of their selfhood* in different ways and to various degrees, and that these differences play major roles for individual risks of psychopathology with or without epilepsy surgery? Who's more in danger, the patient aware or unaware of this intrapersonal process? How could we recognize that?

It's certainly a fundamental need to talk about and clarify the subjective feelings, judgements, and expectations people have about their epilepsy and their treatment and how they actually live and have lived with it. This in sum, according to David C Taylor, is the patient's *predicament* [8]. I feel that the accounts presented by you can teach us much about people with seizures in general especially that we shall explore

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