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Disembodiment and Identity in Literary Depictions of Epilepsy Surgery

Maria Vaccarella

If Dostoevsky had been given the option of treatment, she thought, would he have taken it? *Should* he have?

—Mark Salzman, *Lying Awake*¹

Surgery for otherwise intractable forms of epilepsy has developed greatly over the past century, but only in recent times have researchers highlighted the often discouraging psychosocial implications of this treatment option.² This article analyzes four contemporary European book-length accounts of the experience of being an epilepsy surgery candidate. Laura Doermer's *Moritz mein Sohn* (Moritz my son, 1990), David B.'s *L'ascension du haut mal* (The ascent of the high evil, 1996; published in English as *Epileptic*, 2003), Ray Robinson's *Electricity* (2006), and Alberto Capitta's *Il giardino non esiste* (The garden doesn't exist, 2009) are diverse in style and content, yet they all seem to respond to Salzman's dilemma in the epigraph. Far from being presented as a long-awaited remedy, epilepsy surgery is resisted and finally *de facto* excluded from these four texts—a narrative choice that calls for investigation. Building upon Julia Doyle and Katrina Roen's suggestion that "surgery always involves the (re)negotiation and (re)inscription of embodiment and subjectivity," I will first examine how these four texts narrativize the challenges that epilepsy surgery poses to patients' embodied identity, in order to outline the difficulty in voicing hesitation before surgical treatment in societal and literary contexts.³ I will then argue that the encounter of critical disability studies with the work of French poststructuralists Gilles Deleuze and Félix Guattari will help us make better sense of the impact that the postsurgical alleviation of chronic illness can have on patients, carers, and on their narrative (re)constructions. Finally, I will suggest that, from a narratological

point of view, the rejection of the teleological therapeutic plot in these four texts points in the direction of a positive reevaluation of Arthur Frank's "chaos narrative," arguably the most malleable of current illness narrative templates.⁴

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So, would Dostoevsky have refused treatment for his epilepsy? A much-quoted extract from his autobiographical novel *The Idiot* (1868) could provide us with a satisfactory answer: "What if it is a disease?" he decided at last. "What does it matter that it is an abnormal intensity, if the result, if the instant of sensation, remembered and analyzed afterwards in health, turns out to be the acme of harmony and beauty, and gives a feeling, unknown and undivined till then, of completeness, of proportion, of reconciliation, and of startled prayerful merging with the highest synthesis of life?"⁵ This extract brilliantly captures the tension in epilepsy between a unique illness-generated mindfulness and its social dismissal. The protagonist Prince Myshkin reflects here on the pathological origin of his heightened perception during the pre-ictal status and challenges the reader into a negotiation between a scientifically constructed, socially stigmatized abnormality and what is for him an irreplaceable, enriching experience.

With this canonical text in mind, it will be easier to understand how narratives that turn on the possibility of epilepsy surgery often voice a concern over identity loss vis-à-vis the prospect of seizure reduction or cessation. Alleviation of chronic illness is a complex psychosocial process, still significantly understudied in comparison to the opposite process of adjusting to disability. However, a brief survey of current research on the topic will provide helpful clinical and cultural context for the narratives I am going to discuss. In the case of a much stigmatized and limiting condition such as epilepsy, patients might perceive surgery as what neuropsychologist Sarah Wilson and her co-authors call "a gateway to a new life," that is "the life that should have been, were it not for epilepsy."⁶ From a narratological point of view, these very high expectations fit with Arthur Frank's category of prospective restitution stories, an anticipated celebration of applied science and institutionalized medicine that will warrant patients "a return . . . to the status quo ante" and assuage preoperative uncertainty.⁷ Surgery failure or partial success prevents the ultimate construction of these narratives and increases postoperative psychological distress.⁸

Similarly, the myth of rebirth that, according to Anne Hunsaker Hawkins, informs so many pathographies is evoked here only to be contested in another stream of epilepsy surgery research, which has revealed patients' paradoxical difficulty in readjusting to seizure reduction, and even seizure cessation, in a situation that has been termed "sudden health" or "the burden of normality."⁹ A recent study found that 66% of patients who achieved seizure freedom after surgery developed *de novo* psychopathologies.¹⁰ Patients may indeed be unaware of the extent to which epilepsy is part of their identity and can find themselves unprepared to face the new opportunities and responsibilities created by successful surgery. Postoperative readjustment requires remarkable changes to a patient's self-concept, in a veritable process of what Wilson calls "identity reconceptualization."¹¹ For example, if patients had constructed their self-esteem on the basis of their effort at coping with epilepsy, sudden recovery may be accompanied by a sense of grief for their lost impairment; whereas other patients may risk overload and exhaustion in their attempt to conform to their suddenly expected "normality."¹² We could sum up these results by quoting psychiatrist David C. Taylor, who wrote that "being sick is one manner of being. That may not change by removing an epilepsy focus."¹³

From the above it is clear that, despite the drawbacks of their condition, many patients manage to incorporate their epilepsy in the construction of their selfhood: the surgical removal of their epilepsy focus is perceived as no less threatening than any other attack to their corporeal unity. Though this reflection can possibly be extended to other chronic conditions and disabilities, the clinical and cultural localization of epilepsy in the brain further complicates matters: "lying somewhere within the disputed margins between disability and illness, mental illness and disability," epilepsy constantly spurs reconsiderations of Western mind-body dualism.¹⁴ The affirmative synthesis of body and mind in epilepsy (though the first might be convulsive and the latter fragmented) runs parallel to recent philosophical moves beyond the mind-body distinction. For this reason, I will draw on a number of Deleuze and Guattari's concepts to illuminate the alternative mind-body interrelationships that epilepsy narratives evoke vis-à-vis surgical (and existential) lacerations.

In the four texts I analyze, the localization that presupposes surgery seems to disrupt patients' and carers' ideas of epilepsy and corporeal unity. Epilepsy permeates the patient's body and identity; it is inextricable from the self to the point that its scrutability and "removal"

in the operating theater instills a preemptive fear of disembodiment in patients and carers alike, in line with Margrit Shildrick's contention that "the corporeal cut [is] a decisive break in the materiality of embodiment."¹⁵ A brief reflection on embodiment and disembodiment in epilepsy is in order here. Doctors and patients often move from different epistemological approaches to the issue of embodiment in epilepsy. A good example is to be found in neurosurgeon Katrina S. Firlirk's memoir *Another Day in the Frontal Lobe* (2006), when she explains: "Epilepsy surgery is the purest form of brain surgery. By that I mean that you're actually operating on the brain itself, not around the brain, not underneath it, or through it, as is otherwise often the case. In epilepsy, there is something wrong with the substance of the brain, usually an area of the cortex, and in surgical candidates we have to try to fix it, by finding and removing the abnormal region."¹⁶ In contrast to the ancient myths of the falling sickness or the sacred disease that hinged on the concept of either demonic or divine possession, a much less esoteric epilepsy is here reduced—under the trained neurosurgeon's gaze—to a visible and locatable brain abnormality.¹⁷ This cerebral lesion corresponds to what Foucault terms "derived, complex figures by means of which the essence of the disease, with its structure of a picture, is articulated upon the thick, dense volume of the organism and becomes *embodied* within it."¹⁸

In the preparatory stages of surgery, this is an initial instance of the biomedical penetration of the body: in modern medicine, right from the moment of diagnosis, doctors impose their own vision of the disease onto their patients' bodies to the point of metaphorically forcing their own calculations underneath the surface of the patients' skin. It becomes thus apparent that embodiment acquires two different meanings in doctors' and patients' perceptions of the same disease, a distinction Foucault himself points to when he highlights patients' non-spatial and non-temporal sense of embodiment: "What communicates the essential 'body' of the disease to the real body of the patient are not . . . the points of localization, nor the effects of duration, but, rather, the quality."¹⁹ Once again, from the patient's point of view, epilepsy surgery seems to originate from the wrong assumption, i.e. that a chronic condition with an often significant impact on cognition, memory, and identity such as epilepsy can be reduced to a material, anatomical lesion.

In other words, what the surgeon perceives as an exploration and manipulation of the substance of the brain, the patient understands as an unpleasant disembodying incursion into the self. It is worth

emphasizing here that, following Katherine Young, in this article I understand “disembodiment” not as a flight from the self, but as a dislodgement of the self from the body. This process, which permeates doctor-patient encounters from history-taking onward, is particularly evident in surgery: “the dislocation of the self from the body is crucial to the humane practice of surgery. It ensures that surgeons do not commit trespasses against persons but perform operations on objects.”²⁰ I will later expand on how this practice feeds into the biomedical construction of the human body as organism and the implications of conceptualizing the body as such.

This depersonalization of patients to the benefit of surgeons is ultimately resisted in the four texts in this article, insofar as they do not include any description of surgical procedures, not even in Capitta’s novel, the only case where an actual operation takes place. In this sense, they all differ from what is commonly considered to be the paradigmatic brain surgery narrative, Frigyes Karinthy’s *A Journey Round My Skull* (1938). Here, the Hungarian author recounts in the first person the removal of his brain tumor in 1936 by pioneer Swedish neurosurgeon Herbert Olivecrona. An educated patient married to a neurologist, Karinthy describes the operation in favorable, realistic terms and self-fashions himself as part of the medical team: “I mustn’t lose consciousness! . . . we were really co-operating. I had to look after my side of the business, as [Olivecrona] was looking after his.”²¹ An adventurous atmosphere suffuses the text and Robinson Crusoe is often invoked as an inspiring predecessor. The shipwreck metaphor superimposed on Karinthy’s illness experience becomes most apparent in the last section, in which he addresses a newly found narratee, his Norwegian niece Nini. He thus inscribes his operation within the wider “shipwreck” of Hungary after World War I: “I might have been murdered, like so many others, but the only bones that were broken in me were those which allowed the forces of destruction to be taken from my head, and my skin to be made whole.”²² We cannot underestimate the acute nature of his cancer, which disrupts, rather than contributes to, his sense of self. Hence, his narrative ends on a hopeful note for other prospective patients: Karinthy ultimately reinforces his enchantment with neurosurgery and achieves narrative closure.

On the contrary, there is no sense of finality in the four texts under scrutiny here: the chronicity of epilepsy defies current illness narrative categorizations. At first glance, we might be tempted to categorize them either as quest stories in Frank’s scheme or rebirth automythologies in Hawkins’s model: in both cases, surgery would

be presented as a decisive turning point in the illness plot. Yet, in all four texts, these models dissolve. Here, illness is not perceived as a disruption of selfhood that triggers narration and establishes the requirement for surgery to restore it. If, as Angela Woods suggests, narrative approaches to illness rely mainly on the assumption of teleology, epilepsy surgery narratives question the belief that medical intervention will *tout court* restore patient identity and accomplish narrative closure.²³ In this sense, the patients' hesitation before surgery at the core of these texts points to an intriguing gap in current illness narrative scholarship.

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My first example, *Moritz mein Sohn* (Moritz my son, 1990), addresses epilepsy surgery in the context of Christian beliefs, thus incorporating some interesting reflections on embodiment and faith. The book is an autobiographical account of the early years of German novelist Laura Doermer's son Moritz, who has Lennox-Gastaut syndrome, a severe, usually drug-resistant form of epilepsy. After trying a combination of different drugs, surgery becomes the best treatment option for Moritz, which he will undertake in his twenties. Doermer's retrospective narration of Moritz's pre-surgery years is interrupted at times by her imaginary letters to him; the title of the book itself quotes the opening words of the first of these letters.

Doermer's first letter describes the moments after an otherwise ordinary dental treatment that in Moritz's case required general anesthetic. This preliminary, comparatively minor encounter with the scalpel functions as a *mise en abyme* of the subsequent brain surgery: on a smaller scale, this operation conjures up the same frightening scenario that will trigger Doermer's liberating, rather than cathartic, narrative process years after. She explained in a later essay that the death-like vision of her anesthetized son convinced her to bear witness to his story in writing: "at the beginning of the book there was certainly not the desire to overcome something, rather to get rid of something."²⁴ Moritz's dental procedure brings to the surface his own vulnerability, mediated by his mother-narrator, who describes him as the Crucified, emaciated and wounded in the shroud.²⁵ Christological imagery recurs in Western epilepsy narratives: Dostoevsky's *The Idiot* (1868–1869) and Elsa Morante's *History: A Novel* (1974) contain two striking examples of Christ-like figures (Prince Myshkin and Useppe,

respectively), who conflate suffering and transcendence in their daily experience of epilepsy.²⁶ What is interesting in *Moritz mein Sohn* is that the carer-narrator's perception of Moritz's unfathomable affliction as akin to Christ's passion is not engendered by his severe form of chronic illness, but by the surgical violation of the materiality of his body.

His parents are reluctant accomplices in this desecration, when they consent to brain surgery on Moritz's behalf, since his cognitive impairments prevent him from giving formal consent. Doermer explains: "[Moritz] can't say anything about this and would go along like a lamb to the slaughter, full of trust in his parents."²⁷ This Biblical reference to the binding of Isaac (*Genesis* 22:1–24) reconfigures surgery as a test of the parents' unquestioning reliance on a superior entity, a god-like neurosurgeon in this case. Doermer's only doubtful acceptance of the surgeon's power over her son's body translates into anxious fantasies over the operation: "The thought of this operation makes me shudder. They must drill a hole in your skull to reach the ill region. Nothing has God the Lord so well packed in bones as our brain. He knew for sure what he was doing, as he covered it with many layers, laid it in fluid, sealed it up with bones and also let hair grow on top to protect it from cold and solar radiation."²⁸ With horror, Doermer lists the cortex, the cerebrospinal fluid, the cranial bones and hair as ineffective shielding layers in the disembodied hands of surgeons. In her view, the brain, more than any other bodily area, is meant to be left intact: laying the brain bare and operating on it, as if it were an object, is an act of disembodiment. Moreover, the religious atmosphere of the passage reconfigures the dislodgement of her son's self from his brain as eminently hubristic: it will not merely facilitate the surgeon's work, it will defy God's will.

Doermer's apparently contradictory attitude towards her son's illness and treatment resonates with Christian approaches to health issues. Rosemarie Garland-Thomson explains the dual position of Christian doctrine in this way: reenacting Christ's sufferings leads to salvation, but at the same time a (miraculous) recovery proves God's benevolence and power.²⁹ We can better understand the role of institutionalized medicine in this context with reference to Deleuze and Guattari's dogmatic grounding of the biomedical concept of organism. In their view, doctors derive their authority from subscribing to an originally religious regulation of different body components into an organism: "*The judgment of God*, the system of the judgment of God, the theological system, is precisely the operation of He who makes an organism, an organization of organs called the organism, because He

cannot bear the [Body without Organs], because He pursues it and rips it apart so He can be first, and have the organism be first. The organism is already that, the judgment of God, from which medical doctors benefit and on which they base their power."³⁰ The restriction of human vitality under God's control gives way to biomedical manipulations—all subtended by the practice of disembodiment—along the lines of the abdication of powers we have retrieved in the binding metaphor above. It is this delimited understanding of the human body that will later spur Deleuze and Guattari's theorization of the liberated "body without organs," a horizontal rearrangement of different bodily components that serves no hierarchical or harmonious intention.

In *Moritz mein Sohn*, the exploitive conjunction of religious and biomedical aims does not convince Doermer in the end: an all-too-scientific "miracle" seems to interfere with God's project in very tangible terms, by wrecking what is inside Moritz's "well packed" skull. Despite its pervasive religious imagery, the book ultimately diverts from the template of spiritual autobiography that, according to Hawkins, is a major blueprint of pathographies.³¹

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Catholic iconography features also in French David B.'s *L'ascension du haut mal*, a memoir in graphic novel form that concerns the epilepsy of David B.'s brother Jean-Christophe and the impact it has on their family. This text oscillates between pathography and *Künstlerroman*, as the endless search for an effective treatment for Jean-Christophe's illness runs parallel to David B.'s self-reflexive comments on his formation as an illustrator. What is interesting here is that every conventional and alternative therapeutic approach gives way to a different strand of visual references in the text: for example, the main symbolic representation of epilepsy as an evil snake-dragon is modeled on similar Biblical wicked creatures and derives from the family Catholic upbringing.³² The healing potential of faith is nonetheless downplayed in comments like "Catholicism couldn't help us. God knows that your father prayed for Jean-Christophe."³³ A family pilgrimage to the holy springs of Lourdes is summed up in only five panels that depict a gray landscape with freezing water and no miraculous or inspirational sighting.³⁴

The evaluation of brain surgery for Jean-Christophe also takes place in a gloomy atmosphere of shattered hope. At the age of thirteen, he is referred to leading neurosurgeon, "Professor T.," whom

David B. portrays as a hubristic scientist, along the lines of Doermer's depiction above. Only a child at the time, David B. forms his own mental image of Professor T. on Victor Frankenstein, an easily available, cross-cultural stereotype for an uncontrolled genius.³⁵ Though retrospective, *Epileptic* contains this exact perception of epilepsy surgery as a shocking, fantastical procedure with unpredictable, possibly harmful side effects, a hint at the author's ongoing skepticism vis-à-vis the operation in his adult life. Fear and apprehension infuse the episode of pre-surgery assessment in *Epileptic*, set in an ominous hospital ward, inhabited by ghastly figures that blur into the black background of the panels.³⁶ David B. depicts Professor T. shrinking and doubling, in order to inject gas into Jean-Christophe's brain from an overelaborate piece of machinery during encephalography.³⁷

The sadistic miniature figures in this panel also bring to mind nineteenth-century medical-themed popular art, most notably the cartoon *Le mal de tête* in Honoré Daumier's series "L'imagination," in which miniature demons inflict a headache on a man by means of nails, hammers, bells and ropes.³⁸ Though a substantive iconographic analysis is beyond the scope of this article, I would still like to highlight how David B.'s skeptical attitude towards contemporary neuroimaging techniques builds upon transhistorical cartooning tropes, which have been traditionally deployed to depict societal anxieties surrounding neurological pathologies and their commonly perceived inscrutability.

The hospital panels set the atmosphere for Professor T.'s daunting list of all possible risks of surgery, which conjures up a disquieting visualization of Jean-Christophe's dismembered body and causes his mother to faint.³⁹ Once again, the body of the patient is disintegrated into object-like parts; the patient's self is dislodged from his body, as a stereotypically aloof doctor proceeds with his pre-surgery considerations. When Jean-Christophe's mother voices her concern about her son's loss of peripheral vision, Professor T. scornfully rebuffs: "Then if he wants to see something off to the side he can just turn his head!"⁴⁰

As the story progresses, it becomes increasingly evident that the neurosurgeon fashions himself as a medical hero, determined to impose upon his young patient and his family the restitution story template with a blatant emphasis on medical triumph. In one of the panels, we see him strutting on Jean-Christophe's brain, while the narrative captions reads "Jean-Christophe is the 'case.' He will allow Professor T. to perform a brilliant operation. What do the results matter so long as the surgeon cuts with elegance and precision under the admiring gaze of his assistants?"⁴¹ At this point, Jean-Christophe's disembodied brain

enlarges in the panels and becomes a mere setting for yet another of the surgeon's medical adventures.

This literalized metaphor vividly exemplifies Deleuze and Guattari's concept of "reterritorialization" as it applies to epilepsy surgery and to biomedicine more generally. In the clinic, epilepsy is often reified in the form of an abnormal brain, separate from the patient's body and life. But we can also think of epilepsy as a territory, so much so that, as we have seen in *Epileptic*, surgeons strive to localize and appropriate it. Their "reterritorialization" of epilepsy is anything but innocent: rather, it is "overcoded geometrical space" that subtends the functioning of the organism.⁴² Anatomical and physiological explanations restrict bodily expression and change: "You will be organized, you will be an organism, you will articulate your body—otherwise you're just depraved."⁴³ Or, as John Protevi glosses it: "being an 'organism' in Western capitalism means that your organs are Oedipally patterned for hetero-marriage and work."⁴⁴ It is clear, then, that the biomedical understanding of the body (i.e. all the biomedical reterritorializations of the body that make sense of it as an organism) feeds into broader socio-economic constraints. The neurosurgeon who plans to manipulate Jean-Christophe's brain so that his own desire to excel and be admired is fulfilled, regardless of his patient's postoperative health status, is just another example of hegemonic practice, which aligns surgery with other equally repressive institutions (e.g., the police) featured in the novel.⁴⁵ As Nick J. Fox clarifies, "territorialization provides an explanatory framework for how the forces of the social impinge on individuals or cultures, from the stratification of class, gender and ethnicity through to the construction of subjectivities, for instance as 'women,' 'husbands,' 'patients' and 'risk takers.'"⁴⁶

In addition, the image of the brave surgeon reclaiming diseased anatomical land resonates with a widespread medical epistemology that ultimately encourages the production of illness narratives modeled on Hawkins's battle motif: curing the illness is reconfigured as defeating an exogenous enemy.⁴⁷ This externalization of the disease results in an eventual alienation of the whole patient. Foucault describes this complex triangulation of patient, doctor, and disease: "Paradoxically, in relation to that which he is suffering from, the patient is only an external fact; the medical reading must take him into account only to place him in parentheses."⁴⁸ *Epileptic* provides us with a vivid depiction of these dynamics, especially when David B. visualizes his brother's dismembered body in Professor T.'s hands: surgical disembodiment is equated to a vicious deconstruction of the patient's identity in a

disease-centered clinical intervention. As Derrida would have it, the patient's agency is put under erasure: he is disempowered and indispensable at the same time.

Later in the story, after the family has decided against the operation, both David B. and his mother have fantastic visions in which they operate on Jean-Christophe themselves. They visualize the procedure as a science-fictional option to be performed by means of intricate oversize cables and futuristic machinery, but these fantasies have nothing of Karinthý's desire to collaborate with his surgeon. On the contrary, they epitomize the family members' frustration vis-à-vis the discovery of medicine's limits and their desperate need to understand and intervene anyhow for Jean-Christophe's sake.⁴⁹ David B. reports having similarly dreamed of resuscitating his grandfather by operating on the corpse with the aid of the latter's farming tools. Yet, these panels have nothing of the scary atmosphere of Professor T.'s episode, as if to further oppose heartening forms of manual labor—man's intervention on the soil for harvesting—and merciless physical violence by means of perplexing technology in the clinic. David B.'s and his mother's imaginary interventions can be ultimately explained as "deterritorializations" that attempt to rescue the bodies of their loved ones from biomedical prescriptiveness.

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Lily is the protagonist of British author Ray Robinson's experimental novel *Electricity*. Just like David B., though this time from a first-person perspective, she visualizes fantastic mock-surgical procedures, while evaluating temporal lobectomy to treat her epilepsy: "I imagined it went very dark in the bathroom and I took the top of my skull off. I tilted my head forward and the lights filled the room. Oranges and reds and purples. That was me in there. Me. And I was every colour of the rainbow. It was beautiful, like the Christmas lights along Blackpool seafront. . . . I looked inside my head and saw galaxies and constellations in there. I saw electric meat."⁵⁰ The emphatic repetition of the pronoun "me" suggests Lily's total identification with the abnormal, yet colorful and beautiful, electrical discharges in her brain. In contrast to her doctors, when given the possibility—albeit imaginary—of scrutinizing her own brain, Lily resists the biomedical urge to find a specific locatable lesion: she prefers to enjoy the spectacle of lights and stars produced by the electrically charged materiality of her brain. If,

according to Foucault, “the clinical gaze has the paradoxical ability to *hear a language* as soon as it *perceives a spectacle*,” then Lily subtracts the abnormal electrical activity in her brain from the interventionist surgical rhetoric it is meant to engender within the medical sphere.⁵¹ This is a pivotal instance of a shift in perception that starts from challenging the *a priori* correlation between visible manifestations of the disease and symptomatology: it parallels the novel’s larger resignification of abnormal bioelectricity as a privileged source of creativity.

At the beginning of the story, Lily leads a dispiriting and lonely life in Blackpool, in her flat with tiny pillows on the edges of furniture, rubber bed sheets, and reassuring graffiti on the walls. When she moves to London in search of her mysteriously disappeared brother, she is first presented with the possibility of a seizure-free life after surgery. The fact that in this first-person (and fictional) account the patient’s reaction is not mediated by a carer-narrator does not alter the perception of brain surgery as an inconceivable intervention that presupposes an unwelcome experience of disembodiment: “It was nagging at me, the thought of what they wanted to do. Take my skull apart, ice and slice me. Open me up and take a chunk of me away. They’ve told me the brain has no feeling. No nerves. They said it was like the brain is under anaesthetic all the time. It doesn’t make sense. This thing that causes my body so much pain—it can’t feel pain itself.”⁵² What the first-person perspective amplifies here is the mismatch of doctors’ and patients’ attitudes towards the brain: Lily rejects the notion of her brain as an insensitive organ that will yield to inspection and intervention with no consequences, thus further highlighting patients’ instinctive resistance to the violation of embodied self that we found in Doermer and David B.

Lily’s objection to surgery is later explicitly spelled out, when she admits: “I was scared that if they took my fits away, there’d be nothing left.”⁵³ In line with research results on “sudden health,” Lily is one of those patients who construct their identity around their embodied experience of epilepsy to the point that the surgical intervention will rupture rather than suture their sense of selfhood. We can better understand her perspective in light of S. Kay Toombs’s description of her experience with multiple sclerosis: “My body appears as Other-than-me in that it continually opposes and frustrates my intentions; yet I *am* my body for I cannot escape impaired embodiment.”⁵⁴

The reader is not told at the end of the novel whether or not Lily has decided to undergo surgery. She resolves to embark on another journey, this time to Ireland, in the attempt to find her father

and brother and reconstruct her family, together with her new partner Mel and her unborn child. The overlapping of spatial movement and heightened self-awareness favors an interpretation of this illness narrative in terms of Frank's quest stories or Hawkins's myth of the journey. But the classification of this undoubtedly transformative pathway as a quest or edifying journey is qualified by the fact that its ultimate double goal (displaced homecoming and recovery) is further dislocated and deferred outside of the text.

At the same time, all these literal and metaphorical movements in the novel recall Deleuze and Guattari's proposition of "nomadology" as a profitable strategy to resist fixity and escape sociocultural restrictions. As they explain, "the nomad exists only in becoming, and in interaction."⁵⁵ Fox expands this suggestion by asking "What if there were to be a nomadological refusal of the territory of 'health'" to the benefit of ever-changing self-invention?⁵⁶ In this sense, Lily's "nomadological refusal" of institutionalized medicine, homeland, and heterosexuality releases the "strange power" of her epilepsy that she had never recognized before contemplating the likelihood of a seizure-free life.⁵⁷ This new insight into her epilepsy is the first step towards becoming a "body without organs": getting rid of her seizures is ultimately not deemed necessary to Lily's self-growth in the novel. While she struggles to reconstruct her family and affirm her own identity, apparently spoiled up to that point by epilepsy, she realizes that surgery would abruptly dislodge what is actually a major constituent of her own self. She ultimately embraces what Rosemarie Garland-Thomson calls a "because-of-rather-than-in-spite-of framework" that seeks to understand disability (and chronic illness, I would add) as generative, rather than limiting.⁵⁸ The choice of the adjective "generative" is anything but accidental here, given the importance of Lily's pregnancy as a chance of renewal (that will include a new experience of her own epilepsy) at the end of the novel.

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In contrast to the previous examples, in the Italian novel *Il giardino non esiste* (The garden doesn't exist, 2009) by Alberto Capitta, the story extends as far as about twenty years after little Carmen's brain surgery. The novel alternates realistic descriptions of 1960s Sardinian middle-class life and Carmen's adventures with bizarre characters and talking animals, possibly her own pre-ictal hallucinations. The operation is

only one of the treatment options envisaged for her, but it is strongly wanted by her stepmother, who is ready to try anything in order to cure her stepdaughter's despised epilepsy as quickly as possible.

When her father describes epilepsy surgery to Carmen as a long dream, she voices her childish perplexity and fear of disembodiment in free indirect style: "Then she touched her skull, temples, forehead. Poor little head! In a while they would have cracked it up like an Easter egg. . . . You'll dream and that's that, her father had said. She would dream, then, while they would make their way along her paths and her memories would creak. . . . You'll dream. But maybe this would be the dream her father had foretold: doctors descending within her and disappearing in the vegetation of her thoughts."⁵⁹ Again, surgical intervention is linked to an undesirable violation of the self, an adverse effect that will be described at length in Carmen's postoperative thoughts: "She watched childhood flaking itself off her like a peel. . . . Yes, someone had descended within her realm but they weren't the explorers she had thought. They had dug up and burned forests, uprooted orchards, poisoned springs and destroyed burrows and shot at birds."⁶⁰

Epilepsy surgery relies here on a most unwelcome reterritorialization. Looter-surgeons have forced Carmen out of her safe playground and violently hastened her coming of age, her operation having also coincided with the most dramatic premature demise of her two little brothers in a hunting accident.⁶¹ This is the garden that does not exist anymore in the novel's title. The enchanted garden, a traditional symbol of innocence in children's literature, was sheltered in Carmen's imaginative mind.⁶² She could apparently accommodate abnormal states of consciousness within her general carefree childishness, but making sense of memory loss and other side effects of surgery poses an insurmountable challenge: "This was what she had actually dreamed of: her house being burgled, open closets, drawers inside out and objects scattered all over the place. The signs of the robbery were evident and she realized that, as soon as she started the inventory of damages. All sorts of things were missing. Her mind was a cemetery of waste, limping numbers, limbless words, blind memories."⁶³ Spatial metaphors are evoked again to depict the dislodgement of the self from the body during surgery. Carmen's brain has transformed from garden into burgled house into cemetery, marking the gradual rarefaction of her embodied cognition and the subtle insinuation of a sense of grief for her pre-surgery life. Perhaps unsurprisingly, Deleuze and Guattari recur to a similar image of deception and theft to describe

the disembodiment practice of forcing the organism structure on what would rather be a "body without organs": "The BwO howls: 'They've made me an organism! They've wrongfully folded me! They've stolen my body!'"⁶⁴

The chapter on Carmen's postoperative thoughts sets the atmosphere for the rest of the novel: a gloomier and mysterious narration, increasingly in the style of magical realism, as if Carmen's hallucinations had completely infused the narrative texture. We find here a postoperative counterpart to the fantastic visualizations that have characterized the previous three texts; again, there is nothing of the biomedical restitution plot, for life after surgery is murky and confused. Though Carmen's semantic references are far from science-fictional and definitely domestic, they fail to provide the reassurance we found in David B.'s grandfather's tools or in the Christmas lights along Blackpool seafront that Lily recalls in *Electricity*. With its initial emphasis on the curative approach and its subsequent accent on the imposed coming of age, *Il giardino non esiste* evokes a number of illness narrative plots, only to evade them all in the end. Carmen has no word in the management of her illness. She cannot apparently escape her "body with organs."

However, the narrator alerts readers to the possible delusional quality of the last section of the book: this could be "a long endless attack of [Carmen's] disease," a "dream," or the "boundless night of anesthesia."⁶⁵ Untreated epilepsy, ordinary mental activity during sleep, and drug-induced hallucinations are all plausible explanations for the irrational final chapters. This ultimate ambiguity reinforces Carmen's function as an ex-centric focalizer of the narration: in other words, we experience the story through her doubly marginalized position as a child with uncontrolled epilepsy.⁶⁶ Capitta's magic realist tone serves a common purpose of this narrative modality, which is often employed to convey the brutality of reality by means of fantastic elements.⁶⁷ Similar to *Epileptic*, childish fears and visions serve the adult's anxieties just as well: there is something unfathomable in brain surgery that escapes rationalization, hence *tout court* realistic style. More specifically, Capitta questions the ethics of an elective, maybe eventually unsuccessful, operation: what if Carmen had been given the option of exploring a "because-of-rather-than-in-spite-of framework" in her life as an adult with epilepsy? What if her operation was not in fact performed, and readers are just presented with an unpolished account of impaired cognition in the last part of the novel? As readers struggle to ascertain either the exact temporal framework of the novel's dream-like ending or the successful outcome of Carmen's operation, Capitta

invites them to reflect on the value of closure and reliability between literature and neurology.

*

These four texts elucidate how the master biomedical narrative of surgical reparation fails to accommodate the inevitable disruption of self that, regardless of its outcome, brain surgery entails.⁶⁸ What is at stake in epilepsy surgery narratives is the medical, psychological, and cultural management of the “lesional correlative” of epilepsy in the brain.⁶⁹ If, as Doyle and Roen maintain, “surgery, as a set of discourses and practices, has become central to the mediation between body and psyche in cultural understandings and individual experiences of embodied subjectivity,” this is especially true in the case of a neurological and chronic disease with a complex socio-cultural history such as epilepsy.⁷⁰ As the four texts I have analyzed show, resecting or disconnecting a visible, circumscribable brain lesion questions the whole discursive existence of a patient with epilepsy: just like history-taking and diagnosis, surgery—like all biomedical therapy—functions ultimately as a resignifying of identity. There is a constant tension between the normativizing signification of symptoms within a restitutive medical agenda and the patients’ own attempt to refract the medical gaze towards a broader perception of their identity as people with epilepsy.

In his analysis of surgeon Richard Selzer’s writing, Robert Leigh Davis highlights the coercive and normativizing potential in the straightforward equation of surgical suture and textual closure. Along similar lines, in his 1997 book on autopathographies, G. Thomas Couser highlights the unsuitability of the comic plot of overcoming adversity for many experiences of illness and disability.⁷¹ Building upon this suggestion, Rebecca Garden explains how: “Many people who are ill and disabled . . . have not only come to terms with their physiological and mental differences, they deeply value the way they have shaped their identities. . . . The narrative convention of the happy ending of recovery negatively influences not only the way those who are ill and disabled write, but also the way they experience their illness and disability.”⁷²

All four narrators in these epilepsy surgery narratives challenge the sense of finality that the operation enforces upon patients’ bodies and stories. The only actual suture we find—Carmen’s—undeniably escapes closure with the narrative disintegration of sequentiality into

a magical realist postsurgery scenario. The core problem in finding a satisfactory category of pathography for these four texts is their lack of a strong teleological drive, and this feature itself encourages us to extend the unconventional temporality we find in disability so that it includes epilepsy. As Garland-Thomson maintains, “disability demands that we all might imagine a subject without a future life trajectory perpetually managed in the present moment. In doing so, disability rescripts modernity’s, and the modern subject’s, temporal practices and understandings.”⁷³ Garland-Thomson draws attention to the “giftedness of disability” in the broader context of the counter-eugenic logic of conserving disability, which has striking similarities to the issues of identity underpinning hesitation before epilepsy surgery.⁷⁴

By implementing a “because-of-rather-than-in-spite-of” attitude, these four texts call for a cultural, rather than merely surgical, “deteritorialization” of the epileptic focus and encourage a reconceptualization of the human body as what Deleuze and Guattari describe in terms of “connection of desires, conjunction of flows, continuum of intensities.”⁷⁵ This would bring to fruition the ground-breaking potential of the “body without organs,” which we can understand, following Dan Goodley, as “a metaphorical destiny, a way out of the oppressions of (disabling) society, a cautious ‘escape’ from the brutal ordering of the organism or body or person symptomatic of current society.”⁷⁶

This could eventually favor the filing of these four texts under Frank’s definition of chaos stories, though epilepsy surgery narratives describe chaos from within, actively resisting the move outside of it that would apparently grant the retrospective stance necessary to an effective narrative process.⁷⁷ Frank himself, nonetheless, advocates a broader acceptance of chaos in the clinic and society and this is what I argue these four texts accomplish in the end.⁷⁸ They are focused neither on a stubborn disbelief in recovery nor on the indulgence of chaos *per se*: they all demonstrate to what extent the chronic fragmentation of consciousness and voice in epilepsy can be a perfectly viable way of being. This could ultimately be the giftedness of epilepsy.

NOTES

1. Salzman, 121.
2. For a concise survey of the evolution and different kinds of epilepsy surgery, see Eadie and Bladin, 217–18; and Wrench et al., 23–31.
3. Doyle and Roen, 3.

4. It might be worth recapping here how illness narratives are usually categorized. Anne Hunsaker Hawkins retraces the emergence of illness-centered narratives (or “pathographies”) in the 1950s and describes them as “a form of auto-biography or biography that describes personal experience of illness, treatment, and sometimes death. ‘What it is like to have cancer’ or ‘how I survived my heart attack’ or ‘what it means to have AIDS’” (*Reconstructing Illness*, 1). She maintains that authors convey the experience of illness by appropriating and rewriting transcultural and transhistorical myths, such as battle, journey, rebirth, healthy-mindedness, and so on. Though he rejects the medicalized term “pathography,” Arthur Frank contributes to the definition of this new genre a tripartite model: restitution, chaos, and quest narratives. While chaos narratives ultimately defy narration (as the protagonist is too absorbed in the experience of illness to imagine any progression), restitution and quest narrative both recount the process of recovery from two different perspectives. Institutionalized medicine favors restitution stories, in which illness is not deemed to be as noteworthy as the therapeutic process itself. On the contrary, in quest narratives the patient embraces the experience of illness and reworks its account into a form of ethical testimony (Frank, *Wounded Storyteller*).

5. Dostoevsky, 217.

6. Wilson et al., “Burden of Normality,” 653.

7. Frank, *Wounded Storyteller*, 90, 78.

8. Derry and Wiebe, 116–20.

9. Hawkins, *Reconstructing Illness*, 33. See also Wilson et al., “Burden of Normality”; Seaburn and Erba, 453–67; Wilson et al., “Paradoxical Results,” 13–21; Wilson et al., “Indicators of Psychosocial Adjustment,” 327–34.

10. Cleary et al., 1705–12.

11. Wilson et al., “Indicators of Psychosocial Adjustment,” 328.

12. *Ibid.*; and Wilson et al., “Burden of Normality,” 653.

13. Taylor, 15.

14. Rhodes et al., 390.

15. Shildrick, 40.

16. Firlík, 199–200.

17. See also Stirling.

18. Foucault, 9.

19. *Ibid.*, 10.

20. Young, 97.

21. Karinthý, 222. It is worth mentioning here that, in Karinthý’s text, I found one instance that seems to anticipate the fear of disembodiment that future authors will more explicitly spell out: “I made up my mind to scream at the first sign of pain, but not because I was getting impatient or frightened. . . . I should scream just to let them know I was still alive” (240).

22. *Ibid.*, 287.

23. Woods, 113–28.

24. Doermer, “Schreiben als Bewältigung,” 265 (translation mine, as are all the translations from works that have never been published in English).

25. Doermer, *Moritz mein Sohn*, 6.

26. See, among others, Knapp, 191–215; and Zlobnicki Kalay.

27. Doermer, *Moritz mein Sohn*, 15.

28. *Ibid.*, 15–16.

29. Garland-Thomson, 343.

30. Deleuze and Guattari, 176.

31. Hawkins, *Reconstructing Illness*, 32.

32. David B., “Representation of Epilepsy.”

33. David B., *Epileptic*, 219.

34. *Ibid.*, 220.

35. David B., personal communication.
36. David B., *Epileptic*, 41.
37. *Ibid.*, 40.
38. Honoré Daumier, "L'imagination."
39. David B., *Epileptic*, 42.
40. *Ibid.*
41. *Ibid.*, 43.
42. Deleuze and Guattari, 245.
43. *Ibid.*, 176–77.
44. Protevi, 260.
45. For example, see the episode of Jean-Christophe's arrest in Paris (David B., *Epileptic*, 298–99), also analyzed in Vaccarella, 70–71.
46. Fox, 353.
47. Hawkins, *Reconstructing Illness*, 61.
48. Foucault, 7.
49. David B., "Representation of Epilepsy."
50. Robinson, 240.
51. Foucault, 132.
52. Robinson, 230–31.
53. *Ibid.*, 286.
54. Toombs, 127.
55. Deleuze and Guattari, 475.
56. Fox, 355.
57. Deleuze, 66.
58. Garland-Thomson, 343.
59. Capitta, 105–6.
60. *Ibid.*, 113.
61. Though it is difficult to extricate hallucinations from actual events throughout Capitta's novel, the symbolic end of Carmen's childhood at the hands of her surgeons (metaphorically described as barbarous explorers setting fire to the forest of her thoughts) seems to find an amplified, real-life counterpart in her brothers' death. As she lies in her hospital bed, her father Romeo takes his younger children for an impromptu after-school trip to the countryside and then accidentally kills them, after mistaking their movements behind a bush for a twitching rabbit. In both cases, adults violently interrupt children's metaphorical and real lives, while resignifying a previously welcoming natural environment into the setting of tragedy.
62. Two notable examples are James M. Barrie's *Peter Pan in Kensington Gardens* (1906) and Frances H. Burnett's *The Secret Garden* (1911).
63. *Ibid.*, 116.
64. Deleuze and Guattari, 176.
65. Capitta, 256, 262, 263.
66. See Hegerfeld, 115–56.
67. See Hegerfeld, 199–233.
68. I would like to clarify that my use of surgical reparation is not to be aligned with Sedgwick's reparative reading, as it will be apparent that, on the contrary, the four texts examined here encourage a definitely paranoid reading of surgery. See Sedgwick, 123–52. For an enlightening application of reparative reading to illness narratives, please see Jurecic. Future research could investigate how new reparative readings might counterbalance current cultural depictions and theorizations of epilepsy surgery, possibly focusing on less stereotypical and more sympathetic representations of neurosurgeons.
69. Foucault, 216.
70. Doyle and Roen, 2.
71. Couser, 5.

72. Garden, 127.
73. Garland-Thomson, 353.
74. Ibid.
75. Deleuze and Guattari, 179.
76. Goodley, 260.
77. Frank, 108–9.
78. Ibid., 110–11.

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