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Anthropology & Medicine

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/canm20

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To cite this article: Leah M. Ashe (2021) From iatrogenic harm to iatrogenic violence: corruption and the end of medicine, Anthropology & Medicine, 28:2, 255-275, DOI: 10.1080/13648470.2021.1932415

To link to this article: https://doi.org/10.1080/13648470.2021.1932415



Published online: 06 Aug 2021.



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From iatrogenic harm to iatrogenic violence: corruption and the end of medicine

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ABSTRACT

This paper seizes Ivan Illich's recurring notion of corruption to reflect on medicine's immanent spiral of maleficence. For Illich, the institutionalization of any 'good' necessarily corrupts it, and the institutionalization of health and care under the tutoring hand of medicine has produced counterproductive consequences on every plane. The paper explores the nemetic character of contemporary biomedicine – whose growth in technique has meant a corresponding growth in its capacity for corruption and harm – in an autoethnographic project that apprises and names the escalation from *iatrogenic harm* to *iatrogenic violence* that the author discovered at two UK hospitals in 2014. In January, she went to the hospital for a colonoscopy; in November, she finally left, disabled and unmade. In the interim, she suffered infection, sepsis, pneumonia, cardiac arrest, and – worst of all – a factitious psychiatrizing diagnosis embedded in spiralling loops of iatrogenic harm. By reflecting critically on this experience, interlocuting personal memory and writings with doctors' inscribed notes and insights from medical anthropology, the paper elucidates an iatrogenic spiral, showing how unknowable bodies pose an insurmountable epistemic and existential challenge to medicine's technic mandate, how medicine locates and uses an 'epistemic escape valve' in the face of such challenges, and how snowballing nosocomial harm escalates into brutality and vice. The argument, in short, is that iatrogenic violence (destructive, subjective or agentic, and intentional) is the natural endpoint of iatrogenic harm (destructive but objective or systemic, and unintentional)

ARTICLE HISTORY

Received 11 April 2020 Accepted 18 May 2021

KEYWORDS

Ivan Illich; iatrogenesis; medical harm; violence; epistemic injustice; autoethnography

SUBJECT CLASSIFICATION CODES:

Medical anthropology; Science and Technology Studies

When the intensity of biomedical intervention crosses a critical threshold, clinical iatrogenesis turns from error, accident, or fault into an incurable perversion of medical practice (Illich, 1976, 14)

Introduction

Medical anthropology has recently seen a number of critical autoethnographic encounters with medical nemesis.¹ The discipline's ethnographic gaze enables it to capture particular lived realities at the same time that it locates the mechanisms and bureaucracies of political, social, and economic structures that make the particular possible. In autoethnography, centering the researcher's own experience opens depths, modes, and styles of analysis closed to the once-removed researcher. Susan Greenhalgh (2001), for example, has strengthened the discipline's productive engagement with the researcher as research subject - and as (feminist) social intervener. Her autoethnography of disastrously expert misdiagnosis (a nexus of seeming incongruence that figures centrally also in this analysis) in her struggle with chronic, debilitating pain opened a new window into the power of this special form of scholarship – the self-writing-culture² – to make important critical incisions in intellectual, public, and political spheres. Greenhalgh's work is especially noteworthy because, despite a blossoming enthusiasm for 'narrative medicine,3 little is sufficiently critical, and less still makes the analytical work of patients themselves visible. Here, I add to this promising line of scholarship, drawing autoethnographically on my own nemetic encounter with medicine to uncover and name the epistemic and social aspects of medicine that render it brutal, violative, and deadly - and especially so for persons with certain types of body, skin colour, or gender. This essay follows the critical (Boylorn and Orbe 2016) and analytic (Anderson 2006) lines of autoethnography, confronting issues of power and justice and aiming expressly to give (theoretical) insight to broader social phenomena. My goal is not to deny the inherent value, validity, and potency of the particular, nor to only lay out the sketches of theory: I also want the narrative itself, in all its layers and tangles, to 'speak' in different ways with different readers (cf. Ellis and Bochner 2006). My hope is that, like Greenhalgh's and other more recent (if not first-person) accounts (e.g., Lux 2016, Geddes 2017, Stevenson 2014, Metzl 2009, Hoberman 2012, Pollock 2012, Washington 2006, Nelson 2011), this one might pronounce, expose, and protest the brutality and vice that ordinarily lie unperturbed in medical practice and in ways that are faithful to the power of the story itself.

This special issue takes Ivan Illich, the prophet of nemetic medicine, as its cicerone, and I seize upon his notion of *corruption* – a sense of spoilage of the 'good' – to reflect on medicine's immanent spiral of maleficence. Iatrogenesis is the notion that left Illich's footprint on 1970s counterculture in relation to institutionalized, systemized medicine (Illich 1975, 1977, 1978, 1980, 1986a, 1986b, 1988, 1989, 1992, 1994, 1995, 1998, 2008).⁴ Here I explore contemporary medicine's iatrogenic identity, technic and violent, by meditating on my own experience. I write from a point of special vantage for medical anthropology: knowledge born in the profundity of violation.

My argument – which was also Illich's – is that *violence* in medicine is only the inevitable derivation of a technic medicine whose corrupted seed could hardly sprout otherwise: *iatrogenic violence is the natural endpoint of iatrogenic harm.*⁵ While institutionalized, biomedicine makes available awesome tools and techniques for resolving certain problems of certain bodies, its curative might is bounded precisely by the limits of the technical and of the particular practitioner. In all the ways and to whatever extent the world – and its will-endowed patients and doctors, its momentary configurations of infinite potentialities and actualities, its unmodeled and forever unmodellable mystery – is *not* technical, however, biomedicine discovers its limits (and often fails to recognize them as such). In theorizing medicine as iatrogenic, Illich insisted that we recognize the excisions that the institutionalization and systemization of care necessarily impart to a world that is neither essentially nor completely technical, and all the harmful effects that these excisions incite. He saw the outsourcing and 'expropriation' of care—from the personal to the institutional—as a seed of 'corruption' that grew with health's always greater 'expropriation'.⁶ Illich used *corruption* and

perversion more or less interchangeably, and it may be helpful to think of these two words together (from *corrumpere* and *pervertere*) to understand the meaning that he (and I) intend with *corruption*: a sense of spoilage, breakage, or overturning of medicine's foundational goodness. As I ascribe to medicine here an immanent spiral of maleficence and an inherit capacity – even tendency – for activated harm and violence, it is precisely this conception of medicine's corruption – and of living of, through and in it – on which I am drawing. In the text, I narrate and analyse this downward spiral. To elaborate without interrupting this intention, I have included unusually extensive footnotes, and I invite readers intrigued by one point or another to visit them (just as I invite other readers to ignore them).

Inscribing unknowable bodies

To orient this essay, I focus on two twined aspects of technic medicine that store much of its ever-increasing capacity for violence: (re)inscription and epistemic vice. When the doctor⁷ writes a medical note, a diagnosis, or a treatment order – i.e., *inscribes* his enunciation - he fixes in truth a particular narrative of fact, history, and event that reinforces the doctor's sociotechnic paradigm and weakens the credibility of any challenge to it. It is the doctor's privileged epistemic position that makes this operational, and, at the same time, this operation that reinforces the doctor's privileged position. When a doctor encounters an unknowable body or an unexplainable event, his epistemic and operational competencies are confronted by a potentially devastating confutation. By (re)inscribing the aberrant body - that whose form and presentation fail to align with social and medical expectations - and mysterious event within the strictures of his own paradigm, however, the doctor crafts a new history in which the body and the event are known, and the doctor's knowledge, authority, and expert operational capacity remains intact.⁸ This act of (re)inscription, of course, demands that the doctor suppress evidence whose existence contradicts his narrative, produce evidence whose existence justifies it, and silence the patient - the voice of the aberrant body - whose testimony refutes his. It is a mode of epistemic vice, a dishonest, oppressing orientation the doctor assumes in his project of knowing.⁹

I want to mark the distinctions between description and interpretation, and between description and inscription. The first distinction observes that medicine's technoscientific character and authority command a positivist commitment that rejects the subjectivity and interpretivity deriving from medicine's particularly situated locus of enunciation.¹⁰ The second distinction recognises the escalation of authority that lies in the passage from description (which is really the aforementioned dissembling of interpretation) to inscription that is entailed in the creation of the medical record, whose truthfulness is fixed in its recording and replication. If it is through the 'truth-games' of science that the subject gets constituted (e.g., *as sick, deviant*, or *mentally ill*), and that regimes of truth correspond to regimes of knowledge and to regimes of practice (Foucault 1982), the doctor's writing-down of a particular interpretation is no less than the production and circumscription of truth about the patient – an achievement that carries additive gravitas because of its source.

The doctor's socioepistemic power imbues his truth not only with authority but also with benevolence, rendering it apparently disinterested, impartial, and – most impressively – *good*. The doctor's expertise is not merely rational or technical; it is also moral – a quality that proves especially handy when challenges to their intention or benevolence are raised. At the same time, the doctor's truth carries illocutionary and perlocutionary consequences

of the highest order, since these pass directly to the body and to the Life of his person-patient (cf. Cover 1986). Thus the doctor not only 'writes the body' in a theoretical sense; he also writes into intelligible being *this* body, the concrete particular corresponding to *this* person, and, with directness possible for few beyond the subject herself, writes *on* this body, sometimes with all the grotesqueness that Kafka endows to his well-named *Apparat*.¹¹

The case

I have suffered from severe gastrointestinal problems for years. I was diagnosed with Crohn's disease in 2005, but the mildness of its medically visible intestinal manifestation compared with the severity of the evident material and functional problems leaves me unconvinced that this constitutes 'the full explanation' – and, worse, it leaves some doctors altogether sceptical that there exists *any* biophysical explanation at all. While the symptoms are incontrovertibly real insofar as there exist abundant productions of diarrhoea and pain, they are epistemically and practically problematic for the technique¹²-bound, repair-minded doctor since their scientifically verified mechanism is not clearly legible.¹³*Unexplainability* is an important problem for me - a former engineer professed to vows of analytic rigor and logical rationality - but it is an even greater one for the doctor,¹⁴ whose similar vows bind *him* to a social, even juridical, duty to know and to correct the malfunctioning corporal specimen¹⁵ he encounters.

In 2013, racked by the effects of 90-hour work weeks and an abusive boss, I-my-body exploded into a nine-month streak of extraordinary diarrhoea and body-levelling abdominal pain. As a skinny, athletic woman, I knew doctors to be dangerously presumptive interlocutors – I had been down that road before – and I took (and withstood) pains to avoid them. But after nine months of gruelling gastric troubles, I consigned myself to risk and sought a doctor. The first colonoscopy appointment lay six months into the future – but, the doctor kindly offered, I could 'wait in the hospital' for the first opening to arise, likely within a week. I agreed – and that decision came to transform my existence. I arrived at the hospital on January 15, 2014, in search of relief from my months-long spate of pain and diarrhoea; I left ten months later, permanently disabled, socially excommunicated, and existentially unpersoned.

Unknowable bodies, epistemic escape valves, and nosocomial snowballs

My bed was in an open ward. Although Pasteur had formalised germ theory in the mid-nineteenth century, there were few measures at this hospital, among the worst-ranked and -rated NHS hospitals in the UK, to prevent the most rudimentary of preventable problems: beds were only a few feet apart; nurses went swiftly from one sick patient to the next without washing their hands; and there was no soap in the soap dispensers, in any case. Patients, already weakened from whatever illnesses had brought them to the hospital, fell weaker still as they were confined to bed,¹⁶ nourished poorly,¹⁷ and kept sleepless by a regimen of ongoing noise, light, and blood tests.¹⁸ In short, if your neighbour, nurse, or doctor had a transmittable bacterium, you were likely to soon have it, too.¹⁹

Just as in my previous medical encounters, and tied up with system-trained biases relating to gender and race, doctors moved swiftly to confirm their default diagnosis. *Did I think I was fat? Was I trying to lose weight? Did I restrict what I ate? Vomit? Take laxatives? Run*

weekly ultra-marathons? For reasons at first unknown to me, one doctor performed an exceptionally thorough examination of my mouth: she was looking for enamel erosion, a sign of vomiting. Fortunately, discovering none, she awarded me a probational allowance of credibility.

Poor communication and coordination among doctors and departments made small problems into large ones. Doctors rotated regularly and relied on the short, scribbled notes of previous doctors. Messages, appointments, reports, blood samples, and stool specimens vanished in transit. On January 21, I was ordered to fast from 3 PM for an endoscopy the following morning. I explained to the doctors that this would be difficult for me: since childhood, it has been very difficult to go more than a few hours without eating. In my family, we called this 'food emergency', and the first question my parents asked whenever I left the house was whether I had taken a snack. Once, in another time and another place, I had to fast for (merely) twelve hours prior to a blood test and had an especially serious attack of 'food emergency' that morning. The results of the blood draw that day included one, a glucose level of 37 mg/dL (low enough to threaten loss of consciousness), that prompted an urgent message from the doctor instructing me to go immediately to the emergency room. (By that time, though, there was no need: this was a problem easily and already solved by the 'usual method' - having a snack.) The doctors at *this* hospital, however, were not concerned by my testimony: 'It's only overnight. It shouldn't be a problem'. Not surprisingly, following this hospital-obliged fast, the next morning I felt lightheaded and fainted in the shower. Worse, the exam had been delayed, indefinitely and for unknown reasons, and would not finally occur until the following morning. In short, they compelled me, a skinny woman with a (disregarded) history of hypoglycaemia, to fast for approximately 40 hours (fortunately bolstered by a small amount of IV glucose following the morning's fainting incident). Protocol ... procedure ... technique ...

From this day forward, however, I never felt the same: that ill-advised – and unsurprising ill-supported – fast was the beginning of the Greek-sensed crisis, the moment when my course of health changed decisively and permanently. Within days, I went from being an active (if abdominally pained) person who could hike up mountains to one who could not leave bed. On January 24, the results of a gastric capsule biopsy arrived with a report of multiple ulcers: '*The appearance of this severe active chronic gastritis are not in themselves specific, but would be in keeping with the patient's known Crohn's disease*', wrote the pathologist in his report. The attending doctor seemed satisfied that this was the explanatory keystone, as his notes record in Q&A style:

Stomach biopsy. In keeping with Crohn's ulcers.

[Patient's] questions:

- 1. Is low albumin caused by Crohn's? Answer: Yes: malabsorption.
- 2. How serious is it? Not seen colon and small bowel so impossible to say, but looking at her weight and stomach ulcers, it is a problem.
- 3. Does it explain feeling awful? Answer: Yes.
- 4. Does it explain oedema? Answer: Yes Albumin low.
- 5. Does it explain ascites? Answer: Yes Low albumin > oedema [illegible]
- 6. Does it explain the constipation and diarrhoea? Answer: Hard to say as have not looked at colon and small bowel.²⁰

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On January 27, the doctor recorded that I had 'been trying hard to up calorie intake' and had added two nutrition supplement shakes to my plentiful – in quantitative terms, anyway – daily diet. 'Patient advised calorie requirements need to take into account the calories lost due to malabsorption from the Crohn's'. He also recorded my 'concern at feeling very weak, and only a week ago she felt very energetic'.

On January 28, everything changed - as Yeats (1989) wrote, 'changed utterly'.

Dieticians reported smelling vomit after a big meal last night. Nurses also report hearing [Patient] vomit in the toilet after meals. Based on this information, I want to go and find out about eating disorder which up to now she has strongly refuted. On direct question if she has vomited after food, she denies it. She has been misdiagnosed as anorexic in 2010 when she went for a colonoscopy... She feels frustrated and she feels like I don't believe her. She completely refuses a psychological aspect to her body weight issue. I asked how she would feel if I asked someone to talk to her about this.

The doctor made a note to '*call the Eating Disorder Service*' the next day. Diarrhoea. The nurses had mistaken explosions of diarrhoea for an episode of bulimic vomiting. They did not need to verify their suspicion with an observation. They *knew*. A skinny woman had entered the bathroom, emitted an ugly noise, and deposited a reeking stench: there was only one rational explanation.

In one inscriptive moment, my testimonial integrity vanished, and the doctors' entire diagnostic – and interventive – trajectory changed radically and inalterably. The stomach ulcers that had only the day before explained everything now explained nothing. A new explanatory mechanism, one that could truly and satisfactorily explain everything, had seeded itself in the fertile grounds of medical knowledge-making. Mental illness has served as scientific medicine's epistemic escape valve since the birth of psychiatry, redirecting the mystery of the inexplicable into the mastery of the known and capacitating an evidence-free diagnosis whose truth emerges from the knowing of the expert knower (cf. Foucault 2008, 2006, 2002). At the same time, it offers practitioners a ready justification for their invalidation of the unknowable patient's own testimony. Now, when the technical expectation for mastery is ever greater and the epistemic charism of the doctor always more, the value and service of such an escape valve grow ever grander.

My diarrhoea was lost to sight and mind – a point that struck me with special absurdity, since doctors had twice collected faecal samples for analysis (the first, in typically confused hospital coordination, having been 'lost in transit') and so had at least two voluminous basins of material evidence testifying to a now wholly discredited story. There were more holes in the anorexic story, too, and we will see some of them in the unfolding of events. But the explanatory narrative quickly sprouted. Again, writing on January 28, the doctor recorded the cognitive advance he had achieved in just hours:

? if vomiting after meals – no evidence (hard) at present. [Patient] is adamant she wants to gain weight ... Need to continue to monitor [Patient] post meals to exclude vomiting as a cause of low body weight/lack of weight gain. [Patient] has added [nutrition shakes] to her diet ... Given her reported intake I would expect to see her gain weight.

On January 30, doctors decided to relegate the awaited colonoscopy to a later outpatient appointment and prepared paperwork for my discharge, ordering a final round of blood work first. But the moment of crisis had indeed arrived, and I spiralled swiftly downward.

Four days later, on February 3, the pending blood tests still had not been performed. I reported *'increasingly worsening mobility'* and *'weakness in [my] legs'*, needed to use the commode instead of walking to the toilet, and had another early-morning sugar crash, this time to an extraordinary low of 19.8 mg/dL. My swollen legs had swollen more and were now oozing fluid.²¹ On February 4, I began to slip in and out of consciousness, and they began to artificially feed me. At this point, the diagnosis of anorexia nervosa became unquestionable and unalterable.

The next four months were less a blur than a series of slow-motion iatrogenic catastrophes and consequences: *Isolation-requiring infection. Sepsis. Hospital-Acquired Pneumonia. Cardiac arrest.* And more. Some things were so-called accidents of the technic institution-system (and of an exemplar with particularly bad performance²²); some were the inevitable perlocutionary consequences of an inculpating diagnosis; and some were the noxious, personally mediated interweaving of the two. With every turn of the record-keeping page and every stroke of the truth-making pen, the explanatory pliability of an everywhere-useful narrative grew.²³ From here forward, every handover of the notes began in the same way, shaping the next reader's epistemic space with a truth that – having been originally written down by a colleague doctor and acritically accepted, replicated, and reinscribed by the many colleague doctors who had '*received care of the patient*' in the interim – could not now be questioned or altered:

- Summary. Severe malnourishment and electrolyte imbalances due to anorexia.
- Known Eating Disorder.
- This lady has an eating disorder...She will need Psych to review her when stable.
- FYI: longstanding issues (both psychological and physical) related to anorexia.

There are social dynamics here of corporatism and collegial deference at the same time that there is a cognitive element of epistemic vice. With each reinscription, the truth that I was anorexic – and its correlates, that I refused to eat, that I vomited, and that, when I said that I did eat and that I did not vomit, I was lying – became engraved ever deeper (cf. Luhrmann 2000).

I spiralled downward. On February 5, I was transferred to the Intensive Treatment Unit with severe sepsis and secondary bone marrow insufficiency and renal impairment; blood work indicated bacterial infection. As I became sicker, the always-rotating doctors attributed my decline to the everywhere serviceable psychiatric diagnosis rather than to infection or hospital-induced starvation. Soon they compelled a psychiatric evaluation. It produced a surprising result: the psychiatrist made his best effort but '*was unable to elicit active psychopathology… The history of presenting complaints and mental state examination was not suggestive of Anorexia Nervosa*', and there was '*no collateral information either to substantiate the diagnosis of eating disorder*'. No matter: this interrogation, like the presence of (many) other contraindicating data (such as voluminous faeces or '*big meals*') and the wholesale absence of concrete evidence in support of the diagnosis (e.g., observation of vomiting or food refusal), did nothing to unsettle the diagnosis. It was fixed.

On February 19, the hospital dietician took charge of my 'nutrition', and, knowing me to be anorexic, declared that I be exclusively force-fed²⁴('All nutrients ... need to be given via NGT [nasogastric tube], we cannot rely on oral intake') and totally immobilised ('Patient

should be told that she may NOT have physio[']), two decisions I knew were and would become ever more harmful. Several days earlier, a weekend doctor external to the knowledge-making game in which regular doctors were already entrenched had recorded my concern that I was '*not being fed enough*'; indeed, I remember being very hungry, feeling simultaneously famished and mercilessly assaulted by the force-feeding. While force-feeding did deliver an overabundant dose of pain,²⁵ it delivered less adequately in terms of energy. Knowing that I must have earlier starved myself, doctors prescribed only 1000 to 1600 daily calories, a grossly insufficient supply of daily energy and much less than I habitually ate.²⁶ It is worth noting that even scientific research concurs that force-feeding offers at best questionable therapeutic benefit for patients who are authentically anorexic and refuse to eat (e.g., Garber et al. 2016; Hale and Logomarsino 2019; Kells and Kelly-Wheeder 2016; Bachner-Melman, Laufer, and Lavi 2013). Its functional utility for people who are *able and willing* (even desiring) to eat, if it has one, is certainly not benevolent; and its proscription for use against prison hunger strikers by international human rights law at least begins to suggest its brutality.

On February 23, I pulled out the feeding tube while sleeping – it seems I could appreciate its brutality even while unconscious – and, after they had made numerous failed attempts to reinsert it, I refused to let the ward nurses and doctors continue trying (what is, as we shall see, an act of torture). They reluctantly let me eat one bowl of pureed soup – nothing more – before February 26, when a radiography opening became available and they reinserted the force-feeding tube under 'expert guidance'. That is, rather than let me eat, they starved me for three days. The tissue viability nurse inspected my worsening leg and wrote in her notes that 'this could be end of life'. On February 28, 'Dr. [X] had a frank conversation with [Patient] that she is malnourished and that the team do feel she has an eating disorder ... Patient informed has a high likelihood of dying despite maximal therapy'.

My burning, incapacitated legs were in severe pain, and I was desperate for therapy. The physical therapist recommended that, while physical therapy had been decisively excluded by the anorexia-convinced dietician, at least '*Passive Range of Motion (PROM) [was] required daily*'. Rather than helping me to perform such motions, however, she made a note to check with the nutritionist, who never approved it. On March 5, I began to vomit, and my diarrhoea – which I sometimes lay in for long stretches of time before any nurse would attend to me – worsened. On March 7, a weekend dietician who did not know me subtly acknowledged both the brutality of force-feeding and the unnecessity of it in reporting my clamouring for food: '*If patient's condition was to deteriorate [perhaps she] should be allowed to eat for quality of life*'. It is an odd thing to suggest 'allowing' for an 'anorexic'!

On March 11, I had a cardiorespiratory arrest. Nurses had deactivated the sound on my heart monitor – a seemingly noteworthy fact that was not, in fact, inscribed in the notes²⁷– and my death was not noticed until some minutes after its onset. I was without a heartbeat for more than twenty minutes after they discovered the problem. On March 14, a doctor or nurse filled out a 'short risk assessment for rehabilitation needs following critical illness', checking boxes for '*Pre-existing psychosocial impairment (i.e., mental health)*' and '*evidence of delirium, agitation, or recurrent anxiety*'; to my medication chart, he added Haloperidol.²⁸ The narrative strengthened and expanded.

Doctors continued to insist on force-feeding me long after I awoke from the post-cardiac arrest coma, despite ready evidence of its unmissably noxious effects on my body: regular soiling of the bed with diarrhoea that exceeded the faecal catheter; vomiting; ferocious

nausea; and – not a minor fact given the imputation of anorexia – my loss of twenty pounds during the hospital stay. Nurses had to change the diarrhoea-soiled bedsheets frequently; once they had to change even the mattress. Each time I saw a doctor, I begged for real food. Force-feeding is so extraordinary a violation of one's body and being that it cannot be withstood unaltered,²⁹ and I knew – this is the *cognoscere*, the feeling- and life-invested form of knowing, not the *sapere* one³⁰ – the devastation this was causing. Any observant doctor should have known it, too. But these were not observant doctors; they knew every-thing they needed to know already.

Intermezzo: medicine, corruption, and violation

Gerry Kelly, an Irish Republican imprisoned in England in the 1970s, was (like many prisoners, and like me) force-fed. The practice is expressly forbidden – sometimes held explicitly as torture – by international conventions (WMA 2016, 2017; AMA (American Medical Association) 2013; Reyes 1998; Jacobs 2012), and Kelly's poem (2011) helps to evoke the violative content of this story where I fall short. He paints the dapper doctor in his act of perverting the medical relation:

The dapper doctor announced

That he would return

To force-feed the prisoner.

(He later changed this to

'Artificially feed the patient'.)

The victim-patient is left debilitated and dumbfounded:

Stripped

To helplessness

Then stretched

To hopelessness

Under doctor's orders

•••

No speech is possible

Nor motion of limbs,

Protest undiluted

In dilated eyes

This is the surreal

Experience of nightmares

... All of which, the doctor Hypocratically explained, Was for his own good, To save his life.

That the doctor could torture and call it help, justify brutality in the name of duty and goodness, and do real harm in service to a formal medical ethics! The *hypocratic* recasting at work in Kelly's scene is one that runs throughout contemporary medicine, I claim, albeit usually with more subtlety and almost always (made) invisible. From Kelly's perspective, in the person of the doctor, interpretation becomes fact, violence becomes help, and bad becomes good.

This is my perspective, my experience, my knowledge - my 'research finding' - too.

From harm to violence

In early April, after a particularly vicious bout of diarrhoea, I again pulled out the feeding tube and demanded that they let me eat like a person: '*She says that she doesn't want any feed or NG tube, she wants real food*', wrote the nurse. It was a sort of hunger strike; as in its political version, the power to refuse food was the only agentic possibility available to a being otherwise totally incapacitated. There was no question at that point that I could swallow: sometimes, when I was howling in pain as my necrotising leg rotted to its death, the attending nurse would give me oral morphine. But I was not allowed to eat – that is an act reserved for people, and the psychopathology that doctors had assigned to me disqualified me from such a status. Instead they allowed me to starve for three days (again) before, delirious, I consented to let them reinsert the tube.

Worse still, they continued to deny me all physical therapy – that might '*burn calories*', an argument that seemed absurd since doctors had complete control over the number of 'calories' injected into my body – condemning me to permanent disability and a present of fiery pain as the nerves and tissues in my leg died. On April 7, the nurse recorded my daily appeal for physical therapy like this: '*For psychiatric review again please as patient showing non-realistic feelings about her situation: asked to walk*'. They preferred to give me Haloperidol rather than rehabilitation.

I would not be left crippled, and I began to 'physical therapize myself', thinking of my body as a machine and of myself as the serious athlete that I had once been. I commanded my legs upward from the bed, first a centimetre, then an inch, each minuscule movement taking weeks to engineer. To be sure, I was not paralyzed in the technical sense, as I had enough feeling in my legs to perceive their fiery pain, but I could not move my lower body. The doctors' timely, persistent refusal of any movement ensured that I would never regain full use of either leg and that I would finally lose feeling altogether in my left leg between the knee and ankle. Had they taken even the simplest measures, such as propping my feet upright with a pillow, these would not have atrophied, flopped, in a sort of technomodern foot binding, and I would not today have a lingering 'falling problem'. I was not permitted even to sit up (and still cannot sit upright for long periods), and the reason why is testimony to the force of medical inscription. One doctor had recorded a Grade 4 pressure ulcer on my sacrum. But here was a serious material fallacy: the ulcer was not on my sacrum but on my back, and sitting upright did not exacerbate the pressure but relieve it. This incongruity became the basis for an instructive encounter one day when an especially arrogant doctor dismissed my (daily) request for therapy, telling me that under no circumstance would I receive it, nor even be permitted to sit up, until the bedsore on my sacrum healed. By this point, I had physical therapized myself enough to haul myself upright by the bed's railing into an unsteady sitting position for a few seconds. As I did, I lifted my gown to expose the bedsore on my back, evidencing its location several inches above my sitting bones. The doctor was uninterested, but his curious medical student wagered a – surprised – glance. 'Doctor ... It does look like it's on her back'. 'No', replied the doctor, gesturing at his written record. 'It says right here it's on her sacrum'. That was the end of the truth contest. The doctor moved onto the next patient, the medical student trailed dutifully behind, and my third-person grammatical status lingered loudly.

The saga became more absurd, more grotesque at every turn. After five months of so-construed *care* in the general hospital, doctors, unable to explain my continued weight loss and debility but wholly satisfied with their diagnosis of anorexia, arrived at an effective solution: they legally assigned me a mental illness diagnosis (anorexia nervosa), expropriated my legal agency, and forcibly interned me in a centre for anorexics (called, in socially approbated if materially unsubstantive form, a 'psychiatric hospital') powerfully administered by an eating disorders expert, Dr. X. Here, error and violation escalated, as each 'incongruence' – e.g., that I did not refuse to eat and did not vomit – only reinforced doctors' investment in the (everywhere serviceable) explanation of mental illness, medicine's functional solution to the problem of unknowable bodies like mine. Here, the violence born in hubristic error, epistemic bias, and system (mal)function were compounded by another motive force: cruelty.

Dr. X habitually used force-feeding as a sort of initiation rite for the new patients who, under British law, had become her possessions. It was clear that nothing about this practice derived from necessity; instead it took source in what I can only describe as wickedness.

Force-feeding introduced Dr. X's new patients to the terrible power of her dominion, destroying their worlds, in the terms of Elaine Scarry (1985), and replacing those worlds with one of her own making. Force-feeding, here, had nothing to do with nutrition and everything to do with the master's power to inflict pain according to her appetite for it, to end and begin worlds with the force of her command. Colin Dayan (2013) writes of Guantanamo force-feeding (and feeders) words that resonate so strongly in me that my affirmation is physical: 'Glee and malice work together in the abuse of those targeted for humiliation' (3). Their 'systemic debasement is made to take on the appearance of emergency preservation', the faux 'safeguard [of] health' making 'persons accept their passage from subject to object' (36). Torture is unintelligible and incommunicable, and cruelty and malice spring from bad intent. It is impossible for me, then, to write convincingly that I know any of the three. And yet I do know them.

Dr. X's sneering, satisfied gaze each time she ordered me to be force-fed or exceptionally confined. Her ever-present threats of something more, something worse, or the same again. The moment-blinding, life-condemning lies with which she surprised truth during the kangaroo

court hearings that might have brought me freedom. The (supremely visible) humiliations she managed to extend to other inmates, and the (supremely audible) screams she managed to elicit from them ...

A handful of proclivities or acts do not make one *cruel* or *wicked*, but these are the only sorts of things I can communicate (and especially here, in the castigating limits of several thousand words) as I try to begin to make intelligible the incommunicable malevolence that saturated those millions of seconds during which I was Dr. X's possession. Upon my arrival, Dr. X duly initiated me into her carceral regime by force-feeding me at a viciously high speed. Four months of force-feeding in the hospital had been unequivocally damaging, delivering agony, stupor – and diarrhoea – until its nightly finish. This psychiatrist's meditated use of it, however, was orders of magnitude worse. On the worst day, it made me so sick that I convulsed in foot-high waves on the bed, rendered wordless, thoughtless, capable only of atavistic roars. I-my-retching-body finally began to vomit, and, once I began, I did not stop; I spewed basins and basins full with putrid red-green fluid. The expulsions became so forceful that I vomited up the nasogastric tube no fewer than five times, each time raking the sixty centimetres of its length up my internal cavity and ejecting it from one of my facial orifices. The first time, it emerged simultaneously from my nose and mouth, thick rags of black-bloody slime dangling from its superfice. After each retching ejection, the doctor forced another sixty-centimetre tube down my nose and oesophagus and recommenced, taunting me all the while. After five repetitions of this sequence, I was nearly unconscious and could not speak; I could only retch in agony and nothingness.³¹ One of the functionaries delivered I-my-body to the nearest (real) hospital to be sure that I would not die - that surely would have implied too much paperwork - and the temporary cessation of the torture brought me back to the realm of speakability. It did not, however, bring me back to the dignity of personhood.³²

To end the narrative in ellipsis, after 311 days – or, as I experienced it, 26 million horror-filled seconds – I escaped directly to the airport and fled the country. The same unusual personal circumstances that coloured the rest of this story with such aloneness – much for the worse, I think, since it meant that there was no one in the picture who cared enough, even in the worst moments of abuse, to stand up and say, '*Hey, wait a minute!*' – made for a singular escape, too. Trust is a dangerous thing, and I had learned enough about the limits of human compassion in the previous months not to risk betrayal or its consequences. I escaped alone and lived on the move for two years until they formally 'released' me,³³ supported only but importantly by the friends and landlords I met along the way. And it's a good thing: When I escaped, my keepers reported me to the police, identified the very flight on which I had fled, and sent me threatening emails for seven months afterwards. I finished my Ph.D. de facto on the run from the law.³⁴

The 'grotesquely coherent' end of medicine

This unbelievable, unintelligible series of events³⁵ shows how what began as a series of snowballing nosocomial harms – natural, if still evitable, harms deriving precisely from the system-borne *corruption* that Illich apperceived – escalated quickly into unspeakable violation. The abstracted iatrogenic accidents of the (real) hospital (infection, sepsis, cardiac arrest), agentless and indirect, were sufferable, albeit with Jobian desperation. The latter

violences were different. Particular persons – doctors, the order-givers, and nurses and aids who compliantly fulfilled their civic responsibilities as the bureaucrats of torture – wilfully realised them, and they were directed toward and made immediate assault upon *me* and me alone. The worst of them unfolded behind closed, locked doors and were performed *'under doctor's orders'*. Thus these baroque transgressions were rendered unseeable, inescapable, and – most unbearably – *good*. This double aspect of corruption, as, on one hand, grave but apersonal harm escalated into volitional brutality and, on the other, that brutality dissembled itself as benevolence, is what made my violation in the internment centre so annihilative.

Jean Amery (1980) has tried to describe, to whatever imperfect extent this is describable, the totality and transformativity of torture, showing how it irrevocably displaces, despoils, and destroys the world and one's belonging to it and in it. Elaine Scarry (1985) calls this the 'unmaking of the world', an unmaking that is simultaneously a terrible remaking of the world according to the torturer's commandment. Today I encounter *my* unmade/remade world, everywhere lacquered and mediated by strata of horror, with a sense of Amery's (1980) utter estrangement, a relentlessly astonishing 'accumulation of horror' (40).

'This is the surreal/Experience of nightmares...'

Illich named the transformation inherent in the institutionalization of medicine's *good* and foresaw how its spiralling corruption would degrade ever more the people it touched. The case I describe is no disharmonious, incomprehensible abomination of medicine's ethic, as other critics might argue. Rather 'such extreme abuse of medical techniques [is] gro-tesquely coherent with the dominant ideology of medicine' (Illich 1976, 39). *Pati* (from the Latin, patior, to suffer) now takes on a new inflection at the technic end of medicine: the patient is not she who suffers but rather *s*he who is made to suffer: this is the 'grotesquely coherent' end of technic medicine.

Notes

- 1. *Medical Nemesis* is the title Illich gave to the book in which he developed his conception of iatrogenesis. The arguments I present in this essay emerge from and converse closely with Illich's thought and theory, and I urge readers, especially those unsettled by my claims here, to approach the Illichian writings in which they take foundation.
- 2. Taken in its constituent lexemes, autoethnography is precisely this, the self (auto) writing (graph) on or about the larger sociocultural phenomena (ethno) in which the author-subject is bound. This focus on the analysis of larger cultural phenomena is what distinguishes it from autobiography.
- 3. For an overview of narrative medicine, see especially two works spearheaded by the movement's flag-bearer: Charon (2001) and Charon, et al. (2017).
- 4. Iatrogenic (doctor-produced) and nosocomial (hospital-produced) are two terms used to describe the undesired, harmful consequences of medicine or medicalization (e.g., 'iatrogenic overdose' or 'nosocomial infection'). Ivan Illich's work brought iatrogenesis into the social sciences mainstream in the 1970s, and both terms are commonly used in the medical and medical humanities literatures today.
- 5. In making this claim, I want to make very clear the distinction I intend between harm and violence. The first I intend as destructive and pernicious but not necessarily charged with the malevolence or express intentionality of the performers. Harms are, in the best of cases, the diffuse, system-bound indignities and errors that derive precisely from the de-personalizing effects of institutionalization, and, in the worst of cases, the unthought, unfelt banal evils

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whose very lack of intentionality makes observers shudder. Violence I intend as destructive and intended, subjective or agentic deliveries of pain or disabling from one person (in general, here, the doctor) to another (the patient). Most of the iatrogenic devolution is harm, and most medical workers deliver their harms with nothing but the best of intentions (cf. writings on 'benevolent violence' and the often very bad consequences of actions made with the enunciation of good intentions, e.g., in development or humanitarian intervention; see, e.g., Asad 2015; Barker 2017; Kothari & Harcourt 2004). The intentionality I infer to iatrogenic violence marks a volitional escalation from mere harm, and in this narrative it is reserved to the contents of the final section.

- 6. Jacques Ellul (1964) captured this same sense of ever-growing corruption as the nature of technicity: 'Technique must reduce man to a technical animal, the king of the slaves of technique' (p. 138).
- 7. My general references to doctors and medicine in this paper pertain generally to contexts where 'scientific' or 'Western' medicine is practiced (which includes contexts in and outside the 'West'): I am interested (again, in the general sense) in the epistemic and social authority granted to medicine and its practitioners rather than in their specific institutional or legal apparatuses to consummate that authority.
- 8. Numerous critics including Szasz, Laing, and Foucault have expounded on the codification of the incomprehensible or undesirable as psychiatric illness. In medical anthropology, good work has likewise explored the particular diagnostic rationalization of undesirable deviance and unexplained symptomatology in the terms of psychiatric illness (e.g., Scheper-Hughes 1978; Biehl 2005).
- 9. See the recent body of work on epistemic injustice, epistemic marginalization, and epistemic vice, particularly the foundational works by Fricker (2007); as applied in healthcare (Carel and Kidd 2014; Kidd and Carel 2017); and generally in contexts of system-entrenched oppression (Dotson 2014; Medina 2013). It is a plausible argument (and one I adhere to) that a condition of epistemic injustice and possibly also of epistemic hubris or vice is inhered in and necessary to the achievement and identification of medical expertise.
- 10. See, e.g., feminist work on the situated knowledges thesis (most importantly, Haraway 1988), which rejects contentions of scientific objectivity altogether.
- 11. The Apparat, the grotesque death-penalty machine in Kafka's (2000) Penal Colony (which, of course, operates in conjunction with the penal colony's complementing organizational, administrative, and technical apparatuses) literally inscribes onto the Condemned Man the law he has violated: thus he is made to 'experience [it] on his own body' (136). My suggestion here is that medicine similarly uses its powerful apparatuses of organization, administration, and technique to write on those bodies it identifies as deviant.
- 12. For Jacque Ellul (1964), technique (la technique) is 'the totality of methods rationally arrived at and having absolute efficiency ... in every field of human activity'. Technique is an ever-expanding domain that extends far beyond what we ordinarily think of as technology, and proceduralized, protocolized, mechanistic-systemic scientific medicine is surely one of technique's greatest conquests.
- 13. While I now take pains to document the diarrhoea (in an effort to neutralise my recent testimonial ineligibility, itself an iatrogenic product of this same narrative), the pain, as so many seekers of medical remedy, especially women, have discovered, is unmeasurable, unintelligible, and, as such, often unbelievable for medicine's scientific celebrant. On the abnegation and delegitimization of women sufferers' testimonies in particular, see, e.g., Epstein, et al. (2006) and Werner and Malterud (2003).
- 14. Of course, unexplainability is a routine aspect of medicine's practice. It often results in the delegitimization of the patient's suffering or the assignment of a psychiatric explanation or diagnosis. See the large literature on medically unexplained symptoms (MUS) generally (e.g., Nettleton 2006) and, in particular, in women (again, e.g., Werner and Malterud 2003).
- 15. See the major bodies of work that have developed over the past half-century in philosophy and anthropology on the objectification of the subject naturalized beneath the 'medical gaze' and the conceptual force of the Cartesian body in medicine (e.g., Foucault 2002, Leder 1984).

- 16. Abundant evidence shows that bed rest, particularly hospital-invoked bed rest, produces numerous and significant undesirable outcomes and often leads into a downward clinical spiral ending in death (Cruz-Jentoff et al. 2010; Winkelman 2009; Kortebein et al. 2008). Meanwhile, metanalyses show nutritional interventions to be widely ineffective (Jamieson and Porter 2013).
- 17. For example, food offerings were of generally poor quality from nutritional and gustative perspectives alike; there was a total absence of fruit; and, for the numerous patients who could not feed themselves, no assistance was offered. Research has demonstrated the prevalence of hospital-associated malnutrition (e.g., Barton et al. 2000), particularly in England (Elia 2009; Hiesmayr et al. 2009).
- 18. There is little research studying the effects of in-hospital sleep deprivation on patient outcomes. See Kamdar, Needham, and Collop (2012), Pilkington (2013), and Salas and Gamaldo (2008) for reviews of sleep deprivation consequences generally.
- 19. In its 2014 review by the UK's Care Quality Commission (CQC (UK Care Quality Commission) 2015), this hospital was rated in the worst category, 'inadequate', overall as well as in the majority of department- and criterion-based scoring groups. It was reprimanded for 'essential standards of quality and safety [that] were not being met' and placed under special monitoring and support measures. The local hospital trust tallied the third-highest number of MRSA cases in 2013/14 and 2014/15 across England's 302 trusts (NHS Digital [Clinical Indicators Team] 2018).
- 20. All data and excerpts are taken from the medical record, which I obtained from the hospital following a substantial but superable challenge that was both wilful and bureaucratic in origin.
- My lower legs were oedemic when I arrived at the hospital, likely due to hypoalbuminemia. 21. Doctors attributed this, in what the reader will by now understand as the immutable logic en force, variably to anorexia and/or bulimia (i.e., to protein-calorie deficiency resultant from dramatically insufficient food consumption, or to the Pseudo-Bartter Syndrome that commonly follows purging). While these assume two very different pre-hospital scenarios, they are equally patient-inculpating and – crucially – serve equally well as epistemic escape valves, even in the seeming impossibility of their simultaneity. Of course, there are numerous other systemic causes of lower-extremity oedema, including liver and kidney disease and - notably, given my history and symptomatology - the protein malabsorption and unremitting diarrhoea typical of inflammatory bowel diseases such as Crohn's. While I was in the hospital, the oedema expanded upward to affect also my thighs, arms, and hands, perhaps caused by the progressively worsening series of infections or by hospital-induced starvation. As I describe shortly, a necrotic ulcer emerged and grew to envelop the entire calf of my left leg; post hoc investigation suggests that this was a manifestation of either pyoderma gangrenosum or calciphylaxis, which feature very high degrees of pain and associate with autoimmune diseases (including inflammatory bowel disease) and/or can result as a consequence of iatrogenic infection. Since a visit from the pain specialist could not be arranged for several months, I suffered supreme pain until the necrosis advanced sufficiently that I lost feeling in the left lower leg altogether. For a review of leg ulcer types and characteristics, see Todhunter (2020).
- 22. See note 15. [Database]
- 23. See also Roma Chatterjii (1998) and Rom Harre (1984) on the creation of 'file selves'.
- 24. According to the British National Institute for Health and Care Excellence's guidelines on nutritional support for adults (NICE 2017), enteral feeding should not be given to people unless they 'have inadequate or unsafe oral intake' (s. 1.7). Though it does not explicate the matter, the content and context make it clear that capturing 'adequate oral intake' is first the prerogative of the patient herself; the regulation is not meant to authorize the intentional withholding of food by medical staff so as to enable satisfaction of the criteria.
- 25. Tube feeding via nasogastric tube involves inserting a plastic tube into the nose, down the throat, past the pharynx, through the oesophagus, and into the stomach. Ordinary complications can include diarrhoea, vomiting, lung aspiration, electrolyte perturbance (Pancorbo-Hidalgo, Garcia-Fernandez, and Ramirez-Perez 2001), and infection. More seriously, the tube

can enter and discharge its contents into the lung or bronchus, cause lung collapse, or perforate the oesophagus or sinus; these are not past problems. Following a decade of continuing patient harms and deaths resulting from nasogastric tube misplacement, the NHS Improvement unit (2016) issued a Patient Safety Alert re-inscribing tube misplacement on its list of 'Never Events'. Tube feeding is commonly used with patient consent to provide nutrition in cases of relevantly debilitating injuries and diseases; it is also commonly used (primarily in prisons), with largely the same methods but without patient consent (in which case it receives the name force-feeding), as a method of torture. The degree of pain implicated can be "adjusted" by varying the harshness of the tube insertion, the speed or rate at which feed is supplied, and the nutritional composition of the feed. In any case, the forcible, non-consensual penetration of a second person's bodily orifice by what is essentially the extended, feetlong appendage of a more powerful person seems to be the act's torture-qualifying attribute (as well as, for obvious reasons, its frequent comparison with rape). Force-feeding's variable use can be likened, in this sense, to procedures like foot amputations and dental extractions, which, though therapeutic in certain deployments, can be easily turned into mechanisms of torture. See Ashe (2018a) for a cultural meditation on the use of force-feeding as torture; Miller (2016) for a review of the grasping, impossible experiential accounts of its victims; and the section Intermezzo of this paper for one victim's poetry-woven description of the unfathomable violence the practice invokes.

- 26. A dietary reconstruction concluded that my ordinary consumption totalled between 1800 and 2500 calories per day.
- 27. A witness, the same person who communicated my evident death to the nurse, informed me of this circumstance.
- 28. Haloperidol is an antipsychotic drug.
- 29. Miller (2016, 200) collects the impressive testimonies of force-feeding survivors and observers in British, Irish, and South African prisons. Consider this account in the Irish Press ("The Price Sisters" 1974): "How many of us would want to live after being forcibly-fed? This is an experience much worse than rape. The emotional assault on the person can be permanently damaging... To restrain, even to punish, is one thing; to torture is something very different. it would seem that those who give instructions for forcible feeding and those who obey should be judged like the torturers of the concentration camps, the rapists of certain Far East campaigns, the perverters of children."
- 30. In Italian, the verb *cognoscere* (related to the English word cognition) means to have experienced something and be personally familiar with it, in a deeper manner than the counterpart sapere, which more simply means to know.
- 31. In another telling indication of medical (re)inscription, these details are not recorded in the notes; instead, the notes postulate that I 'dislodged [my] tube', and, following a (single) reinstallation, I was 'compliant'.
- 32. For more on the brutality of force-feeding and the tenure of cruelty regnant in the anorexic internment centre, as I experienced and witnessed these, see Ashe (2018b).
- 33. Several months after my escape, the doctors 'released' me. I later understood why: The NHS keeps a record of escaped psychiatric (or, to the critical eye, psychiatrized) patients. In 2016/2017 as in all other recent years the number of 'unreturned' escapees is zero (CQC (UK Care Quality Commission) 2019).
- 34. Among the constraints of the journal article as a mode of knowledge making is its severely limiting scope. I do not elaborate here on the mechanics, risks, or consequences of my escape. What these involved certainly 'tell' much about the character of psychiatric internment as an operation of sociopolitical control and a bearer of serious social and personal effect. But since those tellings are not essential to the argument I want to make in this essay, I leave them to find (or make) their spaces elsewhere.
- 35. Many events in this story are incoherent: Why did doctors fail to investigate my in-hospital diarrhoea or weight loss? What happened to the historical records of Crohn's disease? To where does an errant faecal sample go? Surely they would not starve me for three days ... twice ...? On the other hand, it is the very incoherence of the particular that gives cohesion to the narrative whole, which turns from one unexplainable, unintelligible event to the next in a

manner that approaches logical predictability. In this sense, I seem to have lived these events, in the beautiful distinction drawn by Desjarlais (1994), as both 'struggling along' and as 'experiencing'. As a narrative of utter incoherence, a series of punctual absurdities introduced abruptly from the noplace to the now, it was an episodic, powerfully tactile engagement with an absurd (and hostile) environment. At the same time, the many months of lying-there-suffering created a peculiarly total form of being that could be engaged – experienced – only with an interiority and reflexivity of depths before unknown.

Acknowledgements

The author is grateful to Anna Geltzer and Tori Davies at the University of Notre Dame's Reilly Center for Science, Technology, and Values; to Emma Varley and Saiba Varma, the editors of this special issue, for their very helpful ideas and criticisms; and to the two anonymous reviewers, who extended to me the most helpful (and gracious) review comments I have ever received.

Disclosure statement

No potential conflict of interest was reported by the author.

Data availability statement

The full medical record is available for consultation upon to the author's representative.

Funding

The author did not receive any funding for this paper. She gratefully acknowledges conference grants from the Marie Curie Alumni Association for presenting earlier related works in the *Knowing Violence* project.

Supplemental online material

This paper draws on earlier materials developed in the *Knowing Violence* project. The project's five papers and three creative videos are freely accessible online via the links listed at https://www.aca-demia.edu/37280600/Knowing_Violence_-_Research_Program_Summary_2017-2019.

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