

Why I won't see you on the barricades

Disability and COVID-19

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Lived experience matters more than ideals, more than ethics and abstract concepts like virtue. Lived experience is *what was* and *what will be*. Consider this: my mother, who was born and raised in the Miramichi, an impoverished part of an impoverished province, loses her father to lung cancer before Medicare becomes a national program (New Brunswick was late to opt in). The hospital bills force my grandmother to sell the farm and they are reduced to homestead only. With only 3 options available to a woman of her station at the time—teacher, nurse, or wife—my mother becomes a nurse, but rather than remaining at the diploma level, goes on to Dalhousie University in Halifax, NS, to obtain a BScN. In the New Brunswick of that era, this is a matter of some distinction. She returns to New Brunswick and begins a career in nursing administration that ends with her being responsible for a large number of health centres in the southern part of the province. Before that, she had been Director of Nursing at the Oromocto Public Hospital for more than 20 years. In short, she gave herself to caring for others, to New Brunswickers.

Less than 10 years after her retirement, she began to have abdominal pain. She went to the Oromocto Public Hospital's emergency department and, presumed to have pyelonephritis, was given an antibiotic. The pain settled. But it happened again, and she went to the hospital once more. Another antibiotic, same course. She told me about the pain at this point over the phone, at my home in Guelph, Ont, and I begged her to get it investigated further; I told her she needed an ultrasound, badly. When she called her family doctor, she learned he was on vacation, so she went to the local hospital a penultimate time, and I still remember what she said to me later, and how she said it: "They didn't even take my blood pressure. I felt like I was wasting their time."

A month later, a huge gallstone burst out of her gallbladder and into her small bowel. The obstruction of her small bowel that resulted forced her to uncontrollably vomit. She was taken seriously at the local hospital that day, but of course they couldn't truly take care of her there. She was, suddenly, too sick. She went by ambulance to the Dr Everett Chalmers Regional Hospital in nearby Fredericton and, in short order, received a surgery that still, in the complexity of its re-anastomoses, befuddles me. A huge transverse incision was made across her entire belly. Postoperatively, she went to the floor, but was neglected there, and when 2 visitors came that morning—the local parish priest and a nursing friend—they found a woman who was about to die. I heard this fact from them both, albeit the nursing friend mentioned that there had been little urine output for at least 5 hours (she checked).

My mother was rushed to the intensive care unit (ICU) and resuscitated, and what ensued was a rather terrible illness course that resulted in her death more than a year later.

When my mother, a woman who gave her life to her little hospital in her little town, repeatedly presented for care for what would turn out to be the most common surgical complaint in a person her age, she was made to feel like she was an annoyance. Though this experience provided me with many lessons, chief among them is this: *when it comes to institutions and other abstractions like municipality, province, and nation, sacrifice counts for nothing.*

In the time of coronavirus disease 2019 (COVID-19), I've heard from multiple organizations that want me to volunteer for reassignment duty, meaning that should the viral apocalypse hit the hospitals and community hard, would I volunteer to work at the "front lines"? A representative from the Ontario Medical Association has asked. The Chief of Staff at the Guelph General Hospital has asked. Part of me wants to say yes, of course—the stupid, idealistic part. The wise part says, "But how does medicine view disability as subject?" (I know the answer, of course. It doesn't—medicine views disability as object; its abject object.) My lived experience, as well as a vast historical record, suggests that medicine has a very vexed relationship with disability involving eugenics, incarceration, experimentation, and euthanasia.

The historical record is constantly refreshed with contemporaneous examples, including the COVID-19 record. Consider the following report from the *New York Times* commenting on the Italian COVID-19 crisis:

Italian clinical guidelines have called for "the presence of comorbidity and functional status" to be evaluated as considerations in the allocation of resources, as "a relatively brief progression in healthy patients could become longer and thus more resource-consuming on the health care system in the case of elderly patients, fragile patients or patients with severe comorbidity."¹

This is the utilitarian ethic. No less august a medical journal than the *New England Journal of Medicine (NEJM)* endorsed that ethic, de facto, by publishing a piece called "Fair allocation of scarce medical resources in the time of COVID-19" that is replete with euphemism and indirection. This is "recommendation 1":

In the context of a pandemic, the value of maximizing benefits is most important Priority for limited

resources should aim both at saving the most lives and at maximizing improvements in individuals' post-treatment length of life. Saving more lives and more years of life is a consensus value across expert reports. It is consistent both with utilitarian ethical perspectives that emphasize population outcomes and with nonutilitarian views that emphasize the paramount value of each human life. There are many reasonable ways of balancing saving more lives against saving more years of life; whatever balance between lives and life-years is chosen must be applied consistently.²

This is hardly a “nonutilitarian” view, nor a balanced one. This is having things both ways, saying 2 things at once. Eventually, the article baldly states what would, should the pandemic overwhelm our ICUs, actually happen:

Maximizing benefits requires consideration of prognosis—how long the patient is likely to live if treated—which may mean giving priority to younger patients and those with fewer coexisting conditions. This is consistent with the Italian guidelines that potentially assign a higher priority for intensive care access to younger patients with severe illness than to elderly patients.²

How one should calculate morbidity is not specifically set out—assign a value of 3 to ischemic heart disease, 2 to cerebral palsy, 1 to a hangnail?—but even generally speaking, medical odds-making is notoriously inaccurate. Moreover, it's untrustworthy. There's an implicit rhetorical signal in vague documents like these: *nonnormative life is less worthy of investment*. In reality, what is meant when “maximizing benefit” amid a neoliberal rhetoric based on “value” is to favour normative life.

One of my heartfelt heroes is George Orwell, who taught me to look to the language for lies. Here is more dissembling from the Canadian Medical Association in their “Framework for ethical decision making during the coronavirus pandemic”:

In Canada, it is well accepted that everyone should have an equal opportunity to access and receive medical treatment. This is possible when there are sufficient resources. But in contexts of resource scarcity, when there are insufficient resources, difficult decisions have to be made about who receives critical care (e.g., ICU beds, ventilators) by triaging patients.³

Often, the first thing Canadians wish to do is signal how “good” our intentions are. Note the rhetorical toxicity of this paragraph: it maintains that our fundamental position is equality ... until it can't be! Then, hard decisions must be made, by normies, for normies. The document proceeds to throw around variations on the word *ethics*—“ethically justifiable informed decisions” and “ethical dilemmas”—what

has always, as a disabled person, been a very threatening word. Then the policy document encourages physicians to turn to the aforementioned *NEJM* article for guidance.

In any policy document, or published recommendation, it is disabled lives that need protection, not “balance.” Without such a view codified, then the battlefield triage mentality will set in and normative people are preferentially given resources. The *NEJM* piece did not consult literature published by disabled scholars in its purview, which is no surprise, and that oversight is one reason why I'm writing this brief piece. Just do the following thought experiment in your head: if a 44-year-old physician without a history of addiction, bipolar disorder, and autism appeared alongside one who did in the emergency department, both in respiratory distress, who gets the ventilator preferentially? I don't need proof-of-philosophy from the *NEJM* to know the answer; I have lived experience to know.

A million war movies—have a million been made? Perhaps a hundred thousand, then—they all go like this: in the context of pain, what was sacrifice in the name of an abstract ideal, of *country*, of *nation*, for? Ask the vet. He knows. I'd like to ask my mother the same question now, but for some reason when I think of her, I never can. All I can see of her now when I try to think of her is the months she struggled to breathe on the ventilator.

Now COVID has called, and I go to work just as I went to work before. We do things differently at work, shuffling most patient encounters onto telemedicine platforms. I still see people in person when appropriate. In truth, I love to go to work, but not for you, not exactly; not for an abstract ideal; definitely not for emergency services vehicles sounding their klaxons in a fluid cordon around a building.

I do it for me, because I like doing it, love it in fact. I do it because I like helping someone else; it makes me feel good. But the second my work becomes an activity oriented toward a utilitarian good, a recruited assent toward devaluing disabled lives, and a requirement I place myself at greater risk (and thereby my family, including my disabled son), I say no. Let the normies fret about the normies they clearly value more anyway. The normies will be alright! They will implicitly take care of themselves, and occasionally they will explicitly say as much as in the Italian case, or in the *NEJM*'s intransigent one. When disabled lives are explicitly protected by a discipline that historically has preferentially extinguished them—that's when I'll join you at the barricades. 🌿

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None declared

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