

OPINION

Who 'deserves' a donated organ, when the alternative is death? How moral judgments creep into medical choices

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Mark Selkirk spends time with granddaughter Adrianna in 2010. She was a comfort to him in the last year

of his illness.

COURTESY OF DEBRA SELKIRK

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Debra Selkirk was watching the love of her life die in slow motion. First came the exhaustion, then came the yellow-tinged skin. But 52-year-old Mark Selkirk was initially reluctant to see a doctor. At last, one weekend in November, 2010, he was so fatigued he couldn't get up from the armchair in the living room.

She helped him up, out the door and into the elevator of their Toronto apartment complex. She tucked him into the passenger seat, got behind the wheel, and focused on the road ahead. When the couple arrived at the Toronto General Hospital emergency entrance almost 30 minutes later, Debra walked through the door and burst into tears. "Please help him," she said. "He's not well at all."

Everything happened quickly after that. Nurses and doctors rushed over with a gurney, and minutes later Mark was in a bed down the hall. After an initial exam and a few tests, the medical team knew exactly what was wrong: Mark's liver was failing.

When Debra learned the diagnosis, she wasn't surprised. Mark struggled with alcohol use throughout their 20-year relationship. The doctors told her he needed a new liver as soon as possible, but they also said that he wouldn't get one. He'd had his last drink only six weeks ago, and the guidelines for a transplant were clear: A patient must abstain from alcohol for six months before being considered for surgery. Over the next few days, Mark remained in the hospital. He seemed to improve with medication and the team planned to discharge him if his progress continued. "Does this mean he's going to be okay?" Debra asked a resident in the hallway.

"No," the resident said.



Mr. Selkirk with wife Debra at Toronto's Sugar Beach, 2010. The pink umbrellas were his last outdoor project in a career that also brought Toronto its distinctive moose statues in the 2000s.

COURTESY OF DEBRA SELKIRK

Debra and Mark met when they were teenagers in the 1970s. They first spotted each other when Mark's band visited a local church in Bracebridge, Ont. But years passed before they reconnected. They grew up, married other people, and had children of their own. It wasn't until the 90s, when they were both divorced, that they rekindled their relationship. "He was my magical person," Debra says.

Mark was an important figure in his west Toronto neighbourhood. He ran for a city council seat, made glass flowers for the local tulip festival, and organized canoe-building workshops at the nearby prison. But the community knew him best for creating 326 colourful fibreglass

moose that dotted the city in the early 2000s – a public art series commissioned by the municipal government.

In his private life, Mark struggled with his alcohol use and was trying to stop drinking. He had fully quit for some time until a night out with friends in February, 2007, when he gave in to a glass of wine. “I was terrified,” Debra says about that day. By March, she says, he’d gone back to drinking heavily. She called and e-mailed his family doctor, trying to get her to intervene, but nothing came of it. So Debra could only watch Mark get sicker and sicker until the day she carried him to the hospital in 2010.

There, she pleaded with the doctors to help. She asked if they would consider giving him a piece of her liver if they were a match, but they wouldn’t test her. “Alcoholics just drink again and waste the organ,” she remembers being told. The day before Mark was scheduled to be discharged, his oxygen levels plummeted and he needed a mask to breathe. When that wasn’t enough, he was placed on a respirator. He died 24 hours later.



Mr. Selkirk's death from liver failure would set off years of questions by his wife about who is allowed

new organs, and who is not.

COURTESY OF DEBRA SELKIRK

Debra spent years thinking about the days leading up to her husband's death. He had died of acute liver failure, and she still couldn't understand why he was denied even the possibility of that life-saving treatment. All she'd been told was that her husband would "waste" any new organ he was given by drinking again after the surgery. But how could the doctors know that?

In 2015, Debra recruited a friend – a neonatal nurse – to help her understand. Together, they sat at her dining table, in the same apartment overlooking the Humber River that she had shared with Mark, and pored over their research on organ transplant protocols.

Deciding who gets an organ is often likened to triage during a mass-casualty incident. It involves layers of ethical questions. You would begin by remembering that there is a shortage of organs. Then, doctors must be sure that a patient will benefit from a transplant procedure. This rules out patients with co-existing conditions that weren't caused by the liver damage (such as an active cancer or an uncontrolled HIV infection), or those who are so far along in their disease that a transplant wouldn't help or would even harm them – although this can be difficult to assess.

Once it's been established that the patient will benefit from a transplant, things get even more complicated. Now comes the question of who will benefit most. Should doctors give an organ to someone who is in worse condition or someone who will live longer with the organ? Should age, or general state of health, matter? For some patients a transplant means 10 more years of life, and for others it means 20. For others still, it might mean one. Should any of this be considered? And how can medical professionals ethically shuffle these factors on a priority list?

Debra had to understand all this before she could figure out what had happened to her husband and why. As she researched, she also began to read about the rationale behind the "six-month rule" that had excluded Mark – a widespread clinical practice that requires patients with alcoholic liver disease to complete a period of sobriety (though she prefers the term "recovery") before they can get on the waiting list for a liver.

First, the thinking goes, the time gives the patient's liver a chance to recover. Sometimes, the patient even improves enough to avoid surgery altogether. Second, if a patient can stay

away from alcohol, they're more likely to keep abstaining after their surgery, and stay healthy. Both of these arguments are fuelled by a significant fear about "wasting" the organ on the wrong patient. In other words, the abstinence requirement takes into consideration a crowded transplant list where patients young and old hope for a chance at a life-saving operation. In 2018, for example, there were 4,351 people standing by for an organ in Canada. That year, 223 people died while waiting.

But it's also difficult not to see a moral angle here.

If doctors are saying a patient wouldn't benefit from a liver transplant because he's likely to go back to drinking, "then they're in effect saying, 'We won't give him a chance at life,'" says Arthur Schafer, founding director of the Centre for Professional and Applied Ethics at the University of Manitoba. And, he adds: "Many people in society seem happy or content to impose a death sentence on someone whose need for a transplant results from smoking, drinking or obesity." Indeed, callous comments underneath news stories about Mark's death proposed that he, and others living with substance-use disorders, deserve their fate.

But studies and medical editorials have begun to contradict the notion that patients would relapse without a sobriety period. A survey published by the Canadian Journal of Gastroenterology looked at all seven transplant centres across the country. Relapse that results in the failure of a transplant is rare, the paper concludes. Not only are people unlikely to return to drinking after a transplant, but those who did take up alcohol again were unlikely to drink enough to damage the new tissue. Another paper, from the World Journal of Gastroenterology, went so far as to call the six-month rule inhumane," since most patients suffering from alcoholic liver disease would not survive for six months.

Since Mark's death, other patients have also been denied treatment. In 2017, Cary Gallant, a 45-year-old man from Sault Ste. Marie, Ont., was told by doctors that he had a 25-per-cent chance of surviving for six months, but that he wouldn't be referred for a transplant until he'd abstained for the same length of time. That year, citing the same rationale, doctors told Diem Saunders, a 25-year-old Inuk activist for missing and murdered Indigenous women and girls, that they were ineligible for a transplant. The case drew widespread scrutiny of the policy, including criticism from Indigenous groups and Amnesty International. Mr. Gallant planned to fight the rule in court but dropped the case when his health improved. Diem Saunders died from other causes.

For her part, Debra has spent the past seven years arguing in Ontario courts that the policy is discriminatory. In 2015, without any legal training, but armed with piles of research, she launched a constitutional challenge. She went up against three giants in her province's health care system: the Ontario Ministry of Health; the Trillium Gift of Life Network, which manages organ transplants in the province; and the University Health Network, which oversees the facility where Mark died.

Are doctors simply protecting a scarce resource? Or are they subconsciously punishing patients who are perceived to have destroyed their own bodies? These questions play into a wider health care dilemma: Do we have an absolute right to treatment, regardless of how we've lived?

"People should get medical care according to need, not according to virtue," Mr. Schafer says. "But sometimes, the two are blurred, and sometimes, moral judgments are smuggled into the medical arena under the guise of medical judgment."

Daniel Buchman, a bioethicist and scientist who studies substance use at the Centre for Addiction and Mental Health in Toronto, argues that transplantation is unique in this regard. "We don't have anywhere else in health care aside from transplantation where people have to demonstrate their deservedness through a commitment to abstinence from substances in order to receive a life-saving treatment."

It's easy for some of us to believe in the fairness of medical decisions. After all, what could be fairer than the science of healing? But cases like Mark's remind us that medicine can also be ruthless – it can operate in a state of pragmatism and triage. At the same time, it's easy to criticize a person who seems to be damaging their own body. We don't like to acknowledge that our health can be precarious, that outcomes are sometimes chaotic – a person who never smokes a day in their life can get lung cancer, and alcohol affects bodies differently. Perhaps we are all much closer to ruthless medical realities than we'd like to believe. Perhaps it's easier to deny that reality by blaming others for their fate.



Flagellants during a 15th-century outbreak of plague. In times when illness was viewed as divine punishment, flagellation was a way to show penance to God.

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As far back as Ancient Greece, humans have seen illness as the result of divine wrath or punishment. In the *Iliad*, Apollo sends a plague upon the animals and people of Greece after his priest is disrespected. As well as the consequence of a collective transgression, the Greeks also understood disease to be the result of a personal fault, or crimes committed by one's ancestors.

Christianity had its own ways of moralizing suffering; pain or illness became retribution for one's sins on Earth. In the Book of Genesis, God punished Eve for her original transgression, and she – and all the future generations of women she represented – would have to suffer the pain of childbirth. This model of punitive pain had such a hold in Western Christianity that women accepted the aches of labour as part of Eve's curse. In fact, in the Middle Ages,

much of the conception of motherhood centred around nurturing through suffering and the continuing emotional pain of raising children.

It was around this same time that the word “patient” was coined to mean one who endures “trials and provocations,” perhaps hinting at some kind of deserved test the sick person must go through. As with the ancient Greeks, mass illnesses such as the Black Death or syphilis outbreaks were considered evidence of collective evil; they were inflicted, not just endured.

By the 19th century, “psychological miasma,” or depression, was thought to bring about sickness. This is perhaps how “purity” and “willpower” began to be held up as guarantors of health. Disease could be viewed as an occasion to repent, to finally behave well. A sick person could choose to fight a disease, or even to not die of it.

At other times, disease was seen as an invader from a foreign land. Humans have spent centuries othering those who are ill: Immigrants, the poor, Jewish people and the Irish were all blamed for contagious diseases at some point in history. Syphilis was known as the “Chinese disease” to the Japanese, and as “French pox” to the English. In the Victorian era, Europe was assumed to be free of homegrown disease, with illnesses spreading from Asia or Africa – an attitude we often still take now. Another common way we other patients today is by calling out their “lifestyle choices” – and at no time has this been more apparent than during the continuing HIV epidemic.

But we also other those who are ill by moralizing health. People who take care of themselves mentally and physically by eating well, exercising, meditating, and staying away from dangerous substances are celebrated in real life and on social media. Meanwhile, those who damage their bodies – and supposedly monopolize the health care system by drinking, smoking, eating too much or not exercising enough – are seen as inherently bad. In the modern world, psychiatrist Rafael Euba writes, “life can only be extended by renouncing and containing hedonism just like the virtuous renounced all pleasures of the flesh in order to access paradise in more religious times than ours.” In other words, those who lack the willpower to live a rigid lifestyle deserve what they get, and they certainly don't deserve scarce donor organs or treatments.

The way we managed the COVID-19 pandemic – where personal responsibility was emphasized over government action – has been a recent example of this. Even during times

when restrictions eased and mask mandates were dropped, we continued to judge each other. Those who attended social gatherings, ate at indoor restaurants, or made different choices about how to protect themselves than we did deserved the illness they got. (I'll be the first to admit, I make these judgments, too.) And although contracting the virus has become almost inevitable, many people still report feeling guilt or shame about getting ill.

We distance ourselves from illness much as we do with other terrors. It's easy for Westerners, for example, to ignore wars across the world, especially if the people involved don't look like us or seem to have similar lives. We pretend the housing crises in our cities could never affect us, that the unhoused must have done something to end up that way. In other words, it's easier to ignore someone's pain if we believe it could never reach us.

Perhaps, in an attempt to preserve our own immortality, we place all the emphasis on personal responsibility. If it is too difficult to acknowledge the relative randomness of illness, chronic pain or addiction, then we push it aside. Because of this, we do not look at sickness with clear eyes. Our medical policies and our personal approach to health are constantly skewed by our terror of illness – and our belief that we can control what happens to our fragile bodies.



Surgical instruments are prepared for an organ transplant. Debra Selkirk would press back against Ontario's policies for who should be eligible for new livers.

MOLLY RILEY/THE ASSOCIATED PRESS

Debra built her life around fighting the six-month rule. She took a mindless job packaging roses in a commercial greenhouse so that she could channel all her mental energy into the court case. For years, she spent evenings reading legal documents and medical studies at her dining table.

And she has seen some progress; the policy has begun to evolve, and Debra believes that's happening because people like her are pressing for it. Four years ago, the Ontario transplant network ran a pilot program that challenged the rule. Instead of sending someone home if they hadn't abstained from alcohol for six months, the research team assessed patients based on the severity of their addiction, their comorbidities, their commitment to a treatment plan and their history of complying with medical advice. They also offered relapse prevention therapy to all patients who participated. After watching 44 patients for

two years, they found no significant differences in survival rates between those who received transplants through the pilot process and those who didn't drink for six months before surgery. Fear of relapse, they concluded, is not a good reason to deny patients treatment.

By 2020, the six-month rule was officially put to rest in the province of Ontario, as well as other parts of the country. But Debra says this isn't enough. Candidates are still dismissed based on the severity of their addiction, and patients who have failed addiction treatment in the past still don't get a spot on the transplant list. Because of this, she's continued to fight the policy in court. She lost her first case in 2018, and lost the appeal earlier this year. The judges argued they needed more evidence that the current criteria are discriminatory.

But Debra says she won't stop until she's exhausted all avenues to prove her cause, and in September of this year she filed her case with the Supreme Court.

Her real goal is for medicine to stop punishing patients for their illness and their behaviour. The medical community does this all the time, albeit sometimes in less formal ways. In 2002, a Winnipeg family doctor declared he would no longer see patients who continued to smoke. Another doctor, a thoracic surgeon in Timmins, Ont., who operates on lung-cancer patients, announced that candidates would have to stop smoking for at least five weeks before he would agree to operate on them. In 2006, a Calgary orthopedic surgeon told Maclean's he was reluctant to operate on smokers or anyone who was "massively overweight." He explained that nicotine impairs bone healing. "If someone has an elective problem and they are not going to comply with my treatment recommendations, I am under no obligation to take them on," he said at the time.

The organizations that govern doctors have no policies that stop them from denying treatment to patients. But withholding care from those who don't follow treatment plans seems especially punitive in light of recent studies that suggest the majority of people fail to follow doctors' orders – including doctors themselves. And while personal responsibility does have some role in healing, these examples illustrate that doctors can and do go too far when making treatment decisions, even when that treatment could be life-saving.

We keep on punishing the ill, blaming them for their sickness; we presume to know who deserves care and who does not. Of course, harsh policies and personal judgments tend to fly out the window when it's your own aging parent who won't walk around the block, your

sibling who forgets their medicine, or your loved one who is grappling with substance-use disorder. Punishing a person for failing to live a perfect life, or for struggling with an addiction, becomes clearly absurd and unjust when the patient is someone we love, as Debra loved Mark.