

## A PIECE OF MY MIND

## Hailey

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**My little sister** was 49 when she died.

The beginning of her life was charmed; we grew up without unmet needs. Our parents were supportive and valued educational achievements. We did well in school. I got better grades, but she had more diverse interests. She went to a small women's college in Missouri where she was the first person to graduate with a triple major: in biology, psychology, and equestrian science. She went to law school, passed the bar, and committed her career to serving the disenfranchised and unfortunate. She was recognized for her work as a child advocate in her state's family court system.

My sister loved animals, frequently caring for ones that were ill or abandoned. She loved horses the most, and she rode whenever she could, frequently competing in English and Western riding competitions. Between college and law school, she operated a horse farm in Fredericksburg, Virginia. Although the endeavor was ultimately unsuccessful, she took great pride in the way that she cared for the horses she boarded and in the horse-drawn carriage tours that she provided.

She was a caring, devoted, and motivated woman. And she died in a jail cell.

When she was about 35, she was thrown by a horse and hurt her back. She went to a doctor who prescribed bed rest, muscle relaxants, and acetaminophen/oxycodone (Percocet).

Her back never got better. She quit riding horses. She missed a lot of work because of her back pain. Eventually, she was encouraged to pursue disability because of her frequent absences. She sought Social Security Disability, was declared totally disabled, and went onto the welfare dole.

The welfare dole is not the panacea that its opponents to it believe it to be. At first, it was difficult for her to find health care professionals who would accept the Medicare and Medicaid plans through which she revolved. She was required to demonstrate ongoing disability on a regular basis and to reapply for benefits annually; when she moved to a different state, her disability benefits had to be reestablished. And her co-payments for medications and diagnostic testing were substantial, particularly for someone who was dependent on disability income.

But she was able to obtain treatment. She had several physicians who managed her care, including a pain physician who was trained as an anesthesiologist, a neurosurgeon, a neurologist, and a psychiatrist.

I feel certain that these physicians were competent and managed her back pain to the best of their abilities. However, over the years, her use of medications accelerated. At the end of her life, she was taking 120 mg of methadone, 40 mg of diazepam, up to 6 mg of lorazepam, and up to 100 mg of oxycodone each day. She was depressed, so she was also prescribed fluoxetine and bu-

propion, as well as triiodothyronine, to augment the antidepressants.

All of the medications she used were legitimate, prescribed medications. All were prescribed by board-certified and licensed physicians. Each of her physicians was aware of what the others were prescribing.

During the last 10 years of her life, she obtained perhaps 15 MRIs of her back. None of them indicated any pathology that was amenable to surgery. Nonetheless, she was offered a variety of operations, from fusion to decompression to spinal cord stimulator implants.

Several months before she died, her pain physician of 14 years was diagnosed with accelerating Parkinson disease. Apparently, he reported his diagnosis to the state board of medicine and, with them, agreed that he should quit caring for patients. He gave my sister a list of physicians who might manage her care in the future, but he did not provide a direct referral. Six weeks before she died, he met with her and gave her a month's supply of all her medications.

My sister made appointments with several of the physicians on the list. At every appointment, she was told that the physician would be unwilling to prescribe her current medication regimen. At every appointment, she was told that she would need to dramatically reduce her use of opioids and benzodiazepines. At every appointment, she felt that the medical establishment, which had prescribed these medications for a decade and a half, had abandoned her.

Having not found a physician to manage her medications, she tried to wean herself, if only to extend her medication supply. She accelerated her alcohol use. She became somewhat desperate, and, withdrawing from opioids and benzodiazepines, she went to an emergency department to try to obtain medications. There, she was identified as a drug seeker (this was the first time she had gone to an emergency department to request medications) and told that her medications would not be refilled. The nurses noted that she had "obtained medications from multiple providers"; however, only one of her physicians had prescribed opioids, and he had done so for 14 years, and only one had prescribed the benzodiazepines.

My sister became defensive and belligerent and said that she might be better off dead. She was put on suicide watch, restrained, and given intramuscular lorazepam (Ativan). In an altercation with emergency department personnel while she was being restrained, she kicked one of the nurses. An assault charge was filed, and she was released the next morning into police custody. The police delivered her to the local county jail, one that had been managed under federal oversight for about 10 years because of a variety of concerns about mental and physical health treatment. Her

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bail was set at \$10 000, pending a hearing the following week. She was found dead in her cell 4 days after she was jailed.

While the final autopsy report determined that her death was of uncertain etiology, the medical examiner wrote that "opioid and benzodiazepine withdrawal were possible causes of death." Having reviewed the emergency department report, I also noted in the autopsy report that she had "obtained medications from multiple providers."

I do not want to idealize my little sister. Chronic pain changed her. She had been determined and became intransigent. She had been feisty and opinionated and became obstinate and recalcitrant. She had put on weight, she drank far too much, and she was quarrelsome. What had been a clear and logical mind became muddled and confused and, seemingly exclusively, somatically focused. I imagine she would have been very difficult to treat.

But I wonder whether she might be alive today if her care pathway had been different.

I wonder whether more conservative initial treatment that avoided addictive medications might have preserved an energetic member of society who was interested in helping disenfranchised people instead of producing one of those disenfranchised people. I wonder if conservative care's outcome might have been a contributing, taxpaying member of society instead of someone on the dole who was jailed and became a corpse.

I also wonder about the quality of her "end-of-life" care. I understand that there is an opioid epidemic, I understand that there are drug seekers, and I understand that physicians who "inherit" patients might want to work with them to change their care pathways.

But I also think that even these drug seekers should be treated compassionately.

In medicine, we treat iatrogenic illness with concern and some trepidation, feeling a little guilty that we were the immediate and direct cause of the pneumothorax or the hematoma or the site infection. Even though some iatrogenic illnesses are just bad luck, we take responsibility and align with our patients to address their treatment complications.

Opioid addiction can bring out the worst in patients and health professionals. Instead of alignment, there is conflict. Instead of taking responsibility for the profession, clinicians may blame previous providers for prescribing high opioid doses and patients for taking them. Instead of harboring misgivings about the role our profes-

sion might have played in contributing to the disorder, we label and blame. Patients are no longer patients; they are "difficult" or "drug seekers" or "noncompliant" addicts of one sort or another. And that labeling clouds our judgment and impairs the quality of the treatment we provide.

I have learned that my sister's story is not unique. Since her death, I became a buprenorphine prescriber; many of my patients have a similar story: they had an injury, were prescribed opioids, accelerated their use of the opioids, and were abruptly cut off, usually because of a change in clinician or because the original one got angry over the patient's accelerating opioid use and simply quit prescribing. Most of my patients turned to illegally obtaining the opioids; many of them reverted to heroin because of the high cost of pharmaceutical-grade opioids.

I worry that recent efforts to address the opioid crisis by the Centers for Disease Control and Prevention, state boards of medicine, and the administration may have the unintended consequence of producing more heroin use, or outcomes like the one my sister had. The profession needs not only to reduce initial and profligate use of opioids, but also needs to recognize and approach opioid addiction as an iatrogenic illness for patients who have already been prescribed substantial quantities of opioids. Professionals need to stop labeling, provide compassionate care, and understand that the drugs we prescribe may have long-term personality effects. Health systems need to ensure that treatment for opioid addiction is available at all points of care. And health policy makers need to take steps to expand the treatment workforce, perhaps most easily and immediately by removing restrictions on the number of patients that a buprenorphine prescriber can treat. After all, physicians have no restrictions on the number of patients for whom they can prescribe opioids. Why should there be restrictions on the number of opioid addicts they can treat?

While a part of me wishes that my sister had sought illicit drugs instead of going to the emergency department, the end might have been the same. There is some comfort in knowing that she is no longer in pain. But a greater comfort to the nation could be realized if the profession took responsibility for the sequelae of a very common treatment, took steps to make that dangerous treatment less common, and compassionately worked with patients who have received that treatment to return them to health.

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