Coming Back from the Dead

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What happens when someone dies? A lot, I recently learned when one of my patients was incorrectly classified as deceased in the Social Security Administration Death Master File. The ripple effects from that error were like a *Twilight Zone* episode, disrupting his finances and his health care. They took months to play out and even longer to undo. His story has implications for the design of systems in which human error is infrequent but inevitable.

My patient's case is odd but not rare: incorrect data entry leads to about the same number of "deaths" per month in the United States as HIV or homicide by firearm (about 1000). It happens often enough that Social Security's website includes "What should I do if I am incorrectly listed as deceased in Social Security's records?" among its Frequently Asked Questions. If I were writing the answer, I would begin with "Brace yourself."

My patient's story begins sadly and then turns Kafkaesque. His wife (also my patient) died after a long illness on December 28, 2015. There was an outpouring of support for her husband, a retired professor in his 80s. I called to express condolences and said there was no rush, but we should review his own medical issues, which had received scant attention during his wife's illness. He booked an appointment with me for April 15, 2016.

The first sign of his "death" came on March 3, when he and a friend were walking to a restaurant for dinner. They stopped at an ATM, where he found that his bank card could not access his account. His friend lent him some cash. The next day, my patient learned that his account had been frozen because he was supposedly deceased.

Around that time, he went to his pharmacy for prescription refills. He was told he no longer had pharmacy coverage from his commercial insurance plan. He paid using (borrowed) cash and realized that a major headache was unfolding.

Soon after that, he went to a physician's office at another Boston hospital for a follow-up appointment scheduled long ago. The receptionist told him he wasn't on the doctor's schedule. When he sought an explanation, he learned that he was classified as deceased in the hospital information system. That was relatively easy to fix. More complicated was that he no longer had health insurance.

It was right around then that he received a letter from Social Security, addressed to his estate, offering condolences on his death. He began to understand the problem.

Meanwhile, his April 15 visit with me was approaching. Three days before that appointment, my administrative colleagues sought, as usual, to verify that the patient's insurance coverage was intact. They learned from both Medicare and his commercial insurer that he was deceased and no longer insured as of December 28, 2015, the same date of death as his wife's.

The news of his death spread rapidly within our institution. Our financial systems were updated at 11:15 a.m. on April 12 to reflect the cessation of his insurance. Medical Records updated his status to "deceased" 18 minutes later, and a Post Mortem Notice was instantly generated for his Care Team — including me, his primary care physician.

I saw that notice 2 hours later when I opened our electronic record system to renew another patient's prescription, and I was horrified. I was aware of the increase in mortality that follows the death of a spouse, and I felt guilty that I hadn't brought him in for a visit sooner. I looked in the record for a description of what had happened — but found nothing. I tried our information exchange tools to see if he'd been hospitalized somewhere else — again, nothing. I searched on Google and, again, found nothing.

Finally, I just called his home phone number, hoping a relative might be there to tell me what had happened. As the phone rang, I prepared to offer condolences. I was taken aback when the patient himself answered. I stammered, "I'm calling for a really weird reason."

"About my death, right?" he said. And then he told me his story.

Over the next 24 hours, my hospital brought him back to life

in our system and rescheduled his appointments, which had all been canceled. Colleagues at my hospital and his commercial payer helped the patient and me with an "information autopsy" to understand how he had "died." We focused on two issues: how the erroneous information had reached the Social Security Death Index, which serves as "the single source of truth" about who is dead or alive in the United States, and how the misinformation had spread from there.

Like most physicians, I have completed many death certificates during my career — often taking two or three tries to get them right — but I was unaware of what happens next. Death certificates are kept at the state level, and the data are entered into registries at state vital statistics offices. They are then electronically uploaded to the Social Security Administration Death Master File, which is updated weekly.

In many instances in which people are inaccurately classified as dead in the Death Master File, someone has incorrectly entered a Social Security number. In this case, Social Security had the same date of death for husband and wife. There is no actual death certificate for my surviving patient, so presumably the error was introduced during data entry of his wife's certificate information.

Errors happen — but they replicate widely when they occur in the Death Index. Financial institutions use the information to freeze accounts, prevent fraud, and stop paying benefits. Social Security itself reached into my patient's bank accounts to retrieve Social Security benefit payments that would have been inappropriate if he'd actually died on December 28, 2015. Medicare stops paying benefits, and this patient's commercial insurer receives a daily data feed from Medicare to update the information it gleans from Massachusetts death databases.

Health care providers like my hospital learn which patients have died or lost insurance coverage through previsit checks. In this case, my colleagues thought they had two sources verifying his death — being unaware that the commercial insurer received its information from the other source, Medicare.

The speed and efficiency with which this system works has real benefits. It's a galling experience for most physicians to have a deceased patient's family get an automated reminder of an upcoming appointment — a painful indication of the chaos of modern health care. I'm glad that these interconnected information systems reduce the frequency of that kind of error.

But the broader implications are highlighted by my patient's experience. In our wired society, misinformation spreads rapidly and widely, and too often there is no process for correcting the rare but inevitable errors. Tejal Gandhi, president of the National Patient Safety Foundation, commented, "This story shows how new advances create new problems. We have been pushing hard for interoperability, but how do we ensure that the information being shared is correct? Think about how incorrect information on allergies, medications, and diagnoses propagate through the system. When we show patients their records, suddenly there are lots of requests to correct information."

My patient managed to persuade each hospital, bank, and insurer — one at a time — that he was not dead. He has been able to weather the disruption of his finances without difficulty — but is quick to note that many others could not. He is working his way upstream, but it takes months to correct erroneous information in the Death Master File. Even though the error rate is well below 1%, he's been told that there is a long line of the living in front of him.

The takeaway message here is that a good system is one that knows it's imperfect and includes a quick and relatively painless

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way to correct errors. Systems need to be designed to anticipate where failures might happen and to determine the best ways to prevent and correct them, without requiring multiple labor-intensive steps. This type of "undo" process is needed throughout the flow of information in health care.

Once we learn how to design these error-correction processes successfully, we can take on the anguish produced by other information-flow enhancers — like the "Reply All" button.

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