

Buried Answers

By David Dobbs

When Dr. Alan Schiller's 87-year-old mother died in January, "it took some convincing," Schiller says, to get his siblings to agree to an autopsy. "They said: 'She had Alzheimer's. Let her rest.' But I told them: 'No, something seems funny to me. An autopsy is the only way to be sure.'" Schiller prevailed. A tanned, quick-minded, gregarious man in his 60's, he is naturally persuasive, and as chairman of pathology at Mount Sinai School of Medicine in New York, he carries a certain authority regarding autopsies. The word "autopsy," he reminded his siblings, means to "see for oneself," and they should see what happened to their mother. Schiller's mother died in Miami, so he called his friend Dr. Robert Poppiti Jr., chairman of pathology at Mount Sinai Medical Center in Miami Beach. She was on the table the next morning.

In a living patient, Alzheimer's is a diagnosis of exclusion, one that should ideally be reached only by eliminating all testable causes of fading memory and mind. Confirming it requires directly examining the brain. The definitive markers are the tiny protein plaques and fibrous tangles that appear under the microscope in stained sections. But a good pathologist can spot advanced Alzheimer's just by looking at the whole brain. The brain will be shorter, front to back, and more squarish than normal -- a reflection of Alzheimer's neuronal decimation, which shrinks the brain up to 15 percent. This would presumably have been the case with Mrs. Schiller. But the autopsist found her brain of normal shape and size. Dissecting it, he discovered a half-dozen cystlike lesions scattered throughout -- areas darker, softer and less elastic than the buff-colored parts surrounding them.

"He called me right away," Schiller told me. "He said: 'Alan, your mother didn't have Alzheimer's. She had multi-infarct dementia.' You know what that is? It's a loss of mental capacity from a series of strokes. You can tell it because these cysts show up, little areas filled with fluid that comes in after a clot cuts off blood flow and the cells die. She had had multiple strokes. She didn't have Alzheimer's at all. She'd been slowly killed by strokes.

"Now, this is useful information," Schiller continued. "For one, it means I should worry less about getting Alzheimer's but maybe more about my cardiovascular health. It also means they could have been treating her for stroke. She might have had a very different life. But Alzheimer's has become a wastebasket diagnosis. You behave strangely and you're old, you have Alzheimer's. But other things, like this multi-infarct dementia, can produce the same symptoms. And no one ever checked for that."

This is the point that Schiller, a champion of the autopsy, means to make: even in today's high-tech medical world, the low-tech hospital autopsy -- not the crime-oriented forensic autopsy glorified in television, but the routine autopsy done on patients who die in hospitals -- provides a uniquely effective means of quality control and knowledge. It exposes mistakes and bad habits, evaluates diagnostic and treatment routines and detects new disease. It is, Schiller says, the most powerful tool in the history of medicine, responsible for most of our knowledge of anatomy and disease, and it remains vital. "Neglecting the autopsy," he says, "is anathema to the whole practice of medicine."

Yet the hospital autopsy is neglected. When Schiller went to medical school in the 1960's, hospitals in the United States autopsied almost half of all deaths, and the autopsy was familiar to medical students and practitioners alike. The United States now does post-mortems on fewer than 5 percent of hospital deaths, and the procedure is alien to almost every doctor trained in the last 30 years. Schiller has fought this. Soon after he took over Mount Sinai's pathology department 16 years ago, a time when many hospitals were closing their autopsy facilities, he built what he calls "a beautiful new morgue," spending more than a million dollars. "I wanted a grand opening, a public thing," he says, laughing. "You know -- ribbons, speeches. The hospital said: 'Are you nuts? It's a morgue!'" The hospital has backed him otherwise. By pushing clinicians to ask for autopsies and by doing good autopsies that quickly give clinicians useful feedback, Schiller has lifted Mount Sinai's autopsy rates from the single digits to the midteens. But only a few hospitals, almost all of them teaching hospitals, like Mount Sinai, still do that many. Elsewhere the autopsy is dying.

Dr. George Lundberg, a pathologist who edited *The Journal of the American Medical Association* from 1982 until 1999 and now edits the online medical journal *Medscape General Medicine*, has, like Schiller, spent much of his career trying to revive the autopsy. The heart of his plaint is that nothing reveals error like the autopsy. As Lundberg noted in a 1998 article, numerous studies over the last century have found that in 25 to 40 percent of cases in which an autopsy is done, it reveals an undiagnosed cause of death. Because of those errors, in 7 to 12 percent of the cases, treatment that might have been lifesaving wasn't prescribed. (In the other cases, the disease might have advanced beyond treatment or there might have been multiple causes of death.) These figures roughly match those found in the first discrepancy studies, done in the early 1910's. "No improvement!" Lundberg notes. "Low-tech autopsy trumps high-tech medicine . . . again and again."

Lundberg doesn't fantasize that the autopsy can make medicine mistake-free; medicine poses puzzles too various and complex to expect perfection, and indeed error rates run about the same no matter how many autopsies are done. But autopsies can keep doctors from repeating mistakes, and thus advance medicine. Doctors miss things. But without autopsies, they don't know when they've missed something fatal and so are likely to miss it again. They miss the chance to learn from their mistakes. Instead, they bury them. This, Lundberg says, "is endlessly galling."

As Lundberg sees it, "If you want to base your medicine on evidence, if you want to reduce error, if you simply want to know what you are doing, then you should start by evaluating the care given to your sickest patients -- the ones who die."

The autopsy's intellectual founder was Giovanni Morgagni, a physician and professor at the University of Padua who wrote one of the most gruesome, humane and riveting early texts of modern medicine, "The Seats and Causes of Disease Investigated by Anatomy." Published in 1761, when Morgagni was 79, the book describes nearly 700 autopsies he performed. His lucid, compassionate accounts demonstrated irrefutably that illness works in traceable, physical ways; medicine, therefore, should be an empirical endeavor aimed at particular physical processes rather than "humors," spirits or other intangibles.

Morgagni's perspective was carried into the present era by William Osler, a Canadian who practiced and taught medicine in the United States in the late 1800's. Osler exerted

more influence on 20th-century medicine than any other doctor, primarily by creating at Johns Hopkins Medical School the model for medical education still used today, with students seeing patients beginning their third year and training in internships and residencies after graduating. Osler placed the autopsy at the center of this education, performing more than a thousand post-mortems himself and insisting that staff members and students do them regularly. Tracking the necrotic footprints of their own missteps, he believed, would teach them lessons far more memorable than any text could.

Osler's argument was strengthened in the early 1910's by the work of Richard Clarke Cabot, who reviewed the records and autopsies of thousands of patients at Massachusetts General Hospital and found that the autopsies showed clinical diagnoses to be wrong about 40 percent of the time -- the finding replicated many times since. His reports helped solidify the autopsy's central role in medical education and practice. Autopsy rates began to rise. By World War II, they were nearing 50 percent, and autopsies had become standard in medical schools and many hospitals, where weekly mortality and morbidity conferences often focused on what autopsies had revealed about the diagnosis and treatment of patients' illnesses.

That midcentury peak helped drive remarkable medical progress. In 1945, for instance, the chance of survival for a patient with an aortic aneurysm was little better than it was a century earlier. But in the 50's and 60's, surgeons like Michael DeBakey, a pioneering cardiovascular surgeon, learned through trial and error -- the errors offering their lessons only through autopsy -- how to repair and replace first lower sections of the aorta in the abdomen and then, working up toward the heart, the biggest, most pressurized and most vital sections. By 1960, aortic repairs were routine. By 1970, the lessons learned helped make open-heart surgery common as well.

Autopsies similarly advanced other areas of medicine. They played central roles in diagnosing and spurring treatment for sudden infant death syndrome, Legionnaires' disease, toxic-shock syndrome, hantavirus, H.I.V., Ebola and other infectious diseases and helped make the association between lung cancer and smoking. These medical advances would have come about much more slowly without autopsies. In 1999, for instance, when four New York City residents died of what was diagnosed as St. Louis encephalitis, it was only because the city's unusually aggressive medical examiner's office insisted on autopsying them that they were discovered to be the first American victims of West Nile virus. (In most cities, the four would have been buried or cremated without autopsy.) The federal Centers for Disease Control and Prevention subsequently established a nationwide monitoring, control and treatment system credited with preventing scores or perhaps hundreds of deaths.

Though yet deadlier pathogens, like those that cause avian flu, mad cow disease and SARS, will almost certainly make their way to the United States, our low autopsy rates may well delay their detection. Prion diseases -- for instance, mad cow, which in humans is called variant Creutzfeldt-Jakob disease -- cause a neurological death that doctors could mistake for multi-infarct dementia, encephalitis or even a fast-moving Alzheimer's. A patient who died of a prion disease might go unautopsied and be cremated or buried, leaving the prion disease and its source undetected. With some 200,000 Alzheimer's and stroke patients buried unautopsied each year, this may have already happened. After 20 years of making arguments for autopsy, Lundberg says that he feels like the football coach in the joke about the dim and unmotivated player. "What's wrong with

you, Jones?" the coach says. "Are you ignorant? Or just apathetic?" To which Jones replies, "I don't know, and I don't care."

When Lundberg talks autopsy to doctors' groups or health-care policy makers, his audiences generally agree that we should do more autopsies. "But nobody takes the steps to make it happen," Lundberg laments. They shake their heads in dismay, then return to business as usual. The forces arrayed against the autopsy -- regulatory, economic and cultural -- seem to overcome any impulse to revive it.

It starts with pathologists. Most pathologists don't like autopsies. The procedure entails two to four smelly hours at the table and as many again analyzing samples, and the work comes atop other duties -- ones that feel more urgent -- like analyzing biopsies of living patients. Autopsies seldom advance careers or status, and most hospitals don't pay pathologists for doing them or provide updated equipment to ease the job or get the most out of the sampled tissues.

Hospitals say the problem is money. An autopsy can cost from \$2,000 to \$4,000, and insurance won't cover it. Most patient families blanch if asked to pay for it, and many can't afford to after paying medical and funeral bills. So the hospital gets the tab. For most of the postwar period up to 1970, hospitals generally paid it, essentially because they had to: the Joint Commission on Accreditation of Healthcare Organizations required hospitals to maintain autopsy rates of at least 20 percent (25 percent for teaching hospitals), which, then and now, is the rate most advocates say is the minimum for monitoring diagnostic and hospital error. The commission eliminated that requirement in 1970. Lundberg says that this happened because hospitals, which had already allowed the rate to drop to close to 20 percent since its 1950's high of about 50 percent, wanted to let it drop further and pressured the commission. The commission's current president, Dr. Dennis S. O'Leary, says it eliminated the standard because too many hospitals were doing poor autopsies -- and often only the cheapest, simplest ones -- just to make the quota. In any event, few hospitals have paid for autopsies since then. Money is too scarce, they say, the needs of living patients too great.

But this argument fails scrutiny. For starters, hospitals do get money for autopsies: Medicare includes an autopsy allowance in the lump sum it pays hospitals for each Medicare inpatient, and those patients account for three-quarters of all hospital deaths. This money could easily finance double-digit autopsy rates. But most hospitals spend it on other things. Lundberg and others have urged the Department of Health and Human Services to make Medicare payments contingent on hospitals' meeting a certain autopsy rate. But the agency shows no interest in doing so.

The hospitals' dodge on this issue reveals less about finance than about attitude. They have the money. They don't use it for autopsies because they don't value autopsies. The hospitals that do -- teaching hospitals like New York's Mount Sinai; Dartmouth-Hitchcock Medical Center, in Lebanon, N.H.; and Baylor University Medical Center, in Dallas -- manage to absorb the costs. Their lobbies may not be as nice. But they have a much better idea where their errors are. "People sometimes ask me how good a hospital is," Lundberg says. "With most hospitals, the answer is that no one knows -- because the hospital has no way to know how many and what kinds of mistakes they make."

Another oft-cited inhibitor is doctors' fears of being sued if an autopsy finds error.

Research shows no link between autopsies and increased tendencies to sue. Patient families say this is because doctors increase trust by asking for an autopsy and encourage suspicion and acrimony when they don't request one.

Doctors seem to overestimate families' resistance to autopsies. In one survey of doctors and families of seriously ill patients, 89 percent of the physicians said they planned to request autopsies and two-thirds of the families said they would probably grant permission. "But only 23 percent of them actually got autopsied," says Dr. Elizabeth Burton, a pathologist and autopsy advocate at Baylor who was one of the study's authors. "Why? We went back and asked the families. Many were never asked. Among those who were, the biggest deciding factor was how strongly the doctor recommended it. If the doctor showed conviction and a good reason, the families almost always went for it."

Some families do object, of course, and variations on the refrain of Schiller's siblings, "Let her rest," have answered many an autopsy request. But if the doctor persists and wins approval, the family often gains a welcome sense of resolution. An extreme example of how a post-mortem is expected to resolve troubling questions surfaced in the case of Terri Schiavo; an autopsy should reveal far more precisely the extent of her brain damage, resolving whether she was truly vegetative, with only her brain stem functioning, as most doctors believed, or even minimally conscious, aware and responsive, as her parents believed. (The Pinellas County medical examiner's office in Florida had not released the results of the Schiavo autopsy as this article was going to press.) More commonly, results clarify family health issues. People who go through a miscarriage or parents whose children have died seem to especially benefit. Tracing death to a particular cause seems to ease anguish about things done or not done. Yet few doctors regularly ask to perform the post-mortem.

Perhaps the most troubling reason for the decline of the autopsy is the overconfidence that doctors -- and patients -- have in M.R.I.'s and other high-tech diagnostic technologies. Bill Pellam of the Pinellas County medical examiner's office says: "We get this all the time. The doctor will get our report and call and say: 'But there can't be a lacerated aorta. We did a whole set of scans.' We have to remind him we held the heart in our hands." In fact, advanced diagnostic tools do miss critical problems and actually produce more false-negative diagnoses than older methods, probably because doctors accept results too readily. One study of diagnostic errors made from 1959 to 1989 (the period that brought us CAT scans, M.R.I.'s and many other high-tech diagnostics) found that while false-positive diagnoses remained about 10 percent during that time, false-negative diagnoses -- that is, when a condition is erroneously ruled out -- rose from 24 percent to 34 percent. Another study found that errors occur at the same rate regardless of whether sophisticated diagnostic tools are used. Yet doctors routinely dismiss possible diagnoses because high-tech tools show negative results. One of my own family doctors told me that he rarely asks for an autopsy because "with M.R.I.'s and CAT scans and everything else, we usually know why they died."

This sense of omniscience, Lundberg says, is part of "a vast cultural delusion." At his most incensed, Lundberg says he feels that his fellow doctors simply don't want to face their own fallibility. But Lundberg's indictment is even broader. The autopsy's decline reflects not just individual arrogance, but also the general state of health care: the increasing distance and unease between doctors and patients and their families, a pervasive fear of lawsuits, our denial of age and death and, especially, our credulous

infatuation with technology. Our doctors' overconfidence, less bigheaded than blithe, is part of the medicine we've come to expect.

Recently I stood in the autopsy room of a large teaching hospital waiting for a body to be brought up from the morgue. The young pathologist who would be overseeing the autopsy told me what little he knew of the morning's patient. The middle-aged man had come to an emergency room suffering seizures. A CAT scan of his head showed a lesion, possibly a tumor, in his left frontal lobe. He initially refused a biopsy, saying that he might seek a second opinion. The emergency-room doctor, worried about pressure in the patient's skull if the mass expanded, put him on anti-inflammatory steroids and sent him home. Sometime later the man came in again with stronger and more persistent seizures. Despite efforts to ease pressure in his skull, he progressed from seizures to a coma and died. Midmorning the day after that he was on a gurney on his way to the autopsy room. The man was not overweight and had no known history of serious illness. His main compromising factors were that he was an ex-drug user and a smoker. "The drug use would suggest infection," the pathologist said. "The smoking, obviously, cancer." So what killed him?

"Most likely he herniated," the pathologist said. "Things got too tight in his skull from whatever this growth was, and the pressure builds and finally it pushes the base of the brain down through the opening where the spinal cord enters the skull. That fits with the way he died. But even if that's right, we still don't know what the lesion is." At this point we heard the rumbling of wheels, and the autopsy assistant pushed a gurney covered with a canvas tent into the room. "We'll know more soon," the pathologist said.

He stepped out to get gowned up, and I went in to watch the assistant prepare things. By then the canvas tent was removed to reveal a body wrapped in sheets. The assistant worked efficiently but with a calm, understated respect. With no more force than necessary, he pulled the body from the gurney onto the autopsy table and unwrapped it. The patient appeared to be thinking: his eyes, slightly open, stared dreamily at the ceiling. In addition to the pathologist, the assistant and a pathology resident, who would do the actual knife work, eight others attended, including a fourth-year medical student, two residents, three neuropathologists and a cardiac pathologist who had just dissected another patient's heart and lingered to see how the brain case played out. As people milled and talked, the assistant sank a scalpel into the flesh behind the man's ear and began cutting a high arc behind the rear crown of the skull. When he reached the other ear, he pulled the scalp's flesh away from the skull a bit, crimped a towel over the front edge of the opening he had made and, using it for grip, pulled the scalp forward over the man's head. When he was done, the man's skull lay completely exposed and his insideout scalp covered his face down to his mouth. Now a neuropathologist, wielding the skull saw (like a cordless kitchen mixer with a rotary blade), carefully cut a big oval in the rear and top of the man's skull. He then used a hammer and chisel to tap around the seam. Finally he tapped the chisel in at the top of the cut and pried. With a sucking sound the skullcap pulled away.

The brain looked unexpectedly smooth. "That's the swelling," the neuropathologist said. "The convolutions usually show much more plainly." He gently pulled back the frontal lobe and slipped scissors behind the eyes to snip the optical nerves, then the carotid arteries and finally the spinal cord itself. Then he gently removed the brain and set it upside down on a table.

Even my untrained eyes could tell things weren't quite right: the left hemisphere was swollen. The growth in the left frontal lobe, less a lump than a slightly raised oval area about an inch long, was paler, yellower, firmer and more granular than the pinkish-tan tissue surrounding it. "Could be a tumor," the neuropathologist said. "Could be an infection. We'll know more in a few days." Similar lesions were eventually identified on both sides of the brain.

With a pair of scissors, he pointed at a bulbous area around the brain stem. "Here's the herniation. See how it protrudes? That's where it got pushed down through the opening where the spinal cord comes through. That's the medulla that pushed through, which, among other things, controls the heart and breathing. That's just not consistent with life." He clipped a few samples from the lesion, and with that he was largely done. The assistant, meanwhile, worked on, and with the brain exam finished, the pathologist soon joined him. They extracted meaty lungs and a big liver. Pus oozed out when the trachea was cut. All this suggested systemic infection. "At this point, I'd call it an even toss between infection and tumor," the pathologist said. "If he tests positive for H.I.V., my money goes on infection."

This initial exam of the organs took some 15 minutes. When they finished, the group spent another hour dissecting the organs. The exercise was now more educational than diagnostic, but the pathologist showed no sign of routine-induced boredom; on the contrary, he clearly enjoyed showing the residents the hidden adrenal glands, the chestwall vessels sometimes used for coronary bypasses and the vagus nerve's lacy, laddered course through the chest.

The full results would take several more days to come in. But they knew by the next day that the patient was H.I.V.-positive, and by the second day that the mass was not cancerous but an infection found mainly in immunocompromised patients like this one. These findings had multilayered implications. That the man had H.I.V., for instance, would presumably mean something to any of his sexual partners. (Many states require the primary physician to contact sexual partners in such cases.) The rest of his family might find some relief in knowing that there was no tumor and that their own cancer risk was thus not raised. Beyond that, the case's main epidemiological significance was its addition to evidence that infections form an ever-growing but oft-overlooked cause of death -- another small correction in our assessment of what kills us. And that makes for better doctors. "You don't learn these things all at once," the pathologist said. "You learn a lot all at once in med school, sure. But after that, you become a better doctor by learning a little bit at a time. Incremental adjustments. That's what makes us better doctors. And this is the place you learn them better than anywhere else."

When a believer is in the full flush of describing autopsy's gifts, when you witness how quickly and effectively the procedure delivers them, it's easy to think that the autopsy will make a comeback. How could it not? At a time when medicine takes continuous fire regarding errors -- politicians and patient advocates outraged at studies showing that 100,000 Americans die each year from medical errors, tort lawyers chasing mistakes on which to hang huge judgments, malpractice rates jumping at triple-digit rates -- how can medicine ignore an instrument proven to detect error?

Yet it does. Other than hoping for a long shot, like Medicare or the Joint Commission on

Accreditation of Healthcare setting autopsy-rate requirements, there is seemingly no quick return to routine autopsies. "We just have to do this one hospital at a time," says Dr. Pat Lento, head of the autopsy service at Mount Sinai in New York. But most hospitals have no plans to revive the autopsy. And while physician organizations like the A.M.A. generally support the autopsy, most doctors don't avail themselves of it. The sad truth is that most of medicine seems to have relegated the post-mortem to a cabinet of archaic tools, as if the body's direct lessons no longer matter. In the end, the autopsy's troubles resemble those in a medical case in which the causes stand clear and a cure stands ready, but the patient doesn't take things seriously enough to pursue the fix.

Toward the end of the autopsy I saw of the man who died from an ignored infection, someone asked the assistant if he could really put him back together for a funeral. It was almost 2 p.m. and the man was in pieces. His torso was a big red bowl formed by his back ribs, his skin hung splayed on either side and his scalp was stretched inside-out over his face. The assistant smiled and said, "Oh, sure." The pathologist added: "Absolutely! This guy could go to his wake tonight."

And so it was. Unlike most things, an autopsied body can be put back together far more easily than it can be taken apart. It took less than half an hour to replace the breastplate and sew up the man's torso; if he had a suit, it would fit as before and hide all. The skull cap all but snapped into place. The assistant rolled the man's scalp back over his head and started to suture it up. When he was done, our patient looked pretty good indeed. It was remarkable, actually, after all we had found about what ailed him, that he should still gaze at the ceiling, unchanged and none the wiser.