Guest Essay
Opinion

A Revolution Is Coming to Medicine. Who Will It Leave Out?

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On Aug. 16, 2011, my father woke up and couldn't get out of bed. Until then, he was an avid outdoorsman, who cast for trout on the Delaware River and trained German wirehaired pointers to track and point pheasant. So after an ambulance ride to the emergency room and then hours of tests, the diagnosis shook our family: Stage 4 non-small cell lung cancer.

Scans revealed tumors all over his body — brain, ribs, pelvis, spine. The tumors on his vertebrae quietly grew until they had cut off nerve signals to his legs.

More people die of lung cancer in the United States every year than from prostate, colon and breast cancers combined. Our family received hope, however, when a biopsy revealed that my dad's cancerous cells had a molecular marker on their surface making them an ideal candidate for erlotinib, a drug that could disrupt their growth. Just weeks after he received his first dose, my mother phoned with tears of joy in her voice to tell me that the tumors were shrinking.

Erlotinib is a textbook example of what physicians call "personalized medicine," or sometimes "precision medicine." In contrast to traditional, one-size-fits-all health care, personalized medicine uses molecular-genetic information about patients to deliver the right treatment, to the right patient, at the right time. Prominent medical geneticists, influential federal scientists, hospital system executives and even elected officials foresee cancer treatments as the leading edge of a genomic revolution, ushering in a new era of miracle cures and biomedical magic bullets, and fundamentally transforming the care of desperate patients.

As health care costs skyrocket, some proponents of personalized medicine envision a more affordable alternative to traditional treatments, one that tailors interventions from the beginning of treatment rather than sending patients off on a trial-and-error odyssey. This approach, they say, could decrease waste while increasing the quality of care. Moreover, the claim is that personalized medicine research that prioritizes the participation of marginalized communities will ensure these breakthroughs extend to everyone, combating racial and sociodemographic health disparities.

It's hard not to get excited about a future guided by this medical revolution. But a closer look at lung cancer, and at my father's experience specifically, paints a far gloomier picture than what the personalized medicine champions would have you believe.

There are some diseases for which genetics is truly saving lives; in particular, patients with rare diseases like spinal muscular atrophy and certain cancers such as chronic myelogenous leukemia may now be prescribed personalized medicine treatments that simply didn't exist a couple of decades ago. For most patients with most diseases, though, the lofty promises have failed to materialize. Even more dangerously, the hype has distracted from alternative approaches to health care that are better suited to improving health for all of us.

One problem with personalized medicine is the cost. As the bills for his biopsies, surgeries and radiation piled up, we

started to call my father the “million-dollar man.” The real eyepopper was the erlotinib, priced at over $5,000 for a one-month supply of the tiny pills. A number of other drugs for lung cancer have emerged in the years since — osimertinib, crizotinib and sotorasib, to name a few — in the $10,000-to-$20,000-per-month range. These, in fact, are on the affordable end of the spectrum; $50,000-per-month list prices aren’t uncommon for personalized medicines.

There’s a straightforward biological explanation for this. Personalized medicine works by carving patient populations into subgroups based on their molecular-genetic profiles. For lung cancer, there are a number of biological distinctions made, and those distinctions result in smaller pools of potential users for any given drug, which incline the pharmaceutical companies to drastically increase prices.

There is thus an inherent tension at the heart of personalized medicine. It purports to both tailor health care and drive down costs, but the more it succeeds at individualization, the higher go the prices. Patients, as a result, can now face an agonizing decision: forgo treatment or suffer financial ruin.

Our family was fortunate. My parents were financially stable, and they had good health insurance that covered the expensive drug. They lived only an hour’s drive to a major hospital network. My father had another thing going for him: the color of his skin. White patients with lung cancer are far more likely than Black patients to receive a diagnostic test indicating whether or not a drug like erlotinib is a good match, and patients from richer neighborhoods are more likely to get access compared with those from poorer neighborhoods.

My dad was ultimately able to leave the hospital and go home, where he continued receiving care, undergoing physical therapy and tying flies in the hopes that he’d one day again wade into the chilly spring waters of the Delaware. The following summer, however, a round of tests revealed that his tumors were growing again. He never regained the ability to stand, let alone cast a fly. On Sept. 23, 2012, a little over a year after he woke up paralyzed, my father died.

Media reports surrounding personalized medicine often forecast a future of health care revolutionized by the arrival of medical magic bullets and biomedical breakthroughs. Erlotinib, though, generally doesn’t cure cancer; it puts it on pause, and when it comes back, it often comes back with a vengeance. Oncologists today can respond by prescribing one of the newer, more expensive drugs. Still, for patients with advanced lung cancer like my dad, the chances of being alive five years after initial diagnosis are terrifyingly small.

Genetic information about patients can result in clinical treatments for certain diseases that are known to be caused by a fairly straightforward genetic mechanism; that’s what made conditions like spinal muscular atrophy and chronic myelogenous leukemia such good candidates for intervention. But those cases are the exception in medicine, not the norm. When we move to common and complex diseases like hypertension, Parkinson’s, diabetes or asthma, where, for a vast majority of patients, there’s no single gene causing the disease,the opportunity for a personalized medicine revolution that can benefit most patients is severely limited.

Taking steps to prevent the development of illness is both more effective and more cost-efficient than trying to eliminate disease after it arrives. Lung cancer is a prime example. Even though there is still no cure for metastatic lung cancer, age-adjusted death rates from lung cancer in the United States have been dropping steadily because of public health research and programs aimed at making our environments more lung-friendly, with asbestos abatement programs, antismoking campaigns and other efforts to control harmful chemicals.

People of color and those living in poverty are particularly susceptible to the harms of unhealthy environments. They tend to be the ones who are living closest to factories and highways and farthest from green spaces and fresh produce. It is abundantly clear that health disparities along racial and economic lines are largely caused by differences in our environments, not differences in our genes. That’s why the health and economic impact of addressing unsafe drinking water, food insecurity, exposure to heavy metals and countless other things is so important: Everyone benefits, not just the people with the right genes, the right skin color or the right bank account balance.

It’s impossible to specify how much time erlotinib added to the end of my father’s life, but there’s every reason to believe that he lived longer because of the drug. I’ll always cherish that period, just as I’m certain that the family members of lung cancer patients battling the disease today soak up every moment with their loved ones. Erlotinib,

however, didn't save him. For a very high price, the drug slowed his terminal disease down for a short time, and even that limited benefit is not available to everyone.

Improving health for us all, driving down the costs of health care and making the world a more equitable place are all noble goals. The most direct route, though, isn't by way of orienting health care around the genetic differences between us. It's by focusing it on the environments we share.

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