

HOW WE DO HARM

A DOCTOR BREAKS RANKS
ABOUT BEING SICK IN AMERICA


OTIS WEBB BRAWLEY, M.D.,
WITH PAUL GOLDBERG



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*Lord, teach me to be generous.
Teach me to serve you as you deserve;
to give and not to count the cost,
to fight and not to heed the wounds,
to toil and not to seek for rest,
to labor and not to ask for reward,
save that of knowing that I do your will.*

—“Prayer for Generosity,”
ST. IGNATIUS OF LOYOLA

PART I

Three from the Gradys

Chapter 1

Chief Complaint

SHE WALKS THROUGH the emergency-room doors sometime in the early morning. In a plastic bag, she carries an object wrapped in a moist towel.

She is not bleeding. She is not in shock. Her vital signs are okay. There is no reason to think that she will collapse on the spot. Since she is not truly an emergency patient, she is triaged to the back of the line, and other folks, those in immediate distress, get in for treatment ahead of her. She waits on a gurney in a cavernous, green hallway.

The “chief complaint” on her chart at Grady Memorial Hospital, in downtown Atlanta, might have set off a wave of nausea at a hospital in a white suburb or almost any place in the civilized world. It reads, “My breast has fallen off. Can you reattach it?”

She waits for at least four hours—likely, five or six. The triage nurse doesn’t seek to determine the whereabouts of the breast.

Obviously, the breast is in the bag.

* * *

I am making rounds on the tenth floor when I get a page from Tammie Quest in the Emergency Department.

At Grady, we take care of patients who can’t pay, patients no one wants. They come to us with the bleeding wounds, their run-amok diabetes, their end-stage tumors, their drama. You deal with the wreckage for a while and you develop a coping mechanism. You detach. That’s why many doctors, nurses, and social workers here come off as if they have departed for a less turbulent planet.

Tammie is not like that. She emotes, and I like having her as the queen of ER—an experienced black woman who gives a shit. When Dr. Quest pages me, I know it isn’t because she needs a social interaction. It has to be something serious.

“We are wanted in the ER,” I tell my team.

The cancer team today consists of a fellow, a resident, two medical students, and yours truly, in a flowing white coat, as the attending physician. I lead the way down the hall. Having grown up Catholic, I can’t help thinking of the med students and young doctors as altar boys following a priest.

I am a medical oncologist, the kind of doctor who gives chemotherapy. My other interests are epidemiology and biostatistics. I am someone you might ask whether a drug works, whether you should get a cancer screening test, and whether a white man’s cancer differs from a black man’s cancer. You can also ask me if we are winning the “war” on the cluster of diseases we call cancer. As chief medical officer of the American Cancer Society—a position I have held since 2007—I often en-

up quoted in the newspapers, and I am on television a lot. In addition to my academic, journalistic and public-policy roles, I have been taking care of cancer patients at Grady for nearly a decade, first as the founding director of the cancer center, and now as chief doctor at the ACS.

My retinue behind me, I keep up a fast pace, this side of a jog. Bill Bernstein, the fellow, is the most senior of the group. Bill is a Newton, Massachusetts, suburbanite, still boyish. He is having trouble adjusting to the South, to Atlanta, to its inner city. He is trying, but it's hard to miss that black people and poor people perplex him. Contact with so much despair makes him awkward. But he has a good heart, a surfeit of common sense—and he is smart. Whatever we teach him at Grady will make him a better doctor wherever he ends up.

Grady suffers from what the administration here calls a “vertical transportation problem.” Our elevators are slow at best, broken at worst. We head for the stairs, rushing down to the first floor, then through long, green hallways into the ER.

Grady is a monument to racism. Racism is built into it, as is poverty, as is despair. Shaped like a capital letter *H*, Grady is essentially two hospitals with a hallway—a crossover—in the middle to keep things separate but equal for sixteen stories.

In the 1950s and '60s, white patients were wheeled into the front section, which faces the city. Blacks went to the back of the *H*. This structure—built in 1953—was actually an improvement over the previous incarnation. The Big *H*—the current Grady—replaced two separate buildings—the whites got a brick building, the blacks a run-down wood-frame structure. Older Atlantans continue to refer to the place in a chilling plural, the Gradys.

You end up at Grady for four main reasons. It could happen because you have no insurance and are denied care at a private hospital, or because you are unconscious when you arrive by ambulance. When your lights are out, you are in no position to ask to be taken to a cleaner, better-lit, suburban palace of medicine. A third, small contingent are older black folks with insurance, who could go anywhere but have retained a dim memory of Grady as the only Atlanta hospital that accepted us. The fourth category, injured cops and firemen, know that we see a lot of shock and trauma and are good at it. We are their ER of choice.

Today, our 950-bed behemoth stands for another form of segregation: poor versus rich, separate but with no pretense of equality. Grady is Atlanta's safety-net hospital. It is also the largest hospital in the United States.

The ER, arguably the principal entry point to Grady, was built in the center of the hospital, filling some of the *H* on the first floor. To build it, Grady administrators got some federal funds in time for the 1996 Summer Olympics. This fueled financial machinations, which led to criminal charges, which led to prison terms. (In retrospect, the bulk of the money was put to good use. Many of the victims of the Olympic Park bombing came through our ER.)

The hallways here are incredibly crowded, even by the standards of inner-city hospitals. Patients are triaged into three color-coded lines—surgery, internal medicine, obstetrics—and placed on gurneys two-deep, leaving almost no room for staff to squeeze through.

You might see a homeless woman drifting in and out of consciousness next to a Georgia Tech student bloodied from being pistol-whipped in an armed robbery, next to a fifty-seven-year-old suburban secretary terrified by a sudden loss of vision, next to a twenty-eight-year-old hooker writhing in pain that shoots up from her lower abdomen, next to a conventioner who blacked out briefly in a cylindrical tower of a downtown hotel, next to a fourteen-year-old slum dweller who struggles for breath as his asthma attack subsides.

When I first arrived in Atlanta and all of this was new to me, I took my wife, Yolanda, through the

Grady ER on a Friday night.

“Oh, the humanity,” she said.

Yolanda, a lawyer with the U.S. Securities and Exchange Commission, feels happier above the Mason-Dixon Line.

* * *

TAMMIE Quest—I use her real name—is cute, has a broad, infectious smile, and comes from privilege. She grew up in Southern California and frequently refers to herself as a “black Valley girl.”

Though she identifies with the West Coast, a lot of Atlanta has rubbed off on her in the Grady ER.

No two ERs are alike. Ours tells the story of Atlanta more clearly, more poignantly than its skyline. Patients everywhere are scared of their wounds or diseases that rage inside them. Here, in the middle of this big, hot, loud, violent city, they have an added fear: they are terrified of each other, often with good cause.

Elsewhere, patients might trust us doctors, admire us, even bow to our robes, our honorifics, and the all-caps abbreviations that follow our names. Here, not so much.

A place called Tuskegee is about two hours away from here. It’s where government doctors staged a medical experiment in the thirties: they watched black men die of syphilis, withholding treatment even after effective drugs were invented.

Tuskegee is not an abstraction in these parts. It’s a physical place, as palpable as a big, deep wound, and eighty-plus years don’t mean a thing. Tuskegee is a huge, flashing CAUTION sign in the consciousness of Southern black folks. It explains why they don’t trust doctors much and why good docs such as Tammie have to fight so hard to earn their elementary trust.

Like me, Tammie is a member of the medical-school faculty at Emory University, and, like me, she has several academic interests. One of these interests is end-of-life care for cancer patients, controlling the symptoms when someone with advanced cancer shows up in your ER.

Seeing us approach, she walks toward us and hands me a wooden clipboard with the Grady forms. I look at her face, gauging the mixture of sadness, moral outrage, and fatigue.

She says something like “This patient *needs* someone who cares,” and disappears.

I glance at the chief complaint.

“Holy shit,” I say to Bill Bernstein and, more so, to myself.

I introduce myself to a trim, middle-aged, black woman, not unattractive, wearing a blue examination gown conspicuously stamped GRADY. (At Grady, things such as gowns, infusion pumps, and money tend to vanish.)

From the moment Tammie paged me, I knew that the situation had to be more than a run-of-the-mill emergency. This patient clearly is not about to die on the examination table. She doesn’t need emergency treatment. Before anything, she needs somebody to talk to. She needs attention, both medical and human.

The patient, Edna Riggs, is fifty-three. She works for the phone company and lives on the southeast side of Atlanta.

Sitting on an exam table, she looks placid. When she extends her hand, it feels limp. She makes fleeting eye contact. This is depression, maybe. Shame does the same thing, as does a sense of doom. *Fatalism* is the word doctors have repurposed to describe this last form of alienation.

In medicine, we speak a language of our own, and Edna’s physical problem has a name: mastectomy. In doctoresse: automastectomy. It’s a fancy way of saying that the patient’s breast has fallen off by itself.

An automastectomy can occur when a tumor grows so big and so deep that it cuts off the blood

supply from the chest to the breast. Denied oxygen, breast tissue dies and the breast starts to detach from the chest wall. At places such as Grady, automastectomies are seen a couple of times a year often enough to be taken in stride.

This case is different from others I have seen only because Edna Riggs has wrapped her detached breast in a moist, light-blue towel and brought it with her for reattachment. I can't help wondering why the towel is moist. Some deliberateness has gone into the breast's care. I cringe at the thought that Edna has kept that package next to her on the gurney in the ER for hours.

In the exam gown, Edna's chest looks surprisingly normal. I ask how long she has had a "breast problem."

She first felt something in her breast when her son was in second grade, she replies. It has grown over the years. She speaks correct English, not the language of the streets. She sounds like someone who has had schooling, a person who reads. Her hair is clean and combed, she is dressed neatly.

What grade is her son in now?

Eleventh.

I don't react, not visibly. She has known she had a problem for nine years—why did she do nothing?

I ask Edna's permission to examine her. She nods. I ask her to lie down, my entourage gathering around.

I help her remove her right arm from the gown, trying to respect her modesty and preserve as much dignity as possible. I undrape the right breast, or the place where the right breast had been. The chest wall is now rugged. I see yellowish, fibrous tissue and dry blood. There is the unforgettable smell of anaerobic bacteria. The wound is infected.

I reach for examination gloves. I palpate her chest wall and feel under her armpit, looking for evidence of enlarged nodes. After examining the breast wall, I look in the towel. Her amputated breast could fit on her chest as if it were a puzzle piece.

I am not looking forward to Edna's repeating her request to reattach the breast. If she asks directly I will have to say that this is not possible and explain why not. My preference is to move slowly, to let her adjust, to make her comfortable with me, with receiving medical care for her condition. I fear that she will get up, leave, and never return. Fortunately, Edna doesn't repeat her request. Perhaps the magnitude of the problem confronting her is starting to sink in.

Edna's breast cancer has been growing for at least nine years. It's unheard-of that cancer such as this would be anything but metastatic. The disease has to have disseminated to her bones, lungs, brain, liver. I feel a wave of frustration and anger.

Another day at Grady Memorial Hospital. Here I sit, talking with a patient whom we would probably have cured nine years earlier, and today I will have to tell her that she has a terminal disease.

The rest is logistics. I arrange for the pathology and radiology to get confirmation. We always get pathologic confirmation of cancer, even when we are almost certain that it is cancer. An old medical saying goes: "When you hear hoofbeats, think horses, not zebras." This saying has an important corollary: "You don't want to be bit on the ass by a zebra." There is a remote possibility that Edna's automastectomy was caused by leprosy or some unusual infectious disease. It's cheap and easy to get verification that it's cancer.

I ask Bill Bernstein to talk with Edna, to take a full history, to perform a full examination. The objective is to rule out neurologic problems from spread of the disease to the brain or spine, to look for other evidence of problems caused by the disease.

If you take me aside and ask why I'm withdrawing from the scene, I will say that I am trying

awaken Bill's compassion. But it is something else as well, something about me. I am afraid of growing callous. I acknowledge this readily, as a means of staving it off. I am trying to avoid accepting the unnecessary loss of yet another life. In the case of Edna Riggs, the abstract, scholarly term *health disparities* acquires a very real smell of a rotting breast.

I take my leave and, with the resident, start arranging tests to confirm the diagnosis and get Edna ready for treatment. We will fight, even though we are going to lose. Metastatic breast cancer always wins. We have drugs to decrease pain and even make most people live longer, but we can beat breast cancer only when it's caught early.

* * *

WE admit Edna Riggs into the hospital, to get the tests done and to start antibiotic treatment of the infected wound. We could have done the workup without admitting her, but I fear that she will leave the system as abruptly as she entered. Psychological and emotional support are legitimate reasons for admittance, though most insurance companies and Medicaid would disagree.

As she starts to trust me, Edna tells me how frightened she was when she found a lump in her breast. Right away, she knew it was breast cancer, and in her experience, everyone who got breast cancer died quickly, painfully. Insurance problems kept her away from the doctor, as did the fear of dying. She knew she would die after going to the doctor. Several of her friends had.

Early on, Edna had some insurance, which didn't do her any good. Her employer wouldn't let her take just two or three hours of sick leave to go to the doctor. If she needed to take sick leave, she had to take it in increments of one day. This guaranteed that an employee would exhaust all the leave quickly. If Edna had been fired for taking time off after exhausting her sick leave, her three kids, too, would have lost support and insurance.

Acknowledging the physical problem and facing the consequences became increasingly difficult. Edna tells me that she feared the disease, but she also feared the system. Would the doctors scold her? Would they experiment on her? Would they give her drugs that caused nausea, vomiting, hair loss? Would the hospital kill her?

Edna's decision to stay out of the medical system was about fear: fear of breast cancer, fear of the medical profession, fear of losing the roof over her kids' heads. Fear intensified after her employer started to require copayments from workers who wanted to be insured. This extra \$3,000 a year made health insurance too expensive to keep.

Payment for medical services and sick-leave policies determine the quality of care we receive. Several years ago, my research team at the American Cancer Society published data showing that people diagnosed with cancer who had no insurance or were insured through Medicaid were 1.6 times more likely to die in five years as those with private insurance.

In breast cancer, patients with private insurance were more likely to be diagnosed with Stage I breast cancer than those who had no insurance or were receiving Medicaid.

In colon cancer, too, the chances of catching the disease at an earlier, treatable stage were lower in the uninsured and Medicaid populations.

Even when the disease was found early, an uninsured patient did worse than one with insurance. For example, an insured patient with Stage II colon cancer had better odds of being alive five years after diagnosis than an uninsured patient with what should be highly curable Stage I cancer.

Another study focused on emergency surgery to treat bowel perforation, peritonitis, or obstruction in colon-cancer patients under age sixty-five. This surgical emergency was 2.6 times more frequent in uninsured patients than in those with private insurance. Among patients receiving Medicaid, the odds

of needing this surgery was 2.1 times higher than in those with private coverage.

ACS epidemiologists estimate that the lack of insurance annually costs eight thousand Americans their lives due to inability to receive cancer treatment. Even controlling cancer pain is no small challenge if you are poor. Uninsured patients cannot afford pain medicines. The social programs that give them medication heavily ration pain meds.

Even if you have insurance that will pay for your treatment, you may still not be able to afford to receive it.

I have seen poor breast-cancer patients choose mastectomy (surgical removal of the entire breast) over a lumpectomy (removal of the tumor) because of employer sick-leave policies. A woman who chooses a lumpectomy must also receive radiation, which has to be given daily, Monday through Friday, for six to eight weeks. The treatment requires fifteen minutes in the clinic, but it's done only during business hours. Unfortunately, this less disfiguring treatment is hardly an option for a woman who knows that longer postoperative treatment will cause her to lose her job.

Most states have laws that require doctors to tell the patients that they have a choice of full removal of the breast or removal of the cancerous lump with follow-up radiation. I do better than that. I tell my patients that I believe that lumpectomy with radiation is a better option, as it is less deforming and likely to lead to less long-term swelling.

* * *

PATIENTS most likely to have the worst outcomes are defined in a couple of ways. Poverty is the biggest driver, followed by race. (Race is complicated. For now, let's think of it as just another snippet of data collected from cancer patients, and delve into its significance later.)

Much of the problem is that poor people don't get care that would be likely to help them. The reasons for this are complex. Perhaps they can't get care, or don't know where care is available, or they haven't been offered insurance or steady access to care by their jobs or social services.

Here is the problem: Poor Americans consume too little health care, especially preventive health care. Other Americans—often rich Americans—consume too much health care, often unwisely, and sometimes to their detriment. The American health-care system combines famine with gluttony.

We could improve dismal health outcomes on both ends of the socioeconomic spectrum if we were simply faithful to science, if we provided and practiced care that we know to be effective.

* * *

EARLY on, Edna ignored her tumor. She accomplished this easily during her busy days, but not when she was alone at night.

The disease progressed relentlessly. The lump grew. Then the tumor broke through the skin, causing a gaping wound, which became infected. The odor caused problems at work. Edna tried to conceal it with body powder and cologne, which worked at first. Her kids started trying to get her to come in and get help several months earlier, after a powerful, relentless stench finally set in.

Since Edna couldn't pay for private insurance and have enough money left over to provide for her family, she had to come to Grady. Officially, Grady treats any resident of the two counties that support it: Fulton and DeKalb. When I arrived in Atlanta in 2001, the hospital was lax in enforcing the residency requirement. It ended up being the hospital for poor people in many surrounding counties, even though only Fulton and DeKalb taxpayers paid. As costs grew, Grady was forced to require proof of residency.

Our doctors are good, but free care comes at the cost of time lost waiting for appointments, waiting for tests. You can spend an entire day waiting for a service that a private doctor's office provides in fifteen minutes or less. People like Edna, who need every day's earnings and who can easily be jettisoned from their jobs, can afford time away from work even less than professionals, who may have some savings and job security. So people like Edna wait until it's impossible to wait any longer, then they come to see us when it's too late.

* * *

WHY do black women end up with more aggressive breast cancer? Is this due to some biological characteristic that correlates with race, perhaps even determined by it? Can there be such a thing as white breast cancer and black breast cancer? Could these be different diseases?

You have to synthesize a pile of statistical data and medical literature to get insight into these problems, but it's worth the effort: You end up with extraordinarily valuable insights into the epidemiology and biology of cancer. More than that, you gain insight into economic structures in our society and, ultimately, something very big: the meaning of race.

At a glance, breast cancer in a black woman like Edna appears to differ from breast cancer in an average white woman. If you plot breast cancer on a spectrum from the worst prognosis to the best, a higher proportion of black women would wind up on the worst end.

One of the most ominous varieties of breast cancer is called triple-negative, because it is immune to three commonly used treatments. The surface of the cancer cell in that form of the disease lacks receptors to the hormones estrogen and progesterone and is similarly devoid of receptors to the HER2/neu protein.

We have drugs that target breast cancer through these three channels. However, in triple-negative breast cancer, these drugs have nothing to latch onto, and all we can do is resort to desperate measures: harsher chemotherapies, which we know are frequently of little or no use.

About 30 percent of breast cancer in black women is triple-negative disease, compared to 10 percent in white women.

This disparity could appear to suggest a biological difference, but in fact it's rooted in cultural, historical, and societal divides. To understand this, we have to look at the potential causes of breast cancer in white and black women.

To start with, let's consider the incidence of better-prognosis cancer among white women. Instead of asking why black women are more likely to get more virulent breast cancer, let's ask why white women are more likely to develop the disease that has a better prognosis.

The answer can be gleaned in part from the incidence statistics.

For the past three decades—or for as long as we have had a national registry—the incidence of breast cancer has been higher in white women than in black women.

In 2000, the National Cancer Institute's Surveillance, Epidemiology, and End Results registry reported that during the previous year, blacks had an age-adjusted incidence rate of 125 per 100,000 women. In the past twenty years, the black incidence rate has bounced between the low of 105 per 100,000 in 1989 to the high point of 126 in 2008.

In 2000, white women had an incidence rate of 143 per 100,000. The breast cancer incidence rate for whites had risen from the 1970s, peaked at 147 per 100,000 in 1999, and has fallen to 129 per 100,000 in 2008.

The incidence rates were substantially apart over the past couple of decades, but have now nearly evened out. Was this occurring because white women were using mammography more and were

therefore more likely to get diagnosed?

Not quite. The proportion of women getting mammography screening is roughly the same among whites and blacks. (I suspect that the proportion getting high-quality mammography is greater among whites than blacks, but this difference has not been adequately studied.)

The delay of pregnancy and childbirth is a more plausible explanation. White women tend to have children later in life than black women. Professional women, regardless of their race, go to college to establish their careers, and then have kids. Delaying childbirth past the age of thirty clearly increases the risk of breast cancer. To be specific, it increases the risk of estrogen-receptor-positive breast cancer, which has a better prognosis.

Also, white women have been more likely to use postmenopausal hormone-replacement therapy (HRT). Doctors prescribed HRT because it made sense logically. Without definitive data on the therapy's biological effect, doctors were, in effect, staging a decades-long societal experiment.

By 2003, 35 percent of postmenopausal white American women had taken this therapy at some time. For cultural and socioeconomic reasons, black women tended not to take HRT. Fewer than 10 percent of postmenopausal black women took HRT. This is important, because HRT is associated with a better prognosis breast cancer.

In 2003, an analysis from the well-designed study called the Women's Health Initiative showed that HRT was correlated with an increased risk of breast cancer. It was actually correlated with a decreased risk of estrogen-receptor-positive, better prognosis breast cancer. The societal experiment was over.

The analysis led to a drop in the use of HRT, which likely accounts for the drop in breast cancer incidence among white women from 147 per 100,000 in 1999 to 129 per 100,000 in 2008.

* * *

A focus on some geographic areas offers insight into what drives breast cancer in educated white women.

Consider Long Island. The area has been known to have a higher incidence of breast cancer than among the general United States population.

In the early 1990s, breast cancer advocates petitioned the U.S. Congress to force the National Cancer Institute to study the "high rates of breast cancer in Nassau and Suffolk Counties on Long Island." This led to Public Law 103-43, which prompted a series of studies, called the Long Island Breast Cancer Study Project.

At the beginning of the project, the incidence of breast cancer among Long Island's white women was 138.7 per 100,000 in Nassau County and 142.7 per 100,000 in Suffolk, compared to 127.8 per 100,000 in the United States as a whole.

Mortality from breast cancer on Long Island wasn't especially elevated. Indeed, several areas in New York State and many areas of the United States had higher death rates. A similarly high incidence was found among white women in the area north of San Francisco Bay.

Could the elevated incidence have been due to electromagnetic fields, hazardous wastes, or some other environmental cause?

After spending at least \$20 million, the Long Island study project did not identify any pollutant that could be responsible for the elevated incidence of breast cancer.

However, those who believed that an environmental factor was at play were right. At least two such factors were driving the disparity between Long Island and the rest of the country: a higher level of education among area women and their choice to delay childbirth.

LET'S return to the disparity in triple-negative breast cancer by race: 30 percent in black breast cancer patients, and 18 percent in white patients.

There is no difference in the proportion of black and white women with progesterone-positive HER2-positive disease. So if we are to focus on the 12 percent disparity, we must look exclusively at the racial difference in the prevalence of the estrogen receptor.

Does *this* suggest that skin color stands for some biological difference?

Not really.

Because of dietary differences that are caused by culture and socioeconomic status, a black girl in the United States accumulates weight much faster than a white girl. In the 1960s, the Centers for Disease Control and Prevention compared the start of menstruation by age. The study showed that the average age of menarche for white American girls was 12.8 years. For black American girls, it was 12.4 years. This is a bigger difference than it might seem. It means that 53 percent of black girls have started menstruating by their thirteenth birthday, compared to 43 percent of white girls.

Body mass index, a calculation based on weight and height, correlates with early nutrition status, which has a lot to do with age at first menstruation. Poor Americans have diets higher in calories and reach the weight of one hundred pounds faster.

Just the simple number of uninterrupted menstrual cycles increases the risk of breast cancer later in life.

The reason for this rapid weight gain in black girls has nothing to do with race, but reflects a high caloric intake and a diet rich in carbohydrates, a socioeconomic determinant of health. It's not about race. It's at least in part about the sort of food that is available in poor areas of inner cities.

The area of Detroit where I grew up and the areas of Atlanta where my patients come from are known as produce deserts. Grocery stores there carry all the chips, sodas, and mentholated cigarettes you may desire, but if you want a head of lettuce, you are out of luck.

You observe the same problems among poor whites, yet you don't see them among wealthy, well-educated blacks.

I cite the CDC data from the 1960s because they measure the racial differences that are driving the breast cancers we are diagnosing today. This disparity has since widened, and if we trace it, we can project the differences in breast cancer rates and prevalence of triple-negative disease for decades into the future.

This extrapolation produces a deeply disturbing picture: the black-white gap in the onset of menstruation and body weight has dramatically widened, which means that the disease disparities will widen also.

FOR the sake of argument, let's set aside everything we know about Grady, Atlanta, and our race-obsessed society. Perhaps the best way to learn about breast cancer is to look at Scotland.

Scotland, which is virtually all-white, collects data at its every-ten-year census using a unique tool called the deprivation index. The index measures socioeconomic factors beyond household income. It asks about indoor plumbing, electricity, even how many servants one might employ. This index can discern that a college philosophy professor earning \$55,000 per year is in a different socioeconomic stratum from a garbage collector earning \$70,000 per year.

Using this index, a group of researchers found evidence pointing to a correlation between soci-

deprivation and incidence of breast cancer that lacks estrogen receptors, a characteristic which makes the disease harder to treat. The deprived or poor who developed breast cancer were more likely to develop this kind of breast cancer. I find it ironic that one of the most important studies in minority health was an all-white study.

My friend Samuel Broder, when he was the director of the National Cancer Institute, used to say that poverty is a carcinogen. Skin color can be a marker of some sort, but you have to be careful not to rely on it too heavily. Wealth is a marker, too, as is education. Area of geographic origin and family history are also important, and all these factors must be considered.

* * *

EDNA has Stage IV breast cancer. Disease has spread all over her body. Had she come to see me earlier in the course of her disease, it would have cost about \$30,000 to cure her. She could have remained a taxpayer. Her kids could have had a mother. Now, the cure is not an option. Still, we'll fight. We will give her breast-cancer chemotherapy that will cost more than \$150,000, even though the chances are that she will still die in less than two years. If you are a caring doctor, you realize she is just fifty-three with kids and folks who love her, and your motivation is akin to a philosophy of Wayne Gretzky: "You miss every shot you don't take."

Every time I start chemo for metastatic disease I think of a patient named Sandra, a lively, young black woman whom I have treated for six years. She had brain metastases when I first met her. She has had active disease ever since, and even the doctor who sent her to me reminds me every time he sees me that he is amazed that she is alive, functional, and enjoying life.

Yes, sometimes cancer drugs give us "long-term survival," in the dispassionate language of those of us who study outcomes. But for every Sandra, we get fifty patients with metastatic disease who "don't do well." They live a median eighteen months, which means that half are living and half are dead a year and a half after diagnosis.

We try three treatments and contain Edna's disease for a while. She dies at age fifty-five, about twenty months after walking into the ER.

Chapter 2

Brawleyism

MY GREAT-GREAT-GRANDFATHER Edward McKnight Brawley was a free Negro born in Charleston, South Carolina. In the 1880s, Edward, who was a Baptist minister and author of a textbook on evangelism, moved his family to Selma, Alabama, to become president of Selma University, an all-black school.

His son Benjamin became one of the premier black intellectuals of his generation. He was educated at Morehouse College, Harvard University, and—like me—the University of Chicago.

Benjamin was the dean of Morehouse and later the chairman of the English Department at Howard University. He was a literary critic, poet, writer, historian, and sociologist. A building at Morehouse is called Brawley Hall. There is a Brawley High School in Scotland Neck, North Carolina. He was quoted by his peers, including the historian W. E. B. DuBois in his treatise *Black Reconstruction in America*.

A biographer describes Benjamin as an intellectual inclined “to move simply as an American citizen in a democratic society.” Liberal arts education and cultural advancement were his weapons of choice in the struggle for the rights of the Negro people.

In the thirties, the writers and literary critics of the Harlem Renaissance turned my great-uncle's name into a disparaging political moniker: *Brawleyism*. To a movement fueled by jazz, outrage, and the politics of the left, Benjamin seemed bourgeois. While his detractors expressed themselves in an unrestrained manner, Benjamin wrote Victorian verse and uplifting biographies of black Americans who were as worthy of admiration as the founding fathers. Benjamin's 1937 book, *Negro Builders and Heroes*, for example, profiles Frederick Douglass, Harriet Tubman, Sojourner Truth, and Booker T. Washington. A section is also devoted to his father, my great-great-grandfather.

Benjamin fought back, accusing his critics of excessive emphasis on the experience of the underclass and overlooking stories of triumph against the odds.

I admire people on both sides of that debate, and I don't side with either Benjamin or his detractors. There is no need to choose. The experience of the underclass cannot be ignored, yet there is no reason to diminish the achievements of Negro builders and heroes.

I view this half-forgotten schism of the pre-civil-rights era in the broader context of a continuum of human struggle against injustice, which goes beyond race and encompasses basic human rights including the right to decent health care. The debate is raging still, and as chief medical officer of the American Cancer Society I list myself among its participants.

In this debate, I consider myself more fortunate than Benjamin Brawley. My form of Brawleyism plays out in science, which—unlike literary criticism—can produce measurable, reproducible results

THIS book is a guided tour of the back rooms of American medicine. When I was fresh out of the University of Chicago medical school and newly admitted behind the curtains of these back rooms, I could dismiss medical horror stories as isolated episodes of the malfunctioning of the system: another person overlooked, another judgment error, another example of bum luck, another case of the frustratingly slow march of progress.

More than a quarter century later, I have seen enough to conclude that no incident of failure in American medicine should be dismissed as an aberration. Failure *is* the system, and those of us who are not yet its victims are at high risk of being sucked into its turbines.

My friend and colleague Peter Bach is fond of saying, “America does not have a health-care system. We have a sick-care system.” Peter, a health-systems researcher and a pulmonologist at Memorial Sloan-Kettering Cancer Center, goes on to say that it’s a stretch to use the word *system* to describe our health care because this word denotes organization.

Too often, helping the patient isn’t the point. Economic incentives can dictate that the patient be ground up as expensively as possible with the goal of maximizing the cut of every practitioner who gets involved. When we, doctors, are at our best, we set aside our self-interest and put the patient’s interest first. When we aren’t at our best, the public pays more in fees, insurance premiums, taxes, and poor outcomes.

I get furious every time I hear politicians and pundits assert that the American health-care system is the best in the world. I heard this far too often from opponents of the 2010 health-care reform bill. I can think of several explanations for repeating this falsehood. Ignorance is the first and most elegant. Being out of touch with reality would explain it, as would lying, either to ourselves or to others.

America is the greatest place in the world to get care for a complicated but treatable disease if you have the ability to get the care and pay for it. It’s not a great place to be sick if you are poor and uninsured or want consistent, basic care.

When you look at outcomes, our health-care system—technology notwithstanding—is closer to Communist states, both former and current, than to other technologically advanced nations.

The CIA publishes a lot of information that is publically available. The agency’s data notes that life expectancy for Americans is 78.37 years. This makes us No. 50 among nations. Taiwan is No. 5, Monaco is on top, with the life expectancy of 89.73 years. Canada is No. 12, with 81.3 years, the United Kingdom is No. 28, with 80.05 years.

Some argue that this comparison is inappropriate since the United States has high homicide and accident rates compared to other first-world countries. I argue that this is the very point. Homicide and accident prevention, and other preventive health measures are a part of the health-care system and are recognized as such by most outside this country.

Life expectancy is heavily driven by infant mortality rates. This is not an area where we have much to be proud of. Forty-four countries have better infant mortality rates than the United States, including Cuba and Slovenia. This means that compared to a lot of other countries—many of them vastly poorer than us—we have a problem getting good care to pregnant women and babies.

And we pay a lot for mediocre results. Per capita, our health-care spending is the highest in the world. Here we are, indeed, No. 1. The No. 2 slot belongs to Switzerland, but our spending exceeds theirs by 50 percent. Americans spend two and a half times more on health care than on food.

Health care’s share of America’s gross domestic product is expanding. It jumped to 17.3 percent in 2009 from 16.2 percent in 2008—the largest single-year increase since 1960. At the current rate of growth, health-care costs are predicted to jump to \$4.5 trillion in 2019.

At that point, health care will account for 19.3 percent—almost a fifth—of our gross domestic

product. Some estimate that these increases are on course to make health care account for 25 percent of our economy by 2025.

Conservative pundits and politicians are fond of maligning the Canadian health-care system. Yet Canadians spend half of what we do per capita. Switzerland is ranked tenth in life expectancy, and Canada is seventh. As No. 50 and the biggest spender by far, we aren't getting what we pay for.

Efforts to slow the expansion of our health-care system predate my career in medicine. Twenty-five years after I earned my white coat, from all my vantage points—as a doc on the ward, as an epidemiologist, and as a policy-maker—I see the same picture: our medical system fails to provide care when care is needed and fails to stop expensive, often unnecessary, and frequently harmful interventions even in situations when science proves these interventions are wrongheaded.

From my vantage points, I see that one painfully obvious approach to health-care reform has never been tried: No one has tried to make the entire system function rationally, based on science.

I devote a lot of time to studying the huge disparities in outcomes observed in the United States. *Disparities in outcome* is a euphemism for needless suffering and needless deaths. And these disparities in health results are often linked to the ability to pay.

In the back rooms of American medicine, the analysis of the patient's financial durability has a glamorous name: *a wallet biopsy*. If it returns positive, you stay in the hospital, you get more treatment, you call to make a follow-up appointment. If it returns negative, you have little hope of getting consistent care.

Off the top, the wallet biopsy denies quality health care to the almost 51 million Americans who have no insurance. Often they get care of appalling quality or no care at all until they become sick enough or old enough for government benefits to kick in. As soon as this happens, the system welcomes them as sources of revenue, because even at Medicare and Medicaid coverage rates, you can make money on uncontrolled diabetes, kidney failure, heart disease, and late-stage cancer.

Here's a secret: wealth in America is no protection from getting lousy care. Wealth can increase your risk of getting lousy care. I spend a lot of time explaining to wealthy, insured patients that the treatments they are convinced they need can't be expected to make them live longer or better lives. (In the following pages I will describe many such conversations.) When wealthy patients demand irrational care, it's not hard to find a doctor willing to provide it. If you have more money, doctors sell you more of what they sell, and they just might kill you.

It's regrettable that the most recent round of debates over health-care reform focused on alleged threats to ration health care—that "death panels" would be formed to save money on caring for the rich and spend it on caring for the poor was an effective scare tactic. People who scream about the rationing of health care fail to mention that rationing is already happening. My colleagues and I, as good doctors, are always arguing with health insurance companies that want to reduce costs by telling us we cannot perform a particular test or use a particular treatment.

Opponents of health-care reform have misstated our national dilemma. Health care is being rationed, while at the same time, irrational spending on unproven care is rampant.

I am not especially concerned about the rationing of health care. I am more concerned about something else entirely: rational use of health care. The problem is, we don't use our expensive drugs and technologies appropriately. Instead of using these interventions to benefit patients, we use them to maximize revenues, and often harm patients. If we could learn to practice medicine rationally, the money we would save would help us provide the most basic care for those who are now shut out of the system. Health care for the rich would benefit as well, because in medicine gluttony equals harm.

A rational system of health care has to have the ability to say no, and to have it stick. This is the only way to protect patients from misguided, scientifically unproven interventions, to cut out wasteful

fraud, and abuse. Those who pay—private insurers or the government—need to be able to protect the public from the miscarriage of medicine.

Denying useless treatment needn't be motivated by saving money. Let's focus on not doing harm, refraining from peddling snake oil and false hope. I empathize with a patient who views an unproved procedure as her only hope for living longer, but I have nothing but contempt for a medical practitioner who labels bullshit "hope" and profits handsomely from it.

It's possible to provide better care at a lower price. It's possible to be justly proud of our scientific and technological achievements and provide quality and consistent primary care.

It's possible to have innovation and quality and access and lower costs.

There is no need to choose.

* * *

I am not worried about breaking ranks. I look forward to it.

Some of my colleagues are willing to play the game, realizing that care—even useless and inappropriate care—makes cash registers emit pleasing sounds. We doctors are paid for services we provide, a variant of "piecework" that guarantees that we will err on the side of selling more, sometimes believing that we are helping, sometimes knowing that we are not, and sometimes simply not giving a shit.

Would a doctor who sells radiation therapy tell you to go across the street to get chemotherapy, even in cases where studies show that it's more appropriate? Would either of these medical entrepreneurs advise you to wait for six months to see whether your disease is of the sort that would actually harm you? All too often, the answers to these questions are no.

The financial incentives that drive the medical community have a devastating impact on patient care and health-care costs, and we will not change unless we are forced to change. Doctors who own laboratories have been shown to order more tests than doctors who don't. A doctor at a for-profit practice is more likely to prescribe the treatments that benefit him the most. I've heard of community oncology practices that hold regular meetings to inform doctors about treatment techniques that maximize billing.

When money is to be made, the system can be proactive, again to the detriment of the patient. Call it "disease mongering" or call it the marketing of disease, but as I write this, a fleet of aquamarine, white, and blue mobile homes is bringing prostate cancer screening to a shopping-mall parking lot near you. These things are long, thirty-nine feet, plenty of room. Come aboard! The blood test is free, but the cascade of follow-up services will ring up considerable sales for treatments that leave guys impotent and incontinent. Treatment that *may* have a minuscule chance of saving them from cancer, but have a much larger chance of treating a cancer that would never have harmed them, or may not even have been there in the first place.

Improvements in health come at a cost, but in the case of prostate cancer, no one has shown a clear improvement in mortality. Despite concerted efforts, screening for prostate cancer has not been clearly proven to decrease men's chances of dying of prostate cancer. But that doesn't mean there isn't money to be made; recently, I noticed that Zero, an advocacy group that operates these screening vans, receives funding from the makers of Depend diapers.

I know doctors who are just plain bad. Why do they continue to practice without impediment? The answer is simple: because no one is looking over their shoulders, no one files a disciplinary complaint, no tribunal of peers punishes them unless they do something spectacularly awful. No one is better suited to police the profession than the profession itself. But our professional societies tend to choose

misguided collegiality over the well-being of our patients, the people who trust us with their lives.

~~I will show how we academic physicians who practice in nonprofit institutions such as Emory are~~ not pristine either. If you don't watch out, we'll sell you on a clinical trial that will get our names on scientific papers, but not necessarily be appropriate for your disease. Even as academics, we may be motivated to maximize billing to support our departments. Or we may simply be enthusiastic about the procedures and therapies we are trained to deliver.

It's not easy to challenge doctors to justify their decisions in the clinic. As we'll see, it's harder still to challenge a wrongheaded consensus of a medical specialty as it marches in lockstep. This is precisely what happens when professional societies of doctors who perform expensive medical procedures issue "evidence-based guidelines" that are anything but evidence-based guidelines. Instead, the purpose of many of these documents is to protect the specialties' financial stake in the system.

Why not just say no to the special-interest groups that peddle interventions that generate billions while doing harm?

Why not center the system on benefiting the patient, not the people who profit from lying to the patient?

Why not set realistic, scientifically based goals for treating our patients?

Why not teach doctors to start using the simple words *I don't know*?

Why not teach doctors and insurers to say no to patients who are determined to get care that has no scientific basis?

Why not stop treatment when—scientifically, based on evidence—there is nothing left to do?

* * *

IF the wreckage of health-care reforms attempted over the past twenty-five years is an indication, change from above will not get the job done.

Yet, high-quality health care for all is as much a civil rights issue as is one man, one vote. In health care—as in voting rights—real change will have to come from below, not only from patients, but from all of us as citizens.

Sadly, patients who understand the system are a small, politically insignificant minority. The majority is placid at best, confused at worst. Many patient groups act as unquestioning advocates for pharmaceutical companies and medical specialties, failing to realize that the interests for which they advocate run counter to their own.

In the most recent round of reform, we saw special-interest groups of all sorts coming to the defense of their entitlements. It was hard not to notice the opponents of change, but if there was even a trace of a public movement on the part of proponents of change, I missed it entirely. Political moderates and progressives remained silent even as debates became dominated by Tea Party conservatives and fictional characters created by PR firms on behalf of business interests.

Proponents of science as a foundation for health care have not come together to form a grassroots movement, and until this happens, all of us will have to live with a system built on pseudoscience, greed, myths, lies, fraud, and looking the other way.

Patients need to understand that more care is not better care, that doctors are not necessarily right, and that some doctors are not even truthful.

Genuine health-care reform—like the right to vote—will not be granted magnanimously. Like civil rights, the right to good health care will have to be won in public struggle. To bring about real change, real people will have to say, "Enough!"

I draw on the best source of information available to me as a physician: patients. What role did the health-care system play in their disease? Have my colleagues made treatment decisions based on the patients' interests or based on self-interest? Have I been able to mitigate harm, or have I caused it? How have we doctors caused harm? Through uninformed but billable trial and error? By denying care? By providing the wrong care, or too much care?

Although the stories in this book are true, names and identifying characteristics of patients have been changed to protect their privacy, except in cases where individual patients went public with their struggles. The names and identifying characteristics of physicians have also been changed to protect their privacy, except where I discuss their scientific publications. In clinical anecdotes, I note when doctors are identified by their real names. The views expressed here are not those of the American Cancer Society or Emory University.

And, of course, the views expressed by the authors of this book are not intended as a substitute for medical advice, diagnosis, or treatment provided by the reader's personal physicians.

Chapter 3

Cadillac Care

WHY DO I WORK at Grady?

To do some good, if I can.

That's part of my motivation, but not all of it. I go to Grady for reasons that wouldn't surprise my grandfather Willie Brawley. Willie, Benjamin's nephew, was a sharecropper.

I can see that in 1930 a man whose name matches my grandfather's was listed among inmates at the Wetumpka State Prison in Alabama. It could be him. According to a family story, he became a union organizer and was lynched in 1948. My family didn't treat his death as something to be proud of. Even my grandmother—his wife, whom I knew well—didn't talk about him much.

As a black man and a union organizer in the South, he surely understood what he was up against. Apparently nothing beckons a Brawley more powerfully than a hopeless cause, and I hear its call of the PA system at Grady. I go to Grady to understand where we are betraying our patients, where we are betraying ourselves, and how we can learn to do better. If you want to stay grounded, Grady is the place.

Respect for people I knew growing up in Detroit could be a part of it, too. As I grow older and more experienced, I become increasingly amazed by the wisdom of those folks. When you are black and poor, you are by definition a survivor, and survivors have reasons to be suspicious. My parents and their friends didn't trust doctors, didn't trust hospitals. A hospital was the place where they withheld treatment or where they tried things on you without telling you what they were doing and why.

White doctors think that we—black folks—worry about becoming unwitting subjects of medical experiments. That's not quite it. Folks I grew up with were worried that the doctors who treated them had no idea what they were doing, that they were experimenting, trying various drugs or treatments hoping that something might finally work. My family members were afraid they would pay the price for exercises in trial and error. It was about trust.

When I was starting my career in medicine, I was contemptuous of such thinking. Initially, I dismissed these folks as outsiders who were suspicious of the system that excluded them. Now, having seen the way medicine is commonly practiced, I see that they were right to be suspicious.

Now I wonder, can all of us benefit from a dose of skepticism? Can the health-care system make itself trustworthy, become accessible and driven by science?

* * *

I begin my search for answers at Grady, where patients are vulnerable, contrasts stark, lessons harsh. Yet, these are not entirely stories of desperation. Since we take patients no one wants, and without

expectation of payment, we are immune to market pressures and the plethora of perverse incentives that spread dysfunction through the health-care system.

Thus shielded, we can—often—provide better care than doctors who treat the rich. Also, any care provided at Grady has to be based on solid evidence. I am not suggesting that Grady is perfect. It has many flaws that come with underfunding, and many challenges that come from caring for the uninsured. Yet, at Grady, an effort to disregard science will be shot down fast.

The technical term for millions of people like Edna Riggs is the *underserved*. Edna didn't receive medical care until the manifestations of her disease became catastrophic. Another of my breast cancer patients—Helen Williams—started out on the opposite end of this scale. She had the most advanced care Atlanta had to offer.

* * *

IN 1990, Helen, then fifty, finds a lump in her breast. Without delay, she goes to her gynecologist, who sends her to get a mammogram. The tumor can't be seen on the image, but the gynecologist does the right thing. He refers Helen to Luther Smith, one of the best-known breast-cancer surgeons in the Southeast.

Smith performs a needle biopsy, which leads to the diagnosis of breast cancer. The tumor looks aggressive under the microscope. Though scared, Helen reminds herself of her good fortune. She is married, her kids are grown, her job benefits at a financial-services company include excellent health insurance, and she is discerning enough to demand the best treatment modern medicine can provide.

The tumor turns out to be four centimeters in its maximum size—quite large. Altogether, twenty-one lymph nodes are resected, and all prove negative. This means that the disease may not have spread. The biology of the tumor is worrisome. It's estrogen- and progesterone-receptor negative, meaning hormonal therapies cannot be used. Hers is the sort of high-grade, aggressive disease that is more likely to occur in black women than in white women. This mixed bag of good and bad characteristics translates into the diagnosis of Stage II disease.

Helen is offered a choice of surgical procedures: a lumpectomy and radiation or a mastectomy. She chooses mastectomy. The insurance company doesn't object. The company also pays a plastic surgeon to rebuild the breast. She is offered postsurgical chemotherapy. Insurance agrees to pay for this, too.

This scary time has a special meaning for Helen, who had witnessed the civil rights movement and integration transform Atlanta in the sixties, seventies, and eighties. Here she is, a black woman in the South, getting Cadillac care. She feels fortunate.

Smith, the surgeon, refers Helen to his favorite medical oncologist, Norman Kuhn, who is known for an especially aggressive approach to treating breast cancer. The oncologist explains that a strong dose of chemo is better than a weaker dose. "More is better" has been a hallmark of the oncology profession since the 1950s: the more chemotherapy you administer to the patient, the more effective it is in terms of killing the disease.

Kuhn has treated a lot of breast cancer, and he favors a take-no-prisoners technique for "adjuvant"—postsurgical—therapy. This is a procedure in which we give chemotherapy drugs after surgery to eradicate cancer that was too small to be seen by the naked eye in the surgical area, or too small to be seen with radiological imaging if it has spread to the distant organs, including the liver, the lungs, and the brain.

The oncologist's plan for Helen's treatment seems logically compelling: a high dose of drugs will be used to kill all the cancer cells that might be hiding in her body. The doses will be so high that the bone marrow—an innocent bystander—will be destroyed. It used to be that this much chemo would

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