LAURIE KAYE ABRAHAM

With a New Foreword by David A. Ansell, MD

Mama might be

The University of Chicago Press • *Chicago and London*

better off dead

THE FAILURE OF HEALTH CARE IN URBAN AMERICA

Contents

Foreword
vii

Preface
xiii

Acknowledgments
xv

Introduction
1

1
"Where crowded humanity suffers and sickens":
The Banes family and their neighborhood
9

2
The rigors of kidney dialysis for Robert Banes
25

3
Gaps in government insurance for Mrs. Jackson
44

4
Fitful primary care fails Mrs. Jackson
60

5
Mrs. Jackson's melancholy
77

6
The inner-city emergency room
93

7
One hospital's story: How treating the poor is "bad" for business
111

8
Who's responsible for Tommy Markham's health?
134

9
Jackie Banes's "patient"
146

10
Empty promises: Preventive care for the Banes children
167

11
Robert Banes plays the transplant game
179

12
The Banes family and white doctors
198

13
Life-sustaining technology
213

14
Amazing grace
232

Epilogue
247

Appendix
261

Notes
263

Introduction

In the fall of 1991, Harris Wofford, a relatively unknown Democrat from Pennsylvania, won a seat in the U.S. Senate after making sweeping health care reform the centerpiece of his campaign. The victory surprised politicians, who had expected his opponent, Richard Thornburgh, the U.S. Attorney General for the first three years of the Bush administration, to coast into office. Wofford subsequently became a symbol of Americans' dissatisfaction with the health care system and desire for change. A January 1992 survey showed that the public ranked health care as one of the top three issues the country's leaders needed to address,[1] and ten months later, Bill Clinton took advantage of that. Campaigning for president on a platform of change, he made fixing the nation's ailing health care system one of his top priorities. As of the spring of 1993, it was not clear what shape health care reform would take under a Clinton administration, but the new president certainly had no shortage of proposals from which to choose. A 1992 article in the *Journal of the American Medical Association* summarized just the "important" health care plans sitting on the nation's plate; there were forty-one of them.[2]

The millions of uninsured Americans and the spiraling cost of health care received progressively more attention through the last half of the 1980s. But what finally pushed health care reform to the top of the national agenda, many believe, was the discontent of the middle class. Middle-class families with sick children were being priced out of group insurance, even plans offered by large companies; others were stuck in dead-end jobs because "preexisting medical conditions" prevented them from getting insurance from a new employer; and still others lost medical coverage when they were laid off during the economic recession that began in mid-1990.

In some ways, this book has nothing to do with the insurance woes of the middle class; in others, it has everything to do with them. At the book's center are four generations of a black family who live in one of Chicago's poorest neighborhoods, called North Lawndale. The grandmother, Cora Jackson, was sixty-nine years old when I first met her in May 1989, and trying to cope with myriad chronic conditions, including high blood pressure and diabetes. She lived with her granddaughter, Jackie Banes, who cared for Mrs. Jackson as well as her own three children and her ailing husband, Robert. His kidneys failed when he was twenty-seven, and he then needed dialysis treatments three times a week to stay alive. Finally, there is Jackie's father and Mrs. Jackson's son, Tommy Markham, who was only forty-eight when he was disabled by a stroke caused by uncontrolled high blood pressure.

For the past three years, I have moved in and out of this family's life in an attempt to discover what health care policies crafted in Washington, D.C., or in the state capitol at Springfield, look like when they hit the street. This book provides a qualitative description that is now missing in our understanding of the much-studied problem of lack of access to care. As a reporter who has covered public health first for a socioeconomic medical newspaper and then for an investigative publication focused on race and poverty, I had written repeatedly about the big picture: high infant mortality rates, the surging uninsured population, the scourge of AIDS. Only by following a family for an extended period of time, however, was I able to get beyond the one-time tragedies and endless flow of health statistics that make the news and begin to understand the oft-repeated phrase "lack of access to care." It can be a slippery concept to grasp, perhaps because its meaning has been deadened by overuse but also because, for the poor, it manifests itself in more subtle ways than their being uninsured—ways that are inconceivable to most of us. I came to know Jackie Banes not as a helpless victim but as a resourceful woman who tried to work the health care nonsystem to the best of her ability. The lengths to which she went to get basic care for her family are one testament to the inadequacy of health care for the poor. The other is that her efforts so often failed.

Cradle-to-grave, this family has been largely left out of a health care system that is one of the best in the industrialized world for those who are affluent and well insured and embarrassingly bad for those who are not. Ten, even five years ago, those of us in the middle class

might have dismissed the poor's struggle to get decent health care as something we would never come close to experiencing. No longer. Most everyone has a relative or friend who is uninsured and crossing her fingers, or who is overwhelmed by huge medical bills or insurance premiums. So far, their hardships may not have approached those the Banes family encountered when they tried to get medical care, but their experience carries a warning for us all: things will get worse, provided that private insurers continue the trend toward pushing all but the healthiest and wealthiest from their rolls, leaving the rest either uninsured or reliant on what are currently inadequate public programs.

But this book was not intended to persuade the middle class that some kind of health care reform is in their personal best interest. Just as doctors use CAT-scans and other instruments to uncover disease, this book exposes glaring inequities in health care access and quality that exist between the moneyed and the poor, inequities that existed long before the middle class began to feel the pinch. The place to start is with the uninsured. The poor are more likely to be uninsured than anybody else, and as Tommy Markham said: "You could be damn near dying, and the first thing they ask is 'Do you have *in*surance?'" Though his words succinctly express his indignation toward a system based on ability to pay, this book suggests that perhaps the *only* time the uninsured have a good chance of getting timely, quality care is when they are damn near death.

Robert Banes could not get reliable, steady medical coverage until his kidneys failed, and it took a stroke for Tommy Markham to get the same. Neither have held the kind of jobs that provide health insurance, and serious sickness or disability often are the only tickets to government health insurance for poor, single men under sixty-five.[3] During Jackie's first pregnancy, she was uninsured and delayed getting prenatal care for six months, when she went to one of the few places where the uninsured are certain to get care, if only after daylong waits: the emergency room of the city's overburdened, underfunded public institution, Cook County Hospital. Though no one would choose to have a baby at Cook County, where pregnant women are herded into narrow stalls like cattle and labor side by side separated by thin curtains, Jackie was lucky in some ways to have County to go to. Public hospitals in other cities, most notably Philadelphia, recently were forced to shut their doors when government support dried up.

Once Jackie gave birth to Robert's daughter Latrice, she and the

little girl were covered by Medicaid—at least as long as Jackie stayed unemployed. Medicaid, the state and federal health care program for the poor, has never lived up to its promise to eliminate the country's two-tiered system of health care. First, Medicaid income restrictions are so tight that the program covers less than half of the poor, defined as those Americans who fall under the federal poverty level. Most of the working poor were and still are excluded from Medicaid and thus are uninsured, although some of their children are being progressively added to the program under reforms that began in the late 1980s. Those who manage to get Medicaid have struggled to find decent doctors. Medicaid pays physicians well below the rates of commercial insurers, and doctors perceive the poor as "difficult" patients, sometimes with reason. Poor patients' ailments are made worse by delays in getting care, and they show up at doctors' offices with more of what one physician called "sociomas," social problems that range from not having a ride to the doctor's office, to drug addiction, to homelessness, to the despair that accompanies miserable life circumstances. As for the physicians who do practice in poor neighborhoods, they may be there only because they are not good enough to work anywhere else. Poor families usually have no way of knowing whether local doctors are up to snuff, even when they have been disciplined by state medical regulators.

While Medicaid recipients are exceedingly vulnerable to the vagaries of state and federal budgets—benefits are cut when times are tight or whole categories of people are eliminated from the program—Medicare is an entitlement program that covers most Americans who are older than sixty-five and certain disabled people. Because Medicare is an entitlement, the federal government cannot cut people from the program willy-nilly. Payments to doctors and hospitals can be reduced, however, and they have been, though Medicare still pays much better than Medicaid, and its lower rates have not seriously curtailed the elderly's access to city doctors and hospitals. What bedevils the poor, as Cora Jackson could attest, are Medicare's gaps. It does not pay for medication, for transportation, for many basics that may sound wholly affordable to those with generous pensions or insurance to supplement Medicare. But such essentials strap the poor, who often end up going without.

The Banes family also faced a special set of hurdles because they are African American. The long wait Robert and other blacks face

when they seek kidney transplants—almost twice that of whites—is a good example. While some of that is rooted in blacks' disproportionate poverty and even biological factors, subtle racism also came into play. Far too often health professionals tended to downplay the effect of race on their interactions with patients or the distribution of resources, and sorting out the influence of race from poverty was not always possible. But race had an undeniable effect in one particularly striking way. The history of hideous medical experimentation with black subjects, and its present day vestiges, made many blacks I interviewed suspicious of the medical system and sometimes compromised their access to care. More than a year after I met the family, I discovered that Tommy Markham had participated in a kind of medical research that today would be unthinkable. His experience helps to explain the persistence of AIDS conspiracy theories among blacks, something many whites perfunctorily disregard as paranoia.

While Medicaid and Medicare have failed poor patients, they also have failed to sustain the institutions that serve them. They, too, are a major part of the story of health care for the poor. The evolution of Mount Sinai Hospital Medical Center, which started the century treating poor Jewish immigrants and ended it treating poor blacks and Hispanics, provides ample evidence of the distortions in a system driven by the relative generosity of insurers. With Medicare and Medicaid paying at cost and below, hospitals have come to rely on a perverse system of cost-shifting: that is, covering the costs of uninsured, Medicaid, and Medicare patients by charging the privately insured higher and higher rates, which in turn increases the premiums employers and workers pay and contributes to the middle-class health care squeeze. It is a game of dominoes, but one that Mount Sinai and other hospitals that treat mostly poor patients cannot play. Only 6 percent of Mount Sinai's patients are covered by commercial insurance, leaving the hospital without shifting room. "It's hard to cost-shift 94 percent of your business to 6 percent," said Charles Weis, the institution's chief financial officer.[4]

Financial realities like these explain why Mount Sinai, which sits in the heart of North Lawndale, one of Chicago's sickest and poorest neighborhoods, spent much of the 1970s and part of the next decade trying to replace local patients with those from other parts of the city

and the suburbs. It is not that Mount Sinai's leaders were particularly cold-hearted or greedy; rather, that is the way most hospitals did and continue to do business. Mount Sinai does not try to fight the inevitable anymore; more than perhaps any other hospital in the Chicago area, its leaders have chosen to devote the institution to serving its natural constituents, the poor. But only great ingenuity and commitment have allowed the hospital to survive, and it still continues to finish most years in the red. As one Chicago health care pundit put it, "I can't tell you Sinai won't go down in a year. Springfield [the state capital] could do it, a lot of things could do it." Hospitals in impoverished areas nationwide have fallen in great numbers, which sets up another game of dominoes, one in which the poor and their institutions are again the losers. The more hospitals that close, the greater the burden on those that remain and the higher the chances that they, too, will succumb. More is less for hospitals when more is more patients who cannot pay their way.

I observed the Baneses' interaction with dozens of doctors, nurses, and assorted health care workers during the course of researching this book. One discovery that at first surprised me, though in retrospect is completely understandable, was that the best of the lot had strong religious ties. Three of those people are discussed in some detail: Sister Mary Ellen Meckley, a home social worker and nun since her teens; Dr. Burton Stone (not his real name), an Orthodox Jewish internist who bases his practice at Mount Sinai; and Dr. Arthur Jones, an internist and urban Christian missionary who founded and runs a community health center for the poor near the Baneses' apartment. What set them apart was the compassion and respect they showed their patients. That is not as easy or common as it sounds. Benn Greenspan, president of Mount Sinai, described a hospital staff simmering with an anger that occasionally erupted. "What does it do to you when every day of your life you try to fulfill your professional responsibilities with less resources than you think you should have, with poorer [health] outcomes than you know you could get someplace else? You get angry, and you can take it out on your patients." Considering that the medical system is set up to reward doctors and other health care workers who care for not the sick but the sick and insured, I should have expected that those who did their jobs with uncommon skill and grace would have incentives other than the ordinary.

Dr. Stone, Dr. Jones, and Sister Mary Ellen worked in primary care,

the front line of medicine designed to detect and treat illness before it becomes serious and costly. It is in this area that shortages are most dire in poor neighborhoods, as the crowds who seek basic care in Mount Sinai's emergency room attest. Once again, the medical reimbursement system takes much of the blame for discouraging physicians' interest in primary care, biased as it is toward acute, high-technology care.

During a meeting with Dr. Jones, I watched him read the results of electrocardiograms, tests that diagnose disorders of the heart. They were printed on strips of paper that Dr. Jones glanced at for a few seconds each. "See how long it takes me to read one of these," he said, disgusted. "And I get $8.65 for each of them [from Medicaid], versus $18.00 for a twenty to thirty minute office visit. It doesn't pay to sit and deal with people's emotional problems. It pays to do a procedure where all you have to do is walk in and walk out." The government has begun to try to correct some of the imbalances in Medi*care* payments, which may seep over into Medicaid, but the changes probably will not be big enough to lure many more doctors into primary care, especially in poor neighborhoods.

Yet Dr. Jones's half-hour sessions of explanation, the time for give-and-take between him and his patients, are as important to the poor as well-equipped hospitals and clinics. Lacking the education or confidence to push doctors and others for the information they needed, members of the Banes family often were in the dark about what was being done to them. And confusion sometimes turned to anger and alienation.

The indifference to primary care reflected in the medical reimbursement system is mirrored by the devaluing of public health programs. Among other achievements, public health has benefited masses of Americans by controlling contagious disease and ensuring safe food and water, but the functions performed by local and state public health departments historically have been shortchanged, the legacy of which has tragic results for poor families. Despite a 1989 measles epidemic that killed nine Chicagoans, I found that the city Department of Health clinics, key providers of immunizations for poor children, were unorganized, understaffed, and unable to sustain a strong, consistent immunization campaign.

Medicaid, which is administered by the state's welfare department and sponsors its own program to promote immunizations and preven-

tive care for children, was just as bad, if not worse. The chapter on preventive health care for children may have been the most sobering to write. If the public and private medical system has not found the will or the way to get basic preventive care to poor children—who, politicians insist, receive the highest priority—is it any wonder that poor women are dying in large numbers from cervical cancer, a preventable disease that can be detected by a simple pap smear?[5]

The Banes family was wonderfully generous with me. All they received in return for letting me snoop around their lives was a chance to share their troubles, perhaps, little else. My hope is that their story—and the stories of the hospitals and clinics that are barely surviving in poor neighborhoods—will be taken seriously by the leaders calling for change in America's health care system. Any reform plan that aspires to be both effective and just must pay careful attention to the day-to-day experiences of poor families. Anything less is not worth the effort.