

Good For Harvest, Bad For Planting

When a kidney transplant is strangely slow to happen, a young physician ponders why—and reaches a decision.

BY VANESSA GRUBBS

I COMPLETED MY GENERAL MEDICINE RESIDENCY TRAINING a few years ago at a San Francisco Bay Area public hospital. A recent experience, however, brought clarity to a disturbing observation that I didn't question at the time. Although we young doctors were often reminded to inform the donor transplant network of every impending death, not once in my three years of training did I hear a nephrologist (kidney specialist) talk about referring anyone from our mostly black patient population for a kidney transplant. I knew that a myriad of patient factors eliminated most from consideration—serious illnesses in addition to kidney failure, ongoing alcohol or drug abuse, or a lack of “social support”—all of which were, unfortunately, too common among our patient population. Later, through a personal experience with the kidney transplantation system, I came to suspect a systemic explanation for why blacks often make for good harvest but are disproportionately left fallow when planting time comes.

My experience came through my partner, Robert, who is African American, as am I. Robert had end-stage renal disease as a result of focal segmental glomerulosclerosis, a kidney disease of unknown cause that was diagnosed when he was sixteen. His kidneys stopped working completely when he was twenty-six, at which time Robert began dialysis.

He had been on dialysis for nearly five years when we started dating. Admittedly, I was hesitant to get involved with him. Did I really want to take the chance to care about someone with such a life-altering and potentially life-limiting problem? But there was an undeniable attraction, and something in Robert's way, easy and honest, that soon led me to Yes. It was a chance I was willing to take.

It wasn't long before I started visiting Robert while he was on dialysis. Every Monday, Wednesday, and Friday from 6 to 10 a.m., the dialysis machine passed his blood through a filter, mimicking the work that his kidneys once did. I wasn't bothered by seeing the blood-filled tubing connecting him to the machine, or even by the faint, sour smell of blood in the air. I'd cared for many dialysis patients. But what I'd never done before, I must admit, is ask what life on dialysis was like.

Vanessa Grubbs (vgrubbs@medicine.ucsf.edu) is a clinical instructor at the University of California, San Francisco.

Realities Of Dialysis

THE WEEKENDS WERE HARDEST FOR ROBERT. Without functioning kidneys, he struggled with limiting his liquid intake in the face of constant thirst. The stretch from late Friday morning to Monday morning, his longest time between sessions, was the worst. Without fail, Monday mornings I would wake to the sounds of Robert vomiting, even though he shut the bathroom door, ran the exhaust fan, and turned on the shower to drown out his retching as he prepared to leave for dialysis. His body was ridding itself of the excess fluid the only way it could.

For much of the first couple of years of dialysis, Robert was able to work full time as a health policy analyst and maintain a workout schedule. “But when I passed out at work because I was too dehydrated,” he told me, “and came to and looked up at the panic-stricken faces of my coworkers surrounding me, I had to accept my real physical limitations and cut back to part time.” Within six months, however, his employer could no longer accept his physical limitations and suggested that he leave entirely. Impromptu business travel and long periods of uninterrupted office time were no longer feasible. Dialysis was saving Robert’s life but simultaneously stealing it away. It held the risk of infections, heart failure, and bone pain, as well as a much shorter life than a transplanted kidney could offer. Dialysis forced him to give up many activities. He no longer planned for the future; what future he would have was uncertain. Yet Robert rarely complained. “More than anything, I miss just having the urge to pee,” he would sometimes say, then add, “It’s cool, though.” His reasoning: Why complain when death was the only imminent alternative?

Moving Up The Waiting List

IT WAS EIGHT MONTHS INTO OUR RELATIONSHIP WHEN Robert was told that he had finally risen to the top of the waiting list for a kidney. He would be scheduled for a “reevaluation” to ensure that he remained an appropriate candidate for transplant. He and five other transplant candidates would meet together to be told about the process. I took the day off from work to be with him.

We both felt a sense of relief and excitement that his transplant day was finally near. Robert had heard that transplant centers assigned pagers as a way to alert patients when it was time; he hoped he would be given one. Secretly I fantasized that day they would keep him there for his transplant. I knew this wasn’t realistic, but he had already waited five years.

Why he still waited was unclear to me, because he had none of the patient characteristics usually cited as explanations for the racial disparity in kidney transplantation. He was young, and kidney failure was his only health problem. His blood carried few factors that would make it difficult to find a kidney match. He

had no drug or alcohol abuse problems, but he did have a vast social support network that included me, his parents, and the “Friends of Robert”—a mini-foundation of more than a hundred people dedicated to helping him. He had both Medicare (for which all end-stage renal disease patients are eligible) and private insurance. He had a graduate-level education and was insightful and knowledgeable about his illness. He even took all of his prescribed medications every day—thus avoiding the “noncompliant” label that health care professionals can place on

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patients. And he was unwavering in his preference to have a kidney transplant; he called the transplant center monthly to ask if he would soon get a kidney, but really to remind the staff that he existed. An ideal candidate, one would think.

Some suggest that African Americans themselves are to blame for the racial disparity in kidney transplantation on the basis of the assumption that one’s genes are most likely to match someone of the same race, thus lessening

the risk of kidney rejection. African Americans just don’t donate enough organs, it’s said. In fact, African Americans donate proportionately to their numbers in this country.¹ And in 2002, the United Network of Organ Sharing (UNOS) recommended that gene matching no longer be required for kidney transplant because today’s anti-rejection medications are so effective. So since race has presumably not mattered in organ matching for the past several years, one would think that Robert would have received a transplant just as quickly as the next appropriate candidate, black or white. But blacks, who are one in three of the candidates awaiting a kidney transplant, receive only one in five of donated kidneys. Whites, too, make up about a third of the kidney transplant waiting list—but receive every other donated kidney.²

Now, of course, no one told us that race was the reason why Robert hadn’t received a kidney, but the reevaluation day certainly implied that race mattered. The day began nicely enough. One poke with a small-bore needle to drain enough blood to fill six four-inch-long tubes. A seasoned veteran of venepunctures, Robert didn’t even blink. Then, along with the other hopeful potential recipients and their significant others, we listened attentively to the transplant nurse deliver an hour-long slide show about what we could expect for the rest of the day and throughout the kidney transplant process: meetings with each member of the transplant team that day, a kidney in four to six months, and a five-day hospitalization.

After the presentation, we chatted with another transplant candidate, a white woman in her sixties whose kidney failure was caused by high blood pressure. She still had some kidney function and required six hours of dialysis each week (Rob-

ert needed the full twelve-hour schedule). She had been on dialysis for two years. (Robert was on year five.) She was blood type O, like Robert.

What's Going On Here?

SOON WE WERE LED TO AN EXAM ROOM WHERE WE WAITED for each member of the transplant team. The nephrologist came in first. He looked over Robert's test results, then briefly examined him and asked if he had any questions. Robert asked how much gene matching factored into being assigned a kidney. Not at all, the nephrologist responded. "We only consider wait times. Nothing else."

Robert also asked him about the criteria for being included in clinical trials. He was aware that clinical trials tested the latest in anti-rejection medications but avoided steroids. Having endured five years of very high doses of steroid treatment to stave off total kidney failure—and its associated weight gain, mood swings, and face swelling—Robert felt that the known downsides of steroids outweighed the risk that the new medicines might not work. The nephrologist's first and unhesitating response was, "African Americans are sometimes excluded from clinical trials because their immune systems are too potent and they reject [transplanted kidneys] more often."

Next Robert and I did our best to persuade the wary transplant team social worker and financial counselor that Robert would be able to maintain two forms of health insurance, afford the \$215 monthly drug bill left after insurance, and have someone to drive him to and from the frequent doctor visits and lab trips after the transplant. Last, when the transplant team nurse met with us, Robert asked her how much longer he would likely wait for a kidney. The same nurse with twenty-plus years of experience who had told the group of transplant hopefuls earlier that the wait would be four to six months, half-glanced at Robert's chart and responded, "For you it will probably be another year." Surprised and confused at this discrepancy, Robert asked, "Why another year for me?" Her answer: "We just don't get that many O [blood type] organs."

One could dismiss the nurse's comment, despite her decades of experience, as ignorance, given that O is the most common blood type in this country and, as such, the most common kidney type donated—even at that transplant center. One could dismiss the nephrologist's comments about blacks' "potent" immune systems rejecting transplants as those of an insensitive jerk, as I've often heard said about those who make blatantly racist comments. But to do so would be to dismiss the fact that these people were in positions where their decisions held power over Robert's life and those of many others. If a transplant nephrologist could decide to exclude African Americans to improve study results, then it doesn't seem much of a leap that he could choose a presumably less risky race to receive a limited resource.

Maybe the nephrologist’s comment was made on the basis of research. Even so, it wouldn’t have been the first time that I’d witnessed doctors making race-based clinical decisions by referring to a study that concluded that African Americans don’t “do well” on medication X. When I was in medical school, reputable medical literature taught us that “hypertensive blacks don’t respond well to beta-blockers” (a class of medications for high blood pressure), and we prescribed accordingly. Now we know that beta-blockers extend life for everyone with heart failure, whether caused by hypertension or something else.³

One might come up with a dozen other excuses for the nurse and the nephrologists—and even the entire kidney transplant system—but the contrasting images of Robert and the older white woman with whom we chatted earlier that day remain fixed in my mind. Despite the transplant nephrologist’s assertion that “only wait times and nothing else” determine a person being assigned a kidney, there she sat—at the top of the list with her two years of dialysis time—right beside Robert. Her doctor might have been a stellar advocate, but Robert’s wait for a kidney—more than twice that of the woman’s—mirrors the fact that the median wait time for cadaveric (deceased donor) kidneys is nearly twice as long for blacks as for whites (3.3 years versus 1.7 years).⁴ Furthermore, Robert’s long wait illustrates the inability of the current kidney transplant system to allocate organs systematically and fairly.

For those who want to believe that racial bias is a thing of the past, or at least that medicine is unaffected by the society that created it, I realize that it must be hard to accept that race could be responsible for Robert’s wait. But without that simple acknowledgment, I doubt that steps will ever be taken to remedy the shortcomings of the existing kidney transplant system.

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Specifically, policy governing how transplant centers allocate organs and how patients get referred for transplant must be rectified. The current system lacks oversight. Nobody scrutinizes how and to whom transplant centers allocate—and don’t allocate—organs. Recent whistle-blowers’ accounts of a prominent transplant center’s egregious short-tracking of a “priority” candidate to the top of the list are a testament to that.⁵ Without sufficient oversight,

“worthiness” is decided with individual biases unchecked.

The subjectivity that governs who gets a transplant also weighs heavily into who even gets on the waiting list in the first place. The kidney transplant system’s lack of standardized and objective referral guidelines was evident in Robert’s case. An automatic referral on the basis of a standard level of kidney function would have placed Robert on the waiting list at least six months earlier. It was Robert, struggling to just understand and adjust to what was happening to his body, who

asked his initial nephrologist about transplantation, rather than the doctor presenting all possible options—including a transplant.

By the end of the day, both Robert and I felt angry. I, a physician, felt vulnerable and powerless against a health system that had shown itself to be unjust. Acceptance was not an option. But just as I know better than to be rude to waiters out of concern about what “secret” ingredient might be added to my meal, I was reluctant to express frustration or outrage about Robert’s treatment for fear that my sentiments would be answered by retaliation against him.

Making It Happen

INSTEAD, I DECIDED TO TAKE OUR POWER BACK, and I pushed the kidney transplant system in the only way that I knew would help Robert. Healthy, and also blood type O, that day I came to a final decision on something that I’d been contemplating for several weeks. I would become Robert’s living donor. I knew the risk to me would be minimal but that the rewards for both of us would be tremendous. Robert’s first reaction was, “No, I don’t want to do that,” feeling that he could never forgive himself if his body rejected my kidney. I pushed forward anyway. My reasoning was simple: When someone I love needs something of which I have two, of course I give one.

The day I learned that our typing was “compatible,” I burst into tears. Hope lived. In the face of my unwavering resolve, Robert allowed himself to accept my gift. The surgery took place two months later, 14 April 2005. As the tubes and staples came out, Robert began making plans again. First on the list: the details of our beautiful outdoor wedding, which took place in August 2005.

Today, a year and a half later, Robert is free of dialysis and feels better than he has in years. Me, I smile every time I watch him gulp down as much of an ice-cold drink as he wants—I know that soon he’ll get the urge to pee.

NOTES

1. U.S. Census Bureau, “Overview of Race and Hispanic Origin, 2000,” March 2001, <http://www.census.gov/prod/2001pubs/c2kbr01-1.pdf>, Table 1, page 3 (accessed 30 November 2006); and United Network for Organ Sharing, “Deceased Donors Recovered in the U.S. by Donor Ethnicity,” <http://www.unos.org/data/about/viewDataReports.asp>, click National Data. Step 1: Choose Category: Donor; Choose Organ: Kidney. Step 2: Choose a Report: Deceased Donors by Donor Ethnicity (accessed 1 December 2006).
2. UNOS, “Organ by Ethnicity: Current U.S. Waiting List,” <http://www.unos.org/data/about/viewDataReports.asp>, click National Data. Step 1: Choose Category: Waiting list; under “Count,” select Candidates. Step 2: Choose a Report: Organ by Ethnicity (accessed 1 December 2006). Editors’ note: The UNOS data site changes frequently, and the sequences above might not yield the report desired. As of 1 December 2006, these data were available on the UNOS site. Contact the site’s administrators for further assistance.
3. C.W. Yancy, S. Laskar, and E. Eichhorn, “The Use of Beta-Adrenergic Receptor Antagonists in the Treatment of African Americans with Heart Failure,” *Congestive Heart Failure* 10, no. 1 (2004): 34–37.
4. C.J. Young and R.S. Gaston, “Renal Transplantation in Black Americans,” *New England Journal of Medicine* 343, no. 21 (2000): 1545–1552.
5. C. Ornstein, “Hospital Ends Liver Program,” *Los Angeles Times*, 4 November 2005.

Concordance

How does a physician who is neither black nor white decide when race is a factor?

BY ALOK A. KHORANA

AS I WRITE THIS, MY PATIENT K.W. IS DYING in a private room on the sixth floor of the medical center. This is his second week in the hospital. K.W. is eighty-two, and, by all accounts, he has led a full life. The other identities he has possessed (amateur musician, Mets fan, preacher, foster parent, horror movie buff) have dropped away, and to my eyes at least, he is defined as the patriarch of a large and supportive family. There's always someone in the room with him when I do my rounds: usually a son, sometimes a granddaughter, and on weekends, his daughter.

K.W. suffers from metastatic rectal cancer, and I have been his sometime oncologist over the past six months. I say "sometime" because K.W. has never received chemotherapy for his disease. His cancer was metastatic when first diagnosed, and his initial surgery was complicated by a wound infection. This took several courses of antibiotics, and several weeks of nursing care provided by his foster son, to heal. During the past months, his family brought him in three or four times to discuss starting chemotherapy, but each time there were complicating circumstances, and we never got around to starting. In the meantime, his overall condition deteriorated, and he reported increasing tiredness. More and more he stayed at home, pushing himself only to make it to church each Sunday. Over the last few weeks prior to being admitted, he stayed mostly in bed, eating very little. When he was finally brought into the emergency room by his family some days ago, he was delirious, with high fever and a cough, and appeared to be dehydrated.

The team of admitting medical residents, mindful of my admonition to treat metastatic colorectal cancer as a chronic disease rather than a terminal state, did not discuss a Do-Not-Resuscitate (DNR) policy. Mindful as well of my other admonition not to emphasize race, the staff identified him on his admission note not as an "80-year-old African American male" but simply as a "pleasant but cachectic 80-year-old gentleman." During his first few days in the hospital, we identified a pneumonia in his right lung, likely caused by aspiration. Worse, we found that his metastatic lesions had progressed significantly compared with the last scan performed just a few weeks ago. We administered intravenous fluids and antibiotics. K.W.'s condition improved, but only to an intermittently awake state. Most of the

Alok Khorana (alok_khorana@URMC.rochester.edu) is an assistant professor of medicine at the James P. Wilmot Cancer Center and the Department of Medicine, University of Rochester (New York). The author thanks Marcia Buckley for critical comments and Faith M. Young for a critical review of the manuscript.

time he lay listlessly in bed, his eyes barely registering the images as his foster son flicked between BET and CNN on the overhead television. Over the next few days, I realized that it was highly unlikely that K.W. could improve much more, and I had misgivings about our ability to make him healthy enough to return home. Much as I hated to give up the idea of starting chemotherapy, I knew that my responsibility now lay in providing appropriate end-of-life comfort.

Making The Tough Decision

I HAD KNOWN THE FAMILY FOR SOME MONTHS NOW, and over the past few visits had discussed the hospice option. I thought I had prepared them well for this final step in decision making for K.W. I arranged for a family meeting and was pleasantly surprised to see the entire family show up: sons, daughter, foster sons, granddaughter. I discussed, openly, how gravely ill K.W. was and how unlikely he was to improve enough to be able to receive chemotherapy. I recommended hospice. The family listened, asked questions, discussed the issues back and forth, agreed in principle, but asked for some time. Since K.W. was still on antibiotics, I felt it reasonable to give them another couple of days to decide.

This was a mistake, as I discovered over the next few days. As I had feared, K.W.'s condition worsened, and he lapsed into longer and longer periods of unconsciousness. I repeatedly tried to arrange for a follow-up family meeting. It took three missed appointments—the son showed up for one meeting and the daughter for the other two; both refused to make a decision without the other being present—before I realized that this family was having trouble making a decision. One of the nurses on the floor finally figured out what the problem was: The family was fine with transferring K.W. to the hospice program, but they were unable to commit to a DNR order. This was not surprising. I had heard anecdotally about the difficulties of approaching African American patients and families regarding DNR orders, although I had previously taken care of several such patients without encountering this problem. A quick MEDLINE search led me to several studies documenting substantially lower rates of DNR orders in black patients. One large, communitywide study found that 18 percent of hospitalized white patients had DNR orders, compared with only 9 percent of blacks.

I have worked in the U.S. health care system now for less than a decade, but that has been time enough for me to become acquainted with the issues surrounding race and health care disparities in what is arguably the premier health care system in the world. I know, for instance, that African Americans and Hispanics constitute more than one-fourth of the U.S. population, but just over 5 percent of physicians and less than 10 percent of nurses. In my chosen subspecialty, oncology, the numbers are even more stark. The American Association for Cancer Research identifies just about 2 percent of its members as African American. Patients from these ethnic minority groups are therefore far more likely to be treated by health

care professionals from a different ethnic background: what researchers describe as a race-discordant physician-patient relationship.

I began to wonder if race discordance was important to my relationship with K.W.'s family. The Institute of Medicine (IOM) report *Unequal Treatment* (2002) described racial and ethnic disparities in health care in great detail. Although several factors are responsible for U.S. health disparities, the IOM report suggested that "bias, prejudice, and stereotyping on the part of healthcare providers may contribute to differences in care." Presumably, such factors would be less likely in a race-concordant physician-patient relationship. They might also affect decisions about advance directives. Indeed, in a study of AIDS patients, nonwhite patients with a nonwhite physician were four times as likely as those with a white physician to discuss resuscitation preferences. This might be related to better interpersonal communication in race-concordant physician-patient relationships. In a study of audiotaped physician-patient conversations, race-concordant visits were found to be slightly longer and led to higher patient satisfaction.

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Neither Black Nor White

AS I READ MORE, TRYING TO GAIN SOME PERSPECTIVE, I discovered a big problem with the race-concordance literature: It didn't apply to my situation. I am neither black nor white. I am brown, but not Hispanic. I am also not alone. International (or "foreign") medical graduates (IMGs) account for one-quarter of this country's physicians, an increase of 160 percent since 1975. IMGs also account for more than one-quarter of current physicians-in-training. IMGs are important when discussing race concordance: One-fifth of physician IMGs and fully one-fourth of trainee IMGs are Indian, as am I. The next seven most prevalent nationalities are Filipino, Cuban, Pakistani, Iranian, Korean, Egyptian, and Chinese. The only predominantly Caucasian nationality on this top-ten list is German (just 2 percent or less of IMG physicians and trainees). IMGs are also of importance when discussing health disparities, because 40 percent of primary care programs depend on immigrant physicians, and two-thirds of IMG residents serve in hospitals providing a disproportionate amount of care to the poor. In other words, a black patient is far more likely to encounter a nonwhite IMG physician than a black physician. In certain Veterans Affairs and county hospitals, one is more likely to encounter a nonwhite IMG physician than even a white physician. Also, consider this: Given the disproportionate number of Indians in the physician workforce as compared to the general population, every physician-patient relationship that I (and other nonwhite, nonblack IMGs) participate in is,

by definition, race-discordant. I found little in the evidence-based literature to help me understand the issues facing K.W.'s family because much of the literature analyzing race concordance specifically excludes nonwhite, nonblack physicians and patients. There is grim irony in the fact that well-intentioned researchers—including IMGs themselves—scientifically probing issues of race and health care are treating as invisible an entire subset of providers and consumers.

This was remarkably frustrating for me. From my readings, it appeared that mistrust of a predominantly white health care system, based on historical precedent, and poor communication were the biggest stumbling blocks to DNR among AfricanAmerican patients. Yet neither applied to me. I had been communicating well with the family for some months now, and I was confident that they trusted my medical judgment. Although indeed part of the medical system, my accent and skin color distanced me enough from historical acts of prejudice. Or, at least, so I thought. Was I wrong? Had I internalized the health care system's prejudices? Did this family perceive me to be making medical decisions based on K.W.'s skin color? Worse, were they right? Did they think of me as if I were, well, white?

A Simple Rearranging Of Words

FINALLY, WITH K.W.'S CONDITION WORSENING and my inability to guide his family to an appropriate end-of-life setting, I threw up my hands in despair and asked for help. The hospital where I work has recently developed a palliative care service, one of whose primary functions is to help families through difficult end-of-life decisions. Yesterday I called the palliative care team and explained the situation, expecting multiple family meetings before a satisfactory resolution. But only a day later, the white nurse practitioner on the palliative care service paged me to inform me that K.W. was now DNR and in comfort care and that she had already placed the orders in the chart.

I was shocked. How could she have helped the family transition to hospice so (seemingly) effortlessly, when I had been unable to do so for nearly two weeks now? "I called the son last night," she said. "I knew him from a previous admission, and he was fine discussing issues with me over the phone." But how did he make the decision? "Well, I helped him by not asking him to make the decision. I told him that his father was dying, that from my prior conversations with him I knew that his father wouldn't want to be put through ultimately futile aggressive cardiac and respiratory resuscitation. He agreed, but asked for more time to discuss things with his sister"—the same temporizing measure that he had used with me.

She continued, "I met with him earlier today. I asked if he had spoken with his sister the night before, and he had. But then he started to stammer and gazed at the floor. It hit me then. He couldn't bring himself to say it. So I gently said that we were going to recommend that his father be made DNR and have his primary team try and keep him comfortable, and I asked him if he had any objection to that, and,

of course, he didn't." A simple rearranging of words, and an emotional burden is lifted from a family that is having a hard time dealing with a decision.

Had she used a similar approach for black patients and families before, I asked. "Oh, we use it for a lot of the families we see that are struggling with this, black or white," she replied. "If it's emotionally difficult for the family, I never make them sign the DNR; I just obtain verbal approval. They think that by signing they are deciding life and death, when you and I know the disease is doing that."

So there you have it. After all my hand-wringing and ruminating on race and race concordance, race was, in this case at least, a red herring. In trying so hard to not let this be about race, I had made it about race. For me, this revelation provided solace. There is no doubt in my mind that greater minority participation in the physician workforce is essential. But is moving toward greater physician-patient concordance a laudable goal? Race is, after all, a sociocultural construct. Should my sociocultural identity (immigrant, physician-scientist, Indian, bibliophile, Bollywood/Coldplay/Jay-Z buff) preclude me from taking care of patients like K.W., or L.F. (farmer, ex-veteran, white, Brooks and Dunn fan)? Should we start assigning our black patients to black physicians, immigrant patients to immigrant physicians, gay patients to gay physicians? Which sociocultural identity should be assigned priority when arranging for concordance? When F.G. (antique dealer, Caribbean American, gay) calls for an appointment, to which physician (black, immigrant, or gay) should our office staff assign her?

There are many, too many, problems of health disparities and discrimination in twenty-first-century America, but do we not close the doors to self-examination and self-improvement if we espouse concordance as a goal? I refuse to let go of my hope: Physicians are, if nothing else, educable. As health care providers and researchers, we are equally humanists and scientists; we betray both sets of principles if we are unable to move beyond our prejudices. We fail our craft if we cannot bring ourselves to look past the skin color or sexual orientation of a patient or, for that matter, the skin color or nationality of a physician. Zora Neale Hurston could have been speaking of an ill patient when she said:

I was and am thoroughly sick of the subject [race]. My interest lies in what makes a man or woman do such-and-so, regardless of his color. It seemed to me that the human beings I met reacted pretty much the same to the same stimuli. Different idioms, yes. Circumstances and conditions having power to influence, yes. Inherent difference, no.

Postscript

K.W. LIES UPSTAIRS. Tonight, or early tomorrow, he will die, or so the nurse taking care of him tells me. I have learned to listen to the nurses when they tell me such things. But he will die in comfort, and with dignity. Dying is never easy, but it can be made easier, and for K.W., we have made it easier. And he will die surrounded by family; a family relieved, semantically but also emotionally, of the burden of a difficult decision. There is solace in all of this too, is there not?

Immigration Pediatrics

An inner-city pediatrician finds himself in a medical no-man's land where social policies undermine the care of his newly arrived immigrant patients—and their contributions to society.

BY FITZHUGH MULLAN

PREFACE: *Travel makes us all foreigners of one sort or another. Travel can be a desperate act, as in the case of Central American economic immigrants coming to the United States, or it can be a volitional one, as in the case of an economist on a study fellowship. In both instances, being foreign creates new obstacles and new perspectives. Fitzhugh Mullan, a pediatrician working in inner-city Washington, D.C., is the first point of contact with the medical system for numbers of immigrant children. The many obstacles and the new perspectives that he and his patients encounter are what he calls "immigration pediatrics." Rhiannon Edwards, a blind health economist from Wales, spent a year in the United States studying health care. During the visit, both she and her guide dog needed clinical attention, back-to-back experiences that provided her with new perspectives on how Americans feel about choice in their lives. As a foreigner who came to the United States with different health care and coverage experiences, she shares her views on what the American penchant for choice really costs and in what ways it produces gains and losses.*

I WAS PERPLEXED. The young woman accompanying the four-year-old to my office for an anemia re-check seemed vague about the child's health and couldn't tell me if he had finished the prescribed course of medication. I suddenly understood. "You're not his mother." "No, I'm not," she told me. "His mother is at work. I'm his sister." She was seventeen years old and understandably uncertain about the child's health, as she had arrived from El Salvador only ten days before. She spoke no English, was undocumented, and had not enrolled in school; she was just getting to know her mother, whom she hadn't seen in five years, and her young brother, whom she hadn't met before. I examined the child, reordered a blood test, and gave the sister an appointment for an exam—for herself, something she would need before she could go to school.

I practice pediatrics at a community health center in inner-city Washington, D.C., and the reality of immigration is with me every day. A full 90 percent of the children I see are immigrants or the children of immigrants. The majority of them come from Central America or the Caribbean, but Vietnamese, Chinese, and East and West Africans are frequent visitors as well. Although my business card says "pediatrics," in reality I practice immigration medicine.

Fitzhugh Mullan (fmullan@gwu.edu) is the Murdock Head Professor of Medicine and Health Policy at the George Washington University and a staff physician at the Upper Cardozo Community Health Center in Washington, D.C. He is a contributing editor to Health Affairs and editor of the Narrative Matters section.

In college I took a course in U.S. social history. "We are an immigrant nation," our professor told us frequently. "The history of the immigrant is the history of America." I was not convinced. The time was 1963, and immigration history seemed interesting but dated. I had an Irish immigrant grandfather, but, to me, immigration was mostly stories from the past—stories of families left behind, the ocean voyage in steerage, Ellis Island, Chinese workers building the Transcontinental Railway, and slave ships making the deadly passage from Africa. This was American history, all right, but it was not America as I saw it in the 1960s. I was short-sighted.

New Arrivals And New Citizens

CURRENTLY AN ESTIMATED 1.5 MILLION legal and illegal immigrants arrive in the United States each year. Some 43 percent of immigrant children live in low-income families, and almost one-third do not have health insurance. Each year 750,000 children are born to immigrant women. One way or another, insured or uninsured, sick or well, many of these children pass under the examining hands of pediatricians in a variety of settings, including community health centers such as the one in which I work. Like teachers and social workers, pediatricians constitute an important reception committee for immigrant children in the United States. We are not Hull House or the Henry Street Settlement—well known to earlier immigrants—but we are the conduit to U.S. social services and the first step on the road to becoming Americans. However, like teachers and social workers, we often staff a system that wasn't designed with the best interests of our patients in mind.

Most of the kids I see are the children of Latino immigrants; they were born in the United States and are U.S. citizens. The neighborhood may be dangerous and the schools lousy, but these children are advantaged compared to their immigrant parents and to children arriving here as immigrants. Kids born here grow up speaking English, are entitled to Medicaid, and enter Head Start and the school system with a leg up. I often see families where the five-year-old responds in English and translates for his non-English-speaking parents.

Many Latino immigrant children have a tougher road. War and poverty have driven their parents from Central America to undertake the perilous, illegal journey to the United States. These people are often among the most industrious and ambitious in the communities from which they come, men and women intent on finding jobs, saving money, and building families. They staff our restaurants, clean our houses and offices, and labor on our construction sites. Adults usually attempt the trip to the United States alone in the hopes of establishing a safe haven to which they can later bring their children. And they do.

The problem is that to save their families, they pull them apart—at least for a time. The children left behind may get the benefit of money, gifts, and clothes sent

home, but they are temporary orphans. Many of the parents in the U.S. remain "illegal," and when they decide to reunite their families, they have to pay \$7,000–\$10,000 to cover the costs for human smugglers ("coyotes"), bribes, car, bus, and airfare to get a child to Washington, D.C. Parents with no wherewithal to manage intervening events initiate the trip in the hopes that their child will arrive safely in the United States. It is hard to know what percentage succeed in making the trip, since we only see the winners, but many surely fail along the way. Win or lose, these trips are dangerous and expensive.

When these children arrive, they are not eligible for Medicaid or most public assistance. They come to offices like mine for the medical examination and immunizations required to enter school. It is hard to fathom the reunions I regularly see—children raised by a grandmother for ten years suddenly back in the care of their mother. Ten-year-olds entrusted to a stranger to convey them 2,000 miles across three countries for an illegal and uncertain rendezvous with their parents. Teenagers crossing the Sonoran Desert on foot in the hope of finding a ride on an Arizona road that will take them to a bus terminal. There is always a celebratory element to the office visit: "He made it! Wonderful. Congratulations!" But powerfully complex emotions are also going on in the hearts and heads of the children in these reunited families. "Why was I left? How am I going to fit in? Who are these people anyway?"

Newly arrived immigrant children, whether legal or illegal, face the daunting gauntlet of a new school in a new language. Most local schools offer English for speakers of other languages (ESOL) for the newly arrived. While this may work for younger students, youths arriving in high school rarely master English with much proficiency, undoubtedly finding it easier to hang with kids who speak Spanish. Parents are working. City life is fast and rough. The cultural gap can be huge, especially for children from rural communities. I recently cared for a newly arrived seventeen-year-old girl from the countryside of Honduras who had no idea what a condom was or how it was used. The D.C. high school in which she was enrolling has a large infant care center—for the children of students.

More Than A Medical Mission

I DO THE STANDARD THINGS: looking for undiagnosed problems, testing for parasites, applying TB tests, giving catch-up immunizations, and seeking any signs of abuse or neglect. But my medical mission today is different from what it would have been in earlier times, when malnutrition was the leading problem for immigrant children and blindness-causing trachoma and "imbecility" were considered hazards to the nation. Today the risks for arriving youth are less what they bring with them than what happens after they get here.

Several years ago I examined a fifteen-year-old boy newly arrived from El Salvador who came to the clinic accompanied by his mother. He was nicely dressed,

clean-cut—and sullen. The mother looked at me and at the ceiling, but never at him. Six weeks in the U.S. and their ten-year-long dream had come unraveled. Talking with them separately, he told me he couldn't believe she had left him at age five, and she told me he was insolent and didn't appreciate what it had taken to get him here. He had started leaving home in the evening and not returning until the next day. The hostility and disappointment in the room was palpable. Was I watching the end of family life and the start of gang life for this young man? Gangs are large and growing in Washington as in other U.S. cities, providing "community" of a sort for many troubled adolescents and recently arrived youths. Kids like my patient can get recruited quickly and lethally. I talked with him alone about gangs, school, drugs, and violence. He admitted to hanging with gang kids and said that he understood the dangers. He told his mom in my presence that he would try to go to school and come home at night.

"As a country, we are schizophrenic about immigrants, welcoming and xenophobic all at once."

..... I have many patients whose lives have gone badly at junctures like this—fifteen-year-olds brought in for truancy, pregnant fourteen-year-olds, a twelve-year-old hit in the abdomen by a stray bullet from a gang shootout. Medical care puts a floor under these kids' feet, but life on the street and opportunities in school will be key to their futures. The importance of a pediatrician in the life of this young man was my ability to refer him—much as I might have done if he had a heart murmur. The "prescription" I used was the Latin American Youth Center (LAYC), a nearby street-smart, multipurpose, safe haven for teens. The nonprofit LAYC beats gangs at their own game by providing a place to belong, social life, and an identity, as well as educational opportunities and jobs. It is the LAYC and organizations like it that stand the best chance of protecting my patients from gangs, early pregnancy, drugs, AIDS, and jail.

Medical No-Man's Land

SUCH ORGANIZATIONS ARE FEW AND FAR BETWEEN, and gangs are ubiquitous and growing. The robust U.S. economy and the ambitions of poor people from around the world are going to keep the arteries of immigration—legal and illegal—flowing briskly for the foreseeable future. Illegal migration in particular creates special hardships for children, of which broken lives, criminality, and disease are too often the outcome. But as a country, we are schizophrenic about immigrants, welcoming and xenophobic all at once. We want their energy and their hustle but not their illnesses or their family problems. We consume their labor in huge quantities, but we're not ready to give them jobs with benefits—or have the government make up the difference. Federal welfare and immigration legislation of the mid-1990s imposed a five-year ban on Medicaid eligibility for all

nonrefugee immigrants; as a result, new programs such as the State Children's Health Insurance Program (SCHIP) don't reach many of my patients. Jobs without insurance and restrictions in public programs mean that 74 percent less is spent on health care for immigrant children than for kids born in the U.S. We want the cheap, flexible, eager muscle of immigrants but not their premature infants, gunshot wounds, or troubled teenagers. As a pediatrician, I often feel as if I labor in a no-man's land between the full-throttle economy and penny-ante social policies.

Fairness, at the least, calls out for change. Reforming immigration laws to give more workers legal status is the place to begin, something the Bush administration has raised as an issue. This would mean that workers could come and go from the U.S. without the fear of arrest and deportation, reducing the pressures that drive families apart and decreasing the number of children raised without parents. This is essential to making immigrant life less intrinsically unfriendly to families. But increased medical and social investments in the immigrant community also are essential, both for fairness and to build better citizens for the future. It is well-funded Medicaid and community health center programs, as well as more youth centers and high-quality schools—all at risk in our current public budgets—that will give these new Americans a better chance at success and make our cities safer as well. The U.S. Supreme Court ruled in 1982 that school systems could not deny undocumented children admission, doing so on the grounds that countenancing children growing up illiterate in America was neither ethical nor in the country's best interests. The same principle needs to be adopted—with the same rationale—for the health care of children. Good access for kids to immunizations, controlling infectious diseases, preventing obesity, providing mental health care, and the like will benefit both the immigrant family and the U.S. workforce of the future. Fully funding Medicaid, ending immigrant-specific restrictions on SCHIP eligibility, providing interpreter services where needed, and requiring employer-sponsored insurance coverage for immigrant workers would be the next steps in building a floor under the health of immigrants.

Recently, the sullen fifteen-year-old boy—now nineteen and smiling—came to visit the clinic to show me, amazingly enough, his high school diploma. He had managed to stay off the streets and master his studies well enough to earn a passing grade, a year or so behind schedule. In English that was accented but clear, he explained his plans to work in construction during the day and take some college classes at night. His mother came with him. She was delightfully proud. She told me that she never thought this would happen. Never. I certainly would not have predicted a positive outcome from the unpromising start in the examination room interview several years before. I was pleased for them and happy to have been a small participant in this tiny piece of American history—the boy becoming a man, the Salvadoran becoming an American, medicine as social service, immigration pediatrics.