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Bad Blood

Diabetes and Its Awful Toll Quietly Emerge as a Crisis

By N. R. KLEINFELD

Begin on the sixth floor, third room from the end, swathed in fluorescence: a 60-year-old woman was having two toes sawed off. One floor up, corner room: a middle-aged man sprawled, recuperating from a kidney transplant. Next door: nerve damage. Eighth floor, first room to the left: stroke. Two doors down: more toes being removed. Next room: a flawed heart.

As always, the beds at Montefiore Medical Center in the Bronx were filled with a universe of afflictions. In truth, these assorted burdens were all the work of a single illness: diabetes. Room after room, floor after floor, diabetes. On any given day, hospital officials say, nearly half the patients are there for some trouble precipitated by the disease.

An estimated 800,000 adult New Yorkers - more than one in every eight - now have diabetes, and city health officials describe the problem as a bona fide epidemic. Diabetes is the only major disease in the city that is growing, both in the number of new cases and the number of people it kills. And it is growing quickly, even as other scourges like heart disease and cancers are stable or in decline.

Already, diabetes has swept through families, entire neighborhoods in the Bronx and broad slices of Brooklyn, where it is such a fact of life that people describe it casually, almost comfortably, as "getting the sugar" or having "the sweet blood."

But as alarmed as health officials are about the present, they worry more about what is to come.

Within a generation or so, doctors fear, a huge wave of new cases could overwhelm the public health system and engulf growing numbers of the young, creating a city where hospitals are swamped by the disease's handiwork, schools scramble for resources as they accommodate diabetic children, and the work force abounds with the blind and the halt.

The prospect is frightening, but it has gone largely unnoticed outside public health circles. As epidemics go, diabetes has been a quiet one, provoking little of the fear or the prevention efforts inspired by AIDS or lung cancer.

In its most common form, diabetes, which allows excess sugar to build up in the blood and exact ferocious damage throughout the body, retains an outdated reputation as a relatively benign sickness of the old. Those who get it do not usually suffer any symptoms for years, and many have a hard time believing that they are truly ill.

Yet a close look at its surge in New York offers a disturbing glimpse of where the city, and the rest of the world, may be headed if diabetes remains unchecked.

The percentage of diabetics in the city is nearly a third higher than in the nation. New cases have been cropping up close to twice as fast as cases nationally. And of adults believed to have the illness, health officials estimate, nearly one-third do not know it.

One in three children born in the United States five years ago are expected to become diabetic in their lifetimes, according to a projection by the Centers for Disease Control and Prevention. The forecast is even bleaker for Latinos: one in every two.

New York, perhaps more than any other big city, harbors all the ingredients for a continued epidemic. It has large numbers of the poor and obese, who are at higher risk. It has a growing population of Latinos, who get the disease in disproportionate numbers, and of Asians, who can develop it at much lower weights than people of other races.

It is a city of immigrants, where newcomers eating American diets for the first time are especially vulnerable. It is also yielding to the same forces that have driven diabetes nationally: an aging population, a food supply spiked with sugars and fats, and a culture that promotes overeating and discourages exercise.

Diabetes has no cure. It is progressive and often fatal, and while the patient lives, the welter of medical complications it sets off can attack every major organ. As many war veterans lost lower limbs last year to the disease as American soldiers did to combat injuries in the entire Vietnam War. Diabetes is the principal reason adults go blind.

So-called Type 2 diabetes, the predominant form and the focus of this series, is creeping into children, something almost unheard of two decades ago. The American Diabetes Association says the disease could actually lower the average life expectancy of Americans for the first time in more than a century.

Even those who do not get diabetes will eventually feel it, experts say - in time spent caring for relatives, in higher taxes and insurance premiums, and in public spending diverted to this single illness.

"Either we fall apart or we stop this," said Dr. Thomas R. Frieden, commissioner of the New York City Department of Health and Mental Hygiene.

Yet he and other public health officials acknowledge that their ability to slow the disease is limited. Type 2 can often be postponed and possibly prevented by eating less and exercising more. But getting millions of people to change their behavior, he said, will require some kind of national crusade.

The disease can be controlled through careful monitoring, lifestyle changes and medication that is constantly improving, and plenty of people live with diabetes for years without serious symptoms. But managing it takes enormous effort. Even among Americans who know they have the disease, about two-thirds are not doing enough to treat it.

Nearly 21 million Americans are believed to be diabetic, according to the Centers for Disease Control, and 41 million more are prediabetic; their blood sugar is high, and could reach the diabetic level if they do not alter their living habits.

In this sedentary nation, New York is often seen as an island of thin people who walk everywhere. But as the ranks of American diabetics have swelled by a distressing 80 percent in the last decade, New York has seen an explosion of cases: 140 percent more, according to the city's health department. The proportion of diabetics in its adult population is higher than that of Los Angeles or Chicago, and more

than double that of Boston.

There was a pronounced increase in diagnosed cases nationwide in 1997, part of which was undoubtedly due to changes in the definition of diabetes and in the way data was collected, though there has continued to be a marked rise ever since.

Yet for years, public health authorities around the country have all but ignored chronic illnesses like diabetes, focusing instead on communicable diseases, which kill far fewer people. New York, with its ambitious and highly praised public health system, has just three people and a \$950,000 budget to outwit diabetes, a disease soon expected to afflict more than a million people in the city.

Tuberculosis, which infected about 1,000 New Yorkers last year, gets \$27 million and a staff of almost 400.

Diabetes is "the Rodney Dangerfield of diseases," said Dr. James L. Rosenzweig, the director of disease management at the Joslin Diabetes Center in Boston. As fresh cases and their medical complications pile up, the health care system tinkers with new models of dispensing care and then forsakes them, unable to wring out profits. Insurers shun diabetics as too expensive. In Albany, bills aimed at the problem go nowhere.

"I will go out on a limb," said Dr. Frieden, the health commissioner, "and say, 20 years from now people will look back and say: 'What were they thinking? They're in the middle of an epidemic and kids are watching 20,000 hours of commercials for junk food.' "

Of course, revolutionary new treatments or a cure could change everything. Otherwise, the price will be steep. Nationwide, the disease's cost just for 2002 - from medical bills to disability payments and lost workdays - was conservatively put by the American Diabetes Association at \$132 billion. All cancers, taken together, cost the country an estimated \$171 billion a year.

"How bad is the diabetes epidemic?" asked Frank Vinicor, associate director for public health practice at the Centers for Disease Control. "There are several ways of telling. One might be how many different occurrences in a 24-hour period of time, between when you wake up in the morning and when you go to sleep. So, 4,100 people diagnosed with diabetes, 230 amputations in people with diabetes, 120 people who enter end-stage kidney disease programs and 55 people who go blind.

"That's going to happen every day, on the weekends and on the Fourth of July," he said. "That's diabetes."

One Day in the Trenches

The rounds began on the seventh floor with Iris Robles. She was 26, young for this, supine in bed. She wore a pink "Chicks Rule" T-shirt; an IV line protruded from her arm. For more than a year, she had had a recurrent skin infection. The pain overwhelmed her. Then came extreme thirst and the loss of 50 pounds in six weeks. In the emergency room, she found out she had diabetes.

She was out of work, wanted to be an R & B singer, had no insurance. It was her fourth day in Montefiore Medical Center. Her grandmother, aunt and two cousins have diabetes.

"I'm scared," she said. "I'm still adjusting to it."

Next came Richard Dul, watching news chatter on a compact TV. Now 64, he has had diabetes since he was 22. A month before, he had a blockage in his heart and needed open-heart surgery. He was home a few days, but an infection arose and he was back. Postoperative infections are more common with diabetes. This was his 21st straight day in the hospital.

Here, then, was the price of diabetes, not just the dollars and cents but the high cost in quality of life.

Simply put, diabetes is a condition in which the body has trouble turning food into energy. All bodies break down digested food into a sugar called glucose, their main source of fuel. In a healthy person, the hormone insulin helps glucose enter the cells. But in a diabetic, the pancreas fails to produce enough insulin, or the body does not properly use it. Cells starve while glucose builds up in the blood.

There are two predominant types of diabetes. In Type 1, the immune system destroys the cells in the pancreas that make insulin. In Type 2, which accounts for an estimated 90 percent to 95 percent of all cases, the body's cells are not sufficiently receptive to insulin, or the pancreas makes too little of it, or both.

Type 1 used to be called "juvenile diabetes" and Type 2 "adult-onset diabetes." By 1997, so many children had developed Type 2 that the Diabetes Association changed the names.

What is especially disturbing about the rise of Type 2 is that it can be delayed and perhaps prevented with changes in diet and exercise. For although both types are believed to stem in part from genetic factors, Type 2 is also spurred by obesity and inactivity. This is particularly true in those prone to the illness. Plenty of fat, slothful people do not get diabetes. And some thin, vigorous people do.

The health care system is good at dispensing pills and opening up bodies, and with diabetes it had better be, because it has proved ineffectual at stopping the disease. People typically have it for 7 to 10 years before it is even diagnosed, and by that time it will often have begun to set off grievous consequences. Thus, most treatment is simply triage, doctors coping with the poisonous complications of patients who return again and again.

Diabetics are two to four times more likely than others to develop heart disease or have a stroke, and three times more likely to die of complications from flu or pneumonia, according to the Centers for Disease Control. Most diabetics suffer nervous-system damage and poor circulation, which can lead to amputations of toes, feet and entire legs; even a tiny cut on the foot can lead to gangrene because it will not be seen or felt.

Women with diabetes are at higher risk for complications in pregnancy, including miscarriages and birth defects. Men run a higher risk of impotence. Young adults have twice the chance of getting gum disease and losing teeth.

And people with Type 2 are often hounded by parallel problems - high blood pressure and high cholesterol, among others - brought on not by the diabetes, but by the behavior that led to it, or by genetics.

Dr. Monica Sweeney, medical director of the Bedford-Stuyvesant Family Health Center, offered an analogy: "It's like bad kids. If you have one bad kid, not so bad. Two bad kids, it's worse. Put five bad kids together and it's unmanageable. Diabetes is like five bad kids together. You want to scream."

The Caro Research Institute, a consulting firm that evaluates the burden of diseases, estimates that a

diabetic without complications will incur medical costs of \$1,600 a year - unpleasant, but not especially punishing. But the price tag ratchets up quickly as related ailments set in: an average \$30,400 for a heart attack or amputation, \$40,200 for a stroke, \$37,000 for end-stage kidney disease.

One of the most horrific consequences is losing a leg. According to the federal Agency for Healthcare Research and Quality, some 70 percent of lower-limb amputations in 2003 were performed on diabetics. Sometimes, the subtraction is cumulative. One toe goes. Two more. The ankle. Everything to the knee. The other leg. Studies suggest that as many as 70 percent of amputees die within five years.

Yet medical experts believe that most diabetes-related amputations are preventable with scrupulous care, and that is why the offices of conscientious doctors post signs like this: "All patients with diabetes: Don't forget to bare your feet each visit."

To witness the pitiless course that diabetes can take, simply continue on the hospital tour. This one day will do. Dr. Rita Louard, an endocrinologist, and Anne Levine, a nurse diabetes educator, were making their way through the rooms at Montefiore.

Here was Julius Rivers, 58, on the sixth floor. Three years with diabetes. He had been at home in bed when he saw a light like a starburst and told his wife to take him to the emergency room. His blood sugar was 1,400, beyond the pale. (A fasting level of 126 milligrams per deciliter is the demarcation point of diabetes.)

This was his third trip to the hospital in seven months. At the moment, he had a blood clot in his left leg. He had a heart attack a few years ago. He was on dialysis. "Tuesday, Thursday and Saturday," he said.

On the sixth floor was Mauri Stein, 58, a guidance counselor, a diabetic for 20 years. She had been at a party recently and "zoned out." Her words slurred. Foam appeared on her mouth. She had had a mild stroke.

Now she tried to control her emotions, tried not to cry. She had had repeated laser surgery on her eyes, and was effectively blind in one. She had recovered from the stroke, but doctors had also found a tumor on her heart and said it would need surgery.

"My feet burn," she said. "My toes burn all the time. My days of wearing my pumps are over. I've gotten more cortisone shots in my feet than I'm sure are legal."

She mentioned her brother, who lived in California. Diabetes had ransacked his body - an amputation, kidney dialysis, heart disease, blindness in one eye. He now resided in an assisted-living center. He was 53.

Ms. Stein's husband walked in and sat on the bed. Six months ago, he found out the same truth: he had diabetes.

This was one day in one hospital.

Inside the Incubator

Little about diabetes is straightforward, and to comprehend why New York is such an incubator for the disease, it is necessary to grasp that diabetes is as much a sociological and anthropological story as a medical one. While it assaults all classes, ages and ethnic groups, it is inextricably bound up with race

and money.

Diabetes bears an inverse relationship to income, for poverty usually means less access to fresh food, exercise and health care. New York's poverty rate, 20.3 percent, is much higher than the nation's, 12.7 percent.

African-Americans and Latinos, particularly Mexican-Americans and Puerto Ricans, incur diabetes at close to twice the rate of whites. More than half of all New Yorkers are black or Hispanic, and the Hispanic population is growing rapidly, as it is around the nation.

Some Asian-Americans and Pacific Islanders also appear more prone, and they can develop the disease at much lower weights. Asians constitute one-tenth of New York's population, more than twice their proportion nationwide.

The nature of these groups' susceptibility remains under study, but researchers generally blame an interplay of genetic and socioeconomic forces. Many researchers believe that higher proportions of these groups have a "thrifty gene" that enabled ancestors who farmed and hunted to stockpile fat during times of plenty so they would not starve during periods of want. In modern America, with food beckoning on every corner, the gene works perversely, causing them to accumulate unhealthy quantities of fat.

But the velocity of new cases among all races has accelerated significantly from just a few decades ago. Genetics cannot explain this surge, because the human gene pool does not change that fast. Instead, the culprit is thought to be behavior: faulty diet and inactivity. Dr. Vinicor, of the Centers for Disease Control, likes to use this expression: "Genetics may load the cannon, but human behavior pulls the trigger."

Of the country's spike in diabetes cases over the last two decades, C.D.C. studies suggest that about 60 percent stem from demographic changes: a population increasingly comprising older people and ethnic groups with a higher risk.

The studies ascribe the other 40 percent to lifestyle changes: the fundamental shift that has people eating jumbo meals and shunning exercise as if it were illegal. At every turn, technology has made physical activity unnecessary or unappealing. Gym class has largely been deleted from schools. Fewer than a third of junior high schools require physical education at all, the C.D.C. says.

On the whole, New York's corpulence is below the national average, with 20 percent of adults qualifying as obese, compared with 30 percent for the country, the C.D.C. says. But the figure is much higher in poor areas like the South Bronx and East Harlem.

When the health department studied diabetes in the city's 34 major neighborhoods, the distribution echoed demographic patterns: Diabetes left only a light imprint on more affluent, white areas like the Upper West Side and Brooklyn Heights. The prevalence was about average in working-class Ridgewood, Queens, and almost nil on the Upper East Side.

But that apparent immunity is weakening. Of those 34 neighborhoods, 22 already have diabetes rates above the national average, and the numbers are rising all over as the city continually remakes itself.

"New York is switching from a mom-and-pop type of environment to a chain-store type of environment, a proliferation of fast food, even in high-rent neighborhoods they haven't had access to before, like the East Village and Lower Manhattan," said Peter Muennig, an assistant professor of health policy and

management at Columbia.

If changes in daily living can bring on diabetes, they can also delay it, though it is uncertain for how long.

A federal program studied people around the country at high risk of getting diabetes, and concluded that 58 percent of new cases could be postponed by shifts in behavior - most notably, shedding pounds.

But Dr. Frieden, New York's health commissioner, says meaningful prevention cannot be achieved at the city level. "I can urge people until I'm blue in the face to walk and take the stairs and eat less, and it won't make much difference," he said.

His emphasis is on trying to better treat those who already have diabetes, an ambitious goal in its own right. Most primary care doctors treat too many patients to provide the attention that diabetics need, or to check for the disease, he said. Specialists are scarce. And compliance among patients is notoriously poor.

Even the most basic step in controlling the disease - watching one's blood sugar - is too much for many diabetics. Doctors recommend that two to four times a year, patients take a so-called A1c test, which gauges the average sugar level over the prior 90 days and is more revealing than daily at-home measurements.

But in 2002, the health department found that 89 percent of diabetics did not know their A1c levels. Of those who did, presumably the most conscientious, four out of five had readings over the level the American Diabetes Association says separates well-controlled from poorly controlled diabetes.

The patients in the survey were not much better at knowing their blood pressure and cholesterol, which are also crucial for diabetics to control.

"Diabetes is an interesting beast," said Dr. Diana K. Berger, who heads the diabetes division at the health department. "It's probably one of the easier conditions to diagnose but one of the hardest to manage."

Shortages and Shipwrecks

There is an underappreciated truth about disease: it will harm you even if you never get it. Disease reverberates outward, and if the illness gets big enough, it brushes everyone. Diabetes is big enough.

Predicting the path of a disease is always speculative, but without bold intervention diabetes threatens to hamper some of society's most basic functions.

For instance, no one with diabetes can join the military, though service members whose disease is diagnosed after enlisting can sometimes stay. No insulin-dependent diabetic can become a commercial pilot.

Shereen Arent, director of legal advocacy for the American Diabetes Association, says she already fields 150 calls a month from diabetics who complain that they are being discriminated against in the workplace, double the number just a couple of years ago. She mentioned a typical case, a man rejected for a job at a baked-bean factory in Texas as a safety risk. "If this continues," she said, "we're in big trouble."

Dr. Daniel Lorber is an endocrinologist in Queens who thinks a lot about the disease's present and future. "The work force 50 years from now is going to look fat, one-legged, blind, a diminution of able-bodied workers at every level," he said, presuming that current trends persist.

As more women contract diabetes in their reproductive years, Dr. Lorber said, more babies will be born with birth defects. Those needy babies will be raised by parents increasingly crippled by their diabetes.

"At a time when we are trying to shift health care out of hospitals, with diabetics you don't have a choice," he said. "Nursing homes are going to be crammed to the gills with amputees in rehab. Kidney dialysis centers will multiply like rabbits. We will have a tremendous amount of people not blind but with low vision. And we have lousy facilities in this country for low-vision problems. These people will not be able to function in society without significant aid."

Cost pressures have been slashing the number of hospital beds, and some exasperated doctors are known to denigrate advanced diabetics as "shipwrecks," because they have so many health problems and virtually live in the hospital.

Not only will the future mean too few beds and unsupportable drains on Medicaid and Medicare, Mr. Muennig said, but if an emergency strikes - a terrorist attack, an earthquake - the city health system's ability to respond may be compromised because all the beds will be full of diabetics.

Most schools do not have full-time nurses. Some public schools, Ms. Arent said, try to turn away children with diabetes, even though that is illegal. Others ban them from field trips and sports teams. And this is now, when diabetes is still relatively rare among children.

If trends continue, people will live through years blighted by disability, then die too young. Diabetes is thought to shave 5 to 10 years off a life.

"Life expectancy usually decreases because there's a plague or there's a massive economic trauma," Mr. Muennig said. "In this case, we will see a decline in life expectancy due to a chronic condition."

In 2003, diabetes vaulted past stroke and AIDS from the sixth-leading cause of death in New York to the fourth. It was fifth, slightly behind stroke, in 2004. But the health department says it believes the actual toll is much worse because doctors who fill out death certificates may ascribe the death to a complication rather than to the diabetes at its root. Lorna Thorpe, deputy health commissioner, combed through medical charts and concluded that diabetes should be third, trailing cardiovascular disease and cancer.

Laurie Raps is a claims representative for Social Security on Staten Island, 31 years on the job. From her perspective, interviewing people embarking on full-time disability, she has seen the disease's long tentacles. When she started, she saw people in their 50's and 60's, hobbled by the usual problems of age: arthritis, herniated discs, heart conditions. Now, every week, she gets diabetic after diabetic, people as young as 30.

In fact, a 2004 study by UnumProvident, a major provider of disability insurance, found that the number of workers filing claims for Type 2 diabetes doubled between 2001 and 2003.

"It's a double whammy," Ms. Raps said. "You don't have these people working and paying into the system, and then you have these people collecting from the system."

Ten years ago, Ms. Raps developed diabetes. Her husband has it. Both her parents have it, their lives being washed away.

"When I look at the people who sit before me with disability claims, I have to check the birth date in their records," she said. "They look 10 or 20 years older. Diabetes does that. It wears you down and wears you down. We're looking at a future of people 10 or 20 years older in sickness than they are. What kind of future is that?"

'A 15-Year-Old Is Immortal'

"I'm Linda and I've had diabetes for 13 years."

"I'm Dominique and I've had diabetes for seven years."

"I'm Joseph and I've had diabetes for two months."

The brisk introductions went on, the ritual start to the monthly meeting of a support group called Sugar Babes Place. All the members had diabetes. All were children.

Sugar Babes is the idea of Dr. Yolaine St. Louis, chief of pediatric endocrinology at Bronx-Lebanon Hospital Center. When she started practicing medicine 16 years ago, the only children she saw with diabetes had Type 1.

Now, of Sugar Babes' 90 official members, roughly 40 percent have Type 2. One is 8. Another is 7.

It scares Dr. St. Louis. It scares many doctors who see the same thing, because they know it does not have to be. Type 2 was supposed to be an old person's disease. Diabetes still increases with age in an almost linear fashion - today, one in five New Yorkers age 65 and older have it - but the starting point used to be mostly in their 50's.

Dr. Alan Shapiro, a pediatrician with the Children's Health Fund and Montefiore Medical Center who has spent 13 years ministering to children in the South Bronx, said there was an easy way to illustrate the change. When he began, there was a "failure-to-thrive" clinic, meant to address the undernourished, because so many children were dangerously thin and small.

"Now I don't think we hardly ever see a failure-to-thrive case," he said.

In the clinic's place is an obesity program. Dr. Shapiro never saw children with Type 2 diabetes in his early years in medicine. Now, the program has about 10 cases.

One concern he and fellow doctors have is the surge in children who take antipsychotic drugs for anxiety and conditions like autism. Some newer drugs can promote weight gain and thus elevate the risk of diabetes. Dr. Shapiro has an autistic patient who he feels needs the new medication. But since taking it, the young man has markedly put on weight and, at 18, developed diabetes.

This extension of the disease to the young is where health care professionals feel society and public policy have most glaringly failed. Diabetes, they say, should never have gotten there.

There has been little research into the long-term impact of Type 2 diabetes on children. But doctors have a rough idea. The harsh consequences that can accompany diabetes tend to arrive 10 to 15 years after

onset.

If people contract diabetes when they are 15, 10 or even 5, they may well start developing complications, not on the cusp of retirement but in the prime of their lives.

There is a big difference between losing a limb at 21 and at 70. There is a big difference between going on dialysis at 30 and at 65.

"I heard a horror story a few weeks ago," Dr. Lorber said, "of a girl who was born deaf, got diabetes at 11 or 12 and went blind from diabetes at 30."

The C.D.C. has projected that a child found to have Type 2 diabetes at age 10 will see his life shortened by 19 years.

"Imagine if kids were showing up at emergency rooms in cardiac arrest," said Dr. David L. Katz, director of the Prevention Research Center at the Yale University School of Medicine. "Frankly, I think that's the next big thing. It's that dramatic. If diabetes doesn't respect age, why should coronary disease? Lord knows, I hope this never happens. But this is what keeps me up at night."

Yet children can be the most reluctant to accept the truths of their condition.

"A lot of them are in denial," Dr. St. Louis said. "They have blood sugars of 300, 400, and they tell me right to my face they don't have diabetes. 'You're wrong,' they say. 'I don't feel anything.' I tell them what can happen down the road, and they shrug. A 15-year-old doesn't care what's going to happen at 35 or 45. A 15-year-old is immortal."

The doctor was telling the Sugar Babes that everyone should have two compact blood-sugar meters, one for home and one for school. Then she warned them, "If your sugar is bad and you don't do anything, you're going to be dropping down all over the Bronx."

Interest was tepid. Some children couldn't keep their eyes off the waiting dinner arranged at a buffet table by the wall. No rapt attention from Joseph, 12, who had begged not to come, until his mother put her foot down. He moaned that he had schoolwork.

"Look at that," said Dorothy Morris-Swaby, a diabetes nurse educator who worked with Dr. St. Louis, nodding at a girl who was talking on her phone. "We're educating about diabetes, and she's on her cellphone. Typical teenager."

As time ran out, hula hoops were brought out. Dr. St. Louis was trying to identify activities other than video games and TV that the children might try. Last meeting, they held a jump-rope contest.

"They have 10,000 excuses why they can't do something," the doctor said. "So you have to give them ideas and then hope."

The meeting wound up. The hoops were stashed away. Some of the children stepped toward the buffet table and began to eat.