

# NARRATIVE MATTERS



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## To Fight Bad Suga', Or Diabetes, My Neighborhood Needs More Health Educators

*A health researcher who's seen the devastation in his poor Chicago community calls for national prevention programs that place these workers at the core.*

BY JOSEPH F. WEST

**B**ad suga' is devastating my neighborhood of North Lawndale, one of Chicago's poorest communities. Diabetes is commonly called "bad suga'" in many African American communities like the one where I grew up and live today. "Bad suga'": because when your blood

sugar levels are out of control, it makes you feel bad, and over time, bad things start happening to your body.

No matter what you call it, the disease is pervasive and destructive, and many people in my community are in its grip. At the same time, some in the community are working to ease the burden that bad suga' has heaped on an already

suffering population.

My home, North Lawndale, is what is known as a "food desert"—a community where there's a large imbalance, or "food security" gap, between grocery stores that provide high-quality food and the much more numerous corner stores and fast-food restaurants offering overripe or poor-quality food options. If they can, residents leave the neighborhood to find better quality and a broader variety of food. But because Chicago is segregated along racial, cultural, and economic lines, traveling across neighborhoods can be difficult. As a result, many residents feel trapped and emotionally defeated.

It's not talked about openly, but feelings of depression and isolation are closely tied to type 2 diabetes in communities like ours. Given the physical toll that diabetes can take, these conditions are crippling the community—sometimes quite literally.

### I No Longer Know These Streets

My family has deep roots in North Lawndale. The first of my relatives settled here in the late 1950s, working as housekeepers and laborers back when the community was still predominantly white and prospering. They were a part of the Great Migration, the movement of millions of African Americans from farms and small towns in the South to northern or midwestern cities like Chicago.

Decades after the Great Migration, however, they and their children and grandchildren now face a very different experience. Today there is a new kind of migration into North Lawndale: The community has become a landing spot for people thrown haphazardly out of Chicago's dismantled public housing, as well as for the formerly incarcerated, the permanently unemployed, and the socially displaced.

Although many residents share the same race, they often hold different values. Consequently, families and young people in particular limit their time

outside, confining themselves to the safety of their homes, to avoid the drugs and street violence from gangs clashing over “turf.” Parks and playgrounds, once an outlet for community connection and activity, now stand quiet and empty, devoid of the laughter of children at play.

Back in the 1960s, when Martin Luther King Jr. brought the Civil Rights movement North, he chose to live in North Lawndale. The community was already in decline, a casualty of the massive economic downturn in the city. Major businesses had begun leaving the community, and work became harder to find for many residents. After King was assassinated, the community erupted in riots and fires. The streets still smolder, it seems—with discontentment, anger, and hopelessness. Anyone who spends even a few moments here can see that there isn’t anything civil or right about the crushing poverty that persists.

I was born in the 1970s, nearly five years after King’s Civil Rights efforts in Chicago. When I was growing up in North Lawndale, the community seemed vibrant enough to me. People had jobs, and families were active in the community—helping out at the high school, in the community garden, or at the churches.

As a child, I was free to play in the neighborhood’s streets, lots, and playgrounds, without having to worry whether it was safe. All of that has changed now.

When I finished high school, I went to rural Champaign, Illinois, for college. But I came back to Chicago after graduation, to work as a social worker and then as a field researcher for a major study on community cohesion and health. In both jobs I entered hundreds of homes all over the city, talking to people for hours. I could see up close the challenges people faced in their daily lives. I also recognized that solutions to these challenges would not come easily. I then proceeded to Harvard University for graduate studies in public health.

Activism and community service are strong and abiding family principles that contributed to my decision to return to the community, to give back in some concrete ways. My current work as a community health researcher has been in large part an effort to do just that.



As an epidemiologist interested in the intersection of community and health, I’ve learned that important lessons can be garnered from sitting in people’s living rooms. I’ve also learned that those private, personal conversations about family issues, financial challenges, and health concerns can directly inform public health interventions and policy.

But each day my community becomes more unfamiliar to me. I see firsthand the wreckage where social policy, race, class, and poor health collide. Adults with chronic illnesses such as diabetes, and children confronting difficult choices on their own without parental guidance, worry about what they will eat, whether they will be safe, and where they can turn for guidance. Powerlessness in the face of meager local food options, rampant crime, and stifling unemployment is on full display here in North Lawndale, and it cries out to be noticed.

### Bad Suga’ In The Blood

In my work life, I direct a program to improve diabetes care for my neighbors through the Lawndale Diabetes Project at Sinai Urban Health Institute. We train current and former North Lawndale residents to become community health educators and work directly in the community. They go out each day and knock on doors, talk about diabetes with neighbors in their homes, and screen people for the disease.

In a recent community survey that we conducted, we found a type 2 diabetes prevalence rate of 29 percent—three and a half times the national rate. We also

surveyed an adjacent community, with a largely Hispanic population. Here the rates were only slightly lower—and still disturbing.

In doing this work, the community health educators on our team witness circumstances that leave them feeling overwhelmed and heartbroken. They meet residents who are living without basic utilities, in unsafe homes in desperate need of repair; residents who are immobile or who regularly go without enough food or medicine. Many have fragile social networks.

Our work requires having difficult conversations with residents about their poorly managed diabetes, laying out simple action steps and identifying scarce resources—such as healthy food from food banks or assistance with transportation or child care. All of this is aimed at lowering blood sugar levels and getting our community healthy again. The work also requires being as empathetic as possible when talking about complications that can occur with poor self-management of diabetes.

Community health educators respond with compassion and training. They help find social services, medical assistance, and community supports for their “clients.” Drawing on a list of social agency phone numbers, stacks of business cards, personal contacts, and old-fashioned know-how, they help residents fight back against the ravages of their socioeconomic and health circumstances.

But it’s hard for residents to stay upbeat when told that they may become blind or lose a limb, or that their kidneys can quit completely if they don’t do a better job of managing the disease. Any light in the room can dim rather quickly after such news.

What’s worse than knowing about the many ways your body may fail you? How about hearing about all of the medicines and supplies you need but can’t pay for, doctor’s appointments you must make, long-standing behavior you must change, and food you need to have but can’t find or afford?

“Fresh fruits and vegetables? Where? Around here? In this neighborhood?” residents ask us incredulously. “And the testing strips, how do I pay for them? It takes me about an hour on the bus to get to the doctor, one way. Who’s going

## Policy Checklist

**The issue:** Especially in the case of underserved populations, combating diabetes requires an array of interventions at the community level to help people manage their condition, improve their health-related behavior, and halt disease progression.

**Legislative support:** Under the Affordable Care Act, the reauthorized Patient Navigator, Outreach, and Chronic Disease Prevention Act of 2003 provides grants to coordinate health care services, health screening and health insurance information, and outreach to medically underserved populations for federally qualified health centers, health facilities operated through the Indian Health Service, hospitals, rural health clinics, and academic health centers.

**For more information on community-based diabetes management, see:**

- RWJ Hamilton Diabetes Care and Self-Management: [http://www.rwjhamilton.org/pages/QHealthSpecialty\\_diabetes.aspx](http://www.rwjhamilton.org/pages/QHealthSpecialty_diabetes.aspx)
- Project Dulce Diabetes Care and Education Program: [http://www.scripps.org/services/metabolic-conditions\\_diabetes/why-choose-scripps\\_project-dulce](http://www.scripps.org/services/metabolic-conditions_diabetes/why-choose-scripps_project-dulce)
- Project DIRECT (Diabetes Intervention Reaching and Educating Communities Together): <http://www.cdc.gov/diabetes/projects/direct.htm>; <http://www.ncdiabetes.org/programs/project-Direct/index.aspx>

**Related reading:**

Kenneth E. Thorpe, "The Affordable Care Act Lays the Groundwork for a National Diabetes Prevention and Treatment Strategy." *Health Aff (Millwood)*. 2012; 31(1):61-6. <http://content.healthaffairs.org/content/31/1/61.full>

E. Lee Rosenthal, J. Nell Brownstein, Carl H. Rush, Gail R. Hirsch, Anne M. Willaert, Jacqueline R. Scott, Lisa R. Holderby, and Durrell J. Fox. "Community Health Workers: Part of the Solution." *Health Aff (Millwood)*. 2010;29(7):1338-42. <http://content.healthaffairs.org/content/29/7/1338.full>

Holly C. Felix, Glen P. Mays, M. Kathryn Stewart, Naomi Cottoms, and Mary Olson. "The Care Span: Medicaid Savings Resulted When Community Health Workers Matched Those with Needs to Home and Community Care." *Health Aff (Millwood)*. 2011;30(7): 1366-74. <http://content.healthaffairs.org/content/30/7/1366.full>

to help me? I didn't know I was sick until you came knocking at my door. Now I have a whole new set of problems."

Often residents with a physical disability or limited mobility don't have help with simple household tasks. They live in fear of falling or accidentally cutting themselves in the kitchen while home alone. One senior resident confided to a community health educator during a home visit, "For all these years I've been there for other people—people in my family. Now there's nobody here for me."

Churches and prayer centers offer some comfort from the social isolation. But although religious centers provide the spiritual salve of prayer, music, purpose, and communal connection for people with diabetes, they can also contain food land mines—cakes, pies, fried foods, and sugary drinks that precipitate dietary backsliding.

Hardship, social disconnection, and loneliness can impart a persistent bitterness, which people try to assuage any

way they can. There is a hunger to be filled up, and cheap calories and processed foods satisfy when no better options are available or obvious. "I don't care if it's not good *for* me. It's what I need right now, and it's good *to* me," the residents will say. There is a deep inner void that no prescription can fill.

### I Ain't Crazy, Just Blue

There are occasions when I venture to a local store, the library, or the park and encounter a familiar face. "Mr. Peel," let's call him, is a community elder with type 2 diabetes. He has a square jaw, deep lines in his face, a warm smile, and the wise eyes of a weathered Chicago bluesman.

One day while visiting a grocery store in the neighborhood that offers regular discounts on fresh fruit, vegetables, and other food low in fat and sugar, I came across Mr. Peel, shopping basket in hand. Mr. Peel is an active, long-standing member of the community and was

one of the first participants in our project. He was so very excited about making strides to eat better, drink more water, and walk a bit more that he yelled out to get my attention.

From the gleam in his eyes and the pep in his step, I could tell he was feeling better. His blood sugar was down considerably, he told me.

"I just feel good," he said. Mr. Peel praised the community health educators who had helped him develop a plan to exercise, change his diet, test his blood sugar, and see his doctor—a plan that, from all indications, was working.

"But lately I have been feeling a little bit down," he went on. "I recently lost my brother to this suga' thing and was scared out of my mind about what was happening to me. It's been so rough lately, some days I haven't even wanted to get out of the bed. But I keep going."

When he felt down, Mr. Peel admitted to moments of relapse, when he'd have a liter of soda, cookies and ice cream, potato chips or fast food, or all of the above. He said he needed it "to cope." He told me that when he shared his feelings and struggles with the community health educator who was working with him, she asked if he'd like to see a mental health professional. She explained that our program would assist with this.

He chuckled and said, "I told her: I ain't crazy, just blue."

According to Mr. Peel, all he really needed was someone to listen for a few minutes. To let him "get it out" and "shake the blues." So he talked to the community health educator, someone he'd come to trust enough to share his feelings with. It was enough to make him feel better, he said.

The educator stayed and talked with him for about twenty or thirty minutes. Yet this brief conversation with a friendly face potentially avoided a more costly visit to a psychiatrist and abated a downward spiral into worsening dietary habits. Mr. Peel and others like him benefit from regular home visits and access to people such as his community health educator, who can sit and listen or help make confusing health care issues plain.

### A Better Way Forward

For people with diabetes living in poor, underserved communities, there is a

recurring and often jarring connection between glycemic control, food choices, hardship, and emotional well-being. Self-management of a chronic disease is far too often a lonely and frustrating endeavor. Issues of emotional well-being cut across race and class barriers.

Similarly at a broader level, there's an urgency to connect the dots between population needs, mental health, and diabetes care. Programs like ours in Chicago that provide home visits by a trained community health educator can help bridge the gaps between clinical care, diabetes self-management education, medical nutrition therapy, social work, and, in some instances, counseling. These educators try to be both delicate about a person's circumstances and emphatic about addressing the disease. They make very modest salaries—less than most schoolteachers—and are a throw-back to grassroots public health. They are essential for making the human connection in patient care, particularly in such vulnerable communities.

For many people in North Lawndale, Medicaid is the principal source of any health care related services they receive. They're not unusual. Within the Medicaid program, more than three-quarters of spending for community-dwelling beneficiaries is allocated to 40 percent of the people who have chronic health conditions such as diabetes.

Interventions like ours that provide community health educators—as well as national prevention programs that follow the Centers for Disease Control and Prevention's National Diabetes Prevention Program guidelines—often collaborate with churches, local nonprofits, and civic groups to offer social support and intensive diet, exercise, and behavior modification classes. The

results are compelling. The money saved from helping a single patient prevent possible kidney failure, blindness, or lower limb amputation more than pays for full-time employment and benefits for nearly an entire front-line preventive care team.

Interventions by other groups—including UnitedHealth Group, Optima Health, and the YMCA—provide health education and diabetes life coaches to community members. These have shown a return on investment of more than four dollars for every dollar spent on preventive care. Given that North Lawndale is in a congressional district where annual spending on diabetes care is approximately \$5,950 per patient, for a total cost of more than \$326 million,<sup>1</sup> even that modest rate of return on investment could yield significant savings and produce much better health for my community.

The Affordable Care Act includes provisions to establish community health teams and continue funding for patient navigators and expanded community health centers, but full realization of these provisions faces challenges. We need a national framework to implement these provisions and improve diabetes management and treatment, much like the plan outlined by Kenneth Thorpe in a January 2012 *Health Affairs* article. First steps would include a national expansion of the community-based Diabetes Prevention Program, administered locally by YMCAs, and increasing the use of community health teams to coordinate care in the community.

Funding is the critical issue. Most North Lawndale residents either have no insurance or are enrolled in Medicaid. However, Medicaid does not cover diabetes self-management education, nutrition therapy, community

health education, or other preventive care practices that have been shown both to be effective in diabetes patient care and to save money. Sustainable funding for community health education and community-centered interventions is important for improving community health.

We can no longer afford to dismiss the fruitfulness of front-line care provisions such as home visitation, which help people like Mr. Peel manage their illnesses and cope with the emotional hardship of living simultaneously with poverty and chronic disease. Less than a nickel of every US health care dollar goes toward prevention, yet three-quarters of current health care spending is for complications and treatment from poorly managed chronic diseases.

Proposals to expand wellness benefits for people eligible for Medicare and Medicaid should include reimbursements for qualifying behavior change programs and preventive care models.

Community health educators can take the time to listen with empathy, understand, and respond to underlying circumstances that can lead to depression among chronically ill people. They can also help patients better navigate the health care system. Such interventions can bolster the odds in favor of better diabetes medication adherence, dietary change, and self-management.

For communities like North Lawndale, Mr. Peel, and other patients suffering from “bad suga’,” this is an essential remedy. ■

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**Joseph F. West** ([joseph.west@sinai.org](mailto:joseph.west@sinai.org)) is program director and senior epidemiologist at the Sinai Urban Health Institute at Sinai Health System and an adjunct professor at Northwestern University's Feinberg School of Medicine, both in Chicago, Illinois. His work is supported by the National Institutes of Health, National Center on Minority Health and Health Disparities.

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## NOTE

- 1 Diabetes Care Project. Your community: Illinois—Congressional District 7 [Internet]. Washington (DC): The Project; [cited 2012 Dec 17]. Available from: <http://www.diabetescareproject.org/il.html#ild7>

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