

## Defining Moments

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***Editor's note:** This article is adapted from the address Ms. Nwankwo delivered as the recipient of the American Diabetes Association (ADA) Outstanding Educator in Diabetes Award for 2012. She delivered the address in June 2012 at the association's 72nd Annual Meeting and Scientific Sessions in Philadelphia, Pa. A Web cast of this speech is available for viewing at the ADA Web site ([http://professional.diabetes.org/Presentations\\_Details.aspx?session=4105](http://professional.diabetes.org/Presentations_Details.aspx?session=4105)).*

Please reflect on the moment when you knew you were in the right profession—when there was no longer a question that you were on your career path. That moment was likely preceded by a series of events that may have redirected your steps and changed your outlook. Your defining moment generally rivets your attention and forces you to evaluate your motivations.

My moment came when my mother died. It felt like the roof was taken off, and I was left exposed and abandoned. I realize that exercising my vocation as a diabetes educator did not keep my 83-year-old mother from dying from lactic acidosis while taking metformin.

### History

Like many of our patients, my mother had had diabetes for many years before her diagnosis around 1997. Her family history of diabetes included her mother and all of her sisters. Mom worked as a domestic worker, which meant cleaning houses for women in Toledo, Ohio's, suburbs. She caught multiple buses and walked about 5 miles each day

to reach those homes. In the early 1970s, her income was about \$5,000 a year. Despite her humble existence she was self-sufficient.

Like many of her generation, she did listen to her doctor, did not complain, and dutifully took all of her medicine. Her diabetes treatment included a morning glyburide dose and metformin. She did not know her A1C and did not want to ask her doctor for it because she did not want to anger him. It took about a year of coaching for her to ask for her A1C results.

She was eventually placed on insulin but also kept on her pills to treat her poorly controlled blood glucose. I was so proud of her for being able to inject her own insulin. Her doctor demanded that she lose weight, which was her usual take-home message. She would, in turn, restrict her food intake to cooked greens or other vegetables with a sliver of cornbread. She knew by experience that this meal helped her lose weight, but she did not attribute her bad feelings to hypoglycemia. She likely treated her lows by craving and binging on desserts. She complained a lot about making many trips to the bathroom at night.

According to her emergency room records, Mom died from a heart attack, secondary to the acidosis, resulting in kidney failure. I did not put it together until I mentioned to a diabetes educator in Toledo that the cause of her death was lactic acidosis. This wonderful and gentle educator informed me that metformin is not indicated for people older than 80 years of age.

**Questions**

What? I had not read the fine print of the drug information. I only saw that lactic acidosis was rare. What was I doing as an educator?

Her lack of appetite, complaint of taste changes, and a passing comments about not urinating as much the week before her death were shelved in my mind because I was focused on helping her adjust her insulin dose with her meals so she could stop blaming herself for failing her diet.

The next day, I confided to my colleague that I did not know why I am a diabetes educator if my Mom died from lactic acidosis. I was plagued with self-doubt. I wondered whether I could really make a difference in my patients' lives or whether I was doing them disservice because of my inability to put two and two together.

I had to define for myself, *why* am I a diabetes educator?

My officemate reminded me that, through our work, we had touched many lives. Another mentor of mine, Mary Lou Gillard, a 30-year veteran nurse and diabetes educator and a

person living with diabetes, spoke to my fragile sense of confidence to let me know what she thought of me.

**Reflections of Denial**

Grief makes us reflect and dig deep to discern our motivations and self-worth. I had to reframe my work with our precious study participants and indeed my whole career. I realized a new sensitivity to our patients' struggle with diabetes.

Like my mother, many patients struggle with denial. Denial takes many forms. In my mother's case, it was following her doctor's orders and expecting her doctor to know the consequences. For others, is denial a way of coping with a lack of access to aggressive health care for diabetes? Could it be a coping mechanism for seeing overwhelmed and diabetes-illiterate doctors striving to balance reimbursement with patient care, where monitoring blood glucose and adjusting medications to lifestyle are just too much to deal with in a 10-minute visit? Or, do patients get so beaten down and fatigued by acute complications such as frequent urination, yeast infec-

tions, blisters, sweets cravings, and poor sleep that their motivation to be a self-advocate is abandoned? I saw this in my family.

**Patient-Centered Work**

Most of my 20-year diabetes career has been working with Robert Anderson and Martha Funnell in providing value-added service under the umbrella of behavioral research of African Americans with type 2 diabetes. In 1991, Anderson et al.<sup>1</sup> wrote the seminal editorial on barriers for African Americans in accessing quality care. This was a defining moment for the Michigan Diabetes Research and Training Center (MDRTC), when members decided to focus on reducing the barriers facing African Americans with type 2 diabetes. This is also where my personal journey and that of the MDRTC as an institution came together.

The editorial addressed the importance of philosophy and the need to approach patients with a different lens. Among other things, it said, "The issue of empowerment poses a dilemma. On one hand, the very act of helping a minority group may reinforce a disparity between the power of the helper and that of the minority clients. On the other hand, adopting the position that we are ready to provide a service whenever you can demonstrate the ability to seek and utilize that service can serve as a justification for abandoning a major segment of our population: people who have not had access to the necessary resources to change the quality of their lives."

This article recommended several principles and offered guidance in how we would change our service and research in working with African Americans in terms of what would be considered to be valuable to the community. Those principles include involving participants in the planning and implementation of service, providing a valued service, empowering participants to change their own behavior and to influence ours to improve quality of life, and, finally, respecting cultural diversity.

**Table 1. Selected Chronic Disease Indicators—Diabetes, Wayne County Residents, 2008–2010**

Mortality, Selected Causes			
Cause of death (ICD-10 code)	Average Number	Crude Death Rate	Age-Adjusted Rate
Diabetes (E10–E14)	536	28.8	27.1
Any mention <sup>a</sup>	1,612	86.7	81.3
Selected Hospital Discharges			
Diagnosis (ICD-9 Code)	Average	Crude Rate	Age-Adjusted Rate
Diabetes (ICD-9 code 250)			
All	5,496	295.6	287.5
With lower-extremity amputation <sup>b</sup>	368	19.8	18.7

<sup>a</sup>Deaths were considered "Diabetes, any-mention" if either the underlying or related cause of death was coded E10–E14.

<sup>b</sup>Discharges with a diagnosis of diabetes mellitus (ICD-9 code 250) without mention of traumatic injury (895–897) and with procedures for major or minor lower-extremity amputation (84.1).

ICD-9, International Classification of Diseases, Ninth Edition; ICD-10, International Classification of Diseases, 10th edition. Data from Ref. 3.

**Table 2. Selected Health Characteristics of Low-Income Adults Aged 18–64 Years, by Insurance and Diabetes Status, 2007–2008**

Characteristic	Medicaid Beneficiaries (%)			Uninsured People (%)		
	All	With Diabetes	Without Diabetes	All	With Diabetes	Without Diabetes
In fair or poor health	27.9	55.3 <sup>a</sup>	24.8	16.5 <sup>b</sup>	54.5	14.5 <sup>b</sup>
Disabled	21.4	36.7 <sup>a</sup>	19.6	0.7 <sup>b</sup>	2.6 <sup>b</sup>	0.6 <sup>b</sup>

<sup>a</sup>Significantly different from nondiabetic Medicaid population ( $P < 0.01$ ), two-tailed test.

<sup>b</sup>Significantly different from Medicaid population ( $P < 0.01$ ), two-tailed test.

Data from Ref. 6.

### Disparities and Access

We chose to work primarily with the residents of Wayne County, Mich., where residents bear a heavy burden of diabetes. U.S. Census data for 2010<sup>2</sup> indicated that Wayne County's population was 1,820,584, with 713,777 residing in Detroit, Mich. Just less than 83% of Detroiters are African American. Selected mortality and hospital discharges indicators for diabetes are listed in Table 1.<sup>3</sup> About 1,600 deaths are due to diabetes and > 5,400 hospital discharges included billing codes for diabetes.

Many of our participants are underinsured. One 2005 study by Anderson et al.<sup>4</sup> found that, of the patients recruited, 12% did not have insurance. The Voices of Detroit Initiative (VODI) is a Michigan collaboration of health system partners in Detroit/Wayne County that provides medical services to the uninsured. Its annual report<sup>5</sup> states that > 300,000 residents of Wayne County have no health insurance. VODI enrollees are characterized as 92.4% African-American adults < 25 years of age, with an average annual income of \$10,581. Thirty-six percent of the enrollees report having at least one chronic condition.

A recent report by Garfield and Damico<sup>6</sup> used national data to survey pre-Medicare and Medicaid populations that had coverage for 1 year compared to their uninsured counterparts. We see from this summary in Tables 2 and 3 that Medicaid adult enrollees and the uninsured with diabetes report poorer health and more disability and have a higher tendency to delay or not fill their prescriptions.

A Centers for Disease Control and Prevention review published in 2012 by Ali et al.<sup>7</sup> shows that there remains a persistent connection between poor glycemic control and lack of regular access to care with health insurance status. The authors showed that those with either public or private insurance were more likely to have regular access to care and better glycemic control than those without insurance.

### Change Happens

I was in denial as well; I ignored my purpose. I thought it was primarily for my family that I worked and learned from great teachers such as Robert Anderson and Martha Funnell. Yeah, I know I'm lucky, and I'm lucky also to work on what is my soul's passion: empowering communities that have so little but are able to change so much.

We learned from our work that we needed to include a psychosocial approach to diabetes care to support patients' choices to make appropriate behavior changes. We learned the value of support. Although what we do may seem like a drop in the bucket, it has a rippling effect. More encouragingly, behavior change may happen after the intervention, even when we are not around to witness or measure the long-term change.

In a recently published study by Tang et al.,<sup>8</sup> recruited patients who had had previous diabetes self-management education were able to sustain their objective measures during the 2-year intervention. Impressively, 1 year after intervention, those patients achieved an additional improvement in both

behavioral and clinical measures, specifically in following a healthy diet, lowering cholesterol, and improving glycemic control.

This tells us there is a very probable change in behavior that occurs beyond the realm of our interventions. This work lays the groundwork to challenge our research approach, the approach that restricted our interventions to those that produce time-limited objective outcomes.

Clinicians struggle with appropriately supporting behavior change. A committee of the American Diabetes Association (ADA), led by David Marrero, soon will release a consensus report entitled "21st Century Behavioral Medicine: A Context for Empowering Providers and Patients with Diabetes" that will describe strategies to implement behavioral methods in a clinical setting. Starting with individuals and developing an understanding of personal characteristics and the contextual influences on individual behavior for both patients and clinicians will assist clinicians in effectively supporting their patients through lifestyle change. In this transformed relationship, patients are able to communicate with their physicians, share their expertise, ask for resources, and see improvements in their A1C, lipids, and blood pressure.

My denial was in ignoring my part of the bigger picture. It was more than helping my siblings manage their diabetes complications and my mother with diabetes self-management. Instead, their struggles sensitized me to the excuses that the community members were left to

**Table 3. Access to Care Among Low-Income Adults Aged 18–64 Years, by Insurance and Diabetes Status, 2007–2008**

Access Measure	Medicaid Beneficiaries (%)			Uninsured People (%)		
	All	With Diabetes	Without Diabetes	All	With Diabetes	Without Diabetes
Have usual source of care	80.8	90.4 <sup>a</sup>	79.7	39.1 <sup>b</sup>	68.7 <sup>b</sup>	37.5 <sup>b</sup>
Unable to get necessary medical care within the past year	3.6	4.9	3.4	10.4 <sup>b</sup>	17.0 <sup>b</sup>	10.1 <sup>b</sup>
Delayed necessary medical care within past year	4.7	2.9	4.9	8.2 <sup>b</sup>	15.5 <sup>b</sup>	7.8 <sup>b</sup>
Unable to get necessary prescriptions within past year	3.1	6.3	2.8	7.1 <sup>b</sup>	17.2 <sup>c</sup>	6.5 <sup>b</sup>
Delayed obtaining necessary prescriptions within past year	3.3	9.3 <sup>d</sup>	2.6	4.9 <sup>c</sup>	15.0	4.4 <sup>c</sup>

<sup>a</sup>Significantly different from nondiabetic Medicaid population ( $P < 0.01$ ), two-tailed test.

<sup>b</sup>Significantly different from Medicaid population ( $P < 0.01$ ), two-tailed test.

<sup>c</sup>Significantly different from Medicaid population ( $P < 0.05$ ), two-tailed test.

<sup>d</sup>Significantly different from nondiabetic Medicaid population ( $P < 0.05$ ), two-tailed test.

Data from Ref. 6.

give when choices are perceived to be limited. Patients struggle, but they want to do better and be healthier. Patients are concerned.

The Diabetes Attitudes, Wishes and Needs study<sup>9</sup> showed us that patients struggle a long time with wanting to do better. The study found that diabetes self-management is less than optimal. Self-management problems are due in large part to psychosocial problems, which are common, but are rarely treated. Eighty-five percent of the people in this study reported severe distress at diagnosis, and 43% continue to experience these feelings 15 years later. Access to team care and communication between patients and professionals was associated with better outcomes. And finally, initiatives to address psychosocial needs must have a higher priority to improve these outcomes.

Tools were developed to increase communication between providers and patients. These tools can be accessed online at <http://www.dawnstudy.com/ToolsAndResources/DialogueTools.asp>. This site also provides more information about the DAWN study, which is now in its second phase, as well as useful statistics.

### Confronting Barriers Through Research

We have seen distress reduced as barriers are eliminated in our studies. In a 1996 retinopathy study,<sup>10</sup> patients willingly came to clinics that were conducted in their neighborhoods. Ophthalmologists volunteered their time to do the half- or full-day clinics. Most study participants could not afford the \$200 out-of-pocket expense because of a lack of health insurance.

Ten percent of the 800 African-American patients who completed the study had serious eye disease discovered at screening and required immediate follow-up treatment. Most of those did not know that they had an eye disease problem. Patients overcame their denial of the impact of diabetes on their vision as they learned that they could prevent blindness.

We noticed that many of our study participants would give half of their cash incentive to their driver for transportation costs. Others stated that they would go and buy healthy food this week because now they have the means to do so. Empowered patients prioritized their health and reallocated their funds to support their health. This was my first project in the MDRTC.

We know patients want to do better. Patients value education on their terms. Patients improve their self-management skills. Patients respond to educators who care and understand. These lessons have helped me to be more patient with our patients. Sometimes just listening and expressing positive reinforcement for their attempts helped patients rally the motivation to do better.

Our studies focused on the role of support in self-management. We heard repeatedly that participants see value in supporting each other and find it easier to stick to lifestyle changes in unsupportive home environments when they have such support.

Patients are willing to be fully engaged when the barriers are reduced. Our work has touched some lives, and they, in turn, have influenced their family members. A woman who attended our support group recruited her daughter and her granddaughter to join us in the ADA Step Out Walk for Diabetes in Toledo. She, with other support group members, took action.

Our current work is focused on reducing barriers to education in 10 churches. Twelve to thirteen members of a church family will receive 10 hours of diabetes self-management education through this randomized,

controlled trial. It is probable that those educated members will then influence others in the church to seek education and to work on improving their self-management skills and will build on the supportive culture of the church to sustain those changes.

This current work brings me full circle to my upbringing, as I recall the biblical passage (Job 23:10) that says, “He, Our Source, knows the way that I take . . .” I watched many of our church elders, mothers, pastors, and congregates suffer from undertreated diabetes, relying on their faith and uninformed others for support. Education was unavailable. Our current work is redeeming.

I am becoming aware. Aware of what my Mom’s example has taught me. My Mom embraced learning in her own way. She accompanied me on many trips to professional diabetes conferences. She continued to quietly change and learn more about her own self-management.

I am taking stock of the present. I have had the opportunity to expand the effort to reduce barriers by traveling to Umahia, Nigeria, in 2010. There, I participated in a medical mission led by my husband to his hometown. I taught a few nurses and worked with Nigerian physicians to screen for and assess diabetes, as well as educate patients about self-management.

Just as there are multiple defining moments, there are also multiple beginnings. As educators, have you considered your impact on the people who come to your clinic and education programs? Does your work remind you to define and refine your role as a diabetes educator? I am grateful to be a diabetes educator.

My journey has been immeasurably enriched by the many people that I have learned from and gotten to know. Work by behavioral experts such as Richard Rubin, David Marrero, John Piette, and Mark Peyrot informs us of tangible strategies to assist in behavior change. My skills in diabetes self-management and nutrition were sharpened by fellow dietitians Ann Albright, Karmeen Kulkarni, Melinda Maryniuk, Marian Franz, and Hope Warshaw. My local registered dietitian friends who shaped my counseling style to include the language of the patient include Susan Bosserd (now deceased) and Andrea Lasichak. I am grateful to my MDRTC colleagues Tom Fitzgerald and Tricia Tang for including me in their work in the area of diabetes-related perceptions and support. And I also want to acknowledge the many people I have not named, and especially to thank the patients who I have had the privilege of working with. Finally, on behalf of the Nwankwo family, I thank the association for this honor and opportunity.

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