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NARRATIVE MATTERS



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Navigating Veronika: How Access, Knowledge, And Attitudes Shaped My Sister's Care

When a tooth infection turns into a health emergency, a woman helps her sister get the care she needs.

BY ELIZABETH PIATT

In the spring of 2010 a terribly infected tooth forced my sister, Veronika, to the emergency department (ED). This story began, however, several months before. It is a story of Medicaid, access to the best care, information and misinformation, and the gap between the haves and the have-nots.

My sister had gone to her dentist because she was experiencing some sensi-

tivity and pain in one tooth. He told her the tooth was badly infected and needed to be removed. He attempted to remove it himself, but the local anesthetic didn't work. Her gums would not get numb, so he couldn't go any further. The dentist referred her to a local oral surgeon—one of only a handful in the county who accepts Medicaid patients.

The oral surgeon couldn't see her for eight weeks, but with no other option,

she scheduled the appointment and waited. Later we would learn this was only for a consultation, but at the time, Veronika didn't understand this fact. "All he did was look at my tooth and take more x-rays," she complained to me after the appointment. "I thought he was gonna pull it!" She would have to wait another eight weeks to have the tooth pulled.

While waiting for that appointment, Veronika lost her Medicaid coverage because she didn't make it to a required eligibility interview with her caseworker. When I asked her why she didn't go to the interview, she said she couldn't get a ride. With no car, my sister relies on me, other family, and friends to take her grocery shopping and get her to appointments. There is a bus stop only a block from her house, but she can't walk that far because of a chronic back problem that causes severe pain when standing for long periods of time or even walking short distances.

Now, without health coverage, she decided not to go to the long-awaited appointment with the oral surgeon. She did, however, meet with her caseworker two weeks later, and four weeks after that her Medicaid was reinstated. By then, the tooth wasn't bothering her as much as it had, so she waited. When the pain eventually returned, she rescheduled the appointment with the oral surgeon. Four months had passed since her dentist told her the tooth had to come out.

This is where I should explain that my sister and I weren't very close. She really frustrated me. We grew up in the same circumstances, raised by a single mom in a working-class neighborhood. I did all the "right" things. I put myself through college and graduate school, delayed starting a family, and now live a very comfortable suburban life as a college professor. Veronika followed a different path. She had her first child when she was sixteen, scraped through high school, and relied on the system to provide for herself and her kids—Section 8 housing, Temporary Assistance for Needy Families, and Medicaid. With

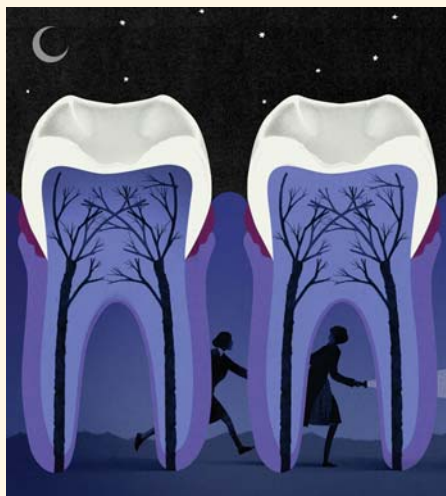
a monthly assistance check of only \$115, she lives in a poor neighborhood in a house that is owned by our mother.

I have to take a deep breath whenever Veronika calls me, and sometimes I just don't answer the phone. She always needs something from me: money, a ride, help with some unfolding drama in her life. Over the years, the constant stress of our relationship has left me feeling burned out. As a consequence, I avoid interacting with her as much as possible, and I don't always treat her kindly. Soon, however, she would need me.

Have Medicaid, Will Travel

The oral surgeon was going to use a "twilight" procedure to pull the tooth because among my sister's many health problems is a heart condition that makes general anesthesia too risky. But the twilight procedure, which uses a combination of local anesthetic to numb the gums and intravenous Valium to sedate the patient, didn't work. During the initial stages of the procedure, Veronika kept asking when she was going to get numb. The surgeon ignored her questions, thinking that it was just the Valium that was confusing her. When he began cutting her gums, however, she screamed. At that moment, the surgeon realized she was alert and could feel everything he was doing. According to Veronika, he then grew angry and pushed back from the exam chair before slamming his instruments onto the tray beside him. In frustration, the surgeon threw up his hands and told his assistant, "I can't do her. Send her to Metro." At that very moment, I am sure my sister was far from the perfect patient. But it's clear that, whatever his intentions, the oral surgeon's condescending response made her feel small.

Metro Hospital has an oral surgery clinic and residency training program. The clinic, forty miles from my sister's home, specializes in hard-to-treat cases and is part of a countywide program for uninsured and underinsured populations. In the days after the oral surgeon's aborted extraction, Veronika had to wait for him to process a referral allowing her to visit the clinic. She dealt with the pain for almost a week, expecting to hear from the oral surgeon any day. Finally,



our aunt convinced her to go to the ED.

The ED physician said he'd never seen a worse infected tooth. One only needed to look at Veronika's face to know her situation was dire. The left side was so swollen that she could not open her left eye and her bottom lip was turned inside out. The infection had driven her heart rate and blood pressure to dangerously high levels. "I was so scared," Veronika told me later. "That doctor said I could die if I didn't get that tooth pulled." But all they could do in the ED was treat the infection. She left after receiving a shot of penicillin, a prescription for penicillin pills, and orders to call Metro Hospital to schedule an appointment immediately.

Spurred to act, Veronika called her oral surgeon the next day to find out why she hadn't heard from his office about the referral to Metro. The secretary said, "We mailed that to you three weeks ago because your phone number wasn't working." My sister wrote down the information about where she needed to go.

She was told to bring someone to the appointment with her, so she started making calls, but none of her friends were able to take all those hours away from work. Next she called my mother. They are very close, but she lives 3,000 miles away. Veronika didn't know what to do. She was scared she was going to die. Our mother told her, "Call your sister! She's only ten miles away!" After hearing her story, I reluctantly agreed to help.

We made two trips to Metro Hospital. "Hey," I said, as she got into my car for the first trip. "Hey," she replied. "How's

your kids?" she asked. "Fine." I didn't ask about hers. The rest of the drive was tense and quiet. When we arrived for the first appointment, I found a wheelchair because the walk from the entrance to the dental clinic was too far for her to manage. The waiting area was crowded with people and noisy with children and the constant bark of smoker's cough. To get to a seat, I had to step over kids playing on the floor, crutches propped on chairs, and oxygen tanks tethered to patients. The cacophony in the clinic waiting room contrasted sharply with the spa-like quiet that I had come to expect at my own dentist's office, with its Muzak, cappuccino machine, ice cream treats, free wi-fi, and private consultation rooms. There, the staff dressed in lavender and white, and greeted me by name.

At the Metro Hospital clinic, Veronika thought she was going to have her tooth pulled that day, but it turned out, once again, that our first appointment was just a consultation with an oral surgery resident. After examining her, the resident explained that she didn't actually have an infected tooth. Instead, the cause of her problems were three infected roots, left over from teeth that had broken off long before. This was the first time anyone had explained this to Veronika.

Metro had received a referral from the original oral surgeon to remove the infected roots but did not have a referral for the teeth that needed to be removed for a partial denture, so Veronika was told to bring the new referral with her to her next appointment or have her dentist fax it. The resident explained how they would pull the teeth when she came back: He was going to perform a nerve block to numb her jaw. Given Veronika's earlier experiences with the oral surgeon, she was anxious. She had hoped that the resident would be able to put her to sleep. He explained that because of her health problems, he couldn't put her under. But he assured her that she wouldn't feel anything after he performed the nerve block.

During our ride home, the air between us felt lighter. Veronika was still anxious about the procedure. She started to cry. "I really want them to put me to sleep," she said. "What if that nerve thing doesn't work?" I tried to reassure her.

Policy Checklist

The issue: Patient navigators are an effective resource to help poor patients traverse a complex health care system, but health care professionals also need to examine their own attitudes and behavior toward the poor.

Related resources:

Center to Reduce Cancer Health Disparities, "What Are Patient Navigators?" <http://crchd.cancer.gov/pnp/what-are.html>

American Dental Association, "Affordable Care Act, Dental Benefits Examined" <http://www.ada.org/en/publications/ada-news/2013-archive/august/affordable-care-act-dental-benefits-examined>

Silow-Carroll S, Alteras T, Stepnick L. "Patient-Centered Care for Underserved Populations: Definitions and Best Practices," <http://hsc.unm.edu/community/toolkit/docs8/Overview.pdf>

Related reading:

Wallace B, MacEntee M. "Access to Dental Care for Low-Income Adults: Perceptions of Affordability, Availability, and Acceptability." *J Community Health*. 2012;37(1):32-9.

Dohan D, Schrag D. "Using Navigators to Improve Care of Underserved Patients: Current Practices and Approaches." *Cancer*. 2005;104(4):848-55.

Satcher D, Higginbotham E. "The Public Health Approach to Eliminating Disparities in Health." *Am J Public Health*. 2008;98(3):400-3.

Link B, Phelan J, Miech R, Westin E. "The Resources that Matter: Fundamental Social Causes of Health Disparities and the Challenge of Intelligence." *J Health and Soc Behav*. 2008; 49(1):72-91.

"He did say he was going to make sure you couldn't feel anything before he pulled them out. It will be OK." Her tears continued, so I added, "I'll be with you, and I will stay in the room until we know you are completely numb. I'll even hold your hand if you want me to." She didn't seem convinced, but she nodded. I felt the need to distract her, so I asked her about her daughter. She smiled and talked about her all the way home.

We returned two weeks later only to learn from the receptionist that the office had not received a referral to pull the additional teeth. Veronika didn't have the referral, either, even though her dentist's office said they would mail it to her. I turned to her, frustrated, and asked her why she didn't call to follow-up.

"I just thought I didn't understand her," she said.

"Jesus, Veronika, really?" I replied, rolling my eyes and throwing up my hands, much like that oral surgeon who had tried to pull her teeth so many months before. "I am *not* driving you up here a third time."

Angry, I turned to the receptionist. "You better call the dentist right now

and have him fax that referral. I am not going to schedule another appointment." The receptionist got red in the face and started to close the window. I put my hand out to block it. "I'm sorry, but this is our second time up here and we drove 40 miles to get here. Can you please call them?"

I was frustrated, and I'm certain the receptionist was, too. At the time, I blamed Veronika for the missing paperwork. I expected my sister to have followed up on the status of the referral, to make sure everything necessary to perform the procedure was in place. That is what I would have done.

By the time Veronika was called back to the procedure room, the receptionist had made the call, but the referral still hadn't arrived. The resident told us he would pull the rotten roots and all the necessary teeth anyway. I stayed through the preliminary exam and held my sister's hand while she was given the shots for the nerve block. Once she was numb, I was sent to the waiting room. Veronika walked out ten minutes later with a wad of cotton in her mouth, after-care instructions, and prescriptions for penicillin and Vicodin. It took four doc-

tors, four health care facilities, nine months, and 160 miles of driving, but the infected roots were finally removed.

The Oral Tradition

I can't help but think about what would have happened if Veronika hadn't called me. Veronika's story is incredible, but, sadly, it is not uncommon. In 2007 Deamonte Driver, a twelve-year-old boy from Clinton, Maryland, died after an infection in his tooth spread to his brain. Deamonte's family had Medicaid coverage, but his mother had trouble finding a dentist who would accept Medicaid patients. She was also focused on getting her other son, DaShawn, to a dentist. He was complaining about his teeth, and Deamonte was not. Just a week before DaShawn's appointment with an oral surgeon, the family lost their Medicaid coverage because some required paperwork was sent to the family's previous address. Deamonte's mother only realized he was sick when he started complaining of a headache. She took him to the hospital, where he was treated for a dental abscess and given antibiotics. His condition worsened, and after three weeks of unsuccessful treatment, Deamonte died.

Both stories illustrate that insurance coverage is only part of the solution to disparities in care. In addition to coverage, issues with access, coordination, and continuity of care all got in the way of Veronika's getting the health care she needed.

Socioeconomic status is persistently linked to health disparities. Higher socioeconomic status provides you with more access to resources such as knowledge, power, prestige, money, and beneficial social connections. So while a mobile phone, free transportation to medical appointments, and access to medical care are important, they reflect only one link in the chain.

Veronika is good at accessing financial resources. She knows where to go, who to see, and what paperwork she needs to fill out in order to get cash assistance, food stamps, and help paying utility bills. But she doesn't know how to translate those resources into improved health. Take, for example, her "government phone." Some of Veronika's friends call it an "Obama

phone,” but it isn’t a new program. Telephone companies have been offering (and covering the cost of) subsidized phone service for low-income customers for more than twenty years, through a program known as Lifeline. Recently, they made that subsidy available for wireless phones. The policy exists so that patients don’t have to worry about missing calls from doctors’ offices or finding a way to arrange for transportation to and from appointments. But the program has struggled to reach the people who might benefit from it the most. Veronika, for example, is eligible for free mobile phone benefits through her Medicaid provider, but she never looked into it because she thought she wouldn’t qualify. “My friend told me you have to be sick enough for a case manager to get that,” she said.

Navigating The System

It seems the health care system is organized in a way that expects patients to be advocates for themselves and to know the right questions to ask of the right people. This way of conducting the business of medicine limits the flow of vital information, especially to patients with limited education and an inability to access information resources. At some level I think my sister has internalized the stereotypes we have about poor and minority people—she doesn’t question, doesn’t challenge, doesn’t say “I don’t understand” when she doesn’t. Instead, she relies on friends and family for information—a social network that is limited to those she trusts.

One solution to this problem would be better access to patient navigators, who not only help patients understand their diagnoses and options for medical care but also assist with insurance and billing issues, coordinate care, and manage transportation and child care problems that may interfere with treatment. For many years, patient navigators have

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helped cancer patients manage their care, and programs are being developed in other areas of health care. If a navigator had been following Veronika, she never would have ended up in the ED because she never would have lost her Medicaid coverage. The navigator could have also followed up with the oral surgeon and the clinic to make sure referral paperwork was processed before the appointment and could have served as a bridge between my sister and the health care system to make sure she understood her diagnosis and treatment.

If navigators are not active in the communities they are serving, however, their effectiveness will be limited. Currently, most navigators are introduced to patients when they enter the health care system. Yet patients who could benefit the most from these services need help long before they make it to a doctor’s office. Navigators who wait for patients to come into the clinic won’t be accessing the community networks where information is shared. To truly be a bridge between the health care system and patients, navigators need to come from, or become a part of, these community networks. They won’t reach my sister, and people in her circumstances, any other way.

What navigators can’t do is change health care professionals’ attitudes and behavior toward poor patients. Just as I had come to feel overburdened by and hardened to my sister’s problems, health care providers serving low-income patients can also become overwhelmed with the level of attention these patients require. Failure to follow

up, no-shows, cancellations, and non-adherence to treatment plans are frustrating. Navigators can help eliminate some of those frustrations by making follow-up calls, answering questions, and managing other patient problems. But everyone has a responsibility to examine his or her own feelings about poor patients. This is difficult to do. It has certainly been difficult for me—difficult because it requires that I confront my own stereotypes, prejudices, and privilege.

Confronting my own attitudes has allowed me to begin to change my interactions with my sister. Veronika still has difficulty navigating the health care system, and she still frustrates me on occasion, but she now knows she can always call me. In early 2013, a few years after her infected tooth was finally removed, she had back surgery and contracted a methicillin-resistant *Staphylococcus aureus* (MRSA) infection that required daily intravenous antibiotics. For six weeks I drove her to the hospital each day and sat with her for an hour during her treatment. On one of those days, quietly talking as her IV dripped, I said, “Veronika, I think we need to tell our story about your tooth.” She looked at me like I was crazy. “Why would people want to know about my tooth?”

“Because it really made me think about how I treated you,” I said. “I think doctors and nurses need to know that.”

“OK,” she replied. “But use my real name. I want them to know who I am.” ■

Elizabeth Piatt (piattee@hiram.edu) is an assistant professor and chair of the Sociology Department at Hiram College, in Hiram, Ohio. This article was previously presented at the Association of Black Sociologists Annual Conference, in Las Vegas, Nevada, in 2011. The author thanks her sister, Veronika Boyer, for allowing her to share this story; Robin Shura, Anisi Daniels-Smith, Erika Hill-Yates, Sarah Berry, and Michael Blackie for their willingness to comment on drafts; and the anonymous reviewers for their helpful feedback.