

My goal was to fulfill a promise. As a member of the Cultural Diversity Project's task force, I promised to listen and to learn from members of a culturally diverse population how they perceive healthcare providers and what we can do to provide better care, especially for patients facing the end of life. I thought I would discover what we were doing right, a little about what we were doing wrong, and some things we could do to make a difference. Listening and learning proved harder than I expected, but the stories I heard compel attention and beg to be heard. My challenge now is to take others — you — where I have been.

Their Story, My Story, Our Story

Finding a Direction

Listening to stories meant going places inside me that I would not ordinarily choose to go. Now, I have to take you there, to a place, for example, in which the unthinkable reality of wearing adult diapers is only surpassed by the thought of not having the twenty dollars it takes to buy them.

Do not, however, succumb to the luxury of debating in your head the economic and political issues surrounding healthcare delivery. I often turned down this side road to get away from the story — to get into my head and out of my feelings. There are safe places inside a theoretical discussion, but that is not where the storytellers live.

Their stories were not easy to hear, and I had trouble staying focused. The storytellers' experience and my reaction to their stories vied for my attention. I thought "What if this happened to me?" Being blamed for being sick because one is poor or being accused of contributing to one's condition because of cultural or religious practices adds a completely new dimension to suffering.

There's something in us that is not yet listening when our concern is "what if it had happened to me." Following the storyteller's lead points beyond that reaction to a concern that, if not exactly selfless, is at least more communitarian. It was clear that the storytellers themselves were filled with hope — hope that they could make the burden of illness lighter, if not for themselves then for another who might one day be in similar distress. Hope for them was not "a way out." Rather, they hoped that an ounce more patience, a smile, a gentle touch, a moment of time, a hint of respect might be generated from even one of those in control of their destiny.

Not the Words I Had Expected to Hear

I heard stories about overwhelming debts owed to medical institutions. In case "overwhelming debt" is too vague, let me be specific. Imagine owing seven hundred thousand dollars to a hospital. How does one face that mountain? How do you respond when someone tells you that you will need hundreds of dollars for medication, when you must live entirely on nine hundred dollars each month. The gentleman who shared this story survives with a sense of humor and a philosophical view of the world. "What can you do," he asked, "but accept life as it comes."

Having head lice is a devastating experience in itself. It is also humiliating when your healthcare providers make no bones about their cultural belief that only "dirt low lives" contract it. In reality, the condition is as common as dirt among children. Children have contact with adults and with objects that make it almost impossible to contain this easily treated but emotionally scarring scourge. One woman who contracted lice while in

the hospital was placed in isolation, barred from physical therapy, and cared for by a nurse who didn't want to be too close for fear of harming her unborn child. More, the patient's privacy was totally violated as the rumor that she "had brought head lice to the hospital spread like wild fire."

How does one tolerate witnessing a loved one in pain and having that pain ignored for no better reason than the color of your skin? The question is unimaginable for those of us who have never experienced such injustice. One man's wife had to undergo an extremely painful bone marrow biopsy when she had only weeks to live. Why? Can it be ethical to use vulnerable, sick, and dying individuals as a means to educate medical students? The emotional wound cuts deeper and opens old festering wounds caused by racism and social inequities when the storyteller recounts that he would allow no more attempts to secure the biopsy unless it was done by a "real doctor." "I can pay for it," he said.

No one has ever assumed that I could not pay for my healthcare because of the color of my skin or the cut of my clothes. Have you faced such assumptions? What would you do if you owed that kind of money and needed to return to the hospital?

Inalienable Rights

We live in a country in which the practice of one's religion is a right protected by law. Indeed. But with the exception of Jehovah Witnesses, most healthcare providers know little about religious beliefs that impact health practices, illness, and end-of-life issues. Mix a language barrier, "strange" beliefs, and lack of time into a life and death situation and the suffering and injustice that result, although predictable, are difficult to fathom. One person strongly believed that his illness was caused by his failure to honor a promise made to Buddha — a promise to return to his homeland and rescue fellow refugees. However, no one among his healthcare providers, all devotees of modern medicine, wanted to know anything about this aspect of his life. His desper-

tion and helplessness were seen as impediments to the treatment plan, not as a possible avenue for healing. We do what is “right,” after all, and we do not have time to ask what is “right,” when, as healthcare providers, we already know. “Right.”

Another woman reminded me that “what does not kill us makes us stronger.” Indeed, she had endured several healthcare “accidents” and was now a wheelchair-bound amputee. Because of regulations on homecare, physical barriers at home, almost no transportation, and limited

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finances, she was locked out of physical therapy and unable to attend church. She talked longingly about the ladies’ group at the church. It had been her source of spiritual and emotional support. Now her world consisted of neat but cramped quarters with religious symbols hanging on the walls.

Isolation and loneliness are symptoms rarely discussed, and even more rarely treated. The home-bound woman lived in a world filled with opportunities for resentment. She had none. She was stoic and accepting of life as it had been handed to her.

Placing ones care in the hands of individuals who “don’t have time for you” or who “don’t want to listen” is frightening. It is also a norm of sorts that the storytellers had grown to accept. A parish nurse provided the majority of real healthcare to one impoverished community. She is a beacon of light in a dark and confusing world.

She negotiates their educational needs, makes transportation arrangements, and helps them through a maze of paperwork and appointments. She is a priceless gift — someone to trust in a world filled with incomprehensible practices and language.

A Blueprint for Change

Other stories, as eagerly told as stories that point to our shortcomings, were tales of gratitude for provider heroism. One voice vibrated with tears as a grandfather talked about the “angels” who cared for his grandchild. Another story warned me with its simplicity; how grateful the teller was that someone took an extra minute to explain a complicated procedure to someone who was frightened. These stories were too few.

Fear, humiliation, disrespect, helplessness and surrender permeated the stories. However, courage, humor, self-respect, and integrity were the substance of the storytellers. What I did not hear was a word of self-pity. I replay these stories, feeling them in my bones. Each person draws me to look again at the sea of faces that come for treatment and help to all our clinics. The voices I heard were those of the vulnerable. Am I, as a healthcare provider, willing to make myself vulnerable for them? ■