SHARE

THE PATIENT'S VIEW

Working from a Recovery Perspective in Primary Care: My Story

Lisa St. George, MSW, CPRP

Ms. St. George is Director of Recovery Practices at Recovery Innovations.

My first message to you is: Please care about me; I am a person. I come to you vulnerably and often with fear. I trust you to help me with my current health issue. I want you to listen to me and value me—to find me worth caring for and caring about. When you look at my list of medications and see that I have psychotropic drugs listed there, do not make assumptions about my ability to report my health needs, my intelligence, or my symptoms.

Once I needed stitches for a cut on my finger, and the nurse who was prepping me for the doctor was chatting with me. She asked me what I did for a living. I replied that I worked in mental health. She stated, "Oh bless you! Give me the blood and guts anytime; when I see one of those nut cases coming, I want to run the other way." Imagine my surprise. I wanted to ask her if she was willing to stay with me because I was a "nut case." However, I did not do this for two reasons. First, I did not want to embarrass her, and second, I thought she might actually leave me while I was bleeding badly. I feared a physical exit, but more importantly, I feared her emotional exit. What if she checked my medication list before beginning her work on me? Would I have gotten the tender care I received from her? Certainly, with my attentive vigilance as a trauma survivor, her discomfort with me would have been clear. As she treated me, I might have interpreted her indifference as dislike, anger, overwork, or something else. Her behavior would have concerned me and lowered my comfort level and trust. She might have disrupted the most important part of our work together—the relationship.

As you, the Internist, and I, the patient with a serious mental illness, engage in our work together, we must develop a trusting relationship. I must believe that you will always do your best to identify what health challenges stand before me. I must believe that you see me as a whole person and that you understand I have a life that means something to me. You must believe I am an individual who is entirely capable of recovery from health challenges and mental health challenges. You must take a risk and care about me.

According to statistics, I have now exceeded my life expectancy. I began life fit, healthy, and was a svelte 105 pounds until I had my first child and was a healthy 120 pounds for the next 10 years. I had mental health challenges first diagnosed at age eighteen. I endured physical abuse from my father until I was seven and emotional and sexual abuse from my stepfather until I was 17. During that important time, I had one year of safety when my mother moved us in with my grandparents after she left my father. At age 18, I began to have intense feelings that I did not deserve to live. I did not want to die, and the feelings were very intense and frightening. These feelings were a trauma response. This response was a "normal" response to terrible events. I coped and received psychiatric care for the next 20 years.

My physical and mental health changed at age 38; I was carrying out the duties of my work as a social service provider in a very dangerous neighborhood. I loved the people in the community and cared very much about them. I had one more responsibility to carry out on Friday before I could go home. However, I was attacked by a stranger while carrying out my duties. Although I was not badly injured, my soul was wounded. I drove home, treated my slight cut, and enjoyed a weekend with my family. On Monday, I got up and got dressed for work and ended up at my friend's house crying uncontrollably. Then, I lost about three months of time. This was also a trauma response.

However, in the continuum of my health care, that turning point was significant. During that time, I was put on anti-psychotics. My husband made sure I took the medication every day. I began to gain weight. I have always eaten a healthy diet, but within about a year, I had doubled my weight.

My primary care physicians told me to lose weight every time I went to them. I felt ashamed. My eating habits had not changed and remained healthy. I did sleep more because the medication made me groggy in the morning, but I still walked a lot with my baby in the stroller, and my husband often took us hiking in the mountains. I often walked with my older daughter who is blind to help her learn routes to buses or to her friends' houses. However, the pounds kept coming.

I complained to my psychiatrist about my weight and was told, "At least you are not addicted to drugs or alcohol." I did not understand what she meant. Years later, giving a speech in San Diego, I suddenly understood that the doctor thought I was addicted to food. I wasn't and have never had a challenge with addictions, but I was not asked for input on that idea. It was so far removed from my lifestyle that it took

continued on page 2

THE PATIENT'S VIEW

continued from page 1

me about 15 years to understand what she meant.

My primary care during this time focused on how fat I was. My blood pressure rose, and my cholesterol got high. I have had several primary care doctors. One told me I was attention seeking when I returned several times within two weeks with terrible nausea, upper back pain, and vomiting. Finally, her physician's assistant sent me for an ultrasound of my abdomen because he thought it might be my gall bladder. He told me he was taking a risk going against her, but he seemed to believe me when I said I felt terrible. I was in emergency surgery within three hours having a badly infected gall bladder removed that had enflamed all of the organs around it. Had I not reported my medications accurately, would I have had my problem recognized earlier and been treated like a person worth believing?

I had another set of experiences that demonstrate stigma against people with mental illness very clearly. I had recurrent chest pain and difficulty breathing over a period of three years. The pain increased in frequency and intensity during that time. I was hospitalized once and often had a low-grade fever and high levels of inflammation. My chest pain would wake me, and I would be terribly uncomfortable lying flat. Once I went to the urgent care and was sent by ambulance to the hospital (with all but one quarter of my right lung full of fluid). The doctor took a look at my medication list, asked me if I had taken my medications that day, which I had not because it was morning and I take them at night, and without examining me, or even listening to my chest, he told me I was having a panic attack. I told him I did not have panic attacks. He still sent me home.

The next day I saw my PCP and told him it was extremely painful to breathe. He told me to take some deep breaths. I reminded him that it hurt and that I could not breathe without pain. Reluctantly, he sent me for a CT. After I received the CT scan, I was sent directly to the ED, and within hours, I had heart surgery. Later an infectious disease specialist read my x-rays and told me that I had been sick for the last three years with pneumonia and coccidioidomycosis (i.e. Valley Fever), which had spread to my heart.

While these are my stories, I have heard countless stories from others that are like mine. In my work at Recovery Innovations, I have known many wonderful people who have died far too young. People with mental illness deserve to have a full life. Our medications are hard to take; they make us uncomfortable and have tremendous side effects. Still, most people I know take their medications. We want to be well, both physically and mentally. You and I as doctor and patient must engage in a relationship built on trust that the other is doing his/her best to make our work together valid. We must listen and work together as a team. I can plan my meeting with you, and you will accept my reporting as accurate. Then, we can learn to work together to create the best outcomes.

SGIM