



PERSONAL EXPERIENCE

LIVING WITH CF FROM A CULTURAL PERSPECTIVE

By Ana Stenzel

When I was hospitalized as a child, a physician told me: “You can’t possibly have CF, you’re not white!” Later in childhood, when I first attended CF camp, a group of campers surrounded me with curiosity. One teenage boy exclaimed: “ You have CF?! I thought Chinese people don’t get CF.” I quickly responded that not all Asians are Chinese, and that I was actually half Japanese and half German. It was moments like these that I struggled with wondering why my mother, seemingly the only Japanese person on the planet who carried the CF gene, was chosen for this fate. My mind often wondered if her ancestors migrated from Russia into Northern Japan, thereby infusing her Japanese blood with Caucasian genes. (My nationalistic Japanese grandmother staunchly denies that her family is nothing but pure Japanese!). Or maybe I didn’t really have CF at all, and this was some kind of mistake in diagnosis.

My symptoms since birth were obvious- meconium ileus, frequent pneumonias, and painful stomachaches whenever I consumed greasy American foods. Meconium ileus at birth was a blessing, allowing for an early diagnosis for myself and my identical twin sister, Isabel. Surely, if I hadn’t had meconium ileus, our CF would have gone undetected for years- after all, who would suspect it in Asian babies?

To my parents, who had immigrated to America just a few years earlier, the diagnosis was a shock, and they were overwhelmed by the task of taking care of sick twin daughters in a foreign country. All but one relative resided in Japan or Germany, so they lacked the extended family support that many families need in caring for CF children. We also had an older brother who was healthy, but only 18 months old when we were born.

Today, as an adult working in the health care profession, I’ve learned how much a person’s culture influences their perception of illness and coping mechanisms. My upbringing was infused with cultural influences. My mother taught me Japanese values of *gama,n* or perseverance, and *shikkari*, or discipline, which helped me fight a demanding disease like CF. She taught me that *muri*, or suffering, was part of life and only makes one stronger. On a less positive note, Japanese values of shame, *mendo* (burden), and stigma towards difference bled into my psyche as well. As for my German physicist father, who spent his childhood walking through Europe during World War II, he taught me that a good walk clears the lungs, and that one should always seek and analyze the facts. This taught me the importance of exercise, and to inquire as much about CF care as possible. We grew up hearing about their childhood war stories in Japan and Germany, and learned to appreciate that our lives in America, despite having CF, were not that bad. We even had the opportunity to live in Japan for a year, where we visited Japanese faith healers and learned about alternative medicines.

Being half Japanese wasn't always easy. The medical professionals often targeted our ethnicity as a reason for our poor health. My poor mother was accused that our malnutrition was because she fed us low calorie rice and fish, and not fattening American hamburgers. When we didn't hit puberty by our late teens, we were told not to worry since: "You're supposed to be skinny-you're Japanese!" My doctor even once thought that my elevated IgE levels and asthmatic symptoms were an allergic reaction to worms I picked up eating too much sushi! He was wrong, of course. My mother, who spoke English as a second language and had to learn to defend herself in an American health care system, often felt guilty, isolated and depressed by these accusations.

I shared the challenge of growing up biracial and sick with my twin sister. As many readers know, having siblings with CF is common because it is a genetic disease. But in my 34 years with CF, I have only met a handful of identical twins. It was enormously helpful to have a twin with CF and that has contributed to our survival, both emotionally and physically. We helped each other with chest physical therapy, were hospitalized together and formed a symbiotic relationship. Competition was inherent- we often had contests about who could cough up the most mucus during treatments, or who could tolerate therapy more rigorously, or who could eat more. This competition kept us motivated and disciplined. But in the back of our minds there was the ultimate fear of wondering who would die first, and the responsibility of keeping each other alive was enormous. When my health deteriorated more rapidly despite our identical medical regimen, Isabel was wracked with guilt and helplessness. I wondered why I was getting sicker- what was I doing wrong and why was it so unfair?

Fortunately, I received a double lung transplant in June, 2000. For several years we lived apart due to the risk of cross infection since I was immunosuppressed after transplant and she had CF lung infections. After years of symbiosis, this separation was excruciating. However, four years later, my sister faced sudden end stage CF. At the very end of her life, I saw her on the ventilator, and the fear I had dreaded all my life was finally clear- she would die first. But then a miracle occurred, and my sister received the gift of life, after being listed for only two weeks for a lung transplant. Our family went from contemplating funeral arrangements to seeing her sit up in ICU, stating, "Did I just have a transplant?" It was the happiest moment in my life.

Years ago, my Japanese friends made us 1000 origami paper cranes, called *zenbarzuru*. This beautiful artwork is a symbol of wishes come true and prayers for healing in Japanese culture. I look at the *zenbarzuru* in my room today and feel the power of my culture in keeping me alive. Today, Isabel and I are both happily and healthily post-transplant and enjoying a life free from CF. We are truly lucky.

CF is most common in Caucasians, but still occurs in other ethnic groups, including Asians. I have recently learned of a number of families with CF in Japan who formed the Japan CF Network. I also attended a conference a few years ago which featured CF patients from Taiwan. Many of these CF patients suffer early death due to being undiagnosed and lacking adequate treatment. As a genetic counselor, I strongly support raising awareness of the symptoms of CF among all ethnicities and advocate for CF newborn screening so babies of all ethnicities can be diagnosed and treated promptly. We await newborn screening in California.



Anabel (Ana) Stenzel and her sister, Isabel (Isa), live in Redwood City, California, USA. They are 34 years old. Anabel is a genetic counselor at Stanford Medical Center and Isabel is a social worker. Both are active with the CF communities through Cystic Fibrosis Research Inc. They are enjoying their new lives post-transplant by traveling, hiking, biking, swimming and enjoying family and friends. They are thankful to their parents, brother, and organ donors. You can email Ana at anana1872@yahoo.com.