Health Advocacy through Objects: Reflections from a Refugee Medical Case Manager

What do an Eritrean woman with stage IV cancer, a Burmese woman requiring a liver transplant, a Karen man with a wooden prosthesis, and a Somali boy with a congenital heart disorder all have in common?

All were refugees resettled in the United States within the last few years. All were my clients. For three years, I was a medical case manager for a refugee resettlement agency. Throughout those years, family, friends, insurance representatives, and medical providers continually asked what exactly was a "refugee medical case manager". My reply always changed: patient liaison, public health professional, social worker. No answer seemed to adequately convey medical case management's breadth. On my last day of work, looking at the objects I had accumulated, I contemplated how they represented my field. In each, I saw the faces of my clients.

Insurance cards: Seven plastic insurance cards were clipped above my computer. During my second meeting with new clients, I would fan out the cards in my hands like we were playing "Go Fish". I then began the daunting task of distilling information about the U.S. healthcare system, Medicaid, secondary insurance companies, and health benefits to clients in an understandable yet succinct explanation. Many had never heard of insurance and did not have a corresponding word in their language. At the end of the session, clients would select a secondary insurance. It was one more complication in a sea of confusing U.S. mechanisms to which they were struggling to acclimate. To make the decision more manageable, I helped prioritize their health needs and identified the company whose benefits covered those needs.

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Between client sessions, I displayed the cards as a reminder of those plastic rectangles' power. For my clients, these cards signified that they had finally gained admittance to an exclusive club: access to appropriate and timely healthcare. For some clients this access came too late, like my 35 years old Eritrean client who succumbed to her stage IV breast cancer shortly after arrival. However, for my Burmese client suffering with liver disease, it meant accessing a network of doctors who manage her conditions so she can live to see her teenaged daughter graduate high school. For thousands of other refugees, these cards meant access to prenatal care, eyeglasses, medication, mental health services, cancer treatments, surgeries, and prostheses to replace limbs stolen by mines and car bombs.

Sticky notes: On the side of my desk was a rainbow of sticky notes. Written on the notes – in either my quick scribble or a client's hesitant attempts at English – were a seemingly random assortment of words in varying languages with English translations. Fragments of languages from a rainbow of ethnicities, cultures, and countries. I showed clients how to navigate our labyrinth of a health care system. In return, they shared pieces of their language, culture, trauma history, resilience, and humanity.

My favorite note translated the Karen word for butterfly. My Karen client had lost his leg from a land mine; the amputation took place in the field. When he arrived at the Malaysian refugee camp, they had run out of adult prostheses and had only children's sizes. It was made of wood. It rubbed against his knee stump, causing great pain and preventing him from walking far or standing long. For four months, I would drive him to his weekly early morning prosthetics appointment. In the office was a picture of a

butterfly. While at doctors' offices, I always asked my clients to tell me words in their languages, trading the name in English. Whenever there was a lull in the prosthetics appointment, my client and I would attempt to communicate and inevitably end up laughing at our misunderstandings. We would then point at the picture of the butterfly and quiz each other. The butterfly became our connection.

Sketch of a heart: A cardiac surgeon at a leading children's hospital drew a heart as he explained to the mom how a heart pumps blood, thus illustrating what was wrong with her youngest son. "Ahmed" had been born with a serious congenital heart disorder. As the doctors explained, if Ahmed had been born in the U.S., he would have quickly undergone a moderately complicated surgery. At seven years old, open-heart surgery was extremely risky. His heart had massive holes, the muscle was stiff from overexertion, his skin was tinged blue from oxygen deprivation, and he had to be carried everywhere. At any given moment he could have a fatal seizure or heart attack. Ahmed was without choices. After fleeing her home and traveling to multiple countries in pursuit of doctors to treat her son, Ahmed's mom well understood. But she had been told, "Only American doctors can save your son."

The surgeon and I were concerned by this promise, and we tried to hedge her expectations. "We cannot do everything. We have never seen someone as sick as your son is still alive." Ahmed's mom listened intently and spread her arms wide. "It is in Allah's hands and your hands." The consent was signed, and Ahmed prepped for surgery. I did not know how to interpret his mom's acceptance. Was it a positive aspect of her personality or a byproduct of decades of traumatizing experiences outside her control? In

defiance of the doctors' concerns, Ahmed not only survived but is also flourishing. He and his mom, I decided, are resilience personified.

On my last day of work, I took the sticky notes and the sketch home. These represent my most triumphant moments of medical case management and lessons learned. I witnessed the ramifications of health care access inequities and realized that working in global health does not require traveling abroad. Now when I am asked to describe medical case management, I will say, "I am a cultural bridge. I am a supporter of health care access as a human right. I am a global health advocate."