



What Does It Take to Care?

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Mrs A, a 57-year-old Pakistani woman, came to the free clinic I worked in because she was without health insurance and in the country without documentation along with her husband and mother-in-law. Previously, she had abnormal liver enzymes, and her most recent labs revealed positive hepatitis C Ab, a viral load of 14.4 million, and a genotype of hepatitis C 3a. As I heard the whole story, my heart felt stuck and weighted down.

She had acquired hepatitis C many years ago via a blood transfusion for severe anemia after delivering her second child. Now she also had hypertension and diabetes. Though she had no bleeding, edema, or ascites, she had elevated liver enzymes and low platelets. How was I to treat this constellation of diseases, appropriately taking into account her lack of resources and status?

I felt helpless. I knew exactly what I would do if she had insurance: consult with hepatology, order an ultrasound and alpha-fetoprotein, and adjust her medications so that she was on fewer metabolized by the liver. Though I could stop the free metformin and recommend insulin, she could not, of course, afford it. Programs for reduced-cost or free insulin are for citizens or people legally in the United States, requiring a social security number and tax return, which she did not have.

Additionally, insulin meant affording syringes. Lancets and test strips were luxuries.

Mrs A still haunts me. I desperately wanted to help her, yet could not in the way that I would help insured, financially-solvent patients. The unfairness of this care inequity stifles me. If she had just been born to money or as a citizen of a different country, she would receive better, appropriate care. As a physician, I want to serve through empowerment, knowledge, and resources. In election years, campaigners tout love of the community, family values, and the importance of proper health care. Yet, I see a different world, in which these ideals are reserved for citizens or people with immigration documents. Mrs A is a person just like me, with the same foundational nucleic acid bases. Her skin consists of the same structural layers as mine: cutis, dermis, and epidermis. Her heart beats with the same sinus rhythm. Yet a quirk of birth circumstance means she receives less than the standard of care.

I hallway-consulted a hepatologist whose recommendations were to biopsy to determine the cause of the liver damage, plus a screening ultrasound and alpha-fetoprotein, none of which the family could afford. All I can offer is compassion and knowledge. My knowledge, though, seems only to reveal additional ways that I cannot help her. There is no

standard of care here. There are no guidelines about what to do in this case. Guidelines presume insurance and access to hepatologists, biopsies, and testing. Certainly, when this patient becomes febrile with spontaneous bacterial peritonitis, or has ascites causing shortness of breath, or is jaundiced with increased bilirubin, or bleeding out, the emergency room will give her the minimal necessary care in the most expensive way possible. In addition to feeling helpless, I am angry at our broken system, at her marginalization.

I did not vow to care only for patients who could afford it. I have come to believe that when society closes its eyes to Mrs A, the person who cannot access adequate health care because of her immigration status, it loses some of its own humanity. Those here without visas are people, too.

I am still wondering weeks after that visit, what does it take for people to care in the sense of opening one's heart, not just attending to medical issues? When I open my heart to others' deepest vulnerabilities, it stirs up my own past vulnerabilities. Mrs A's lack of financial resources uncomfortably reminded me of my childhood and growing up without financial stability myself,

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but it also allowed me to better connect with her struggles. Anyone could easily be jobless or homeless if circumstances change.

If I do allow myself to care, what then? Does caring mean fixing everything? I want to, but it's impossible and overwhelming. For me, it did mean reassessing my values. I grew up steeped in racism and sexism, yet these principles did not fit me well. They chafed and rubbed me raw. I had to rethink the foundations of my life. Ultimately, I rejected the oppression of those who looked or believed differently than my family. Medical school firmly sealed my belief in equality when I saw all those various-skinned cadavers were so similar after their skin was removed.

For me, caring for Mrs A requires opening my heart, which takes a certain internal environment, founded on a belief in equality as well as much self-care, that allows me to be available and listen to the stories of those who do not look like me or even those who push my buttons, exuding racism or sexism. Caring takes courage to hear even that which violates my own convictions, and walking the line based on principles rather than righteousness. Caring for all people, including Mrs A, is a way that, on a daily basis, I reaffirm my own humanity. I am reminded of my responsibilities as a physician to empower, educate, and give care. This patient's struggle is my struggle.

What does it take to care? It means knowing that I am connected to all those around me, including Mrs A. It means doing what is not easy, and getting creative in management while also accepting my personal and professional limitations. It means processing how helpless I feel and how angry I am at this broken system and those that perpetuate it, but doing what I can and continuing to open my heart to one patient at a time.

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