



# I Couldn't Convince Mama

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It has been 9 years since Mama passed, and every time I see a patient with anemia, I find myself retelling and reliving her story. Anemia has been difficult for me to manage since 2008 because it brings back the hurt and sadness of dealing with my own mother's anemia secondary to blood loss, which we would find out later, was due to rectal carcinoma. Mama was a very determined woman, from a small country town of about 5,000 people; a lady who felt like I had left the team of family and friends and joined the team of health care providers when I went to medical school. She wasn't too fond of health care providers. Even though she and my father encouraged me and fully supported me through my medical training, she wouldn't tell me about her ailments until they grew worse and had a major impact on her independence. I recall once when she and my dad came to visit, her saying that she was tired and just didn't feel well. I remember finding blood-soaked bathroom tissue in the trashcan in the bathroom after they had left my home. I can still see that wicker trashcan in the corner, with piles of bathroom tissue in attempts to hide the contents and the odor of blood and stool that we in the health professions have come to know so well. I remember calling her on the phone and urging her to let her doctor know about her symptoms.

Mama was religious about going to her doctor. She did not miss an appointment and she took medicines that she was prescribed. She didn't always fully disclose her problems though, and I think she was just more concerned with getting her prescriptions refilled. She wasn't so keen on procedures and she didn't trust hospitals or physician recommendations beyond a written prescription. Sometimes she would get the prescriptions filled and decide later how she was going to take the prescribed medicine.

The historical mistrust of hospitals and physicians by minorities stems from racial injustice and mistreatment such as those experienced by the unconsented, exploited subjects of the Tuskegee experiment.<sup>1</sup> Mama's distrust was compounded by personal experiences. Her younger sister was admitted for "a stomach problem", but lost a leg and started dialysis while in the hospital. Mama told me other stories of family members and their negative hospital experiences. She would always say that people go into the hospital with one problem and the hospital gives them others or kills them.

Mama was the authority on everything, whether I got a degree in it or not. That made discussing things challenging for me. I was her "little boy" even as a man, a physician, who had gained knowledge that could improve her health. I quietly accepted

my role and realized peace knowing I had helped her all I could.

"Mama, you really should have a colonoscopy," I told her on many occasions.

"I don't want to have anybody doing that to me," is what she would tell me, and she would say the same things about mammograms. She had bought a book from a bookstore on natural and herbal healing and told me about home remedies that she had gotten from a niece. She had planned for those to be her cure.

The only primary care doctor that I ever knew growing up was a general surgeon. I don't know that he ever talked about health maintenance with my mother. Mama saw an internist for a while after the surgeon retired, but didn't see a family physician, my own personal physician, until becoming frail and thin to the point that little could be done to help her. She was later admitted to the hospital, and gave herself over to whatever the doctors wanted to do to her. I don't know if she felt like they were her last hope at life or if she had accepted death as her fate and was trying to appease me by being compliant.

We as health professionals work to increase access to care and provide high quality, person-centered care,

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From the East Carolina University Office of Diversity Affairs.

especially for those who feel that we may be maleficent toward them. The challenge for me in Mama's case was her distrust of the medical system when it came to anything beyond taking oral medications. It was as if she distrusted anything the medical profession would physically do to her, and taking pills didn't count, as she was in control of what she took and what she didn't. It didn't matter that her black physician son made the recommendation for her to have a medical procedure that he himself routinely recommends for patients.

Were fear and a loss of control the real issues here? I believe she felt that as she grew sicker, she was losing more and more control; losing independence as she lost strength, to the point of total submission to the cancer growing inside her. As a physician who has seen countless patients in difficult clinical situations, and as a son, this was a difficult and painful story to see unfold. The lesson here is that lack of trust doesn't

just create difficulty for race-discordant, white-black, patient-physician relationships. Even race-concordant relationships that involve loved ones can be difficult, with the inability to overcome years of mistrust of the health care system, even when someone as close as a son has become part of that system.

I learned a lot from Mama's illness and the experiences that it brought; more about being a son than about being a doctor, what it means to watch a loved one succumb slowly and helplessly to illness. I have drawn from my faith and have peace with her death, and passionately try to continue very personal discussions with my patients regarding colorectal cancer screening. Even though I couldn't convince Mama, I continue to try to convince my patients, listening as carefully as I can to their fears and mistrust and sharing with them the story of pain and loss that I hope they and their loved ones never experience.

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## References

- 1 Jones JH. *Bad Blood: The Tuskegee Syphilis Experiment*. New York, NY: Free Press Publishing; 1993.