A Patient Guides Her Provider: A Dialogue Over Cultural Awareness

The following text describes an exchange between a patient (Mrs Wilson) and her nephrologist (Dr Ullian). The nephrologist’s perspective is in serif font, and the patient’s perspective is in sans serif italics.

I am an academic nephrologist. When not assigned to inpatient duties, I visit with patients weekly at my outpatient hemodialysis unit. During one weekly visit each month, laboratory values, volume status, blood pressure, and angio-access are assessed (the “Long Note”). Usually, my other weekly visits (“Short Notes”) are more brief and open-ended.

However, a unique, eye-opening experience occurred between me and one of my long-standing patients receiving hemodialysis during one such “Short Note” visit. Mrs Wilson is an African American woman in her 60s, who runs a business and who often works via laptop computer or cell phone during her dialysis sessions. Her questions to me are always nuanced. She has asked about blood pressure targets, medications to help control her Raynaud syndrome, concerns related to her platelet count, and questions about safety and cleanliness issues in our dialysis unit. On this visit, Mrs Wilson asked if I had ever observed skin darkening in African American patients receiving maintenance hemodialysis. I shrugged my shoulders perfunctorily and responded that yes, I had heard this complaint from patients intermittently over the years. To my surprise, she did not ask about potential treatments for lightening skin color. That night, I reviewed the causes of this phenomenon, which include retention of hemosiderin, carotenes, urochromes, or β-melanocyte-stimulating hormone.

One week later, Mrs Wilson suggested that I should not dismiss psychological trauma resulting from skin darkening in African American dialysis patients receiving hemodialysis. “Dr Ullian, maybe you might think more about the stress of skin darkening when one of your young lady dialysis patients is found dangling in her closet.”

My eyes widened, my mouth became dry, and my heart pounded. Composing myself a little, I blurted, “Well, uh, Ma’am, I am an ‘MLK baby’—I judge people by the content of their character, not by the color of their skin.” I quickly explained that as a teenager during the civil rights movement I had been nurtured by the impactful words of the Nobel Peace Prize laureate Dr Martin Luther King Jr. A change in skin color, I argued, without morbidity like pain or pruritus, was medically trivial. I told her what I had read about the biological mechanisms underlying skin darkening in kidney patients. I hoped that we had arrived at a détente … but I was not sure.

I am a patient living with kidney disease. I was diagnosed in 1993 with lupus, which progressed to kidney failure. I began dialysis in 2000 using at-home peritoneal dialysis, followed by a kidney transplant, and I am currently undergoing in-center hemodialysis under the supervision of Dr Ullian.

Living with lupus and kidney failure has required me to constantly adapt to changes in my appearance and body image, all while managing a business, caring for my home and family, and trying to maintain some semblance of a social life. Kidney failure has added a dry, ashy, grayish and darkened undertone to the skin of my face, arms, and hands, particularly when I am “wet.” I have received comments about this from family members, and I recall my spouse once commenting, “You look gray.” On occasion, I’m even unrecognizable in photographs.

This issue prompted my recent exchange with Dr Ullian. I hesitated to ask why kidney failure causes skin discoloration and what, if anything, could be done about it, because doctors (in particular, those who are men) seem to have little concern for cosmetic issues. Sure enough, Dr Ullian’s response was blusé, prompting me to reply, “Don’t be surprised if you find a patient hanging from a rope one day.” I was not trying to be jarring or exaggerating. The truth is, in my early years of lupus and kidney failure, the stress of weight loss, hair loss, Raynaud disease, finger amputations, lupus skin lesions, skin discoloration, dietary restrictions, and multiple hospital stays could have made me the woman at the end of the rope, if not for the overwhelming support of loved ones.

I was delighted to hear that Dr Ullian did not dismiss my concern and actually investigated the biochemistry of my skin color changes. I was equally impressed that Dr Martin Luther King Jr had an effect on Dr Ullian’s approach to society. However, in this scenario, I don’t agree that Dr King’s ideology was relevant to our discussion. I believe that Dr King used the word “color” to refer to ethnicity—skin tone or shading was not relevant to the points made in his speech. I’m not interested in skin lightening or tanning but prefer the color and texture of the skin that I had before I developed kidney disease. I understand that lupus and kidney failure are incurable but treatable, just as skin changes may be a fact of life that one must adapt to and accept. Doctors have a daunting and challenging task of helping patients maintain good physical health. Although internal health is the priority, physicians should be more cognizant that outward appearance and cosmetic issues are also important to some patients.

My exchange with Mrs Wilson made me wonder why I had used the phrase “MLK baby.” I remembered my Embryology professor from nearly 45 years ago, who dubbed us first-year students “Watson-Crick babies.” At first we were flattered to be named after scientists whose work had been critical for deciphering the genetic code. Soon, we were dumbfounded as the professor, in his disparaging yet loving manner, emphasized that inheritance did not derive solely from the chromosomal pattern of adenine, thymine, guanine, and cytosine, but also from cytosolic factors contained in the ovum. Only
years later would we learn about other levels of complexity in inheritance, such as environmental and stress-related effects on DNA methylation.

Although I am in my mid-60s, I am a baby still, an “MLK baby.” I realize that I am not as experienced in the art of medicine as I thought; that I may, at times, be insensitive to some important feelings that my patients are experiencing; that I can be hubristic and lack cultural humility; that I may listen but not hear; and that I sometimes lecture people when a lecture is not necessary. Anticipating potential social/cultural disconnects, participating in continuing medical education offerings focusing on cultural differences, and maybe most of all paying attention to what patients are feeling may assist medical providers in overcoming biases and more effectively honoring the cultural diversity of the patients whom we serve. As it turns out, this “MLK baby” is still growing.

An unexpected benefit to me resulting from my interchange with Mrs Wilson was the bond that developed between us during the writing of this essay. I found the exchange so profound that I asked her if she would write an essay with me about the experience. She was willing (and enthusiastic) to do so. This writing collaboration gave us a unique link, something above beyond the usual doctor-patient relationship. We greatly enjoyed discussing the essay and passing it back and forth by email until we were mutually satisfied with the result. In addition, we were able to share the anticipation of the peer review and the excitement of the positive preliminary decision.

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CALL FOR SUBMISSIONS

“A doctor, like a writer, must have a voice of his own, something that conveys the timbre, the rhythm, the diction, and the music of his humanity, that compensates us for all the speechless machines.”

—Anatole Broyard, Intoxicated by My Illness

In this space, we hope to give voice to the personal experiences and stories that define kidney disease. We welcome nonfiction, narrative submissions focusing on the personal, ethical, or policy implications of any aspect of kidney disease in adults and children (acute kidney injury, chronic kidney disease, dialysis, transplantation, ethics, health policy, genetics, etc). Submissions from physicians, allied health professionals, patients, or family members are encouraged.

Types of submissions for this feature include essays of up to 1,000 words; short poems; or original visual art accompanied by 1-2 paragraphs of text. In submissions that refer to real patients, the patients must either be unidentifiable or approved by the patient(s) described.

Items for consideration should be submitted online at www.editorialmanager.com/ajkd.