

Hey Doc, Here's What I See

Deidra Hall; Celeste Castillo Lee

We appreciated being given the opportunity to participate in the North Carolina Institute of Medicine Task Force on Chronic Kidney Disease and also being given space in this issue of the *North Carolina Medical Journal* to provide a voice for those affected by chronic kidney disease (CKD). Representing the interests of thousands of patients and families is an honor for us. Together we have a combined total of 43 years of experience living with CKD, end-stage kidney disease (ESKD), and/or transplantation. Deidra Hall explores *Hey Doc, here's what I see* with a pediatric perspective on CKD and the ways we can make an impact. Celeste Castillo Lee has a conversation with "Doc" from a vantage point of what she *does* and *does not* see for patients with end-stage kidney disease.

Deidra Hall

Kidney disease—with no warning signs that it would come, no preparation on how to handle it—is a scary term for a family that has never known sickness. What did we do wrong? Is it something I could die from? Oh my goodness...is it contagious? Could I give it to my little sister? I was 12, and all these questions ran through my head the day I visited my pediatrician with what I thought was a sinus infection. My face and body were so swollen I couldn't fit into my normal clothes. Previously a fairly thin and athletic girl, I now had to wear extra large sweat suits. We knew something was wrong—but this?

Every family of a child with kidney disease goes through the unfortunate reality of having to cope with newfound information for every stage their child reaches in the progress of the illness. Doctors play a critical role in that journey. So what are the steps a doctor can take to help make sure this child survives for as long as possible and in a healthy way? After living through

chronic kidney disease and living with a healthy transplanted kidney for over 13 years now, it was in my heart to start a nonprofit organization. I started the Kidney Coaching Foundation, Inc. (KCF), to directly target the pediatric nephrology population and their families. In doing so, KCF has introduced 3 key messages for the population it serves. So, *Hey Doc, here's what I see...*

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I had to know my enemy.
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enemy was not my doctor,
it wasn't my mother, and it
certainly wasn't me."*

Message 1: Personal advocacy. Every child will handle his or her disease differently. I wanted to be as involved in my care as I possibly could. Early in my treatment, I had a doctor who would only talk to my mother—even though I was sitting only inches away from him. I hated that feeling of being ignored, as if talking to me didn't matter. If this was going to work, I needed to be included. From that point on, I knew there were some decisions that I could not make, but for the most part I was going to be an integral part of the decision-making team. One thing I genuinely believe is that it is important to make your patients own their disease. They need to be involved in every aspect—asking questions and being educated. Not including them in discussions and allowing them to disconnect allows

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room for noncompliance. If young patients feel that “mom will handle everything,” then it is easy to put the blame on mom in the event that they become sicker.

Self-advocacy also includes education. In order for me to fight this war, I had to know my enemy. I had to realize that my enemy was not my doctor, it wasn't my mother, and it certainly wasn't me. Realizing this helped me to have the correct perspective on *what* I was fighting, not *who*. My enemy was the disease. The more I knew, the more empowered I was. I was empowered to ask important questions for the present and hard questions for the future. In KCF, we make sure each child and caregiver researches their disease, interviews others who live with it, and does whatever else it takes to know their disease better. It is true that “the more you know, the more you grow!” Being an advocate also includes being honest, responsible, and accountable. Patients can own up to their accomplishments as well as their mistakes. In this organization the coaches don't allow the patients to play the blame game or the victim card; they encourage each individual to see what role he or she had in the way things played out. Then they give them ownership again by asking what they might do differently in the future. The coaches also teach responsibility and being proactive. In this context, being proactive means making sure the patients ask for help in advance. Invincible teens sometimes have a hard time asking for help, but the failure to ask for help in advance can lead to trouble down the road. Part of being responsible is knowing when and how to ask for help and understanding the fine line between needing help and being needy.

Message 2: Discovery. Patients always need to be in discovery, not only about the disease but also about themselves. Fostering the urge to find out more goes a long way toward being healthy. Questioning and wanting to know more is exactly how new ideas are created! Patients should not settle for what people tell them they *cannot* do (eg, a poor kid with CKD cannot reach her dreams because she is too sick). Rather, encourage young people with CKD to discover for themselves *who* they can be. This will give them a sense of purpose and something to live for. The result is twofold success: first, they have a goal for the future, which will hopefully help them to also become active citizens and important contributors in their communities, and second, they have a reason to be compliant with their treatment which may ultimately lead to better management of their disease.

Message 3: “You can do this!” It is so easy for teens to be depressed even without the added stress of being sick. But teens will not feel as alone if they are constantly told, “You can do this!” Those 4 words are a pick-me-up when the teen gets off track with their treatment and feel as if they have failed. These words are reinforcements to those striving to lead healthy and purposeful lives. Saying those words with passion and love lets

the young patient know many things: I can go to college and be successful; I can have a family of my own when I'm older; I can help others who are down about their disease. *I can do this—live a healthy life—be successful in everything I do—survive!*

Instilling just these few messages will serve youth well in their everyday lives and will also create informed, involved, and most importantly, compliant patients. When it's time for them to transition out of their parents' care and into the phase of life where they take the lead for their care, they'll be prepared, and you'll be satisfied in knowing you helped in that preparation.

Celeste Castillo Lee

Hey Doc, here's what I see as an end-stage kidney disease (ESKD) patient in North Carolina.

On Tuesday, Thursday, and Saturday mornings from 7:00 to 10:00, I sit in a lazy-boy recliner pulling off the last 48-72 hours worth of liquids and toxins in my bloodstream. I read, work, and—thanks to the wireless age—explore the Internet. Together with my fellow patients, I share in the collective experience of undergoing a lifesaving treatment available to those with ESKD. We also share, in the chapters of our individual lives, heartaches, frustrations, joys, fears, successes, and setbacks. These are all part of our daily existence with ESKD, and I would argue, part of life in general. We reluctantly come together from a variety of backgrounds, experiences, and cultures.

However, Doc, I see a disproportionate number of African Americans and Latinos on dialysis. I see them missing treatments, and missing toes, missing fingers, missing feet, and missing eyesight. I wonder why. I see a receptionist becoming a dialysis technician in 8 weeks with no state certification required, while the person who gives me a hair cut has to be licensed by the state. Again, I wonder why. I see our facility getting older, our technicians and nurses becoming disillusioned and leaving, our nutritionist and social worker overburdened and understaffed.

I see patients discussing their history to the fourth new rounding physician we have had within the past year, only to have him respond to patients in a patronizing tone no matter a patient's age, gender, ethnicity, or educational background. Yet again, I wonder why.

Doc, what I don't see is any pre-education for chronic kidney disease (CKD) patients in stages 3 or 4, or any case management, or any coordinated care. I see new patients arriving at our unit, scared and unsure of what to expect, never having been given the opportunity to choose their preferred modality of dialysis (if one could use the word “preferred”). Most simply arrive in the unit with a catheter inserted in their chest, like a stranger in a strange land. Because of what I see, I want to say “shame on us.” Shame on a system that covers services to people once they have ESKD, but puts in so little preventive effort to help people control illness prior to getting ESKD. Shame on a system that provides only bare assistance to people in making the transition to dialysis.

“Let's challenge the status quo of health care delivery.”

From the confines of my lazy-boy I am an ESKD patient, and I experience the lack of control in a routine yet invasive treatment. I don't want others to join me in my chair, Doc. I want them to know what their kidneys do and how they function. I want them to know how to control their blood pressure, blood sugar, and diet to keep them out of this unit and out of my chair. I want them to have access to preventive health care, case managers, nursing assistants, and physician assistants. I want them to be part of a new model of care that guides them in their journey as a CKD patient and finds best practices that help them adhere to proper medical regimens. And if after all that, even in the best of circumstances, they still are headed towards ESKD, I want them to be empowered. I want them to know what to expect financially, personally, physically, and emotionally. They should be given the information to make the best choices for themselves and their families. And once they have come to dialysis, I want them to be able to lead a quality life. I know that if a patient is empowered, encouraged, and guided, he or she can continue to work and contribute to society. We can only do this if the treatment we offer and receive is high quality, safe, and affordable.

Doc, we have our job cut out for us, and we have to do it now. If the statistics are correct, and there are thousands more CKD patients transitioning to ESKD and taking seats next to me in my lazy-boy, we really will be in a financial bind. We can't afford to wait any longer, both in terms of human capital and medical dollars.

Doc, I also see opportunities. We are in such a state of need that innovation is our only tool to address these challenges. Let's be "disruptive." Let's challenge the *status quo* of health care delivery. Let's ask "what if"—what if we change the way we bring treatments to the perpetual patient, what if health care providers no longer see ESKD patients as just "kidney" patients but whole persons, what if different components of our health care systems learn to communicate with each other, what if we invest in trying to stop early the progression of diseases before ESKD, what if we do more education to bring CKD and ESKD to the conscience of the public?

The time is now for us to build a grassroots effort to educate the public about the causes and effects of CKD. Look at what a powerful and unified voice has done to increase public awareness of and research and funding for breast cancer. If 1 in 9 people in this country have CKD, then we have a huge group of patient advocates who, if educated and motivated, could become a powerful force for change.

Doc, I am dedicated to being an advocate and educator wherever and whenever possible. As the chair of the Executive Committee of the Patient and Family Council of the National Kidney Foundation, I know firsthand the potential we have to make a difference because of the commitment of patients and their families. Doc, I invite you to join me in being an instrument of change—to change what I see and change what I don't see. **NCMJ**