

Functioning on Dialysis An Oxymoron?

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Neither the childhood memory of my 28-year-old cousin's death from kidney failure nor the knowledge of my own kidney disease prepared me for the outcome of my visit to the emergency department one Friday night some 26 years ago. To say that starting dialysis is like being hit with a silent freight train barely begins to describe the magnitude of the changes that take place physically and emotionally with the failure of one's own kidneys. In parallel with the loss of "functional status," the topic of this article "Association of Initiation of Maintenance Dialysis with Functional Status and Caregiver Burden" published this month in *CJASN* (1) came the loss of the independence, choice, and control that accompanied the changes overtaking my body and the impact this would have on my close-knit family.

The word "sick" was not part of my vocabulary, and both the term "chronic illness" and the need for Medicare were foreign to me as a 38-year-old single man with multiple commercial interests, owner of a successful greenhouse business, and one who lived life on my terms. As an initial introduction (or harbinger) of what was to come, my visit to the emergency room prompted a call to the university kidney specialist who immediately insisted I be flown by helicopter to the tertiary care center a little over an hour away. This seemed like overkill to me and receiving a helicopter bill that was sure to cause a fatal heart attack in the future seemed much less preferable to taking the risk of driving myself. I had been "functioning" on my own up until now... why not let one of my siblings drive me? Little did I know this was the first of many situations over which I would have little control or "say."

Once hospitalized and officially diagnosed with ESKD, I learned about the renal diet and vowed to avoid foods with potassium and phosphorus (and to this day cannot bring myself to eat a tomato). I was educated on the risk of missing treatments, which required a family member to drive the hour or so to and from the outpatient dialysis center. It was here, upon my first glance at the other patients, that I realized life as I had known it was over, and I began to fear I would become as ill as these patients all looked.

Despite adhering to the treatment schedule and diet, the physical limitations became overpowering and I could not summon up the energy to function. I

took a handful of pills after each meal but still had "bad labs." I slept in my recliner the nights before dialysis so I could breathe, though sleep was elusive. I never did regain my muscle mass and rather than improve on dialysis, I had neither the emotional nor the physical energy to explore transplantation despite more than a few of my 11 siblings being more than willing to donate their own kidney.

One day the social worker woke me up from a deep sleep on dialysis with the question, "are you depressed?" As I looked around myself at the other patients (none of whom looked even close to the age of my oldest brother), I felt a rush of anger at her cluelessness. Depressed or not, I was barely getting by and if it wasn't obvious looking at me, just knowing that I could no longer work or drive myself should have been a clue. It seems astonishing to read that "little is known about the functional course after initiating dialysis" and surprising to think that a study on such a topic would be needed. It is not just the elderly who feel the effects of kidney failure and dialysis. Age may make it all worse, but it is hard to imagine feeling less functional than I did after starting dialysis at 38 years old.

Thankfully, my family took charge when I was too sickly and weak to do so. The "caregiving" was spread across my siblings and parents who never wavered in their willingness to do what was needed for me despite it requiring them to alter their own lives to my treatment schedule or other needs.

My story is one of good fortune as I was lucky enough to receive the gift of life from my sister. The transplant was transformational and gave me my life back, a testament to the lack of functional restoration provided by dialysis alone. I married the doctor who had insisted I take the helicopter and later it was she who helped my family from a small town in rural West Virginia navigate the logistics and complexities of a transplant evaluation and weather the storms of my medical and surgical complications.

Kidney disease may jeopardize our functional status and place burden on our caregivers, but it does not take away our birthday or make us less entitled to choices about our care (I did not take the helicopter). Old or young, frail or strong, the physical ramifications of our lives on dialysis can be devastating and life-changing in

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ways that are unique and individual. We depend on our medical team to recognize and respect these differences, and when we aren't wearing our agony on our sleeve, insight and kindness go a long way.

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