

# A Dialysis Patient's View on Dialysis Employment Loss

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I was a sophomore in high school when I learned I had gout and my kidneys were damaged. My first job was delivering papers, and I worked throughout college. After graduating, I accepted my first professional job. But it never occurred to me that at the age of 36, kidney disease would cut my career short. I am grateful for the opportunity to provide my perspective on the article "Estimated Loss of Lifetime Employment Duration for Patients Undergoing Maintenance Dialysis in Taiwan" (1) in this issue of *CJASN*.

The objective of the Chang *et al.* study was to create a model that could accurately estimate the loss of lifetime employment duration due to kidney failure, to assist in the evaluation of societal financial burdens in Taiwan. They attempt to estimate loss of lifetime employment as a proxy for productivity loss among patients with kidney failure on the basis of real-world data.

Their analysis revealed the loss of lifetime employment duration in the dialysis population mainly results from loss of life expectancy. Chang *et al.* report that their results "strongly correlate" with the assertion that dialysis not only saves lives, but also increases lifetime employment length (1).

These results are likely due to Taiwan's People with Disabilities Rights Protect Act. Unlike the US Americans with Disability Act—which does not set preferential treatment for those with permanent disabilities, rather it provides job protection with reasonable accommodations—the Taiwan act states that public and private agencies are rewarded if they hire people with disabilities up to stated percentages. Chang *et al.* point out another reason for this conclusion is that dialysis centers are plentiful in Taiwan and most provide services after 5:00 PM.

The health care system in Taiwan fully reimburses dialysis, whereas Medicare in the United States reimburses 80% of dialysis. This is a large societal burden in both countries. Having patients remain employed significantly eases this burden and provides dignity and a livelihood for patients.

I was in the middle of a doctoral program and working full time when my stage 3 CKD accelerated to kidney failure. Within 4 months, I crashed into dialysis. Then 4 months later, my spouse donated one of her kidneys to me. It began to fail, and a biopsy showed it to be FSGS. I attempted to go back to work but traveling to the university hospital for dialysis three times a week

and regular plasmapheresis proved too difficult to manage. So I stopped working.

After struggling with in-center hemodialysis for a year, I opted for a peritoneal dialysis catheter and was able to go back to my job. I performed exchanges in my office and overnight with a machine. With peritoneal dialysis, I had more energy and my productivity improved. But I struggled with anemia, and my body reacted inconsistently to erythropoietin and iron management. I stopped working because I could no longer regularly perform my duties. Soon after, I was on federal disability.

Later, I started training for home hemodialysis with a portable machine and again felt energetic. Since 2008, I have been doing nocturnal home hemodialysis. Although I feel better, I still struggle with the inconsistencies of anemia. And I can spend a few days researching and writing an article, but often I will require a couple of days to recuperate.

After reading the article by Chang *et al.*, I created a spreadsheet to determine my year-to-date employment loss earnings. I then projected out 10 years, to when I will hopefully turn 65, and determined my loss of lifetime employment earnings, and my estimated lifetime tax payments. I further determined my lifetime federal disability earnings and my lifetime cost of dialysis. Obviously, the numbers are personally staggering, and there is no benefit to contemplating what could have been. Dialysis roots us in the now, and how to make it from day to day. And, yes, I am a societal burden. If it were not for my employer-based disability insurance and my spouse's income, it would have been extremely difficult for my family—as it is for a significant portion of those on dialysis.

But there are many ways patients on dialysis ease that burden in noneconomically quantifiable ways. For me, I became the stay-at-home parent, easing our costs for childcare and being there for our children. I was active in my son's Boy Scouts troop and my daughter's 4-H Club. I am also there for my spouse. I have been able to volunteer as an advocate for patients with kidney disease and volunteer locally. Although kidney failure took away my lifetime employment, home hemodialysis has so far provided me a lifetime of quality living.

## Disclosures

The author has nothing to disclose.

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**References**

1. Chang Y-T, Wang F, Huang W-Y, Hsiao H, Wang J-D, Lin C-C: Estimated loss of lifetime employment duration for patients undergoing maintenance dialysis in Taiwan. *Clin J Am Soc Nephrol* 16: XXX–XXX, 2021

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See related article, “Estimated Loss of Lifetime Employment Duration for Patients Undergoing Maintenance Dialysis in Taiwan,” on pages XXX–XXX.