

# Employment among Patients on Dialysis

## An Unfulfilled Promise

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Dialysis is a life-changing event for patients at multiple levels. Employment is one of several challenges faced by individuals with progressive CKD transitioning to ESRD. Such patients face multiple disincentives to employment, including medical, logistical, and financial disincentives. The 1972 federal legislation that provided Medicare entitlement for patients with ESRD assumed that most individuals receiving dialysis would remain in or return to the workforce and therefore, would be partially self-funding through the payment of income taxes (1). There is little doubt that this promise has not been kept for the majority of patients on dialysis in the United States, where a high unemployment rate has become almost taken for granted. Employment rates among patients on dialysis in the United States have been reported to be as low as 18.9% in one study (2). This seems to be a worldwide problem. A report from Finland (3) showed a low employment rate of 33% on the basis of data from the Finnish Registry for Kidney Diseases. A recent study from India reported an employment rate of 29.9% among patients after initiation of dialysis, with rates of loss of employment of 44% and 51% among patients initiating hemodialysis and peritoneal dialysis, respectively (4).

In this issue of the *Clinical Journal of the American Society of Nephrology*, Erickson *et al.* (5) report their findings on employment trends among patients initiating dialysis in the United States between 1996 and 2013. The study included patients ages 18–54 years old from the US Renal Data System (USRDS) registry with employment information acquired from the Centers for Medicare and Medicaid Services (CMS) Medical Evidence Report (form CMS-2728). The study method is unique insofar that it examined the employment rates at dialysis initiation compared with rates 6 months before onset of ESRD. Over the entire 18 year study period, employment rates ranged between 23% and 24% at initiation of dialysis, a decrease from 37% to 38% from 6 months before ESRD onset; 81%–85% of adults in the general population with similar age are employed. Although the absolute employment rate among patients with incident ESRD declined by 1% in the 2008–2013 period compared with the 1996–2001 period, the model adjusted for patient characteristics and unemployment in the general population showed a 4.7% increase in employment between 1996 and 2013. The authors examined differences in employment rates in three vulnerable populations: blacks, Hispanics, and patients residing in zip codes with the

lowest quintile of median income. These populations had 7%–8% lower probability of employment at the time of dialysis initiation in the 2008–2013 period compared with their controls. There was a modest improvement in employment rates among blacks and Hispanics in 2008–2013 compared with 1996–2001. No significant change was seen in employment of patients residing in low-income zip codes between time periods. This provides an unsurprising association between poor access to health care (including early diagnosis, patient education, and financial and social counseling) and lower employment rates.

One limitation of the study by Erickson *et al.* (5) is the definition of employment as both part-time and full-time employment in addition to attending school. Although patients attending school are not in the workforce, one may argue that they are probably more likely to join the workforce afterward compared with the unemployed. The distinction between part-time and full-time employment remains important, and it is not clear whether a substantial number of patients who remained in the workforce switched from full to part time. This can lead to a significant lifestyle change for the patients because of lower income in addition to a decrease in their partial self-funding of dialysis through payment of income taxes.

The main questions for the nephrology community to consider are how the likelihood of patients being employed at the time of initiation of dialysis can be increased, how can employed patients be assured to stay in the workforce after initiation of dialysis, and how unemployed patients can be helped to join the workforce. Understanding the factors influencing employment rates and the disincentives to employment is the first step. Prior studies have examined factors influencing employment status among patients on dialysis. Curtin *et al.* (6) found that predialysis employment and higher level of education are associated with significantly higher likelihood of employment among patients with ESRD. Patients with higher education levels are more likely to have white collar jobs, receive salaries greater than disability benefits, and have more job opportunities. In the same study, patients who believed that patients on dialysis in general should remain in the workforce and who had supportive significant others were more likely to be employed. These findings further emphasize the importance of early counseling and lifestyle planning long before ESRD supervenes.

The choice of dialysis modality is another important factor predicting employment. In a retrospective study

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using USRDS data, Muehrer *et al.* (7) reported that United States patients who started peritoneal dialysis had higher employment rates compared with patients who started hemodialysis. Studies from Finland (3) and India (4) also showed significantly higher employment rates among patients receiving home therapies compared with those receiving in-center hemodialysis. The reason is obvious given that home therapies offer more scheduling flexibility and independence. A possible confounder could be that patients with limited social support and poor performance status are more likely to receive in-center hemodialysis rather than home therapy. Such patients are less likely to be employed for the same reasons that they chose in-center hemodialysis. Dialysis facilities with late evening hemodialysis shifts and those that offer training in peritoneal dialysis or home hemodialysis had higher percentages of employed patients (2). In 2005, only 18.4% of United States dialysis facilities offered shifts that began after 5 p.m. (8). Patients who underwent treatment for anemia with erythropoiesis stimulating agents before ESRD onset had higher employment rates at initiation of dialysis (7). Early access to nephrology care, access to home dialysis modalities, and proper management of complications of CKD, including anemia, are important factors for patients to remain in the workforce. Rasgon *et al.* (9) described a multidisciplinary orientation program for patients with CKD before they initiate in-center hemodialysis. This consisted of nephrology referral, assessment and counseling by a social worker, orientation to the dialysis unit, and continued multidisciplinary collaboration. All of the patients were blue collar workers. Those who received the intervention had a 2.8 times higher likelihood of maintaining employment than those who did not.

Helping patients rejoin the workforce after unemployment is as important as and perhaps more challenging than assisting patients in maintaining employment. The amendment to the Social Security Act (10) that established the ESRD Networks charged them with “encouraging, consistent with sound medical practice, the use of those treatment settings most compatible with the successful rehabilitation of the patient and the participation of patients, providers of services, and renal disease facilities in vocational rehabilitation programs.” In the 2005 ESRD Networks summary report (8), employment rate was 19.65% among patients on dialysis ages 18–55 years old. Only 2.6% of patients received vocational rehabilitation. Dialysis facilities with higher employment rates reported vocational rehabilitation in a higher percentage of patients (2).

Patients with ESRD face many barriers to remaining in or joining the workforce after starting dialysis. These include poor employment opportunities because of disadvantaged socioeconomic status, fatigue and other symptoms of renal failure, depression and feelings of social isolation, comorbid diseases, transportation issues, potential loss of disability and/or medical assistance benefits with employment, scheduling conflicts with dialysis, and the assumption by some employers that patients on dialysis are too sick or undependable to work. The societal perception that patients with ESRD are unable to work completes a vicious cycle of low expectations for employment. In this study by Erickson

*et al.* (5), employment rates remain 23%–24% among patients with incident ESRD (6). Vulnerable groups, including blacks, Hispanics, and patients residing in zip codes with low median income, have an even lower employment rate. The authors’ call to action for greater upstream counseling of patients approaching ESRD is reasonable, but it does not consider that one half of patients with incident ESRD in the United States were not under the regular care of a nephrologist before initiating RRT. For employment-preserving strategies to succeed, there must be a fundamental change in the way that health care is delivered to vulnerable populations in the United States, with improved disease management and funding for the social services required to overcome the employment disincentives. Improving access to medical care, including early evaluation by a nephrologist; availability of home dialysis modalities; proper patient preparation, including integrated predialysis education models; and encouraging vocational rehabilitation are possible interventions to assist patients in rejoining or remaining in the workforce, and they help to fulfill the promise of 1972.

#### Disclosures

None.

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