

## A Matter of Choice: Opportunities and Obstacles Facing People with ESRD

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### Abstract

**Kidney failure is an overwhelming, life-shattering event, but patients with ESRD do not see themselves as being at the end stage of their lives. On the contrary, patients opting for kidney dialysis are choosing to live. Ideally, then, public policy would support patients' choices about how to live—specifically, the choice to continue working. Many patients with ESRD faced with the limitations of their health status and the demands of their treatment understandably choose to leave their jobs, a choice that is facilitated by the availability of public disability and health insurance. However, other patients who have the desire and opportunity to continue working may not get the guidance and support that can actually make their employment possible. Specifically, current disability and health insurance may fail to provide timely treatment and employment counseling to help patients with ESRD remain in their jobs. We, therefore, propose that the Center for Medicare and Medicaid Services support ESRD Networks to initiate more timely employment and treatment counseling in both the ESRD and the late-stage pre-ESRD setting. Although it is too late to require such counseling in the new network scope of work for 2016–2020, active experimentation in the next few years can lay the groundwork for a subsequent contract.**

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### Kidney Failure and Employment: Background

Entitlement to Medicare benefits for ESRD was originally enacted in 1972, with the promise that such entitlement, combined with vocational rehabilitation, would allow some patients to maintain employment or return to work (1). In this context, renal rehabilitation has been defined as the move from disability to ability, of which return to or maintenance of employment, if desired, is one aspect (2). Despite this noble vision, there has been little progress toward this goal in the past 40 years. As of 2012, the US Renal Data System reports there are approximately 440,000 patients on dialysis (3). Although recent data are not available, a special study previously showed that, although 42% of patients were employed before dialysis, only 21% remained employed at the start of the dialysis, and only 13% remained employed 6 months later (4).

The employment rate for patients with ESRD in the United States is considerably lower than it is in Europe and Japan (D.M. Dickinson, *et al.*, unpublished data). There may be options for the United States to do better. The high rate at which patients on dialysis in the United States leave the workforce may reflect factors other than age or education—specifically, the lack of timely counseling on employment and treatment options for people with late-stage CKD or ESRD.

### The Paradox of Disability Policy

Public policy facilitates enrollment for disability payments and health benefits after dialysis begins. Either the patient or the dialysis facility submits a claim to Social Security, which directly approves the Medicare

claim and submits the disability claim to its disability operations office. Patients are automatically deemed disabled if they are medically determined to have ESRD and undergoing dialysis that is expected to last at least 12 months (5), contingent only on insured status for Social Security Disability Insurance (SSDI) or income and asset levels sufficiently low to qualify for Supplemental Security Income (SSI). Medicare entitlement generally begins 3 months after the beginning of dialysis, with the exception of for those patients who initiate peritoneal dialysis or undergo transplant (6).

Economically, monthly disability benefits are modest, averaging only \$1145 in 2014 compared with the United States average individual income of \$3625 (7). For patients who leave work, the income reduction is likely substantial. In addition, patients may face higher out-of-pocket costs for medical care when they shift to Medicare from employer-sponsored insurance, where cost-sharing protections are more generous than those for Medicare. In contrast to older Medicare beneficiaries, beneficiaries under age 65 years old lack federally guaranteed access to supplemental or Medigap insurance that can mitigate Medicare's relatively significant cost-sharing obligations (8). Patients with ESRD are also explicitly excluded from participation in Medicare Advantage plans that sometimes supplement Medicare coverage at no extra costs (9). As a result, patients with ESRD in many states can be denied access to supplemental coverage or charged higher premiums that reflect their compromised health status.

The fact that so many patients with ESRD give up employment, despite these financial disincentives, may

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reflect a persistent paradox in disability policy. Eligibility for SSDI and SSI disability benefits for patients on dialysis, as with all beneficiaries historically, has been premised on the beneficiary's permanent inability to work (10). However, today's social norms and civil rights laws have evolved to enable people with disabilities to work, while still providing them public support. Although disability policies have advanced somewhat to reflect these norms, effective support for patients with ESRD (and perhaps, others) who have the capacity and desire to work is still missing.

One policy intended to encourage employment is the long-standing trial work period that allows beneficiaries to work for a period without losing benefits and when that period ends, quality for expedited reinstatement of benefits if their income falls. A more recent policy initiative, the Ticket to Work program, enacted in 1999 gives SSDI and SSI beneficiaries access to employment networks or state vocational rehabilitation providers who furnish a variety of services to help people with disabilities return to work, enter a new line of work, or even, work for the first time. These services are paid for by Social Security (11). However, after they are on the disability rolls, beneficiaries generally do not leave; 10% of new beneficiaries completed a trial work period, and 2.8% returned to work over a recent 10-year period (12).

The limited effect of SSDI and SSI work incentive programs suggests that they offer too little too late—beginning, as they do, only after a disability claim is allowed. Earlier referral for employment counseling has, in fact, been shown to help people stay connected to the workforce (13). Creating a supportive infrastructure to maintain employment rather than aiming to find new employment might be more effective in enabling patients to remain employed. To that end, we propose a policy shift to provide more educational efforts before or alongside the initiation of dialysis.

### A Policy Proposal to Sustain Employment

Changes in the policy environment create the potential to end the disability paradox for people with ESRD or late-stage CKD. Policy commitment to better align medical treatment with patient preferences is taking place along with a longer-standing commitment to better integrate people with disabilities into the workforce. Both commitments call for a new approach to patients with late-stage CKD or newly diagnosed ESRD: specifically, engagement of the ESRD Networks in providing employment counseling in addition to treatment modality counseling that could assist employed patients who are about to start dialysis keep their jobs.

We propose that networks focus on new rather than existing patients on dialysis to avoid or minimize a lapse in employment and thereby, maximize the potential for job retention. The alternative (assisting patients on dialysis in finding new jobs) is intrinsically more challenging, not only because of patients' compromised health status and treatment needs but also, their relatively advanced age, because one half of all patients newly on dialysis are over the age of 65 years old (14).

Networks would provide new patients with a combination of treatment and employment counseling. Traditionally, modality selection may occur without attention to psychosocial considerations, such as desire to work, but encouragement of

comprehensive education—addressing not only complex medical factors but also, psychosocial factors, including a wish to work—is appropriate to decisions that affect overall quality of life.

The greater flexibility that a patient has in managing treatment, the easier it is for him or her to maintain a job. Peritoneal dialysis rather than hemodialysis makes employment easier for some, because it requires less time in the clinic (15). Similarly, home or nocturnal dialysis rather than center-based dialysis provides greater flexibility to accommodate work schedules (16). Combining education on treatment options with employment counseling could further enhance patients' choices and opportunities.

Comprehensive treatment and employment counseling could be implemented most easily through Medicare's contracts with ESRD Networks, which are modified on a periodic basis. Ideally, future contracts for scope of work would be modified to hold networks responsible for implementing a pre-ESRD education program in conjunction with employment support from state vocational rehabilitation centers. Although it is too late to modify the upcoming contract for 2016–2020, now is the time for the Center for Medicare and Medicaid Services to encourage networks to experiment with such an initiative as one of their quality improvement projects or initiate a demonstration program across multiple networks. Specifically, networks would be expected to add employment-related counseling to the modality and transplant education that they currently provide patients who are new to dialysis as well as patients with late-stage CKD on referral from the patient's nephrologist. This counseling would then parallel the widely accepted approach to predialysis vascular access preparation.

Early referral for employment counseling has been shown to help people stay connected to the workforce (13,17). If networks show their capacity to successfully implement more extensive counseling, it could become part of a future ESRD Network scope of work. Improvements in performance over time may reduce the labor needs for two major activities for ESRD Networks, data quality and vascular access quality improvement, creating capacity for ESRD Networks to work on employment counseling.

Although Medicare currently pays individual physicians to provide pre-ESRD treatment education, that benefit is not available to patients who are not already Medicare beneficiaries and does not include employment counseling. However, some ESRD Networks are already providing treatment counseling to all patients pursuant to Medicare's requirement that networks support rehabilitation of patients on dialysis (18). If Medicare were to make pretreatment education a requirement in its network contracts and connect that to employment counseling, the full range of patients with ESRD could receive comprehensive counseling in a timely fashion.

For some patients, remaining employed may significantly affect their quality of life. Those patients would also likely receive enhanced earnings and health insurance coverage. Additionally, there may be a health benefit as well, because observational research shows that, in ESRD, working is associated with better health status, although this can only be taken as associative and not causal (19).

At the population level, greater employment among patients with ESRD also has the potential to reduce public

costs for patients on SSDI and Medicare (20)—avoiding or delaying disability payments and delaying Medicare coverage for the first 30 months of dialysis. Additional health insurance costs for employers could potentially be offset by reductions in nonmedical benefit costs—such as payouts under disability and life insurance policies—that could be avoided or reduced if patients with ESRD remain employed (21). Finally, timely comprehensive counseling would fulfill the promise of renal rehabilitation made when Congress instituted health and disability protections for people with ESRD.

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#### Disclosures

None.

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