

Threading the Needle to Complete the Stitch: Rehabilitation—Dialysis through Transplant

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There are many obstacles to leap across on the road to successful rehabilitation for someone diagnosed with end-stage renal disease (ESRD). Yet, there is likely no obstacle perceived by the professional that is larger than the obstacles perceived by the patient. Life Options Rehabilitation Advisory Council (LORAC) provided the opportunity for a paradigm shift in rehabilitation thinking in the mid-1990s.

The moments of our first encounter with patients are important. At different stages of chronic kidney disease (CKD), we may feel the need to communicate a great deal medically. If the patient can see the reflection of hope in the people they are working with, their hope endures and increases during the time(s) of crisis. With hope, we can conquer much more than without it.

In terms of employment, research has shown that it is easier to help someone stay employed than to have an interruption in employment and help them to prepare for and seek re-employment. However, whether the patient is working as they prepare for transplant or if they are on dialysis and haven't worked for some time as they prepare for transplant, planning for return to work begins prior to transplant.

Perhaps the transplant social worker is poised to make the best "game plan" with the patient during the evaluation process. As Stephen Covey notes in *The Seven Habits of Highly Effective People*, beginning with the end in mind, there are at least three important rehabilitation-focused issues to help the pre-transplant patient absorb at the time of the pre-transplant evaluation:¹

1. Social Security (SSA) considers transplantation "potentially disabling" for

one year. This means that any time after one year, if SSA reviews a person, the person will not be found to be disabled based on kidney disease. (Action: Start thinking about retraining during the pre-transplant period.)

2. If a person returns to work before SSA calls them for a review, they are entitled to a "Trial Work Period" (TWP) of 9 months. If they complete the TWP, they may have a "Continuation of Medicare" for 7 years and 9 months after the TWP. (Indication: This can be very helpful for someone who is uncertain that they can hold a full-time job in order to get insurance. This is called a *work incentive*.)²
3. If a person is not disabled for another reason other than ESRD and is not 65, Medicare will end 3 years post-transplant. (Action: A patient needs to start thinking about return to work when they begin thinking about a transplant.)

If the "game plan" is not communicated to the dialysis *team*, the chances of executing the "play" are not good. Looking for a win-win in an ideal world, if a patient has stopped working, he or she could engage with their state rehabilitation agency to consider part-time work that would keep a resume active and build self-esteem, consider skill building while awaiting transplant, or consider volunteer work. With the transplant waiting list hovering at 90,000 for kidneys, we want to help the patient plan realistically if they do not have a living donor.

Working with state vocational rehabilitation counselors (VRC) is not without barriers. Helping VRC understand the

opportunities available to them in working with patients who have kidney failure can increase the likelihood of success. Therefore, continuous education as well as building partnerships increases potential for patients and successful outcomes. A valuable resource is the *27th Institute on Rehabilitation Issues*.³ This resource was developed to help vocational counselors understand the unique opportunities available to them as they work with people who have kidney failure.

Let's examine how we help patients to see that *yes*, it may be a difficult time when initiating dialysis; *yes*, there may be bumps in the road as they go through treatment. However, keeping life as much the same as it was *before* dialysis or transplant will help the patient feel as if chronic kidney disease is *a part* of their life, not *all* of their life.

The Medical Education Institute's "Renal Rehabilitation: Bridging the Barriers" provided a formal definition of rehabilitation created by a multidisciplinary team of experts assembled by LORAC: "The ideal process of rehabilitation for a dialysis patient is a coordinated program of medical treatment, education, counseling, and dietary and exercise regimens designed to maximize vocational potential, functional status, and quality of life."⁴ The ability to assess the complex interrelationship of psychosocial variables that impact rehabilitation is increasingly important in the era of managed care and bundled services.⁵ As Alt and Schatell noted, rehabilitation efforts are positioned for success: the goal of rehabilitation has been defined, data has been collected through Centers for Medicare and Medicaid Services (CMS), the Dialysis Practice Patterns Outcomes Study, and the

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2008 United States Renal Data Systems Comprehensive Dialysis Study, CMS has focused policies to improve rehabilitation outcomes with a focus on measurement of health related quality of life as it relates to rehabilitation and publications over the last 20 years have urged changes in clinical practice to support renal rehabilitation.⁶

When we are looking for a touchdown, the dialysis or transplant team can work collaboratively with VR on the following common barriers to employment outcome while the patient is in the pre-transplant phase:

1. Eliminate the gap in work history (volunteer, begin retraining, work part-time—even if it's only 4 hours a week).
2. Work with the dialysis team to manage the ups and downs of CKD/ESRD through completion of the quality of life measurement and planning.
3. Encourage patients to talk with Area Work Incentives Coordinators (www.ssa.gov) to begin to better understand work incentives and when Social Security Disability or Supplemental Security Income will end.

Additionally, helping the patient learn self-management skills will be crucial to rehabilitation and transplant success. The teams can use a common framework for supporting CKD patients in developing self-management skills and strengthening the rehabilitation process.

Newly-diagnosed patients almost always have the same questions: “How long will I live?” And, “How well will I live?”⁷ The dialysis and transplant team can work in unison to *encourage* and *educate* patients to know that multiple modalities, including transplantation, can be a part of a successful treatment plan

for them across a long lifetime. As we encourage patients early, we can help them understand and overcome anxiety as they increase self-management of their health. Being open to home dialysis, transplantation, and in-center dialysis allows a patient to consider multiple options for school, work, volunteerism, and living life to their fullest potential. In order to accomplish this, people receiving treatment for ESRD must remain physically active—even though this may be harder than it was before dialysis. You guessed it, the third “E”, according to LORAC, to build toward employment (rehabilitation) is exercise. These building blocks can be put in place while on dialysis to keep the patient strong and focused on their goal. Measurement through a health related quality of life instrument, like the KDQOL, can assist the patient and team evaluate micro and macro outcomes.

Studies have found that patients had higher employment rates when they received treatment at facilities that offered a late dialysis shift, when home dialysis services were offered to them, when frequent HD was provided, and when at least one patient at their facility had been referred for VR services; they also found that mean Mental Component Summary (MCS) scores were significantly associated with rehabilitation activities.^{8,9}

Sometimes in our busy practices, rehabilitation becomes fragmented. There are so many indicators we look at to support the patient from CKD, through dialysis, to transplant, and sometimes back to dialysis and back to transplant. If rehabilitation were to become an overarching primary outcome from dialysis through transplant might we, as renal professionals, focus our time differently? What stitch would be used to pull the thread through needle?

Communication between renal professionals, throughout the dialysis and transplant waiting period, combined with an atmosphere of encouragement toward rehabilitation, can boost the long-term employment outcome for the patient and will help everyone keep their eyes on the ball!

For information on helping dialysis patients remain fit, visit www.lifeoptions.org for a free exercise booklet to download, or an exercise DVD available for purchase. 

References

1. Covey, S. *The Seven Habits of Highly Effective People*. New York, NY: Simon & Schuster; 2004.
2. Social Security Administration. *2011 Red Book: A Guide to Work Incentives*. www.ssa.gov/redbook. Updated January 2010. Accessed July 4, 2011.
3. 27th Institute on Rehabilitation Issues. *Effective Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease*. www.rcep6.org/iri/books/27IRI_kidney_disease.pdf. Updated 2001. Accessed July 4, 2011.
4. The Life Options Rehabilitation Advisory Council. *Renal Rehabilitation, Bridging the Barriers: For Patients and Their Families*. Madison, WI: Medical Education Institute/Life Options Rehabilitation Program; 2000.
5. Callahan MB. The role of the nephrology social worker in optimizing treatment outcomes for end-stage renal disease patients. *Dial Transplant*. 1998;27:630-642.
6. Alt PS, Schatell D. Renal rehabilitation in 2009—the future looks bright. *Neph News Issues*. 2009;23:24-29.
7. Juhnke J, Curtin RB. New study identifies ESRD patient education needs. *Neph News Issues*. 2000;14:38-39.
8. Kutner N, Bowles T, Zhang R, Huan, Y, Pastan S. Dialysis facility characteristics and variation in employment rates: a national study. *Clin J Amer Soc Neph*. 2008; 3:111-116.
9. Curtin RB. Renal rehabilitation and improved patient outcomes in Texas dialysis facilities. *Amer J Kid Dis*. 2002;40:331-338.
10. U.S. Department of Health and Human Services. *The Surgeon General's Vision for a Healthy and Fit Nation*. Rockville, MD: U.S. Department of Health and Human Services, Office of the Surgeon General; 2010.