

Renal rehabilitation in 2009—the future looks bright

By Paula Stec Alt, MBA, and Dorian Schatell, MS

The field of renal rehabilitation in the United States admittedly got off to a slow start. And even 20 years after funding for the Medicare End-Stage Renal Disease Program was approved by Congress in 1972, one expert claimed that “there is no well-developed field of renal rehabilitation research or practice in the United States....”¹ The reasons identified were a lack of data about patient outcomes and the “failure of the renal community to press for a national rehabilitation agenda.” Just one year later after that statement was made—in 1993—the renal community did begin to address the issue of renal rehabilitation in a systematic way. Since then, research and data collection on rehabilitation topics have grown. Progress in the areas of policy and practical application of interventions has been slow—but significant.

Defining the goal

When Medicare benefits were extended to people with ESRD, based on promising outcomes among a highly selected and motivated group of early users, the goal was simple and straightforward: to enable full, productive (working) lives by providing life-saving dialysis treatments.² Congress was told that 60% of patients would need retraining to continue as working, taxpaying citizens, but 40% would need no rehabilitation at all if medical treatment (dialysis) was provided.³ Ten years later, it was clear that this goal was unrealistic. Not only were the majority of people on dialysis unemployed, but many could not even do basic self-care.⁴ Published reports in the 1980s and early 1990s referred to the rehabilitation of dialysis patients as “dismal”⁵ and “failed”⁶ based on their poor ability to function in their day-to-day lives. The definition of rehabilitation thus informally evolved to encompass health-related quality of life.

Throughout the 1980s and early 1990s, new definitions of renal rehabilitation were proposed, with no universal agreement. In a 1993 conference on “Measuring, managing, and improving quality in the end-stage renal disease treatment

setting,” the Institutes for Medicine committee charged with evaluating the quality of ESRD care noted that payers, providers, and patients lacked a common understanding about the treatment goals.⁷

Publication of the white paper, “Renal Rehabilitation: Bridging the Barriers” in 1995⁸ providing a formal definition created by a multidisciplinary team of experts assembled by the Life Options program. The new definition encompassed every aspect of renal rehabilitation: “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.”

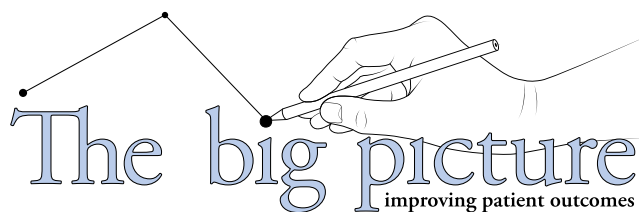
Rehabilitation data

A clearer understanding of the goals helped move the field of renal rehabilitation forward. Over the past two decades, many researchers

have made significant contributions to the rehabilitation literature. The renal community has come a long way in terms of collecting rehabilitation-related data and measuring outcomes. Here is a timeline.

- ▶ In 1988, the United States Renal Data System was established, and each year its Annual Data Report expands our knowledge of how patients are faring clinically.
- ▶ In 1996, the observational Dialysis Outcomes Practice Patterns Study began collecting clinical, demographic, health-related quality of life, and other data from dialysis clinics around the world.⁹
- ▶ The Centers for Medicare & Medicaid Services began to collect data in 2000 for the ESRD clinical performance measures project to assess—and ultimately improve—dialysis quality.
- ▶ The Comprehensive Dialysis Study, presented by the USRDS in 2008, collected data on physical activity level, health-related quality of life, and work/disability.

Renal rehabilitation advocates provided the impetus that pushed data collection initiatives beyond strictly clinical indicators. For example, through advocacy by the Life Options Rehabilitation Advisory Council (LORAC), two fields were added to the CMS 2728 form in 1995 to collect data on each new patient’s employment status.



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Unfortunately, these data have shown us that while 50% to 60% of people on dialysis under age 55 with a college degree worked prior to starting treatment, fewer than 25% to 30% were still working afterward.¹⁰ Clearly, improving the percentage of working-age patients who keep their jobs, health plans, and dignity is a future target for renal rehabilitation.

An analysis of factors predicting employment among working-age dialysis patients published in 2008 will help—availability of evening dialysis shifts, home dialysis (peritoneal dialy-

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sis or home hemodialysis) training, and more frequent dialysis were all associated with higher employment.¹¹

Data-driven change

The availability of data linking health-related quality of life with outcomes has the power to demonstrate the value of renal rehabilitation and change clinical practice. Consider these compelling examples within the “Rehabilitation Works” box.

Changing clinical practice

Publication of research results showing the value of rehabilitation efforts has had an impact over the years. Interest in renal rehabilitation has increased dramatically—as seen in a 240% increase in the number of published articles about renal rehabili-

tation from 1993 to 2008 compared to 1978 through 1993. Interest in specific rehabilitation interventions has grown as well. The number of published articles about the effects of exercise in dialysis patients increased by 318% during the same comparable 15 years.

Equally important were the efforts to put rehabilitation research into practice. From 1978-1994, the Department of Rehabilitation Medicine at Emory University held annual conferences on renal rehabilitation. Started by Samuel Chyatte, MD, professor of rehab medicine and a dialysis patient, these conferences focused on maximizing renal rehab. Selected presentations were published in two books^{17,18} and more recently, the NKF-KDOQI CKD guidelines included a health-related quality of life guideline.¹⁹

Rehab-friendly CMS policies

CMS policies that institutionalize renal rehabilitation have the potential to impact clinical practices on a much larger scale than guidelines or how-to protocols. After years of hard work, there has been some recent success on the rehabilitation-friendly policy front. The American Association of Kidney Patients and Life Options joined forces to successfully advocate for health-related quality of life as a new clinical performance measure.²⁰ This new CPM represents a true milestone in renal rehabilitation since it is the first time patient-reported health-related quality of life data (using the KDQOL-36) will be included as an indicator of quality care. These data will begin to be collected and reported in 2010.

Changes in the Conditions for Coverage—published this past April 15 that took effect on Oct. 14—represent another huge leap forward for rehabilitation policy. The Conditions require the following:

- ▶ All patients must be educated about all treatment options, including home dialysis, and where to get those treatments if their center does not offer

them. Further, working patients must be told about alternate dialysis schedules. A recent *The New York Times* article questioned why cancer patients lack information on where to get effective treatment for their disease.²¹ Thus, these new provisions may well give dialysis patients a right that is unique in medical practice.

- ▶ Social workers must assess each patient’s physical and mental functioning at least annually and incorporate the scores into an individual care plan for each patient.

- ▶ Dialysis clinics must track facility-level physical and mental functioning scores as a measure of treatment quality.

- ▶ Facilities must provide patients self-management education. Specifically, “The patient care plan must include, as applicable, education and training for patients and family members or caregivers or both, in aspects of the dialysis experience, dialysis management, infection prevention and personal care, home dialysis and self-care, quality of life, rehabilitation, transplantation, and the benefits and risks of various vascular access types.”²²

Positioned for success

It has taken decades, but the unflagging determination of dedicated renal rehabilitation advocates is finally beginning to bear fruit. By regulation, dialysis facilities must measure and document their patients’ health-related quality of life scores—and plan and conduct interventions to improve those scores. The availability of health-related quality of life data coupled with ongoing efforts to translate research into clinical practice should accelerate the rate of renal rehabilitation activities and expand successes in the years ahead. **N**

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Rehabilitation Works

Multidisciplinary predialysis interventions help patients keep their jobs

- ▶ 74% of home dialysis patients who were employed at the start of dialysis kept their jobs after participating in an educational/counseling program at Kaiser Permanente.¹²
- ▶ A significantly higher proportion of blue-collar workers who took part in a predialysis educational/counseling program kept working after they started dialysis.¹³

Patients with self-management skills enjoy better health-related quality of life:

- ▶ Self-care during dialysis and sharing responsibility for care were associated with higher physical functioning scores in a study of 372 in-center hemodialysis patients.¹⁴

Knowledge about dialysis is linked with higher health-related quality of life:

- ▶ Patients with higher scores on a kidney disease knowledge test were more likely to report better health-related quality of life.¹⁴

Health-related quality of life scores are statistically significant predictors of morbidity and mortality.

- ▶ Higher scores on both the physical and mental component summaries of a health-related quality of life survey are significantly associated with reduced relative risk of death and hospitalization.¹⁵
- ▶ DOPPS researchers found that low health-related quality of life scores were at least as powerful as nutrition scores (albumin) in predicting hospitalization and death.¹⁶

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A data-driven look at rehabilitation

By Nancy G. Kutner, PhD

The United States Renal Data System (USRDS) is the national data registry that collects, analyzes, and distributes information on kidney disease patients in the U.S. The USRDS was created in 1988 and is funded by the National Institute of Diabetes and Digestive and Kidney Diseases of NIH. The mission of the USRDS is to:

- ▶ Describe the prevalence and incidence of kidney disease along with trends in mortality and disease rates
- ▶ Investigate relationships among patient demographics, treatment modalities, and morbidity
- ▶ Prepare/release subsets of the database to support investigator-initiated research
- ▶ Conduct and support special studies

Three USRDS Special Studies Centers (SSCs) carry out special studies in the areas of Rehabilitation/Quality of life, Nutrition/Malnutrition, and Cardiovascular Diseases. Special studies are expected to have significant biomedical importance and to generate conclusions that may be generalized for improvement in the health of the kidney disease population.

The Rehabilitation/Quality of Life SSC is located at Emory University in Atlanta. Examples of studies conducted by this SSC include an investigation of the cost-effectiveness of dialysis patients' receipt of cardiac rehabilitation after coronary bypass surgery, the association of dialysis facility characteristics with patient employment, and the association of

intensified hemodialysis (HD) with patient survival and hospitalization.

The Rehabilitation/Quality of Life and Nutrition SSCs collaboratively developed the Comprehensive Dialysis Study (CDS), a new data collection study implemented 2005-2007. The CDS represents the largest dataset obtained from incident dialysis patients containing detailed information on patient-reported physical activity and macronutrient intake, as well as one of few cohorts simultaneously measuring laboratory proxies of nutrition and inflammatory

Participant age ranged from 19-94.

- ▶ The CDS includes patient employment status and validated measures of health-related quality of life, physical activity level, sleep disturbance, and depression collected from all participants, as well as dietary intake patterns and serum samples from a subset of participants.
- ▶ Associations among these measures, with appropriate stratification by patient demographics, will be of interest in cross-sectional analyses.
- ▶ In longitudinal analyses, by linking

The primary goal of the CDS was to better understand the interrelations among general health, nutrition, physical function, and health-related quality of life in a representative sample of patients recently starting maintenance dialysis.

status. The data are relevant for informing design of interventions to prevent or correct deficiencies in these parameters.

The primary goal of the CDS was to better understand the interrelations among general health, nutrition, physical function, and health-related quality of life in a representative sample of patients recently starting maintenance dialysis. A random sample of maintenance dialysis facilities was selected, stratified by ESRD Network and state, which matched the overall population closely on facility type, chain/nonchain, and dialysis modalities offered. Characteristics of patients from these facilities who participated in the CDS were generally similar to those of the overall population of incident patients.

these data with patient-specific information in USRDS files, researchers will be able to examine the predictive significance of early physical and nutritional status for morbidity and mortality outcomes.

Consistent with the objectives of Healthy People 2010, the goal of the CDS and all work conducted by the USRDS and its Special Studies Centers, is to better understand ways to reduce complications, disability, death, and economic costs of chronic kidney disease. Ideas are welcomed from the renal community for research and for intervention strategies that provide opportunities to improve care. **N**



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