

# International Encyclopedia of Rehabilitation

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# **Kidney disorders: end stage renal disease/dialysis**

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Persons with chronic kidney disease (CKD) who reach end-stage renal disease (ESRD) have impaired kidney function that requires dialysis or a kidney transplant to sustain life. Clinical care for ESRD patients prioritizes the goal of maximizing patient survival, but optimizing the patients' functioning and well-being should also be a prominent objective of care (Chyatte 1979). Interventions that have been shown to promote physical, psychosocial, and vocational rehabilitation of ESRD patients are highlighted below. Rehabilitation interventions are most frequently discussed in relation to dialysis patients, who comprise the majority of ESRD patients, but rehabilitation programs are also relevant for persons who have a kidney transplant (e.g. Gordon et al. 2005; Müller et al. 2010).

## **Exercise/physical conditioning programs**

A large research literature documents a variety of potential benefits that ESRD patients may achieve from exercise training (Johansen 2007). Improvements in reaction time and lower extremity muscle strength (van Vilsteren et al. 2005), left ventricular systolic function (Deligiannis et al. 1999), and psychosocial functioning (Kouidi et al. 1997) have been demonstrated in randomized clinical trials. Studies also provide evidence supporting the association of exercise training with improvement in arterial stiffness (Mustata et al. 2004), decrease in pulse pressure (Parsons et al. 2004), increase in aerobic capacity (Johansen 2007), reduced need for antihypertensive medications (Miller et al. 2002), increase in hemoglobin concentration and hematocrit levels (Goldberg et al. 1980), and improved lipid metabolism (Goldberg et al. 1980). Many of these outcomes are relevant for reducing patients' risk for cardiovascular mortality as well as for improvements in physical functioning, even though patients do not approach age-adjusted  $VO_{2peak}$  levels after training. Strength training may have additive or synergistic effects with aerobic training, because muscle atrophy may limit  $VO_{2peak}$  due to the small mass of working muscle. Patients with known or suspected cardiac disease should undergo exercise testing before participating in vigorous training programs. When moderate-intensity training is the objective, it may be sufficient to rely on history, physical examination, and/or electrocardiographic testing to determine if participation in an exercise training program is appropriate for a given patient (Johansen 2007).

Cycling exercise before or during dialysis is an option in some treatment centers. Exercise training during dialysis treatments may improve solute removal by increasing blood flow to muscle and efflux of urea and other toxins into the vascular compartment where they can be removed (Parsons et al. 2006). At the same time, there is a possibility of reduced exercise tolerance during dialysis resulting from fluid and electrolyte shifts, and exercise could exacerbate dialysis-associated hypotension (Johansen 2007). It appears; however, that exercise is generally well tolerated within the first 1-2 hours of a hemodialysis (HD) session (Painter et al. 2002).

Almost any method of increasing activity in ESRD patients is likely to be beneficial (Johansen 2007). The general principles for beginning any exercise are similar: receive an initial assessment, start at a low level as tolerated, and gradually progressing toward specific goals. Most patients should be able to participate in a walking program, gradually achieving 30 min on 3 days/week, keeping the intensity at a moderate level. Pedometers may facilitate goal setting and provide evidence of progress (Croteau 2004). Tai Chi, yoga, water exercise or swimming, and low-level strengthening programs are other recommended exercise options. Studies of Tai Chi among peritoneal dialysis (PD) patients in Canada have shown improvement in self-reported physical functioning (Ling et al. 2003) and in mental health scores (Mustata et al. 2005).

Physical therapy (PT) designed to meet the physical functioning needs of individual patients can be valuable (Pianta 1999). Persons who have difficulty walking, have severe muscle wasting, or are severely deconditioned can benefit from referral to PT for muscle strengthening, gait training, and help with ambulation. Complaints of weakness, difficulty with ambulation, fatigue, decreased range of motion, pain, and difficulty with activities of daily living are all considered indications for PT referral by a physician. The physical therapist can then further evaluate the patient's condition and develop a treatment plan based on limitations identified during the initial evaluation. Structuring therapy with the goal of renewing patients' ability to participate in valued activities enhances individuals' motivation. In one U.S. community, a dialysis unit arranged to collaborate with a local rehabilitation facility so that a licensed physical therapist could provide incenter PT services. Twice weekly PT sessions were generally 20-30 minutes in duration, during the first hour of dialysis. Patients were also given a home exercise program consisting of stretching exercises. After patients achieved defined goals they began a maintenance program supervised by PT students from a local college (Stugart and Weiss 1999).

A 3-month physical therapist-led program targeted to elderly patients at an inner-city dialysis unit in Atlanta (GA) showed that patient age was not a barrier to patients' achieving improved physical functioning and improved sense of well-being and confidence. The mean age of participants in this program was 61 and the median age was 70, with the oldest patient being 83 years old (Pianta and Kutner 1999).

Physical activity/exercise options, with or without exercise equipment, can be made available within the dialysis setting, depending on the commitment of the medical director and the interests and expertise of staff. These programs have the advantages of on-site medical oversight and convenience for patients; they also offer peer support as patients see others participating. Bennett et al. (2010) recently reviewed the literature to identify elements needed to sustain inclusion of exercise in routine care and/or as a normal part of the individual's daily life, whether performed on or off dialysis. Factors contributing to sustainable exercise programs were determined to include availability of dedicated exercise professionals as well as committed dialysis and medical staff, adequate physical space and equipment, interesting and stimulating exercise options, and

individual exercise prescriptions. This review confirmed that patient age is not in itself a limiting factor.

Cardiac rehabilitation (CR) programs include individually prescribed exercise for individuals who undergo coronary artery bypass grafting (CABG), sustain an acute myocardial infarction, or have stable angina. Cardiovascular mortality is the primary cause of death in ESRD patients, and referral to CR is recommended for patients who qualify (NKF 2005). In a cohort of 6,215 ESRD patients who initiated chronic HD and received a CABG procedure 1998-2002 in the U.S. we found that patients who received CR following CABG had a 35-36% reduced risk for cardiac and all-cause mortality compared to patients who did not receive CR following CABG, after adjusting for sociodemographic and clinical risk factors including recent hospitalization (Kutner et al. 2006). Additional analysis showed that patients' receipt of CR was highly cost-effective (Huang et al. 2008).

### **Inpatient rehabilitation**

Inpatient rehabilitation, which addresses generalized weakness and loss of self-care ability that may accompany a patient's hospital stay due to an acute illness or a major surgery, is indicated for patients who have an amputation or stroke, experience post transplant complications, or have age-related decline in functioning. Treatment goals are to improve endurance and function, maximize any spontaneous recovery, and return the patient to the home. Case reports as well as several studies that have compared outcomes of renal patients and non-renal patients following inpatient rehabilitation stays have shown functional gains in renal patients (e.g. Forrest 2004; Forrest et al. 2005) and support the conclusion that renal patients "merit a trial of rehabilitation even though they may have compounding impairments" (Sioson and Kerfoot 1994). A recognized challenge is the time that is typically required for the patient to receive dialysis treatment away from the rehabilitation unit, potentially limiting the amount of rehabilitation therapy that the patient receives or leaving the patient too fatigued to fully benefit from rehabilitation therapy (Kutner and Jann 1998; Forrest et al. 2005).

The average reported age of renal patients receiving inpatient rehabilitation is 60 or older. If inpatient rehabilitation does not include specialized geriatric care, elderly renal patients' level of functioning at discharge may not be consistent with return to the community (Chaplin and Barger 1995; Frank and Morton 2002). Li et al. (2007) at the Toronto Rehabilitation Institute in Canada designed a program specifically for older patients with complex medical issues who experienced acute functional decline and were unable to manage their own personal care if they returned to their home setting. Twelve dedicated nephrology rehabilitation beds were made available. The program was able to provide short daily dialysis onsite after a 6-station dialysis suite was built two floors below in the same building. Weekly interdisciplinary team meetings led by the nephrologist involved rehabilitation and geriatric staff as well as nephrology staff. In the first 36 months 164 patients were admitted, almost all of who had difficulty walking and most of whom required help with transferring. Patients' mean (SD) age was 74.5 (7.8). After a median of 48.5 days, 69% of the 164 admitted patients could be discharged home. Of the patients who completed therapy, 82% met some or all of their rehabilitation goals.

The program demonstrated benefits consistent with the results reported from a Canadian geriatric facility for interdisciplinary rehabilitation for non-dialysis-dependent patients (Patrick et al. 2001). The program developers believe that making short daily dialysis sessions available to patients not only limited the time conflict that often occurs between dialysis and inpatient rehabilitation therapies but also had physiological benefits for patients that may have increased the efficacy of the rehabilitation program. They note that the hospitalist and the nephrologist involved in the program were strongly committed to rehabilitation outcomes and that there was close collaboration among the various health professions that were involved (Li et al. 2007). In addition, the median length of stay (LOS) of 48.5 days in the Toronto program was considerably longer than the average LOS (12 days) that has been reported for dialysis patients (average age = 62) receiving inpatient rehabilitation in the U.S. (Forrest et al. 2005).

### **Psychosocial and vocational interventions**

Mental health needs, especially debilitating levels of depressed mood and even clinical depression, are prevalent among renal patients (Finkelstein et al. 2008). Antidepressants are frequently prescribed, but negative side effect profiles and drug interactions are of concern (Chilcot et al. 2010). Recent evidence supports the value of psychotherapeutic approaches, especially cognitive behavioral therapy (CBT). A study of a 12-week CBT intervention conducted with dialysis patients in Brazil indicated improvement of depressive symptoms at both three months and nine months compared to patients receiving standard care (Duarte et al. 2009). In a study of PD patients in Taiwan, researchers found that patients who received CBT reported improved sleep quality (Chen et al. 2008).

One of the key components of depressed mood is loss of interest in doing things. Depressed mood is often associated with decreased behavioral compliance with therapy, and nonadherent patients may be viewed by staff as “unmotivated” or “self-destructive” (Johnstone 2005). Positive changes in patient mood have been reported, however, in a social-worker led cognitive-behavioral approach termed “wellness programming,” which emphasizes an invitation to guide one’s own health outcomes, the development of positive health behavior skills, and the emergence of a sense of empowerment as the individual begins to take responsibility for his/her health and outcomes. Wellness classes offered to patients can focus on goals such as increasing physical activity, managing fluid intake, addressing sleep difficulties, building social skills and increasing social engagement, and depression management.

Psychosocial interventions also have been developed to emphasize encouragement for patients to pursue vocational objectives, within the context of a supportive approach to life planning and goal setting. A career planning workshop for renal patients was developed by individuals affiliated with the National Kidney Foundation (NKF) and the Rehabilitation Services system of the state of Michigan in the U.S. (Wright and Newhouse 1989). This workshop model offered patients a setting in which they could examine perceived barriers to considering a range of options and making choices about their future. In this setting employment fears could be discussed among peers sharing similar circumstances, with rehabilitation professionals available at the workshops to

provide support and information on career decision-making and job seeking. Participants targeted for inclusion in the career planning workshops were young working-age patients with expressed interest in being able to work and in getting a job, concern about risking loss of disability payment benefits, and desire for independence, but who had inadequate knowledge regarding effective job-seeking. In the final workshop session, all participants completed a contract outlining what they wanted to achieve and what they were going to do to achieve their goals. At a three-month follow-up, most workshop participants reported having engaged in some form of employment-directed activity. Successful ingredients of the Michigan program were believed to be providing patients an opportunity away from the medical treatment setting (the “sick role context”) to discuss their choices and options with peers, while simultaneously acquiring sound information from vocational counselors who demonstrated genuine interest in their futures. Vocational counselors also saw evidence contradicting the myth that dialysis patients are too sick to be vocational rehabilitation clients (IRI 2001).

The Michigan career planning workshop model fostered development of additional programs, including RISE (Rehabilitation: Information, Support & Empowerment), offered nationally in the U.S. through NKF affiliates; Springboard, offered by the NKF of Georgia to patients aged 19-30; and Forward Bound, offered by the NKF of Mississippi to patients aged 19-40 (IRI 2001). In addition to fostering vocational planning and activity, the Springboard program had the goal of helping young adults address age-related needs of transitioning to independence. Springboard, a life and career development program for young adults with kidney disease was started in 1989 as a joint effort of the NKF of Georgia and the Georgia Division of Rehabilitation Services. About 100 young people in Georgia ages 19-32 on dialysis and with renal transplants participated in the annual Springboard programs held between 1989 and 1998. Among approximately 50 of these young people who were contacted for a follow-up survey in 2000, 54% were currently working, in school or receiving job training, or were both working and in school--far exceeding the number that would be expected to be involved in work or school based on regional and national surveys of the U.S. renal population. Several young people reported having been depressed when they first enrolled in Springboard but felt that they had developed a much more positive outlook on life when they graduated. The program was successful in helping young people who would otherwise be at high risk for long-term disability to believe in their futures, including a willingness to take advantage of vocational opportunities (Knapp 1992).

A predialysis program designed to help hemodialysis patients integrate dialysis into their lives and to maintain employment after beginning dialysis treatment was described by Rasgon and colleagues (Rasgon et al. 1993). This intervention was provided prior to patients' initiation of dialysis and included a large proportion of blue-collar workers, who are less likely to continue employment after starting dialysis than are individuals with higher occupational status jobs. Blue-collar participants were primarily male and Hispanic or African-American, with a mean age of 50; almost 59% had less than a high school education. The program included several education and counseling sessions conducted by a social worker prior to dialysis initiation, with the goal of changing patient, family member and employer perceptions of patient work ability when on

dialysis and helping patients understand how to fit dialysis into their current lifestyle. The patient's physician also provided education, support, and monitoring of the intervention effects. Workers who received the intervention were significantly more likely to remain employed after starting chronic dialysis than were the members of comparison groups of similar patients who did not receive the intervention. Patients' affiliation with a large health maintenance organization facilitated implementation of this predialysis program. In contrast, many patients start dialysis on an emergent basis and are not followed regularly by healthcare providers.

ESRD patients who are employed after starting dialysis are much more likely to continue a job they held prior to dialysis than to re-enter the labor force after stopping work. The opportunity to use a form of home dialysis such as PD can facilitate job maintenance (Hirth et al. 2003). Patients treated by in-center HD are more likely to be employed if they receive dialysis in facilities that offer a treatment shift that begins at 5pm or later, and dialysis facilities in the U.S. with the highest employment rates are more likely to have patients who receive vocational rehabilitation services (Kutner et al. 2008). A comprehensive overview of strategies for improving employment outcomes for people with chronic kidney disease in the U.S. was compiled under the sponsorship of the Institute on Rehabilitation Issues (IRI 2001).

## **Conclusion**

An optimistic view of the potential for renal rehabilitation opportunities to become more widely available stems from growing acknowledgment of the value of physical activity/exercise and of the need for interventions to address depression in the renal population. Research that has linked low physical activity/exercise and depression to renal patients' mortality risk is an important contributor to this momentum. There is also growing recognition of the value of integrating insights from geriatrics with nephrology, consistent with the increasing average age of the treated ESRD population in many countries. The geriatric phenotype of frailty (Fried et al. 2001), with its risk for individuals' subsequent morbidity and mortality, has been validated in elderly persons with CKD (Shlipak et al. 2004), and a modified operationalization of this phenotype has been shown to predict frailty and related outcomes in incident dialysis patients (Johansen et al. 2007). Low physical activity, a key dimension of the frailty phenotype, is an obvious target for intervention.

Short validated screening tools to assess physical activity (Johansen 2007), depressed mood (Kroenke et al. 2003), recent falls (Cook et al. 2006), and functional impairment (Cook and Jassal 2008) are available and can be easily incorporated into clinical care of ESRD patients. The first step in rehabilitation is an evaluation process. Screening tools that are easily applied can help to increase awareness and targeted attention to rehabilitation issues in the clinical setting. Most important, however, is that rehabilitation must be a routine part of care, an orientation that appears to be prominent in Hong Kong (Painter 2010). ESRD care providers in that city have built on the foundation outlined by the Life Options Rehabilitation Advisory Council, which stresses the importance of the "5 E's" (exercise, encouragement, employment, education, and evaluation) as cornerstones of rehabilitation programming for ESRD patients and for which reference

materials are available from the Medical Education Institute (<http://www.lifeoptions.org>). For example, at several Hong Kong hospitals all ESRD patients' physical functioning is evaluated, using the six-minute walk or treadmill testing. An invitation to exercise program is held for three months under the supervision of physical therapists. Patients, many of whom are on PD, are then given an exercise program to follow at home, with physician and nurse follow-up as part of routine practice. For patients treated by HD, cycling during treatment is available, supervised by a physical therapist that also provides other strengthening exercises during the HD treatment. Contacts are made with community programs that offer exercise opportunities. Tai Chi classes are available, and some patients participate on gate ball teams. This example of locally available multiple opportunities for physical activity demonstrates what is possible within an ESRD treatment culture--opportunities that facilitate patient empowerment, which is a "sixth E" and the ultimate goal of renal rehabilitation (Painter 2010).

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