

Building Quality of Life:

*A Practical
Guide to Renal
Rehabilitation*



Developed by
The Life Options Rehabilitation
Advisory Council

Funded by
An Educational Grant from
Amgen Inc.

Administered by
Medical Education Institute, Inc.

Getting Started

Introduction:

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The *Practical Guide to Renal Rehabilitation* provides recommendations for individuals on dialysis regarding programming issues for the “5 E’s” of renal rehabilitation: Encouragement, Education, Exercise, Employment, and Evaluation. In using this Guide, the reader should be aware of certain limitations. First, the Guide may not cover all possible topics related to such issues, and it may not address aspects of such issues that may be relevant to you in light of your particular circumstances. Second, future legislation, regulations, administrative interpretations, and court decisions may significantly change the current law or the interpretation of current law cited in this material. Please note that neither Amgen Inc., the Medical Education Institute, Inc., nor the Life Options Rehabilitation Advisory Council intends to update the information contained in this Guide. It is based on information available as of the date of publication. Third, although the authors have used their best efforts to assure that the information contained herein is accurate and complete as of the date of publication, the authors cannot provide guarantees of accuracy or completeness. Fourth, practical suggestions provided throughout the text are based on the opinions of the Medical Education Institute staff. Suggestions may or may not reflect national experience and may instead reflect local experience. Finally, this Guide is provided with the understanding that neither the Guide nor its authors are engaged in rendering medical, legal, accounting, or other professional advice. If legal advice or other expert assistance is required, the authors recommend that the reader seek the personalized service of a competent professional.

The information in this Guide is offered as general background for the clinician who is interested in improving the quality of rehabilitation opportunities for dialysis patients. The Guide is not intended to provide practice guidelines or specific protocols and cannot substitute for the physician’s knowledge and experience with individual patients. The reader must recognize that exercise, in particular, involves certain risks, including the risk of severe injury or disability, including death, which cannot be completely eliminated, even when the exercise program is undertaken under expert supervision. Use of these materials indicates acknowledgment that Amgen Inc., the Medical Education Institute, Inc., and the authors will not be responsible for any loss or injury, including death, sustained in connection with, or as a result of, the use of this Guide.

Foreword

The purpose of dialysis is to rehabilitate patients—to enable them to live as normally as possible with a disease that, in years past, was always fatal. Over the past several years since the Life Options Rehabilitation Advisory Council published the *Bridging the Barriers Report*, the whole notion of renal rehabilitation has come of age. Now there is a fuller understanding of the need for it, a vocabulary for speaking about it, journal articles written about it, presentations made about it, and tools being developed to measure its outcomes. But, there was still a void in the information available—renal professionals had no clear directions for how to *do* renal rehabilitation, how to implement it in the real-life setting of the dialysis facility.

Building Quality of Life: A Practical Guide to Renal Rehabilitation fills that void. Comprised of an overview module and a how-to module for each of the “5 E’s” of renal rehabilitation (Encouragement, Education, Exercise, Employment, and Evaluation), the *Practical Guide* picks up where *Bridging the Barriers* left off. It puts the tools necessary to begin rehabilitation programming in the hands of those who will actually be responsible for renal rehabilitation activities in the dialysis setting—the renal professionals who will plan it, implement it, oversee it, and evaluate its outcomes.

By providing the directions and rationales for renal rehabilitation activities, we hope to help renal professionals across the nation continue to improve the care they provide to patients and to enhance patient outcomes through renal rehabilitation. Armed with the *Practical Guide*, we are poised to accomplish these ongoing goals in the most efficient and effective manner possible.

Our best wishes go with each and every one of you who share this professional commitment to engaging patients through renal rehabilitation to fulfill the promise of the ESRD program.

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Introduction

Renal rehabilitation is the process of helping dialysis patients resume productive activities, including independent living. As conceived by the Life Options Rehabilitation Advisory Council, the core principles of renal rehabilitation are the “5 E’s”: Encouragement, Education, Exercise, Employment, and Evaluation (*Renal Rehabilitation: Bridging the Barriers*, 1994). Using the 5 E’s as a basis, this guide will help you consider ways to incorporate rehabilitation into the daily activities of your dialysis facility.

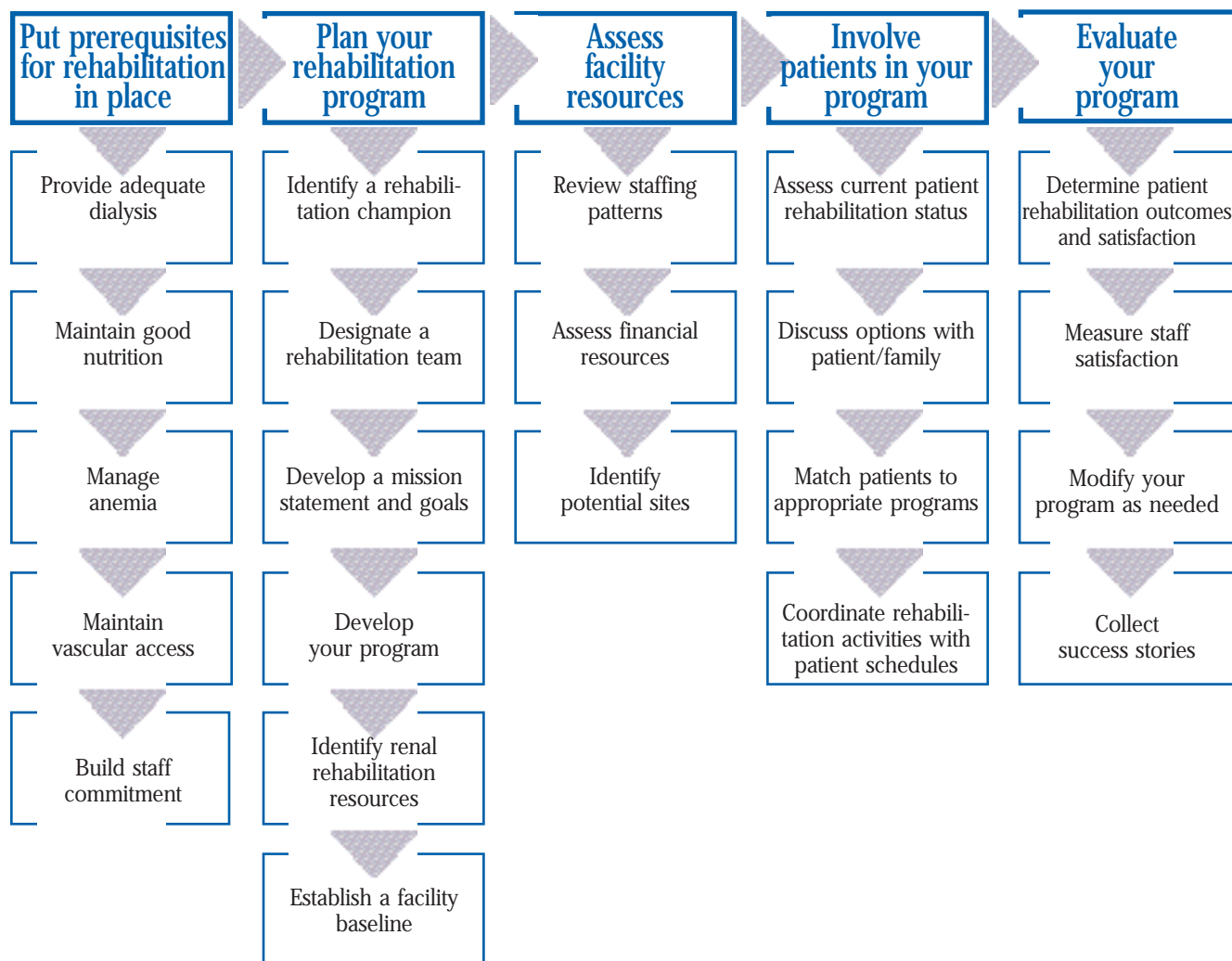
Improved technology and knowledge about how to help rehabilitate patients have created new challenges and opportunities for dialysis staff. Rehabilitation in action creates a sense of excitement in the facility. More importantly, both patients and staff benefit from improved patient outcomes. Rehabilitated patients can live more active lives; these patients also are more rewarding for staff to work with. However, initiating a renal rehabilitation program in a busy facility can seem overwhelming. Where do you begin?

This Guide has been designed to meet the needs of front-line dialysis professionals in urban and rural, free-standing and hospital-based, for-profit and not-for-profit facilities with varied patient demographics and acuity levels. It is not aimed at any single discipline; it is meant to enhance knowledge, skills, and interest in renal rehabilitation among all members of the renal team. The Guide will help you to put together a rehabilitation team, develop goals, evaluate patient and staff attitudes toward rehabilitation, assess resources, decide which projects to try, and determine benchmarks to evaluate programs—in a way that is feasible with *your* staffing and financial resources.

Included are five modules, each addressing one of the 5 E’s. Each module contains a table of contents, key points, background information, a process flowchart, ideas and tips, practical examples from renal dialysis centers, and references. The *Renal Rehabilitation: Getting Started* flowchart on page 3 outlines the major steps needed to begin a rehabilitation program in your dialysis facility.



Renal Rehabilitation: Getting Started



Put Prerequisites for Rehabilitation in Place

The goal of any rehabilitation program is improved patient outcomes. However, certain prerequisites must be met before *any* renal rehabilitation program can be successful—and before most patients will have much interest in pursuing rehabilitation. Patients must feel well enough physically and emotionally to have the motivation and enthusiasm to participate in a successful rehabilitation effort. The following prerequisites are essential.

Provide Adequate Dialysis

To be successful in a rehabilitation program, patients require adequate dialysis. Healthy kidneys work 24 hours a day, seven days a week, but even good dialysis replaces only 10% of normal kidney function. Therefore, if the prescribed dialysis therapy is compromised for any reason, patients are at increased risk of morbidity and death. Patients who are inadequately dialyzed are more likely to be hospitalized (Rettig & Levinsky, 1991).

The dose of dialysis is commonly measured by the product of solute (or urea) clearance and time normalized by total body water—Kt/V. Studies of hemodialysis patients have noted an association between improved patient outcomes (reduced morbidity and mortality) and a dialysis dose of Kt/V > 1.2. While an *optimal* dose of dialysis has not been defined, it is recommended that the *minimum* dose of dialysis should be a Kt/V of 1.2 (*NKF-DOQI Clinical Practice Guidelines for Hemodialysis Adequacy*, 1997).

In peritoneal dialysis patients, the dose of dialysis is also measured by total creatinine clearance (C_{Cr}). For CAPD patients, an adequate dose of dialysis has been defined as a Kt/V_{urea} of at least 2.0 per week and a C_{Cr} of at least 60 L/week/1.73 m² of body surface area (*NKF-DOQI Clinical Practice Guidelines for Peritoneal Dialysis Adequacy*, 1997). Numerous studies have shown that outcomes are superior with doses of PD that are higher than previously accepted (weekly Kt/V_{urea} of 1.7.) It is especially important to monitor the dialysis dose in patients who are malnourished, since they may appear to have an adequate Kt/V_{urea} due to calculation of V from the actual (malnourished) body weight, rather than the desired body weight.

Maintain Good Nutrition

Poor nutrition is a strong predictor of illness, hospitalization, and even death (Lowrie & Lew, 1990). According to one large study, the top three predictors of patient death are creatinine concentration <12.5 mg/dL, albumin levels <4.0 g/dL (both reflecting poor nutrition); and urea reduction ratio (URR) <60%, reflecting inadequate dialysis (Lowrie et al, 1994). This same study found that predialysis serum creatinine and albumin are highly correlated, with higher concentrations of creatinine seen in better nourished individuals. As albumin levels drop, the risk of death increases. Following the prescribed renal diet is important for patients to feel as healthy as possible and pursue enjoyable activities.

Manage Anemia

Chronic renal disease reduces the ability of the kidneys to produce erythropoietin, needed to avoid symptoms of anemia, such as fatigue with poor exercise tolerance, brain and cognitive dysfunction, and poor quality of life. A hematocrit “floor” of 33% to 36% has been recommended to address anemia in ESRD patients (*NKF-DOQI Clinical Practice Guidelines for the Treatment of Anemia of Chronic Renal Failure*, 1997). There are no data available to define an *optimal* hematocrit level.

Studies have shown that increased hematocrit is associated with improved energy and endurance levels (Delano, 1989), improved exercise tolerance (Davenport et al, 1992), improved brain function (Marsh et al, 1991), and improved quality of life (Levin et al, 1993; Delano, 1989). Patients with higher hematocrits are able to maintain and enhance their health status (energy, pain, depression, sleep, social isolation and mobility, patient perception of health status, sexual functioning, and health satisfaction), appetite, subjective quality of life (well-being, life satisfaction, and psychological affect), and happiness across all treatment modalities (Evans et al, 1990). A recent matched-pair study by Churchill et al (1996) also demonstrated that patients treated with EPO to address their anemia had significantly fewer hospitalization days than untreated patients (15.3 days for treated patients vs. 23.2 days for untreated patients).

Maintain Vascular Access

As the patient's dialysis lifeline, a patent vascular access is essential to rehabilitation success. Hospitalizations, loss of limb, and death can accompany access failure. Identify and address access problem areas through systematic quality improvement efforts.

Build Staff Commitment

Beginning a rehabilitation program takes time and commitment from every member of the team. The more staff members involved in rehabilitation education and planning, the more successful your efforts will be. Everyone from clerical staff to facility administrators needs to "buy-in" to ensure a successful program, elicit ideas from a variety of perspectives, and communicate a consistent message to patients.

You will need to know whether your facility's staff is comfortable beginning a rehabilitation program with the knowledge they have right now, perhaps by using a short questionnaire like the one at right. The answers to these questions will help you to determine if there are knowledge gaps that can be addressed through education. The answers can also help you to identify individual staff members who are already committed to the idea of rehabilitation, and which staff members are not convinced that rehabilitation would be worth the effort.

There are two attitudes that seem particularly important for facilities attempting to start a rehabilitation program. The first is staff support of rehabilitation. The second is the staff's belief that investment of time and resources in rehabilitation will provide benefits for themselves and for patients. Both commitment and belief in the value of rehabilitation are necessary for success of a rehabilitation program.

If staff lack commitment to rehabilitation, they may not fully understand its potential benefits. Sharing rehabilitation success stories and providing in-service training may help change negative attitudes. In addition, collecting and sharing research papers on positive rehabilitation outcomes may help convince reluctant staff members of its benefits. Including promotion of patient rehabilitation in all job descriptions reinforces the message that rehabilitation is important and the responsibility of every staff person.

Sample Staff Attitudes Questionnaire

1. Do you think you know enough about rehabilitation to begin a program right now?
2. Can you identify the general areas in which more information would be useful?
3. Would you be willing to put in the effort to help make rehabilitation possible for patients in our facility?
4. Do you believe the benefits of rehabilitation for our patients are worth the costs?

Plan Your Rehabilitation Program

Once you decide to begin or modify a rehabilitation program, your facility can use a step-by-step approach. The following steps will help you begin.

Identify a Rehabilitation Champion

A viable rehabilitation program needs one or more champions—dialysis professionals whose belief and energy will kick off the program and convince others to join in. Communicating a consistent message among all patients and staff is key. It is essential to build consensus and excitement to ensure successful implementation.

The rehabilitation champions need to explain the importance of rehabilitation to the rest of the staff and create enthusiasm. Along with this Guide, renal rehabilitation speaker's kits with scripts, slides, and answers to frequently asked questions can help you accomplish this goal. Speaker's kits are available on loan from the Life Options Rehabilitation Resource Center at (800)468-7777.

Designate a Rehabilitation Team

A rehabilitation team, perhaps chaired by your rehabilitation champion, needs to plan and implement your facility's program. Team members may include administrators, nephrologists, nurses, social workers, dietitians, technicians, patients, family members, and clerical staff.

Consider broadening the team's resources by consulting other professionals, such as psychiatrists (physicians specializing in rehabilitation medicine), pharmacists, physical or occupational therapists, exercise physiologists, and employment or vocational rehabilitation counselors. Some facilities have obtained volunteer services or tax deductible donations of time from these professionals.

While a core team of staff may develop a renal rehabilitation program, buy-in from the entire staff is key to any program's success. Whether through an encouraging word from a dialysis technician or an

exercise prescription from a nephrologist, patients need to be assured that their rehabilitation efforts are expected, appreciated, and important. The entire unit must create an expectation that patients can lead productive lives. Every team member should ask, "Will this action encourage patient rehabilitation?" In addition to buy-in and support, there is an important role for everyone on the rehabilitation team:

- **The administrator:** to support the program administratively and financially, and to integrate rehabilitation planning into the operation of the facility.
- **The nephrologist:** to prescribe the most effective dialysis treatment and medical supervision for each patient to enhance physical rehabilitation.
- **The dialysis nurse:** to ensure that patients receive the prescribed treatment and comprehensive education about their illness, its treatment, and areas for them to participate in their own care.
- **The social worker:** to provide education about services and rehabilitation programs, and emotional counseling to enhance strengths and skills that will help patients achieve their rehabilitation goals.
- **The dietitian:** to ensure that patients are informed about the importance of good nutrition and exercise while helping patients learn how to fit foods they enjoy into the renal diet.
- **The dialysis technician:** to deliver the prescribed treatment, encourage patient participation in care, and provide emotional support without fostering dependence.
- **The clerical staff:** to encourage patients and provide administrative support for programming.
- **The patient:** to ask questions, to adhere as closely as possible to the prescribed treatment, medications and diet, and to actively participate in care.
- **The family:** to support and encourage the patient without doing things for the patient that the patient can do for himself or herself.

Develop a Mission Statement and Goals

The first task of the team is to establish a mission statement for your program, perhaps like the examples below. A short mission statement will clarify your program's purpose for interested individuals, including current patients and staff, referral sources, prospective patients and families, payers, and government regulators. Along with your mission statement, a written set of program goals should reflect the outcomes you would like your program to achieve.

a Mission Statement

“Our mission at the Dialysis Center of Lincoln is to provide high-quality, progressive dialysis therapy and education to clients with acute and chronic renal failure and support those clients and their families in an environment that contributes to their holistic health, quality of life, and eventual rehabilitation.”

Courtesy of the Dialysis Center of Lincoln, Lincoln, Nebraska

a

a Mission Statement

“The mission of DCA Crestwood Unit’s rehab program is to provide our dialysis patients with the resources to improve their psychosocial, vocational and clinical status, as well as their physical functioning and quality of life.”

Courtesy of Dialysis Centers of America -
Crestwood Unit, Crestwood, Illinois

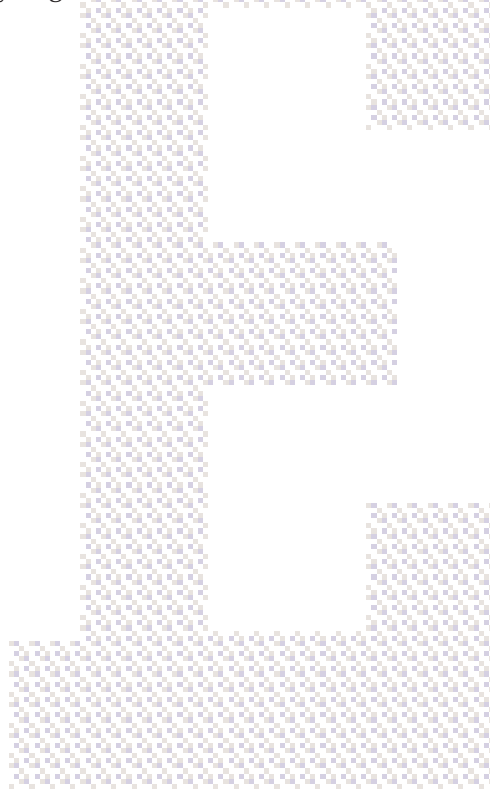
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Develop Your Program

Besides the mission statement, a comprehensive written rehabilitation plan with program goals will help you to focus all players, reduce the potential for misunderstanding, and serve as the basis for future revisions as patient needs and the scope of rehabilitation change over time. Your plan will need to include:

- Goals and objectives
- Action steps for each objective
- A person responsible for each action step
- A timetable
- A list of resource needs
- A means of measuring outcomes

If you are just beginning a renal rehabilitation program, choose small goals that you can achieve. Success will help your team to become more ambitious over time. Each module of this Guide includes a segment of the *Unit Self-Assessment Tool For Renal Rehabilitation (USAT)*. The *USAT criteria*, at basic, intermediate, and advanced levels, will help you to see how your facility is currently doing with regard to rehabilitation programming, and will suggest programming ideas to help you get started.



Identify Renal Rehabilitation Resources

Large quantities of excellent renal rehabilitation materials and information are available from a variety of sources.

Rehabilitation Resource Center (800)468-7777

The Rehabilitation Resource Center (RRC) is a clearinghouse of the Life Options Rehabilitation Advisory Council (LORAC), with a collection of information specific to renal rehabilitation. RRC materials are provided free of charge, courtesy of an educational grant from Amgen Inc. The RRC is staffed Monday through Friday from 8:30 a.m. to 5 p.m. CST, with a voice mail call-back system available for after-hours inquiries. Knowledgeable RRC staff can help answer your questions and provide information about a host of programs and materials that may be of interest to patients and staff at your facility. Services available from the RRC include:

- Phone consultation and technical support
- Life Options Rehabilitation Advisory Council materials about the 5 E's
- Speaker's kits for 20-minute presentations on renal rehabilitation, containing slides, scripts, and answers to frequently asked questions
- Referral to appropriate local and national resources
- Potential sources of grant funding
- Information and contacts for *Exemplary Practices in Renal Rehabilitation* winners

Local and National Resources

As you develop your rehabilitation program, you may also find the assistance and resources of various local, state, and national resources very helpful. The **American Association of Kidney Patients** (800)749-2257, (813)223-7099, or <http://www.aakp.org>, and the **National Kidney Foundation** (800)622-9010, (212)889-2210, or <http://www.kidney.org> often have local branches that offer support groups, publications and other materials that can be incorporated into your rehabilitation plans. The **American Kidney Fund** (800)638-8299, (800)492-8361, (301)881-3052, or <http://www.arbon.com/kidney/home.htm> has educational materials and programming for patients and professionals. In addition, senior citizens groups such as the **American Association of Retired Persons** (800)424-3410, employment counselors, rehabilitation professionals, vocational rehabilitation counselors, equipment manufacturers, and pharmaceutical companies may have the expertise or resources to help you develop a rehabilitation program.

Establish a Facility Baseline

Before you can begin a new program of renal rehabilitation, you'll need to look systematically at what your facility is currently doing. A baseline will permit your facility to measure progress, determine priorities, and build on existing successes.

Each of the 5 E modules of this Guide includes a section of the *Unit Self-Assessment Tool for Renal Rehabilitation* (USAT), a rehabilitation program inventory you can use to assess your current rehabilitation level. The USAT divides rehabilitation program ideas into a basic, an intermediate, and an advanced level. By using the USAT to score your program, you will have a baseline for each "E" at each of the three levels, as well as an overall baseline.

Case Study:

Medical Center Dialysis, Detroit, Michigan: Through Adversity to Excellence

In 1994, the Life Options Rehabilitation Advisory Council (LORAC) introduced its *Exemplary Practices in Renal Rehabilitation* competition to recognize outstanding programs through awards in the categories of Encouragement, Education, Employment, Exercise, Evaluation, and General Excellence.

Medical Center Dialysis (MCD) of Detroit, a peritoneal dialysis program, received a General Excellence award in 1996. MCD faced a major challenge in overcoming obstacles too often associated with inner city programs—poverty, homelessness, high rates of peritonitis and anemia, and poor dialysis adequacy. But overcome they did.

Initially, MCD staff realized their patients needed major doses of encouragement. The Center accomplished this through orientation sessions, educational materials, and incentives such as certificates of achievement and posting of improved lab results. To increase self-esteem and foster camaraderie, MCD also developed mentor and role model programs.

Realizing that education is essential for positive outcomes, staff supplied information on new PD techniques and on the importance of activity, including employment. In addition, they introduced formal education sessions, support groups, a newsletter, and monthly cooking classes.

To encourage employment, MCD authorized delivery of dialysis supplies to patients' homes and workplaces. Staff members also scheduled clinic visits around patients' work hours and discussed the need for reasonable accommodations with employers. For unemployed patients, team screenings were conducted, prospective employers contacted, appropriate modalities considered, and links established with employment education programs in the community.

MCD also recognized the value of exercise. Patients were encouraged to participate in weekly exercise classes that incorporated dance techniques and isometrics. The program quickly improved patients' mobility and muscle strength, enhanced their self-esteem, and decreased their dependency.

Evaluation reveals that program initiatives have exceeded expectations. Fewer hospitalizations occur, due to increased mobility, decreased peritonitis rates, and reduced complications. Patients are more independent and take a more proactive approach to their care.

Cathie Clark, RN, clinical nurse manager, is quick to credit patients with the programs' success. "They are the ones who did all the work and met with all the struggles. We just pointed out the direction and showed the way."

Assess Facility Resources

Any rehabilitation program under consideration must reflect the realities and constraints of your facility's particular configuration of personnel and patient demographics. Consider the following possibilities.

Review Staffing Patterns

Sometimes it seems there is not enough time to provide appropriate dialysis care—much less rehabilitation. Yet, rehabilitation can be addressed at a basic, intermediate, or advanced level; large commitments of staff time are not always needed. Even brief conversations with patients at the beginning or end of a dialysis treatment can be very fruitful.

Staffing for a successful rehabilitation program can be accomplished in a number of ways. Estimate your own staff time and other rehabilitation elements. Once you know how much staff time is available, you can determine whether it is feasible to accomplish your rehabilitation goals within the constraints of present staffing, or whether additional personnel time will be needed. You might be able to consider adjusting some staff members' responsibilities, increasing staff hours, or creatively reassigning some tasks to other personnel. For example, having a part-time clerk do transportation planning could free a social worker or nurse to help with your rehabilitation program.

Assess Financial Resources

Assessment of the financial investment needed and available resources is essential. Unfortunately, there is limited information currently available about the costs of rehabilitation efforts at the three levels. Of course, the fiscal impact of a program will depend on how extensive it is, and whether additional staff time and materials are needed to accomplish your goals. Nonetheless, before planning rehabilitation interventions, each facility will need to consider cost implications. If you are interested in applying for foundation or industry grant funding, you may call the Rehabilitation Resource Center at (800)468-7777 for information about potential funding sources.

Identify Potential Sites

The physical setting must be considered when planning rehabilitation programs, since some programs will require additional space, such as a room for classes and meetings. On-site exercise programming may require space to use and store exercise equipment. If no space is available in your facility, look elsewhere. Possibilities at no or low cost include: VFW or other similar halls, churches, YMCA/YWCA facilities, Department of Vocational Rehabilitation facilities, NKF Affiliate offices, school and community recreation facilities, senior centers, libraries, rehabilitation hospitals, shopping malls, and community fitness centers.

In

volve Patients in Your Program

Having rehabilitation programs available is not enough to guarantee rehabilitation success. Patients must be willing participants. You cannot force rehabilitation on patients; they must actively seek it. If your existing program—however ambitious—is not producing positive changes in patients' rehabilitation status, it is time to reevaluate and modify it. Consider surveying patients about what they think of your facility's rehabilitation programming. Assure patients that their responses will be anonymous, and use their responses to help focus your efforts more effectively. If you are planning a new program, include patients in the process.

Assess Current Patient Rehabilitation Status

Just as you obtained a baseline for your facility's current rehabilitation programming, you will also need to assess *each patient's* current knowledge in key areas of rehabilitation. A set of eight simple questions to ask patients, the *Assessment of Patient Current Rehabilitation Status*, is included in the sidebar. The questions are common sense and practical—to provide you with a quick preliminary “estimate” of each patient's status in Encouragement, Education, Exercise, and Employment. More detailed assessments will be recommended in other modules of this Guide. This instrument is not to be confused with or substituted for other standardized quality of life instruments that have been tested for

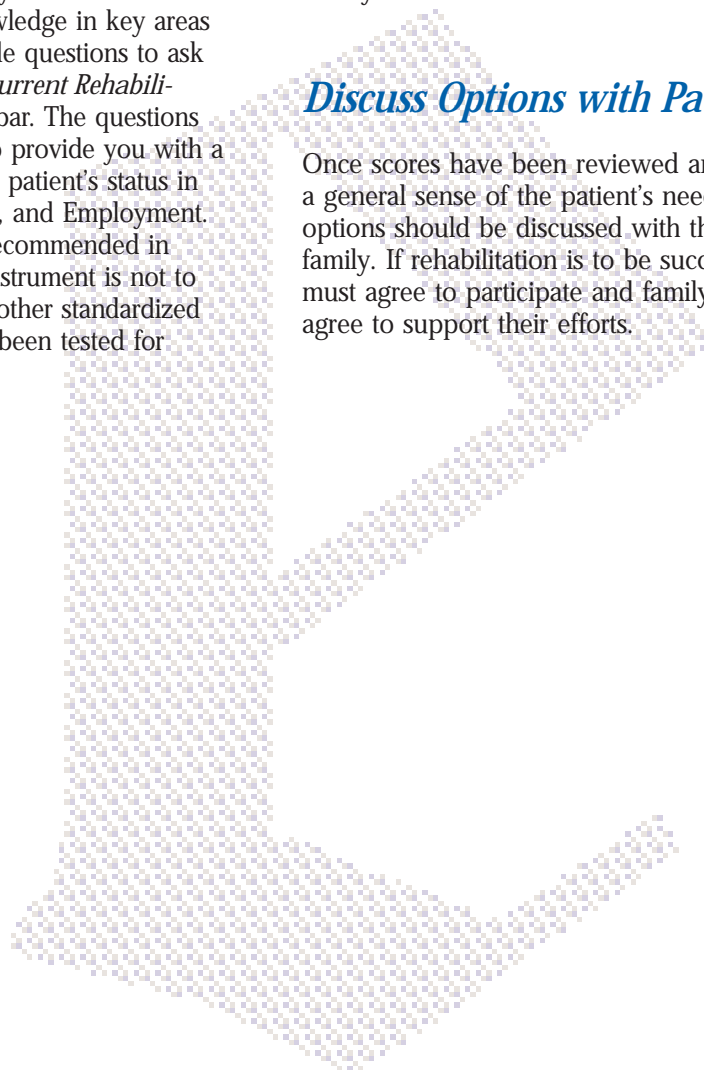
reliability or validity such as the Kidney Disease Quality of Life™, the Medical Outcome Study SF-36, or other tests that are discussed in detail in the Evaluation module.

Patients who are physically able to fill out the assessment should do so themselves. Assist other patients in an unbiased, non-judgmental manner. Ask the questions of patients at regular intervals so you can compare their scores over time.

Interpret the results based on common sense. In general, lower scores suggest a higher need for rehabilitation efforts in a particular “E.” For example, patients who answer no to both Encouragement questions clearly need an encouragement program. Individual patient scores can help you determine what specific areas of rehabilitation are needed for a particular patient. Aggregate, or group scores, can help you to determine which “E” or “E's” to target on a facility-wide basis.

Discuss Options with Patient/Family

Once scores have been reviewed and your team has a general sense of the patient's needs, rehabilitation options should be discussed with the patient and family. If rehabilitation is to be successful, patients must agree to participate and family members must agree to support their efforts.



Assessment of Patient's Current Rehabilitation Status



Encouragement

- 1a. Are you pretty satisfied with your life as it is now?
(**Score:** Yes = 1, No = 0)
- 1b. Do you think anything can be changed to make your life better?
(**Score:** Yes = 1, No = 0)

Sample interpretations:

Two points for Encouragement probably means the patient is feeling encouraged or empowered. One point may mean the patient would be receptive to an Encouragement intervention. Zero points probably means an encouragement/attitudinal program is needed. You know your patients best, and should use these questions as broad indicators of their frame of mind and educational needs.



Exercise

- 3a. What are you doing for exercise?
(**Score:** Any exercise = 1, No exercise = 0)
- 3b. What would you say are some of the effects of exercise on dialysis patients?
(**Score:** Any correct positive effects = 1, No positive effects or negative effects = 0)

Sample interpretations:

If anything other than regular (preferably aerobic) exercise is reported for 3a, an educational/exercise plan will probably be needed. Patients who don't know about the positive effects of Exercise (3b) need information and ideas about how to proceed.



Education

- 2a. What does the term Kt/V (or URR) mean to you?
(**Score:** Concept of Kt/V or URR, or notions of adequacy = 1, No concept of adequacy = 0)
- 2b. Why is your weight gain between dialysis treatments important?
(**Score:** Includes hypertension or fluid buildup = 1, Does not include hypertension or fluid buildup = 0)

Sample interpretations:

Questions 2a and 2b focus on two areas all patients should understand—dialysis adequacy and fluid intake. Wrong answers probably indicate a need for Education, not only about these specific topics, but in general. Patients who can answer these questions correctly are probably relatively well-informed about their condition, and might be ready for more sophisticated topics.



Employment

- 4a. Are you now performing most of the activities you want to do?
(**Score:** Yes = 1, No = 0)
- 4b. Are you now employed or in school or involved in volunteer or other activities full- or part-time?
(**Score:** Yes = 1, No = 0)

Sample interpretations:

Questions 4a and 4b are intended to determine whether patients are active and involved with life. Zero points indicates a need for intervention in this area.

Match Patients to Appropriate Programs

Based on the review of scores and your discussion of options with patients and their families, assign patients to rehabilitation programs that most closely meet their needs. If a patient seems to lack motivation, you could match that patient with another patient in a “buddy program” to provide peer support and encouragement. If a patient’s score shows that education is needed, target information to meet the patient’s learning needs and style. If a patient is not exercising, obtain an exercise prescription from the nephrologist and provide incentives for exercise. For the patient who is isolated and not engaging in life activities, the social worker could evaluate the patient’s skills and interests and provide information and encouragement about activities that focus on these strengths and interests.

Coordinate Rehabilitation Activities with Patient Schedules

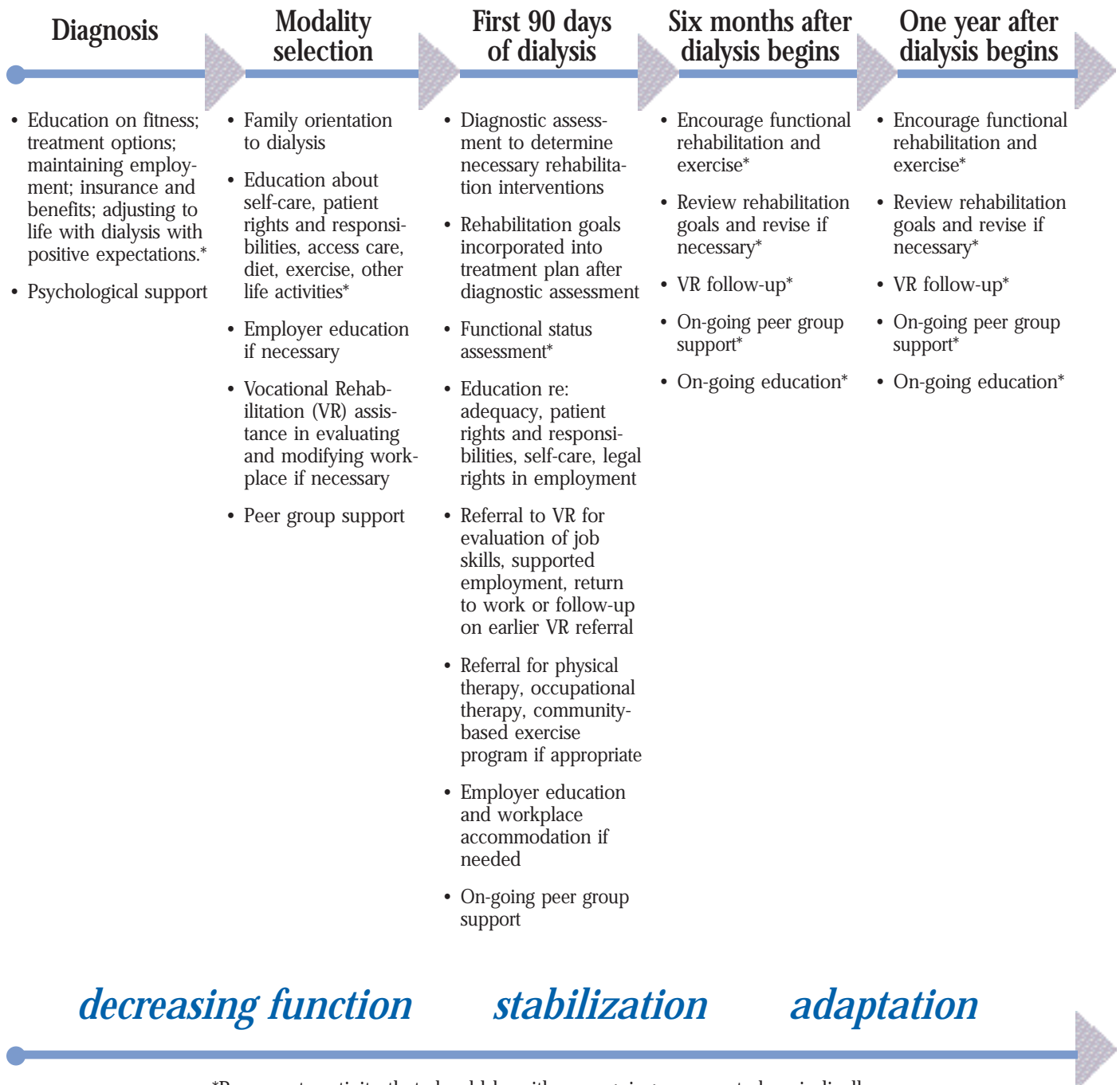
Flexibility is helpful when scheduling rehabilitation programming around dialysis. If several patients are interested in and appropriate for a given activity, possibilities include offering the activity at different times, rescheduling the patients to the same shift, or making the activity available during a dialysis shift and inviting non-dialyzing patients to take part.

Think about patient and staff schedules and time of day, week, and year when you determine a schedule for your rehabilitation projects. For example, beginning a rehabilitation program during the last 15 minutes of dialysis or starting an ambitious program during summer vacations or winter holidays may result in poor participation.

Beginning a rehabilitation program may take only a few months, but refining and enhancing your program may—and should—go on continuously. While the length of time it takes to implement a program will vary from facility to facility, the following timeline represents how and when to implement each of the 5 E’s of renal rehabilitation.

A Sample Renal Rehabilitation Timeline

Focusing rehabilitation efforts early in dialysis yields better outcomes.



*Represents activity that should be either on-going or repeated periodically throughout the course of the patient's total dialysis program

Evaluate Your Program

You'll learn more about the evaluation process in the Evaluation module of this Guide, but think about the dimensions of program success you will want to measure, including patient rehabilitation outcomes and satisfaction, and staff satisfaction.

Determine Patient Rehabilitation Outcomes and Satisfaction

Patient outcomes are the measurable, positive results of your rehabilitation activities. It is necessary to use common sense in some cases to determine whether outcomes seem to be positive. In some cases, you can assess these results anecdotally. Are more patients participating in self-care? Do patients seem to have more positive attitudes? Are they better informed about dialysis adequacy and other aspects of their treatment? Are they doing more of the things they want to be doing? In other cases, improvements can be measured using a formal standardized assessment tool.

Also important is evaluating patient satisfaction with care, including rehabilitation programming. The most effective way to find out how satisfied patients are is to ask them, using a survey you create or a standardized questionnaire. You will find additional information about assessment instruments in the Evaluation module.

Measure Staff Satisfaction

No program can succeed unless staff “buy in” to its concepts and execution. The direct approach is most effective. Questions you might ask include:

- How satisfied are you with the rehabilitation programming we provide for our patients?
- How has our facility's rehabilitation programming affected your job satisfaction?
- What would you change about the rehabilitation programming we provide for our patients?

Modify Your Program as Needed

When physical, psychosocial and vocational outcomes, patient satisfaction, and staff satisfaction measures are considered together, a clear picture of the effectiveness or success of your rehabilitation program should emerge. Based on the combined results of these measures, you will want to continue activities that are working well and determine how problems will be addressed, using a continuous quality improvement (CQI) model. CQI involves all members of the treatment team in evaluating, collecting data, and making improvements. Refer to the Evaluation module for more information about CQI.

Collect Success Stories

One way to sustain interest in rehabilitation is to celebrate your successes. As you conduct your evaluations of rehabilitation interventions, make note of the success stories and, most importantly, *share them* with staff, patients and family members. The Encouragement module will discuss how to share these stories and further the importance of encouragement in the success of your program.



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Encouragement

Module 1:

*A Practical
Guide to Renal
Rehabilitation*



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The *Practical Guide to Renal Rehabilitation* provides recommendations for individuals on dialysis regarding programming issues for the “5 E’s” of renal rehabilitation: Encouragement, Education, Exercise, Employment, and Evaluation. In using this Guide, the reader should be aware of certain limitations. First, the Guide may not cover all possible topics related to such issues, and it may not address aspects of such issues that may be relevant to you in light of your particular circumstances. Second, future legislation, regulations, administrative interpretations, and court decisions may significantly change the current law or the interpretation of current law cited in this material. Please note that neither Amgen Inc., the Medical Education Institute, Inc., nor the Life Options Rehabilitation Advisory Council intends to update the information contained in this Guide. It is based on information available as of the date of publication. Third, although the authors have used their best efforts to assure that the information contained herein is accurate and complete as of the date of publication, the authors cannot provide guarantees of accuracy or completeness. Fourth, practical suggestions provided throughout the text are based on the opinions of the Medical Education Institute staff. Suggestions may or may not reflect national experience and may instead reflect local experience. Finally, this Guide is provided with the understanding that neither the Guide nor its authors are engaged in rendering medical, legal, accounting, or other professional advice. If legal advice or other expert assistance is required, the authors recommend that the reader seek the personalized service of a competent professional.

The information in this Guide is offered as general background for the clinician who is interested in improving the quality of rehabilitation opportunities for dialysis patients. The Guide is not intended to provide practice guidelines or specific protocols and cannot substitute for the physician’s knowledge and experience with individual patients. The reader must recognize that exercise, in particular, involves certain risks, including the risk of severe injury or disability, including death, which cannot be completely eliminated, even when the exercise program is undertaken under expert supervision. Use of these materials indicates acknowledgment that Amgen Inc., the Medical Education Institute, Inc., and the authors will not be responsible for any loss or injury, including death, sustained in connection with, or as a result of, the use of this Guide.

Life Options Rehabilitation Program



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Key Points

- *Positive patient, family, and staff attitudes are key to successful patient rehabilitation.*
- *Autonomy and independence improve quality of life.*
- *Encouragement is an effective and inexpensive way to foster autonomy in any setting.*

Why Should You Encourage Your Patients?

Psychologists believe that most behavior is learned and behavior that is rewarded continues. In the dialysis setting, *encouragement*, or rewarding positive progress toward rehabilitation goals, helps patients form attitudes that will allow them to participate actively in life. As a dialysis professional, your beliefs about your patients' capabilities are crucial to their quality of life.

Patients beginning dialysis don't know what to expect—but they fear the worst, a fear that makes dialysis and their future seem bleak. Beyond the needles, diet, medications, and changes in routine, many patients feel that the most frightening thing about dialysis is the threat of losing control, independence, and their valued lifestyle. Our society promotes personal autonomy; most people dread long-term dependence on others (Clark, 1991). Patients and their families rely on dialysis staff when they form their impressions of how much their lives will change after dialysis. It is the promise of rehabilitation and a fulfilling life that makes dialysis worth the effort.

You may be less likely to encourage rehabilitation if you believe patients are unmotivated or have little chance of succeeding. On the other hand, if you expect patients to continue valued activities, you may be rewarded by patients who do just that. In a recent study of employed vs. unemployed working-age patients, the critical correlate of employment status was not renal failure itself, type of dialysis, number of years on dialysis, or even comorbidities.

Instead, patients' perceptions of their own abilities and the support they received from their families and the dialysis staff were significant factors (Curtin et al, 1996).

Therefore, the single most important part of any renal rehabilitation program is *your* belief that your patients can be successfully rehabilitated. Positive attitudes—yours and your patients—are the most cost-effective rehabilitation activities you can engage in.



Members of the Life Options Rehabilitation Advisory Council have encountered dialysis patients who spend their time doing things you might consider exceptional, such as:

- Body-building
- Designing airport facilities
- Dialyzing other patients as a nephrology nurse
- Playing regular gigs as a jazz musician
- Touring the country in a recreational vehicle
- Writing the ESRD Network patient newsletter

Are these patients unusual? They shouldn't be. Hope and a belief that it is possible to succeed are key to successful patient rehabilitation.

Encouragement Helps Adjustment to Dialysis

As with any major life change, adjustment to ESRD and dialysis treatment occurs in stages. Each time a physical setback occurs—such as a vascular access surgery, a hospitalization, or a new symptom—the patient must readjust. Patients make peace with kidney failure in various ways; some patients may eventually experience their illness as a spiritual or learning experience, while others may never accept it and may never fully “comply.”

One researcher (LeMaistre, 1995) has proposed a series of six stages of emotional adjustment to chronic illness. *Crisis* accompanies a physical onslaught of an illness or an exacerbation of symptoms (perhaps a hospitalization). *Isolation* occurs when the patient understands that the condition is chronic—it will never go away—and pulls back from sources of support. *Anger* and despair at self or others can result from feelings of “why me?” In severe cases, these feelings can lead to suicide. During *reconstruction*, the patient has begun to feel better or to master new ways of performing old tasks; there is a growing sense of safety. *Intermittent depression* is a common response to the realization that despite new skills, life was much easier before the illness. Finally, *renewal* is a capacity to be aware of and thankful for abilities rather than focus on disabilities. Encouragement, and appropriate counseling if needed, can ease the transition from one stage into the next and help the patient move toward renewal and rehabilitation.

Regardless of where patients are in the stages of adjustment—and backsliding can occur—dialysis professionals can acknowledge their patients' struggles, encourage their efforts, and, most importantly, expect that they can make progress toward rehabilitation.

Encouragement Enhances Patient Decision-making

Dialysis patients differ in age, education, strengths and skills, physical limitations, ability to understand, and interest in knowing about their treatment. Nevertheless, it is possible to help patients gain a greater sense of control without pushing them beyond their capabilities. The answer lies in a new way of thinking about dialysis patients.

When dialysis patients appear hopeless and dependent, the natural tendency is to believe that these personality traits are long-standing. However, this may not be the case. Research has shown that even people who are normally independent are likely to *temporarily* want to hand over their fate to “powerful others” when they are diagnosed or hospitalized with a chronic illness (Halfens, 1995).

This desire for temporary dependency during acute illness meshes well with the traditional medical model, which has trained medical professionals to be active deliverers of care to passive patients who take on a “sick role” (Childress & Siegler, 1984; Johnson, 1995). In a serious, acute illness, this paternalistic model effectively transfers personal control to medical experts, to be regained by the patient when the condition improves.

Unfortunately, in a chronic illness, when improvement is not expected, the traditional medical model does not have a mechanism for transferring control back to the patient. Instead, the long-term “failure” to be cured can frustrate medical personnel and reduce patient self-esteem. In addition, the long-term dependency that often ensues is counterproductive for rehabilitation.

For example, a study of 45 patients with peptic ulcer disease looked at the effects of active participation in medical care compared to the usually passive patient role. The researchers found significantly fewer limitations in physical and role-related activities in active participants (who were coached to read their medical records and ask appropriate questions of their physicians) than in passive patients who did not receive this help (Greenfield et al, 1985). Common sense would suggest that dialysis patients who are encouraged to become actively involved in medical decision-making can also have better outcomes.

As a form of chronic disease management, one goal of ESRD treatment should be to empower patients to participate actively in their medical decision-making and dialysis care. Once patients learn about treatment and can take on more responsibility, you, as a dialysis professional, can redirect your expertise to become a consultant, or partner, in care.

Researchers have long known that partnership approaches, where decision-making about the illness is shared by the patient and the care provider, lead to better outcomes and adherence to treatment. For example, nearly twenty years ago, a study showed that psychiatric patients kept significantly more referral appointments when a negotiated approach was used to ensure that their concerns were heard (Eisenthal et al, 1979).

Encouragement Increases Autonomy, Control, and Participation in Treatment

Studies have found that autonomy is key to quality of life among the chronically ill. Life satisfaction among 140 patients with spinal cord injuries was related to their perceived control and social support—not to the severity of their injuries (Fuhrer et al, 1992). A study of 707 arthritis patients found that patients who learned self-care behaviors had significantly less pain, *even though the behaviors themselves did not directly affect their health status* (Lorig et al, 1989).

In cancer patients, where the outcome of the illness may be fatal, perceived control is still key to a better outlook. A study of 273 patients with various types of cancer found that patients who felt more in control had significantly better quality of life and mood (Cunningham et al, 1991). Malignant melanoma survivors who believed they were in control had a better sense of well-being (Dirksen, 1989). Another study of 57 late-stage cancer patients found that patients who felt more control over their lives had significantly higher self-esteem and less anxiety (Lewis, 1982).

Lacking appropriate education and encouragement to learn responsible self-care behavior, some patients may seize control anyway, even though it may be detrimental to their own long-term survival. Liver transplant patients risked graft rejection by adjusting their own immunosuppressant medications to maintain personal control (Thomas, 1993). You've surely seen dialysis patients who maintain "control" by eating and drinking whatever they like. Offering positive ways to regain personal control can help patients learn more constructive behaviors.

In fact, research does demonstrate that dialysis patients who were encouraged to learn about their treatment had better outcomes with enhanced personal control. A study of life satisfaction in 138 patients found that transplant recipients and home hemodialysis patients had the highest quality of life, followed by patients on CAPD—all treatments that rely on patient participation for success. The lowest quality of life was found among in-center hemodialysis patients, who are often less involved in care and presumably feel less control over treatments (Morris & Jones, 1989). A recent study reported that self-care training for dialysis is *itself* a form of treatment that can improve quality of life. Self-care trained patients had significantly better quality of life than untrained patients matched for age and comorbidity (Meers et al, 1996).

Encouragement Can Improve Functioning and Reduce Care Costs

Low levels of physical functioning (strength, endurance, and flexibility) have been linked to poor survival, hospitalizations unrelated to dialysis access, and use of additional staff time and supplies to resolve problems during dialysis. A study of 527 hemodialysis patients from seven facilities in one state showed that patients who scored very low (10) on the Karnofsky Performance Status Scale (a staff-reported scale of physical functioning) were *47 times more likely to die* than those who had a high score (100) (Jones, 1990).

In the same study, hospitalization rates were five times higher and resource utilization was three times higher for very low-functioning patients compared with high-functioning patients. Fortunately this trend was reversible: improving physical functioning to the next highest level reduced hospital days, resource usage during dialysis, and mortality risk. Logically, assessing physical functioning early and monitoring it regularly, encouraging patients to set goals, offering specific recommendations, and rewarding progress could save both dollars and lives.

A Little Encouragement Can Go a Long Way

The dialysis nurse who spent several months patiently helping Doug Strickland of Overland Park, Kansas, overcome his paralyzing fear of needles didn't know she was changing his life for the better. Diagnosed with Alport's Syndrome at age seven, Doug began maintenance hemodialysis at 18. Although he continued to work as a laborer in a warehouse, his life was limited by his perception that he couldn't accomplish much. All that changed the first time he "slew his dragon" and finally dared to insert his own dialysis needles. He's been doing his own needle sticks successfully ever since.

Amazingly, although dialysis access problems are the number one cause of patient hospitalizations, Doug's first access, a bovine graft, lasted 17 years. His current graft is still going strong at four years. He is also proud that in 21 years, he has never blown a stick.

This one act by a caring nurse "opened a door to a feeling of control and empowerment," says Doug, who despite numerous surgeries and setbacks, successfully completed a business degree. He now works full-time for the federal government as a computer analyst, exercises regularly, and he and his wife recently adopted a baby girl.

How to Begin Your Encouragement Program

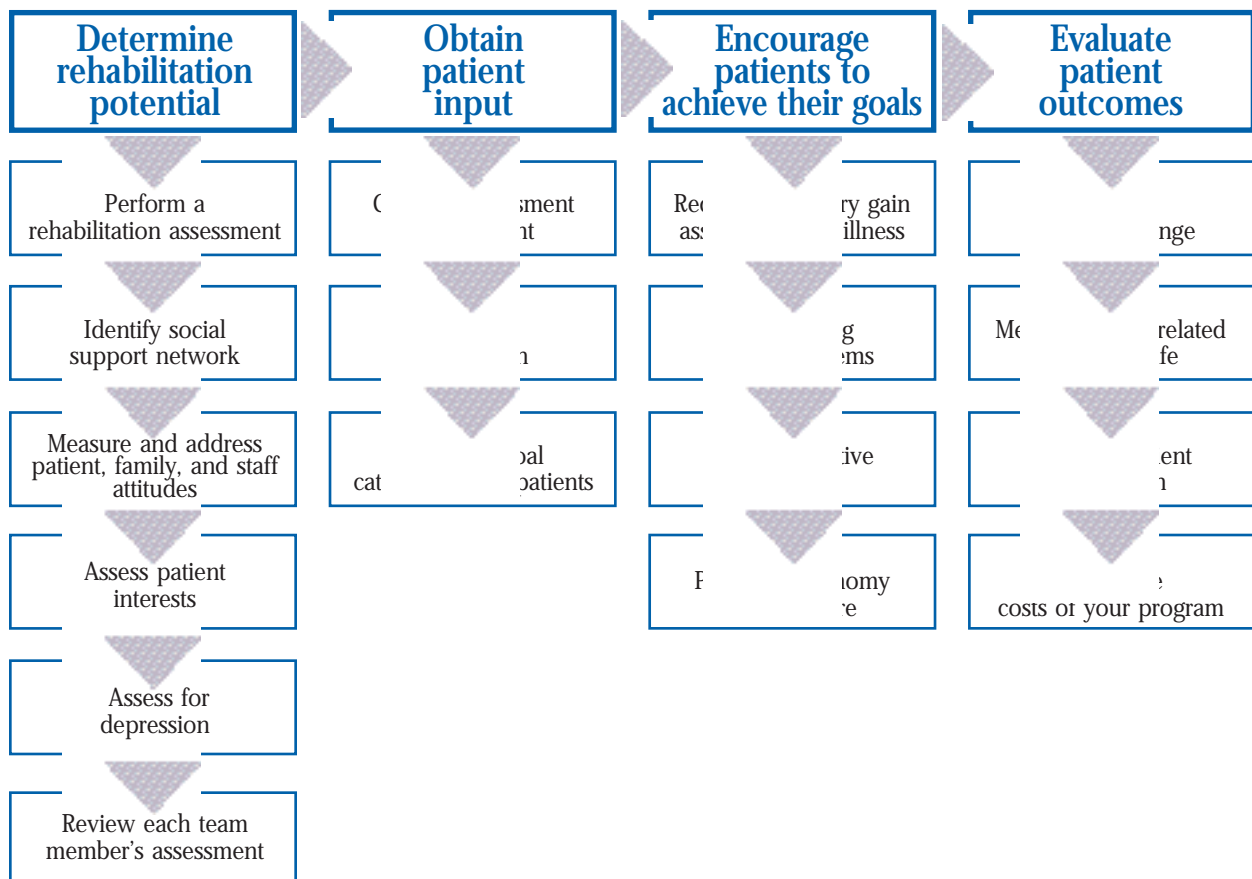
Encouragement should be part of all aspects of a rehabilitation program. Informal integration of support and encouragement can occur in many ways in everyday settings. Whether it's a friendly greeting when a patient enters the unit, a casual comment about improving health status, or a "pat on the back," continuous reinforcement of positive rehabilitation efforts can encourage patients to keep up their hard work.

The rest of this module will help you to encourage rehabilitation in your facility. The approach is based on common sense and continuous quality improvement principles. Step-by-step instructions will guide you through the process of assessing rehabilitation potential, obtaining patient input, encouraging patients to achieve their goals, and evaluating patient outcomes. Strategies in each section are arranged from least to most resource-intensive. Throughout this module, real-life examples will help you understand how other facilities have successfully taken on the challenges of encouraging rehabilitation. The

Renal Rehabilitation: Encouragement at a Glance flowchart below will help you to understand the essential components of encouragement.

The Encouragement section of the *Unit Self-Assessment Tool for Renal Rehabilitation* (USAT) (Appendix A), developed by the Life Options Rehabilitation Advisory Council, lists criteria for good rehabilitation programming for the Encouragement "E." Like the strategies in this module, the *USAT* criteria are arranged by levels—basic, intermediate, and advanced—based on their complexity, resource use, and potential impact. You will find periodic references to the USAT criteria throughout this module, and specific criteria will be referenced by a number in parentheses, such as (EN-10), so you can find them in Appendix A. Additional information about use and interpretation of the USAT is available in the *Unit Self-Assessment Manual for Renal Rehabilitation* (USAM), which you can obtain by contacting the Rehabilitation Resource Center at (800)468-7777.

Renal Rehabilitation: Encouragement at a Glance



Determine Rehabilitation Potential

Patient readiness for rehabilitation will depend on a variety of factors, including religious beliefs; attitudes about rehabilitation; stage of adaptation to the illness; availability of social and financial support; educational and employment history; mental, physical, and functional status. Before you can encourage your patients to make progress toward rehabilitation, you must first obtain a baseline assessment. This baseline will also help you to evaluate progress later.

Perform a Rehabilitation Assessment

A multidisciplinary assessment of each patient is the first step toward individualized rehabilitation goal setting. Areas to assess include physical and psychiatric history; cultural/ethnic background; language; religion and beliefs about illness; family background; educational history (including goals and barriers to learning, if any); functional status (ability to perform activities of daily living, including personal care needs); use of assistive devices or attendants; participation in exercise or other physical activities; and employment history.

Ideally, a rehabilitation assessment focuses on patient strengths rather than weaknesses, and does not judge the patient. Although patients who are very uremic must be medically stable before they can participate fully in their treatment, rehabilitation efforts can begin immediately by projecting future goals.

Strategies to perform a rehabilitation assessment:

- Complete the Encouragement section of the USAT (Appendix A) by assigning one point for each encouragement-related activity you are already doing in your unit. This will give you a global impression of how you are doing and where you might do more. The USAT can also suggest other activities that might fit the needs of your patients and your overall rehabilitation planning.
- Recruit members of the renal team to collaborate in rehabilitation assessments using their unique training and expertise. The physician examines

medical parameters, the nurse assesses clinical and functional factors with input from the patient-care technician, the dietitian considers nutritional components, and the social worker evaluates emotional and social variables that promote or limit patients' ability to set and achieve goals. Bringing all the assessments together helps to create a more realistic portrayal of the patient's needs and strengths.

- Obtain or devise a rehabilitation assessment tool to help systematically collect individual patient data. The National Kidney Foundation's Council of Nephrology Social Workers (CNSW) has a pediatric and an adult rehabilitation tool in narrative form that includes demographic information (age, race, marital status, etc.), developmental history (e.g., family background), educational history, financial status, living situation/peer relations/social issues, medical/psychosocial history, suitability for treatment modalities, clinical assessment, recommendations, and plans.

Identify Social Support Network

Dialysis patients may experience isolation due to declining physical health, depression, their own stage of adjustment, and others' discomfort with illness. Although loss of social support can be a problem for any patient, the elderly may be at particular risk due to death of family or friends, decreasing functional status, and geographically or emotionally distant family members. Deteriorating functional status limits participation in activities and reduces quality of life for some geriatric patients (Ifudu et al, 1994). Reduced participation in desired activities and poor quality of life can lead to withdrawal from dialysis, the third leading cause of death among elderly ESRD patients (USRDS, 1990).

Support from family and friends has been shown to be an important component of vocational rehabilitation (Curtin et al, 1996). Social support has been shown to reduce depression (Anehensel & Stone, 1982); while its loss is associated with increased depression (Errico et al, 1990).

Strategies to identify social support networks:

- Ask patients informally about whether they feel supported, and on whom they feel they can count for assistance with daily activities, emotional needs, or financial assistance.
- Use a standardized assessment tool. The Norbeck Social Support Questionnaire (NSSQ), and the National Kidney Foundation's Council of Nephrology Social Workers' psychosocial assessments for adult and pediatric patients all assess social support.
- Re-evaluate patients periodically to determine if their circumstances have changed.

Measure and Address Patient, Family, and Staff Attitudes

Since patients' attitudes about life on dialysis are greatly influenced by their knowledge of kidney disease and its treatment, it is important to find out whether patients harbor misconceptions that may jeopardize their chances for rehabilitation, and then address those attitudes through education. For instance, the dialysis experience of a friend or relative (perhaps years ago) may color perceptions of a future on dialysis, and even affect the choice of modality. The media may have fostered misperceptions about dialysis among some patients.

Family members' attitudes are also crucial for rehabilitation success. Patients are more likely to have high expectations of their possibilities on dialysis if their family members share those expectations (Curtin et al, 1996). Family members who believe patients are incapable of doing anything because they are on dialysis can unwittingly foster patients' feelings of worthlessness.

Finally, positive staff attitudes and beliefs are essential (Curtin et al, 1996). While it can be difficult to separate future patient expectations from past experiences,

allow for the possibility that patients can be successfully rehabilitated. The Life Options Rehabilitation Advisory Council's *Exemplary Practices in Renal Rehabilitation* competition has shown that dialysis staff, serving patients of all socioeconomic levels, races, and ages, can help patients achieve rehabilitation success, and so can you.

Strategies to address attitudes:

- Address negative attitudes and misconceptions through education: invite rehabilitated patients to speak at your facility, or provide occasions for staff to talk about rehabilitated patients' experiences with new patients (EN-2). Borrow a rehabilitation speakers' kit from the Rehabilitation Resource Center by calling (800)468-7777. Collect articles and success stories and post them on a bulletin board where patients and staff can see them (EN-1, EN-3). Show motivational videos (EN-4). The Education module of this guide contains more information about how to educate patients.
- Observe staff attitudes for a week or two, writing down examples of beliefs about what patients can accomplish. Listen for positive or negative belief statements like "she needs to get back to work as quickly as possible," "he can't do that by himself," or "our patients are sicker/older/less educated than those other patients." Better yet, have several staff members from different shifts do this, and compare notes. Encourage positive beliefs and look for patterns in negative staff attitudes that can be addressed through education. Misperceptions can be changed by providing the correct information (EN-3).
- Use a standardized tool to measure attitudes of patients and family members. The CNSW psychosocial assessment instruments, available from the National Kidney Foundation, include a rehabilitation status and goals section that addresses perceptions as well (EN-10). The Kidney Disease Quality of Life (KDQOL™) addresses the burden of illness. Systematic evaluation and goal setting are intermediate rehabilitation activities.

Assess Patient Interests

Dialysis staff who take the time to talk with patients about their interests are often surprised by the number and variety of interests. These interests—activities or ideas that capture patients' imaginations—can be the “hook” to encourage patients toward rehabilitation. An important aspect of any patient assessment includes an inventory of the interests and activities the patient enjoyed prior to dialysis, current participation in those interests and activities, and expectations for the future. Assessment of patients' interests is a good example of a rehabilitation strategy that is practical, but not specifically captured in the USAT. Such strategies are important and can be acknowledged and scored in the “other” (EN-7) category on the USAT.

Strategies to assess patient interests:

- Talk to patients informally about what they enjoyed doing in the past, what they still do, and what they would like to do in the future (or had planned to do before beginning dialysis).
- Talk to family members about patient interests.
- Use the CNSW's psychosocial assessment instruments to determine patient interests. Document patients' interests in the patient care plan.

Assess for Depression

Perhaps in reaction to feelings of anger and helplessness about the illness, depression is the most common psychological reaction experienced by persons with ESRD. The problem is widespread: Studies report that between 10 and 100 percent of ESRD patients are depressed (Burton et al, 1986; Royse, 1988; Hinrichsen et al, 1989; Peterson, 1991; Calder & Banning, 1992). Depression can affect the whole body, with symptoms such as loss of appetite, fatigue, insomnia, and difficulty concentrating—which overlap the symptoms of uremia (Kimmel, 1994).

However, what seems to be most important is not so much how patients feel physically, but how they *think*. A two-year prospective study of 57 ESRD patients

found that cognitive aspects of depression—disappointment, sadness, guilt, difficulty making decisions—were a predictor of mortality (Peterson et al, 1991). In fact, a one-point increase in cognitive depression was associated with an 11.3% increase in the risk of death. Fortunately, once identified, depression can be successfully managed in ESRD patients.

Strategies to assess depression:

- Use a standardized instrument to measure depression (EN-10). The Cognitive Depression Inventory (Rapp et al, 1988) (the first 15 items of the Beck Depression Inventory) (Beck et al, 1961; Beck et al, 1988) was the instrument used in the Peterson et al study cited above. The Beck Depression Inventory can be obtained from Harcourt Brace Jovanovich's Psychological Corporation, by calling (800)211-8378. Please note, only an MD or PhD may order the test, which costs \$45. The ECB Renal Patient Questionnaire (Calder & Banning, 1992), a 30-item paper-and-pencil test filled out by patients, assesses the need for immediate social work intervention for depression or other disorders. The ECB, available from the National Kidney Foundation's Materials Order Department, (30 E. 33rd, New York, NY 10016), correlates highly with the Beck Depression Inventory. The Kidney Disease Quality of Life (KDQOL) (Hays et al, 1995), subscales for mental health functioning can also serve as a broad indicator of depression. To order the KDQOL, write Caren Kamberg, RAND, 1333 H St. N.W., Washington DC 20005, fax (202)296-7960, or e-mail caren_kamberg@rand.org.
- Ensure that the clinical social worker has sufficient time to assess patients for depression. While every staff member has an important role to play in rehabilitation, the clinical social worker has the necessary post-graduate training and experience to differentially diagnose and treat depression and other emotional problems, and to assess patient and family coping strengths.

Review Each Team Member's Assessment

Whether rehabilitation goal setting is part of routine patient care conferences or is a separate part of a rehabilitation program, you will need to assess progress, share information with patients, and set new goals. It is important to complete all assessments. Assessments are essential to team patient care planning—this is the reason that Medicare regulations require it. This information, documented in the patient record, can help everyone involved in the care of a patient obtain a more well-rounded picture.

Staff meetings to discuss patients' rehabilitation status are an essential part of a solid rehabilitation program for the Encouragement "E" at both the intermediate (EN-11) and advanced (EN-16) levels. Such meetings keep staff focused on patients' rehabilitation needs and also help to periodically rejuvenate staff's interest in and commitment to their patients' progress. Rehabilitation care planning should include data collection on health-related quality of life variables such as functional status, vocational status, and sense of well-being; clinical variables, such as symptoms and signs, laboratory values, and longevity; and patient satisfaction with care. The Exercise, Employment, and Evaluation modules of this Guide recommend ways to measure outcomes in these areas.

Strategies to review assessments:

- Establish a timetable for staff review of assessments. Review the rehabilitation plan regularly for stable patients and more frequently for unstable patients, or as required by current federal regulations (EN-10).
- Draw on the resources of your rehabilitation team for periodic, scheduled patient conferences. Nephrologists, nurses, technicians, dietitians, social workers, and administrators all have valuable rehabilitation ideas, and each can offer a different view of the same patient (EN-11). Invite patients and family members to participate in care planning whenever feasible.
- Use an agenda or specified order of presentation to maintain a systematic flow of information. For example, some facilities begin with clinical information; discuss anemia, blood pressure, interdialytic weight gains, and nutrition; then address coping and rehabilitation.
- Consider establishing alphabetic or numeric codes for certain key rehabilitation concepts and entering these into the computer record to help you find trends in patient and facility data for care planning and program evaluation.

Obtain Patient Input

As the person who experiences each symptom, takes each medication, endures dialysis and access surgery, and interacts with medical professionals, the patient is pivotal to the treatment team. While this may seem obvious, caring medical professionals sometimes come to feel that they “own” the disease. In a chronic disease such as ESRD, the staff are experts in the disease process, but the persons with the illness are the experts in how the disease affects them. Therefore, rehabilitation planning must be a joint process between patients and staff, and each patient’s input should be carefully considered.

The patient you see right now may not be fully reflecting his or her real potential. Depending on the stage of adaptation to kidney disease, the patient may seem terrified, withdrawn, angry or defiant, depressed or hopeless, helpless, or any number of other reactions. Talk to the patient about his or her life before renal failure, and talk to family members and friends to get a better sense of the individual’s potential strengths and real capabilities. The patient is—and should be approached as—an important individual, not discussed as a “thing.”

Confirm Assessment with Patient

Your team has compiled a picture of the patient’s clinical and rehabilitative status. Now you need to confirm your assessment with the only individual who really knows what is going on—the patient. An exception to this statement may occur in patients who are depressed, however, because these patients may not be aware of their own depression. The next section discusses treatment for depression.

Strategies to confirm assessment with patient:

- Invite patients to attend team meetings.
- Ask patients if their perceptions match the team’s report. This provides an opportunity for education.
- Identify strategies for improvement. Ask the patient how the team can help him or her focus on positive behaviors.

Address Depression

Sad feelings associated with multiple losses come and go throughout the course of dialysis. However, depression expressed as poor self-esteem, hopelessness, and persistent thoughts of suicide can be treated. Talk therapy can be helpful when patients are willing to discuss emotional issues (Levy, 1994). Focused counseling approaches that are problem-oriented and goal-directed rather than analytical get to the patient’s primary concerns immediately so change can be implemented quickly. This allows faster results and encourages patients to continue programs that can lead to other successes. Some patients are concerned about the stigma of treatment for a psychiatric illness; reassurance may be helpful.

Antidepressant medications can be another safe and effective way to manage depression or other psychiatric conditions in dialysis patients (Levy, 1994). It is important to consider the interactions of these drugs with other medications used in ESRD. Although any physician can prescribe medications, a psychiatrist has the most up-to-date information on psychiatric medications; a team approach may be helpful.

Participation in regular exercise has also been shown to improve mood and combat depression.

Peer Counselors Help Integrate New Patients in Ann Arbor, Michigan

The University of Michigan Medical Center in Ann Arbor has had great success with patient encouragement. Peer counseling plays a large role in this facility's rehabilitation program thanks to the vision of one patient, a former high school teacher who became the center's first peer counselor. Patients who volunteer to become counselors receive 32 hours of training in both classroom and group settings. Every new patient is visited by a peer counselor. Early intervention is the key—a computer printout of patients with creatinine levels over 5.0 are introduced to peer counselors early, when new potential patients are frightened by the unknown.

Peer counselors listen and share their experiences one-on-one with other patients—reducing isolation, building a sense of personal control, and improving quality of life. Peer counselors also facilitate support groups for young adults, spouses, survivors, transplant recipients, and diabetics. An active handicraft group also meets monthly to produce hand-made items for the annual Christmas craft sale, while building friendships.

The peer counseling program helps patients and keeps the staff more involved and aware that patients are the ultimate consumers and decision-makers. The program builds understanding and trust between patients and staff, as patients instantly trust the counselors and, in turn, have more faith in the staff. Costs are low—about \$50 to \$65 each for peer counselor training, volunteer recognition, small holiday gifts, and reimbursement for counselor travel over 20 miles.

Strategies to treat depression:

- Encourage moderately depressed patients to begin regular exercise. Exercise successes can help combat depression. See the Exercise module of this guide for more information.
- Refer depressed and debilitated patients to the nephrologist or a psychiatrist (rehabilitation specialist) for a thorough medical screening. The screening should address medical conditions that would warrant rehabilitation therapy (such as physical therapy), medication side effects that could be contributing to debilitation, undiscovered medical conditions requiring treatment, or problems with dialysis. Once identified, medical problems must be addressed before rehabilitation outcomes can be achieved. Maintain continuity of care by communicating regularly with all the caregivers involved with the patient.
- Refer depressed patients who are not immediate threats to themselves or others to the clinical social worker at your facility for an initial assessment. To make a case for counseling, ask a willing patient who has been helped with counseling to talk to the patient needing help.
- Seek an involuntary psychiatric consultation for a patient who is immediately dangerous to himself or others (e.g., has considered a method for suicide, begun to give away prized possessions in anticipation of death, or made threats against others). Involuntary psychiatric admission for a limited time period is allowed in most states under these circumstances to allow time for assessment and beginning intervention.
- Explain to patients concerned about a stigma that counseling can be brief and goal-directed to address issues they identify. Tell the patient that although the social worker is an excellent resource (for no out-of-pocket cost), referral can be made to an outside counselor if needed.

- Learn as much as you can about counseling resources in your community. If a patient needs an outside referral, you will then be able to recommend someone whose personality will “mesh” with the patient’s.
- Re-evaluate the rehabilitation potential of a depressed patient as the condition begins to improve.

Prioritize Goal Categories with Patients

There are a number of areas where patients can make progress toward rehabilitation, including knowledge of treatment—e.g., access care, the dialysis machine, medication purpose and schedule, dietary and fluid restrictions; ability to perform activities of daily living or other household tasks; higher levels of physical functioning, such as exercise; ability to maintain friendships and other social contacts; economic self-sufficiency; coping with medical emergencies; and others. Beyond the information critical to survival, patients must be involved in helping to set priorities for what to learn or do first, next, and last.

Strategies to prioritize goal categories:

- Talk with patients about their goal choices—or their inability to choose. Patients who are unmotivated but not depressed may be engaged in rehabilitation with ideas that consider their interests. For example, a patient who misses a family member living far away may be willing to learn what is needed in order to travel.
- Encourage patients to be as specific as possible about what they would like to do, when they will do it, and how staff will be able to measure their progress. For example, a wheelchair-bound patient who wants to walk might first make an appointment with a physical therapist, then begin to use a walker, progress to a cane, and finally walk unassisted.
- Keep a copy of the rehabilitation goals in the chart, and give a copy to the patient.
- Ask indecisive patients to rate a particular item on a 0 to 10 scale. For example, rate social activity on a 0 to 10 scale, where 0 is totally homebound without visitors and 10 is participation in more activities than time permits. Help the patient assess how to move to the next level. This exercise can help patients see that change occurs in small steps over time.
- Devise a facility checklist of areas for potential goal-setting (EN-10). The Education module of this Guide can help you with this process.
- Share the list with patients either verbally or in writing, and ask them to number the topic areas to indicate which they would like to pursue first. Be sure to leave room for patients to add their own high-priority goal areas that may not be on the list.

*E*ncourage Patients to Achieve Their Goals

Over time, patients will learn enough about dialysis and their part in treatment to take on some responsibility. Until then, encouragement mainly consists of assuring them that the confusing new treatment rituals *will* become more manageable; they *will* begin to feel better; they *will* be able to participate in activities they enjoyed before, and they *will* be able to lead a fulfilling life. More tangibly, however, there are ways that staff can help patients to achieve their goals, including reducing secondary gain, using existing support systems, rewarding positive steps, and promoting autonomy and self-care.

Reduce Secondary Gain Associated with Illness

Patients may enjoy the attention—positive or negative—that illness brings, called “secondary gain.” This attention can come from family members, friends, even dialysis staff. Sometimes attention comes from a family member who caters to every whim when a patient is playing “poor me.” Other times it can come from dialysis staff chastising a patient for gaining too much fluid weight. When patients have little contact with others, any attention—even negative—is better than none.

Strategies to reduce secondary gain

- Talk with family members about how to eliminate possible sources of secondary gain.
- Review with other members of the team any actions by dialysis staff that reinforce patient dependency, and eliminate these behaviors (EN-13).
- Reward behaviors that foster independence by providing positive attention and recognition.
- Teach patients how to ask for the help they need, rather than relying on negative behaviors to bring them attention (EN-13). Sometimes a desire for independence and self-determination can lead patients to stubbornly refuse offers of help. Point out persons the patient has helped who want to return the favor. When appropriate, add that

accepting help now doesn’t have to mean ongoing dependency, but may make it more possible to set realistic rehabilitation goals to achieve independent living.

Use Existing Support Systems

Group activities in the dialysis facility or community are opportunities for peer interaction, support, and encouragement. Participating patients feel a sense of community and reduced isolation. When motivation wanes, patients can provide “positive peer pressure,” motivating each other to continue progress. This “can-do” environment provides an ideal climate for rehabilitation success. Support groups facilitated by staff, or groups run by patients, are intermediate level rehabilitation activities.

New and established patients can benefit from a peer counseling program. Patients who feel discouraged, depressed, angry, and afraid when facing kidney failure may feel less anxious if they talk with someone who understands. And established patients can gain self-esteem from helping others. As a bonus, dialysis centers with trained peer counselors frequently find they have an excellent resource for facilitating support groups.

Family members can also help other families learn from their experiences. Through formal and informal counseling and support programs, family caregivers can realize they are not alone in their struggles, allowing a sense of release and lightening of their load as they seek information, suggestions, and hope.

Centrally located bulletin boards are also effective ways to build a sense of community, inform patients about upcoming events and activities, provide a forum for patients to express themselves, recognize patients who are succeeding in their rehabilitation efforts, and encourage healthy lifestyles. Informational articles, inspirational quotes, farewells to patients who have moved or died, congratulations to transplant recipients, a vacation spotlight, and recipes can be included to promote support and encouragement among patients and staff. These basic rehabilitation activities are low-cost, high-yield ideas for the encouragement “E.”

Strategies to use existing support systems:

- Survey patients' interests to ensure topics of interest to most patients.
- Bring in special guests—a nephrologist, nurse, dietitian, social worker, attorney, transplant patient, Social Security representative, vocational counselor, or representatives from a renal organization—to make education part of support (EN-3).
- Serve snacks that renal patients can eat and provide recipes for them to take home.
- Gather information about ESRD or other community organizations that offer emotional support, financial assistance, or therapeutic or caregiving services (EN-5). Sometimes community support during a difficult time will provide a patient with the incentive to return the favor through volunteer work.
- Recruit patients to write articles for your facility newsletter if you have one, and to begin one if you don't. Desktop publishing can make newsletter layout easy and fun.
- Contact the American Association of Kidney Patients (800)749-2257 or the National Kidney Foundation (800)622-9010 for information about peer counselor training (EN-5).
- Determine what resources are available in your area for peer counselor training when you identify a patient who has the capability of being a mentor, or peer counselor.
- Consider training patients at your facility to become peer counselors if no training is available in your area (EN-8). Training should include basic information about confidentiality, communications skills development, and when to refer questions to an appropriate professional. Contact the Rehabilitation Resource Center at (800)468-7777 for information about other facilities that have successfully used peer counseling programs.
- Refer a patient who could use support to enhance adjustment and goal-setting to a peer counselor, and encourage a meeting during dialysis (EN-17).
- Recognize peer counselors with an annual luncheon or event.

Reward Positive Progress

Patients who express *any* interest in the future are good rehabilitation candidates. You can encourage individuals while demonstrating to the entire facility that rehabilitation goals are achievable by rewarding progress. Some goals are intrinsically rewarding. That is, achieving a goal such as improved stamina gives a patient the energy to do more desired activities. Other goals may be worthwhile in the long-term—such as taking phosphate binders to help avoid bone disease—but not rewarding in the short-term.

Extrinsic (external) rewards can help encourage progress toward these types of goals. Some applicants to the *Exemplary Practices in Renal Rehabilitation* competition have promoted patient success through bulletin boards, newsletters, and display charts showing patient exercise progress. Of course, obtain patients' permission before posting individual information.

Strategies to reward positive progress:

- Ask patients who have low self-esteem or who have not yet made any progress toward rehabilitation about their past successes. By doing so, you can help these patients look beyond the moment to see how skills developed in the past can lead to future successes.
- Recognize even minute progress toward goals. For example, praise any progress a bed-bound patient makes toward the goal of walking, including willingness to accept rehabilitation therapy, exercise to build strength in arms and legs, and so on.

- Provide opportunities for staff to share success stories of other patients (with permission) with patients whose energy or self-esteem needs bolstering (EN-2).
- Point out situations where successfully performing a task is its own reward (e.g., patients who follow their fluid restrictions will feel better during and between treatments).
- Develop incentive programs for less intrinsically rewarding behaviors—such as following diet restrictions or complying with oral medications. Recognition is a strong motivator and it can foster healthy competition within a unit (EN-6).
- Suggest that patients use charts to help them remember to exercise or to take their medications. The act of writing down a success on a chart can be very rewarding.
- Recognize more important successes, such as completion of a job training program, with a graduation ceremony, certificate of achievement, trophy, or other special “award” program. This type of recognition honors the hard work of the recipient and makes it apparent to other patients that such successes may be within their grasp as well (EN-16).

Promote Autonomy and Self-care

Autonomy in a chronic illness setting means participating actively in medical decision-making and care—which enables the patient to participate actively in other areas of life as well. Self-care means learning to perform tasks that would otherwise be done by medical staff. Both autonomy and self-care can help patients achieve mastery over their illness and reclaim their lives.

Strategies to promote autonomy and self-care

- Encourage patients to learn about dialysis so they can participate in their treatment decisions (EN-3, EN-4).
- Introduce autonomy carefully so patients understand the benefits to them. Otherwise, they may resent the apparent reduction in the services you provide. Once patients understand the key role of autonomy in rehabilitation, introduce increasing levels of personal control (EN-13).
- Avoid performing tasks that patients can do for themselves. Nearly every hemodialysis patient can call to set up an appointment, wash the access arm, and tear tape strips to hold the needles in place (EN-13).
- Develop a list of types of self-care activities in which hemodialysis patients can participate and rank each item according to level of skill required. Ask several patients, especially those trained to do home hemodialysis or self-care, to offer their input on your ranking. An example of how a facility might rank order a list of self-care steps is given in Appendix A. Each facility should devise its own list of self-care activities. Provide the list to patients and their families (EN-14).
- Using your list of activities, stratify patients into several broad levels of self-care (e.g., no self-care, low self-care, moderate self-care, total self-care), depending on their current capabilities. Graph the number of patients in each level, then assess areas of educational need to help patients assume successively higher levels of self-care. Regularly reassess all patients and generate a graph to monitor your facility’s progress (EN-19).

Facilities that are interested in evaluating the outcomes associated with encouragement activities should look at behavioral changes as well as changes in health-related quality of life. The Evaluation module of this guide provides more in-depth information about evaluating outcomes.

Evaluate Patient Outcomes

Observe Behavior Changes

Every member of the treatment team can observe behavioral changes. Nurses and technicians will be the first to observe adherence to fluid restrictions and prescribed medications, whether patients are coming for all treatments and staying for the prescribed dialysis time, and positive or negative changes in functional status. The dietitian will see whether patients are adhering to the renal diet and may recognize changes in fitness level. The social worker will observe changes in activity level and appearance that may reflect change in emotional status, and can observe whether the patient is following through on vocational or other rehabilitation goals.

Strategies to observe behavior changes

- Record behavioral observations in the patient's record. Refer back to the observable goals and progress measures you and the patient developed earlier.
- Examine laboratory reports to assess compliance with medications and diet prescriptions.
- Use the data to identify trends, both for the individual patient and for the facility as a whole (EN-19).
- Repeat the initial assessment of rehabilitation potential and look for changes in each measure, both individually and across groups of patients (EN-19).

Measure Health-related Quality of Life

Several instruments are available that measure components of health-related quality of life, which includes factors such as mood state, activity, limitations, and perception of illness. Four commonly used instruments with renal patients include the Duke Health Profile, the Dartmouth COOP Charts, the Medical Outcomes Study SF-36, and the Kidney Disease Quality of Life (KDQOL). All of these have been standardized for chronic illness. Refer to the Evaluation module for more information on these and other instruments used to evaluate rehabilitation outcomes.

Evaluate Patient Satisfaction

In today's consumer market, it is important to institute a program of regular patient satisfaction surveys. These surveys can help the dialysis team assess patients' perceptions about facility services and programming and can help set the direction for new efforts.

Strategies to evaluate patient satisfaction

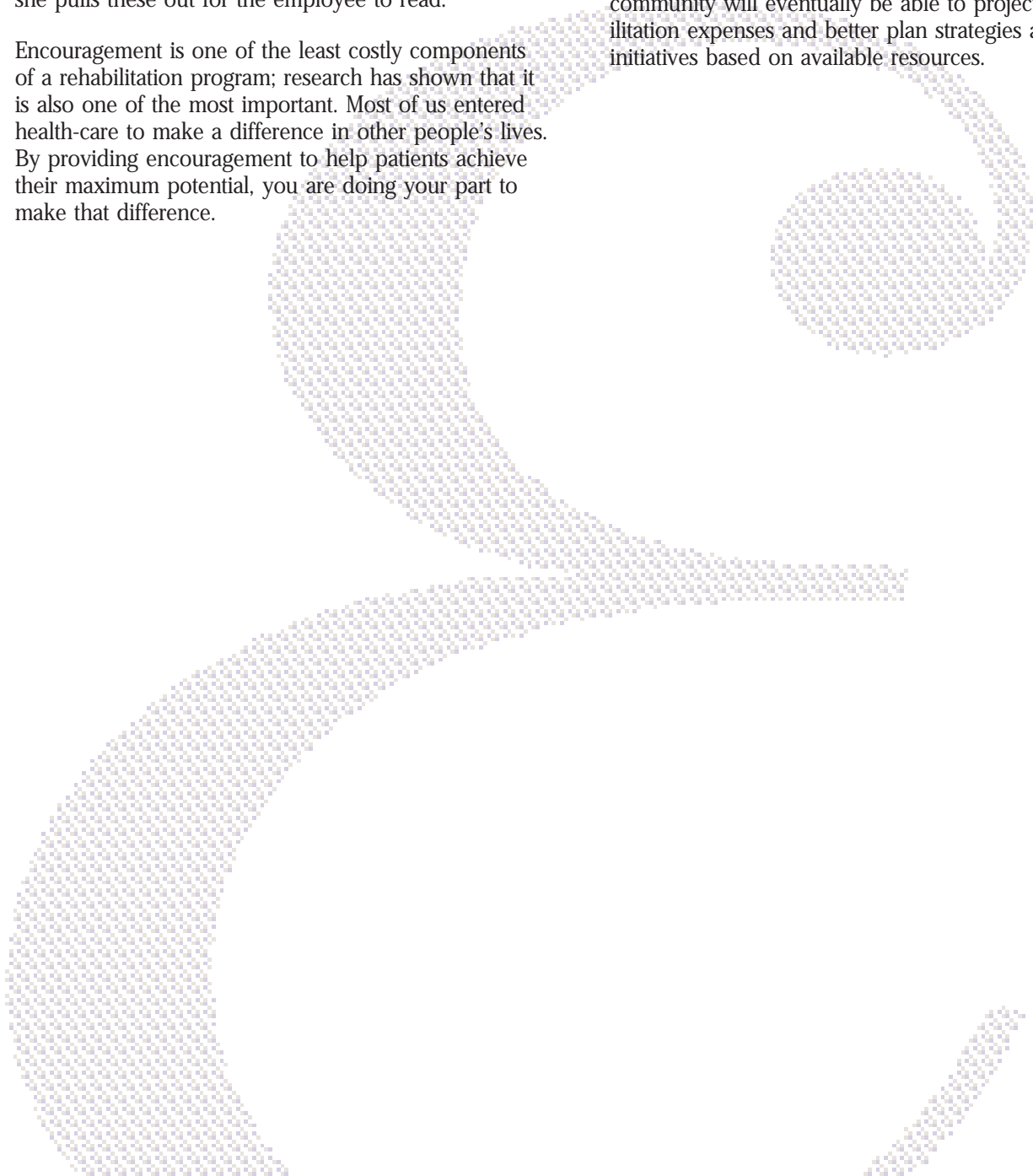
- Write and distribute a patient satisfaction questionnaire. Promise anonymity to respondents. Repeat this survey periodically to note any changes after rehabilitation interventions (EN-19). (The KDQOL also includes a global measure of patient satisfaction.)
- Hold a forum for patients and their families to share expectations and concerns with staff. Staff will gain a better understanding of how patients define quality, and the patients will have an opportunity to offer suggestions.

Providing day-to-day encouragement to dialysis patients requires the commitment of both staff and administration. Encouragement efforts take time to plan and implement, and require innovative thinking. Sometimes these efforts require modeling from administration. One nurse manager starts her day with ten compliments in her pocket and doesn't go home until they're all handed out. Another writes down one thing each employee did that was outstanding or appreciated each week. At performance review time, she pulls these out for the employee to read.

Encouragement is one of the least costly components of a rehabilitation program; research has shown that it is also one of the most important. Most of us entered health-care to make a difference in other people's lives. By providing encouragement to help patients achieve their maximum potential, you are doing your part to make that difference.

Assess the Costs of Your Program

Finally, cost tracking is an important activity for every rehabilitation program. The goal of making renal rehabilitation a routine part of ESRD patient care can only be realized when the costs of various activities are available. A good way to collect critical information about renal rehabilitation costs vs. benefits is for each unit to keep track of its own rehabilitation-related costs and outcomes. By sharing experiences, the renal community will eventually be able to project rehabilitation expenses and better plan strategies and initiatives based on available resources.



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Appendix A: USAT Encouragement Criteria

BASIC REHABILITATION INTERVENTIONS

Score 1 point for each “yes” answer

- EN-1 ___ Do you have a centrally located bulletin board featuring patients who actively pursue rehabilitation?
- EN-2 ___ Do you provide occasions for talks with patients about positive outcomes of other patients (without violating patient confidentiality)?
- EN-3 ___ Do you provide written educational materials to patients/families/friends?
- EN-4 ___ Do you provide educational videos to patients/families/friends?
- EN-5 ___ Do you provide information about ESRD organizations?
- EN-6 ___ Do you provide or sponsor patient rewards or incentives for progress made toward rehabilitation goals?
- EN-7 ___ Do you provide or sponsor any other encouragement-oriented activities that are not enumerated above?

INTERMEDIATE REHABILITATION INTERVENTIONS

Score 1 point for each “yes” answer

- EN-8 ___ Do you have patient support groups that are run by a facilitator?
- EN-9 ___ Do you have patient support groups run by patients?
- EN-10 ___ Do you perform systematic and routine evaluation and set goals for *all* patients?
- EN-11 ___ Do you hold periodic staff meetings to assess patients’ rehabilitation status?
- EN-12 ___ Do you provide a special “orientation shift” or in-unit “orientation-to-dialysis session” for new patients?
- EN-13 ___ Do you provide any information to families and patients about the possibility of involvement in self-care?
- EN-14 ___ Do you have any programs or resources to teach families how to support/what to expect from the renal patient?

ADVANCED REHABILITATION INTERVENTIONS

Score 1 point for each “yes” answer

- EN-15 ___ Do you have a regular program of predialysis or early (within first 6 weeks on dialysis) intervention to encourage positive patient attitudes and expectations?
- EN-16 ___ Do you have motivational sessions/incentive programs to encourage rehabilitation efforts by patients or staff?
- EN-17 ___ Do you promote a one-on-one buddy system for new dialysis patients to help their adjustment to dialysis?
- EN-18 ___ Do you actively encourage and provide assistance for patients’ participation in their dialysis and other treatments in order to encourage their independence?
- EN-19 ___ Do you track the outcomes or results of your encouragement-related efforts?
- EN-20 ___ Do you track the costs associated with your encouragement-related activities and programs?

_____ ***SUBTOTAL (20 possible)***

Explanations of USAT Encouragement Criteria

BASIC: EN-1 TO EN-7

EN-1: Providing a bulletin board is a simple, basic intervention with the potential for positive impact on patients. Patients' successes, individual stories, solutions to common problems, and other news and accomplishments can be posted in a central location and shared by everyone.

EN-2: Patients take great comfort in the accounts of other dialysis patients' successes. Taking some time to elicit permission from "successful" patients so their stories can be shared with others reinforces "successful" patients while encouraging new patients.

EN-3: There are many printed educational materials for dialysis patients available from a variety of sources. Many of these materials can be obtained free of charge. Providing such materials for dialysis patients is an inexpensive, yet potentially effective method of empowering patients, facilitating their overall adjustment, and promoting positive attitudes and perceptions.

EN-4: Video presentations might have more impact than printed materials because they educate and inform patients through two senses rather than just one. Material missed in a written presentation might well be taken to heart when presented as a video.

EN-5: ESRD organizations can only be a resource to renal patients if patients know about them and use their services. Telling patients about the organization's purposes, prerequisites for obtaining services, and contact information can be a very inexpensive and useful way to encourage ESRD patients.

EN-6: Rewards potentially have a big impact on patients' overall outlook. Even simple rewards can help to remind patients that their efforts and achievements are recognized and appreciated. Certificates, small prizes or gifts, public acknowledgment on a bulletin board or in a newsletter, a party or treat in the patient's honor—all such activities contribute to patients' overall satisfaction with the unit and with their lives in general.

EN-7: There are many other simple activities that might be undertaken to promote positive attitudes, to inform, and to empower dialysis patients. Any other methods or activities you have identified can be credited here.

INTERMEDIATE: EN-8 TO EN-14

EN-8: Support groups provide an excellent opportunity for encouragement of dialysis patients. Regular meetings provide a chance for patients to share experiences and vent feelings. With a staff facilitator, such sharing can take place with the careful monitoring and facilitation of staff who are trained to optimize the interaction and its effects on patients' encouragement level.

EN-9: A support group run by patients can provide the opportunity for patients to share general information and helpful advice, as well as accounts of their triumphs and frustrations. Being able to discuss common concerns with others who understand what they are talking about helps patients to continue dealing with dialysis and to establish and maintain positive attitudes.

EN-10: Routine assessment and goal setting are activities that help patients to identify where they want to go and what they want to accomplish. It also provides them with a way to keep track of their progress. If realistic, practical goals are set, patients may begin to feel better about themselves and may surprise themselves and staff by doing even more than was initially expected.

EN-11: Staff need to be aware of patients' rehabilitation needs, just as they are aware of patients' clinical management needs. Regular staff meetings to assess patients' rehabilitation needs can keep the topic of rehabilitation fresh in the minds of staff and patients. This process can contribute to the rehabilitation esprit of the unit overall and will help to encourage patients to be and do all they can.

EN-12: New dialysis patients have a special need for information. An educational program that introduces patients to the information essential to their successful transition to life on dialysis is a MUST!

EN-13: Self-care has been shown to contribute positively to several facets of patients' functioning and well-being. Providing information about self-care possibilities to patients and families imparts a sense of increased control to patients. Any aspect of self-care, no matter how small, has the potential to contribute to patients' and families' outlooks and attitudes.

EN-14: Patients who have the support and help of their families and/or other social support persons seem to adapt better overall. Educational efforts (in the form of printed information, formal or informal classes) for families/significant others are very important to ESRD patient rehabilitation.

ADVANCED: EN-15 TO EN-20

EN-15: The presence of a formal, regular program for intervening with renal patients *before* they begin dialysis is an advanced rehabilitation intervention because, although it is relatively resource-intensive, it has been shown to positively affect several patient outcomes. Such a program would likely have information and activities directed at four of the five rehabilitation “E’s”: Encouragement, Education, Exercise, and Employment.

EN-16: Patients can make more progress toward their rehabilitation goals if they are motivated and if staff are motivated and committed to helping them. Providing motivational sessions that discuss the purposes, benefits, and very real possibility of improved dialysis patient functioning will help to keep patients and staff focused, positive, and alive to the potential for rehabilitation.

EN-17: Patients often serve as the best role models, teachers, and mentors for other patients. Information that is “preachy” when presented by staff is pertinent when presented by another patient. A buddy system that pairs up new patients with successful veteran patients can contribute greatly to the new patients’ adjustment to life on dialysis.

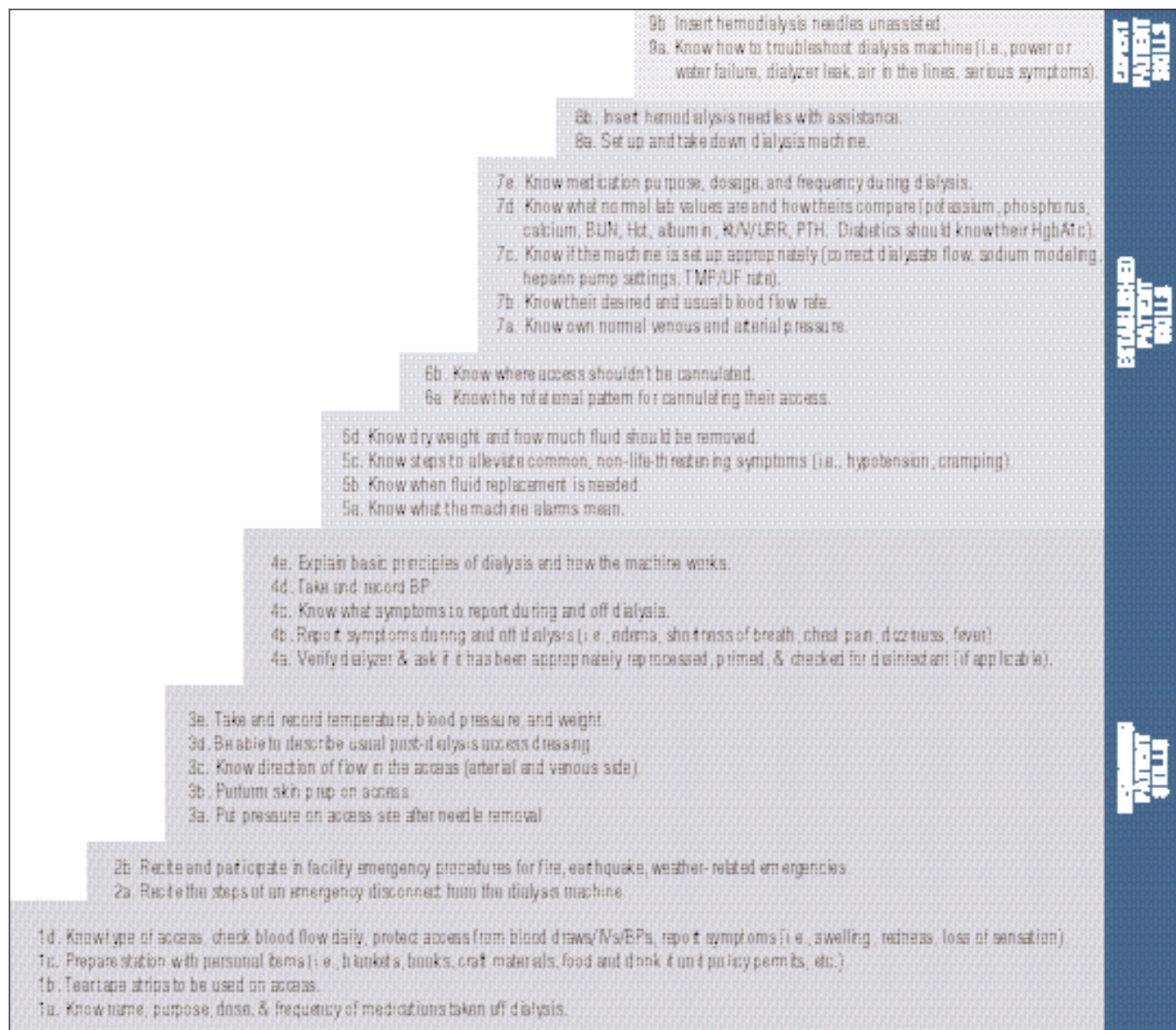
EN-18: Programs that actively encourage and facilitate patients’ involvement in their own care are advanced interventions with the potential for significant positive impact on patients’ well-being. Sessions in which levels of self-care involvement are discussed and patient decisions are made, in addition to sessions of programmed learning about how to perform self-care activities, would be required for this criterion.

EN-19: Outcomes assessment is an essential component of any rehabilitation intervention. To know whether an intervention is really worthwhile, its results or impact must be carefully evaluated. To meet this criterion, outcomes resulting from the interventions must be measured regularly using either a unit-developed or a standardized assessment tool.

EN-20: It is essential that the costs associated with facilitating renal rehabilitation be known. To this end, cost tracking should be performed whenever a rehabilitation activity is undertaken. Any system of cost tracking or monitoring that allows an estimate of all expenditures involved with a particular intervention (time, materials, etc.) fulfills this criterion.

Appendix B: Self-care Steps

Example of a Technique for Arranging Facility-specific Self-care Steps



Education

*Module 2:
A Practical
Guide to Renal
Rehabilitation*



Developed by
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The *Practical Guide to Renal Rehabilitation* provides recommendations for individuals on dialysis regarding programming issues for the “5 E’s” of renal rehabilitation: Encouragement, Education, Exercise, Employment, and Evaluation. In using this Guide, the reader should be aware of certain limitations. First, the Guide may not cover all possible topics related to such issues, and it may not address aspects of such issues that may be relevant to you in light of your particular circumstances. Second, future legislation, regulations, administrative interpretations, and court decisions may significantly change the current law or the interpretation of current law cited in this material. Please note that neither Amgen Inc., the Medical Education Institute, Inc., nor the Life Options Rehabilitation Advisory Council intends to update the information contained in this Guide. It is based on information available as of the date of publication. Third, although the authors have used their best efforts to assure that the information contained herein is accurate and complete as of the date of publication, the authors cannot provide guarantees of accuracy or completeness. Fourth, practical suggestions provided throughout the text are based on the opinions of the Medical Education Institute staff. Suggestions may or may not reflect national experience and may instead reflect local experience. Finally, this Guide is provided with the understanding that neither the Guide nor its authors are engaged in rendering medical, legal, accounting, or other professional advice. If legal advice or other expert assistance is required, the authors recommend that the reader seek the personalized service of a competent professional.

The information in this Guide is offered as general background for the clinician who is interested in improving the quality of rehabilitation opportunities for dialysis patients. The Guide is not intended to provide practice guidelines or specific protocols and cannot substitute for the physician’s knowledge and experience with individual patients. The reader must recognize that exercise, in particular, involves certain risks, including the risk of severe injury or disability, including death, which cannot be completely eliminated, even when the exercise program is undertaken under expert supervision. Use of these materials indicates acknowledgment that Amgen Inc., the Medical Education Institute, Inc., and the authors will not be responsible for any loss or injury, including death, sustained in connection with, or as a result of, the use of this Guide.

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Key Points

- *Education helps ESRD patients maintain a sense of control.*
- *Increased patient control is linked to improved compliance and life satisfaction.*
- *Effective patient education meets patient-identified needs, involves patients as active participants, takes advantage of individual learning styles, and addresses barriers.*



Why Educate Your Patients?

Dialysis patients who learn right from the start that they can pursue hobbies, exercise, work, and enjoy their family lives are more likely to become involved and responsible. They are also less likely to develop long-term dependence on others. By assuring your patients that a productive, fulfilling life on dialysis is possible, and by educating them continually about topics that are important to them, you can build positive attitudes toward treatment and rehabilitation and help patients to be more independent.

Knowledge is power: the more patients know about ESRD, its treatments, and rehabilitation options, the more they will be encouraged to reach their potential. Education helps patients function as members of the treatment team and make appropriate choices. Learning coping strategies enhances patients' feelings of control (Cunningham et al, 1991). Control that patients gain through education increases dignity, self-worth, and belief in their own intelligence—and reduces negative feelings about the illness (Burckhart, 1985). Patient education can also reduce fear and increase hope (Himmelfarb, 1992).

Education can't begin too soon. Early referral into an ESRD education program offers invaluable benefits to patients. The predialysis period following diagnosis of end-stage renal disease is very stressful. Since patients and family members feel extremely vulnerable during this time, it is a period when education can have a profound effect. Predialysis education for patients and families is a basic level component of a successful renal rehabilitation program. The earlier education occurs, the better the outcome.

It is crucial to involve family members in any patient education efforts. Including family members helps them to cope with the illness and to encourage patients to be as self-reliant as possible (McLennan et al, 1996). Family education has also been linked with improved patient compliance (Mayeaux et al, 1996) and other benefits, and should always be recognized as a basic component of any good rehabilitation effort.

On-going education for dialysis patients has so much potential for positive impact on patients' overall well-being that it constitutes an advanced rehabilitation strategy on the *Unit Self-Assessment Tool for Renal Rehabilitation* (USAT), which divides rehabilitation activities into basic, intermediate, and advanced levels. You will find the Educational section of the USAT at the back of this module as Appendix A. Below, you'll find a more specific discussion of how education can benefit patients.

Education and Adaptation to Chronic Illness

Nephrology nurses, social workers, dietitians, and technicians can improve patients' adaptation to dialysis by providing support and one-on-one teaching and by actively involving patients in their own care. For example, dialysis patients completed a 3-month nurse-run education program of weekly teaching and support sessions focusing on physical and psychosocial aspects of care. After the program, these patients had better psychosocial skills and ability to perform activities of daily living (ADLs) than patients who did not participate in the program (Korniewicz & O'Brien, 1994). A program like this one is an advanced level rehabilitation activity.

Physician education and interaction can also improve patients' health status and quality of life. Chronically ill patients who participated in decision-making with their doctors had better health outcomes, including physiological and functional status (Kaplan et al, 1989). The physician visits did not have to be lengthy to be effective—positive health outcomes occurred after visits of only 20 minutes.

The patients most likely to be included by their doctors in decision-making ask questions, interrupt, and give their own opinions. Often they are highly educated. On the other hand, patients over age 75, patients aged 18 to 30, patients who perceive their health to be poor, and minority patients may be less likely to be routinely included in decision-making. (Kaplan et al, 1995). As a member of the renal team, encourage your patients to ask questions—it can help you to help improve their health outcomes.

Education, Autonomy, and Self-care

Patients with a variety of chronic illnesses, such as heart disease and asthma, can learn self-care skills (Barnason & Zimmerman, 1995; Kelso, et al, 1995; Strecher et al, 1986; Staudenmayer, et al, 1981). Patients who take more responsibility for their treatment are more likely to succeed in rehabilitation (Korniewicz & O'Brien, 1994).

Research in ESRD also shows better autonomy, or independence, in patients who receive education. Patients who received pre-ESRD education knew more about ESRD and were more interested in home dialysis (Grumke & King, 1994), indicating that they felt comfortable assuming a high degree of responsibility for their own care. Self-care improved autonomy in a study of self-care and full-care hemodialysis patients matched for age, gender, and comorbidity. The self-care patients had better Health Related Quality of Life (HRQOL) scores for *role function* (performance of roles such as work, child care, and housework), *social function* (social activities with family and friends), and *emotional well-being* than full-care patients (Meers et al, 1996). (See the Evaluation module for more information about HRQOL.) Self-care patients also had higher perceived energy levels.

“In the past 30 years, it has been shown that a wide range of ordinary individuals, without medical or nursing backgrounds, are able to master one of the most complex medical treatments (home dialysis) and increase the quality of their own health. Patients, if suitably educated, are able and can be relied upon to perform their treatment with outstanding success, thereby releasing money and staff to further expand the treatment to others in need.”
(Baillod, 1995)

Education and the Impact of Illness

Education can improve the attitudes of patients with chronic illnesses, with long-lasting benefits. Carefully designed, disease-specific educational programs can have major impact on participating patients. In fact, these types of programs are considered intermediate-to-advanced level rehabilitation activities. For example, cardiac patients, particularly women, who participated in just four 2-hour educational classes were less nervous, irritable, hopeless, frightened, and forgetful—even 12 months later—than patients who did not attend classes (Clark et al, 1992). The participants were taught a self-regulatory system called PRIDE that helped them to select a **P**roblem, **R**esearch their daily routine, **I**dentify a behavioral goal, **D**evelop a plan to reach the goal, and **E**stablish a reward for progress. Peer counseling was also included. These same components can be helpful in dialysis education.

Education and Behavior Change

Lorig et al (1989) found that education changed behavior and improved health outcomes. However, another study reported that diabetics incorporated blood sugar monitoring and insulin adjustment into daily routines more easily than lifestyle changes such as diet and exercise. Lifestyle changes may not offer the kind of *immediate* reinforcement a patient might obtain from checking and recording blood sugar levels (Rubin et al, 1991). Dialysis patients, like diabetics, report that living with a restricted diet and remembering numerous medications are difficult. Finding a way to provide immediate reinforcement, for example, by encouraging patients to chart and reward their own successful efforts, may help patients with these lifestyle behavior changes.

Education and Symptoms

Patients remember self-care procedures they learn, and this learning reduces their symptoms (Kim et al, 1990; Treasure et al, 1994). Many of the benefits of education are achieved because patients feel more confident about their ability to manage symptoms, resulting in fewer complications (Bartlett, 1995). Education is key to achieving the improved patient outcomes demanded by payers, providers, and consumers.

Education and Cost Containment

Education improves satisfaction with health care (Schauffler et al, 1996) and helps to contain costs. For example, asthma education reduced emergency room visits by 64 percent and reduced absenteeism from work by almost 76 percent (Boulet et al, 1995). A review of 19 studies on the effects of patient education in chronic diseases from diabetes to arthritis found that for every dollar invested in patient education, \$3 to \$4 were saved. Costs **never** exceeded savings in any of the studies on patient education that were reviewed (Bartlett, 1995). Well-designed education programs benefit patients, staff, and the health-care system.

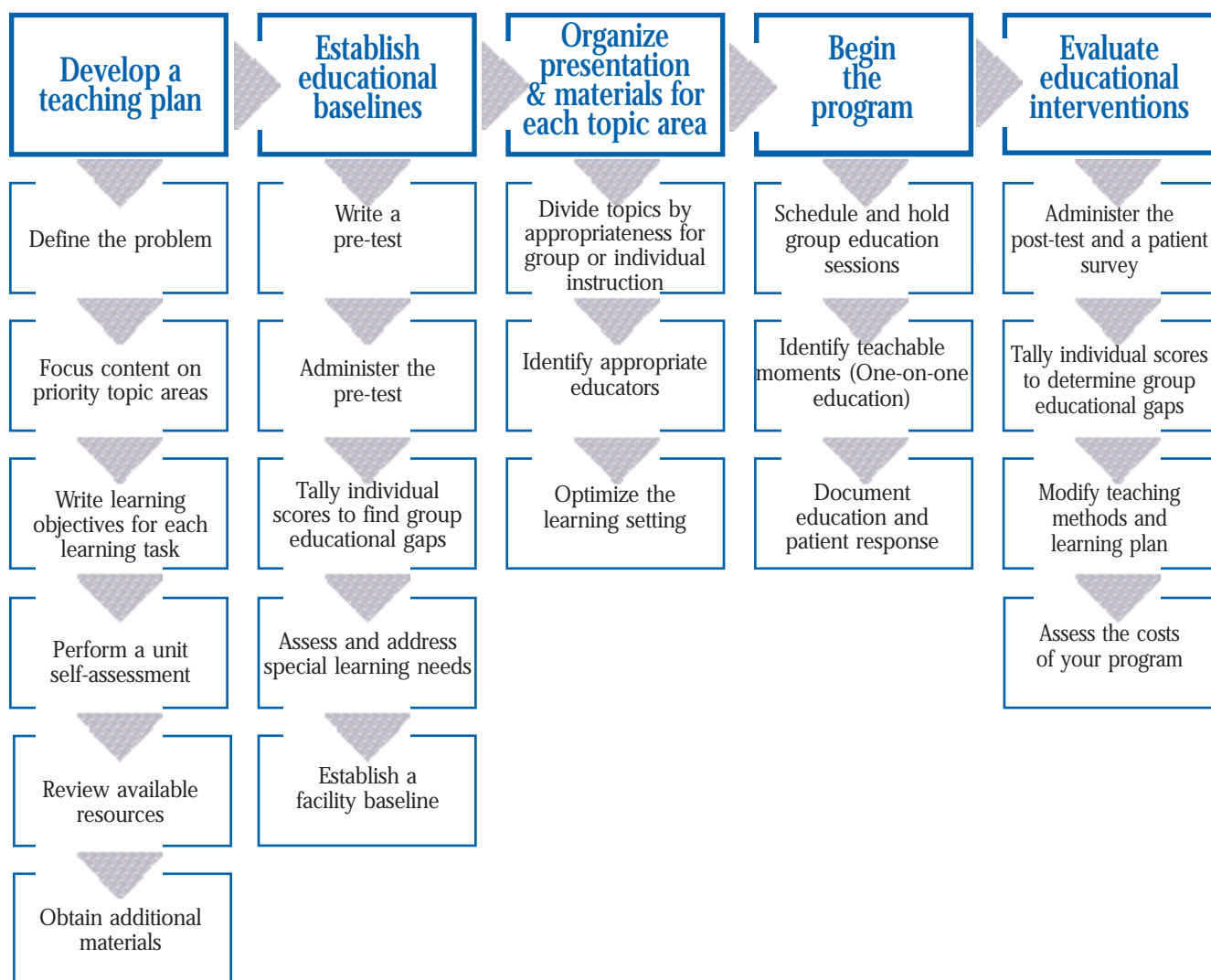


How To Begin Your Educational Program

This Module cannot tell you *what* to teach your patients, because you will need to choose topics with the needs of your own patient population and facility resources in mind. Instead, the module will guide you through the steps of assessing your patients' learning needs, establishing educational baselines, organizing your presentations and materials, beginning the program, and evaluating your educational activities so you can improve them. The *Renal Rehabilitation: Education at a Glance* flowchart below will help you understand how the rest of the module is organized. Each section includes strategies arranged in order from easiest and least time-consuming to most difficult and resource-intensive.

The Education section of the Life Options *Unit Self-Assessment Tool for Renal Rehabilitation* (USAT) in Appendix A of this module lists criteria for good rehabilitation educational programming. Like the strategies in this module, the *USAT* criteria are arranged by levels—basic, intermediate, and advanced—based on their complexity, resource use, and potential impact. You will find periodic references to the USAT criteria throughout this module, and specific criteria will be referenced by number in parentheses, such as (ED-10) so you can find them in Appendix A. Additional information about use and interpretation of the USAT is available in the *Unit Self-Assessment Manual for Renal Rehabilitation* (USAM) which you can obtain by contacting the Rehabilitation Resource Center, at (800)468-7777.

Renal Rehabilitation: Education at a Glance



Develop a Teaching Plan

In any teaching/learning situation, you must consider a number of factors. What needs to be learned and who decides? What factors make it difficult for the learner to concentrate? Who will teach and with what qualifications? Teaching is a complex skill; and teaching patients information they never thought they would need, to deal with a disease they wish they didn't have, is a real challenge. Before you can design an educational program, you must first assess the learning needs of your patients.

Define the Problem

Dialysis patients face many challenges in attaining their fullest potential. When planning a health education program, you need to be specific about what outcomes you would like to improve through patient education.

The first step in program planning is describing the health or social problem that will be addressed. The content of programs developed should address information and skill-building that will enable patients to have a positive impact on the health problem identified. The more specifically you can describe the desired outcome of the program, the more likely it is that you will be able to plan and execute effective education sessions.

Focus Content on Priority Topic Areas

To determine the teaching plan, your rehabilitation team will need to translate the elements of the health problem to be addressed into priority topic areas. Remember that *patient-selected* topics are more likely to be both learned and applied. HCFA regulations require that you teach certain information, such as emergency preparedness and patient rights and responsibilities. If your facility decides that patients must learn particular topics, be prepared to explain why the information is important. New patients will need to understand what they will need to learn—and why—to have a fulfilling life on dialysis.

It may be helpful to organize your teaching plan priorities according to what knowledge is needed at *each stage of adaptation* to dialysis. For example, Baillod (1995) recommends that dialysis patients need to understand immediately that:

- Dialysis is not a cure.
- Both diet and medications are important to maintain health.
- Weight gain is related to fluid intake rather than food intake.
- Weight loss can occur with illness.
- Large weight gains and, therefore, rapid weight loss during dialysis can make a patient feel worse.
- Potassium intake can kill.

Additional topics of concern at various stages of adaptation might include prevention of renal osteodystrophy through compliance with diet and phosphate binders, the role of EPOGEN® and iron supplements to combat anemia, and the ability of dialysis patients to be successfully rehabilitated.

Information can also be prioritized on the basis of skill level, including: *beginning patient skills*—information all patients need to know; *established patient skills*—information for patients who are accustomed to treatment, which will take more time to teach; and *expert patient skills*—information needed for self-care or home dialysis. Patients who have strong control needs or who dislike living with dialysis facility routines might be encouraged to learn established patient skills, for instance. The following checklist is an example of a skill level categorization of educational topics.

Checklist of Possible Dialysis Topics by Patient Skill Level

<i>Beginning Patient Topics</i>	<i>Established Patient Topics</i>	<i>Expert Patient Topics</i>
<input type="checkbox"/> Facility services	<input type="checkbox"/> Cannulation sites to avoid	<input type="checkbox"/> Setting up machine
<input type="checkbox"/> Work & dialysis	<input type="checkbox"/> Rotational pattern for cannulation	<input type="checkbox"/> Tearing down & disinfecting machine
<input type="checkbox"/> Treatment pros & cons	<input type="checkbox"/> Taking and recording own blood pressure	<input type="checkbox"/> Pros and cons of different coefficient dialyzers for self
<input type="checkbox"/> Rights & responsibilities	<input type="checkbox"/> Direction of blood flow through access	<input type="checkbox"/> Determining blood flow rate
<input type="checkbox"/> Disaster preparedness	<input type="checkbox"/> Monitoring machine alarms	<input type="checkbox"/> Determining dialysate flow rate
<input type="checkbox"/> Financial aspects of care	<input type="checkbox"/> Types of dialyzers and own prescription	<input type="checkbox"/> Inserting needles
<input type="checkbox"/> Grievance process	<input type="checkbox"/> Determining fluid to remove	<input type="checkbox"/> Adjusting dialysis machine during treatment
<input type="checkbox"/> Access type & care	<input type="checkbox"/> Meaning of lab results and normal limits	<input type="checkbox"/> Administering IV and subcutaneous medications during dialysis
<input type="checkbox"/> Team members' roles	<input type="checkbox"/> Monitoring machine	<input type="checkbox"/> Troubleshooting and resolving dialysis symptoms
<input type="checkbox"/> Advance directives including the right to stop treatment		<input type="checkbox"/> Troubleshooting machine problems and when to call a technician
<input type="checkbox"/> Own diet restriction		
<input type="checkbox"/> Own fluid restriction		
<input type="checkbox"/> Role in adequate dialysis		
<input type="checkbox"/> Medication purpose, dosage, and frequency		
<input type="checkbox"/> Facility reuse policy		
<input type="checkbox"/> Dialyzer verification		
<input type="checkbox"/> Dialysis process		
<input type="checkbox"/> Symptoms to report during dialysis, at home		
<input type="checkbox"/> Taking temperature & weight pre-/post-dialysis		
<input type="checkbox"/> Washing arm pre-dialysis		
<input type="checkbox"/> Holding needle site post-dialysis		
<input type="checkbox"/> Scheduling priorities		
<input type="checkbox"/> Transportation resources		
<input type="checkbox"/> Coping & dialysis		
<input type="checkbox"/> Sexuality & dialysis		
<input type="checkbox"/> Travel & dialysis		
<input type="checkbox"/> Safe exercise		

Write Learning Objectives for Each Learning Task

Written objectives clarify what you want your learners to be able to *do* with the information they learn. Most patient learning will need to be applied to another situation. For example, patients must translate their fluid restrictions into real-life decisions about when and how much fluid to consume.

Strategies for writing learning objectives:

- Make your learning objectives as specific, concrete, and measurable as possible. Rather than expecting patients to “learn self-care techniques,” it is more useful to write: “patients will learn how to take their own blood pressure and record it correctly in the appropriate place on the flowsheet.”
- Keep a written record of each patient’s learning objectives and refer to it at a predetermined frequency to be sure individuals are making appropriate progress.

Perform a Unit Self-assessment

Once you have decided what topics to cover in a patient education program, you will want to decide how to present the information. Complete the education section of the USAT (Appendix A) by assigning one point for each initiative you already have. This will give you a global impression of how you are doing and where you might do more. The USAT will also suggest other ideas that may fit into your overall plan.

Review Available Resources

Review and categorize the information you have available for patients. Does the information adequately cover all the topics you wish to cover? What additional materials will you need to fill in the voids? Don’t feel that you must have all patient education resources available in the facility. Some communities have access to high quality comprehensive predialysis education programs, for example, such as the National Kidney Foundation’s *People Like Us: Live* series, and these should be considered as available resources for your patients.

Obtain Additional Materials

Educational materials for dialysis patients, including brochures, booklets, and videotapes, are available from a variety of sources (ED-1, ED-6). If you are missing information on specific topics, contact the Rehabilitation Resource Center at (800)468-7777 or one of the other sources listed in the Getting Started module of this Guide.



*E*stablish Educational Baselines

Now that your rehabilitation team has identified essential topics for patient education, with learning objectives for each, how do your patients measure up? Testing their current knowledge will help you determine where the learning gaps are so you can target your educational efforts to the most important areas.

Write a Pre-test

The most direct way to assess learning is with pre-tests that can be repeated later as post-tests. It is likely that you will need to develop a pre-test/post-test for your facility. Test questions should be based on the key topics and learning objectives you have already developed. You may need to develop more than one test, depending on how much information you plan to teach and how it is organized.

Test writing is both an art and a science. Questions that do not accurately reflect the information or that are unclear will not effectively measure patients' knowledge. Read the Assessing Special Learning Needs section later in this module to find out more about testing considerations for elderly patients, patients with hearing or visual impairments, or patients with severe uremia.

Strategies for writing a pre-test/post-test:

- Test on all of the material. If you teach three topics, your test should measure all three.
- Write clear and unambiguous questions. Avoid double negatives, jargon, and confusing language. Use short sentences and short words.
- Vary the types of questions to make the test more interesting for patients to take. Knowledge of facts can be tested with multiple choice questions, by matching key words with their definitions, true/false questions, fill in the blanks, or even crossword puzzles or word search games.
- Test applied information by having the patient show you or tell you how to perform a task. Determine several levels of ability for scoring purposes, such as “performs skill correctly,” “requires assistance,” and “unable to perform skill.”
- Make your tests just long enough to measure essential knowledge and skills—if they are too long, fatigue can lead to careless answers.

Administer the Pre-test

You can identify gaps in individual knowledge with your pre-test. However, set the stage before you give patients a test that may be intimidating to them. Make it clear that you hope to identify ways to improve their knowledge, and therefore their lives—not to judge or ridicule anyone. The pre-test will also help you and your patients see how much progress they have made when you give them the post-test later. As you score each patient's pre-test, it should become obvious where the knowledge gaps are.

Strategies to identify gaps in knowledge and skills:

- Preview the test on patients to be sure it is clear. Change any ambiguous questions or answers before giving it to patients.
- Document pre-test results and the conditions under which you give the pre-test so you can duplicate the conditions for the post-test. For example, if you give the pre-test to patients at the beginning of dialysis, give the post-test at the beginning of dialysis as well.

Tally Individual Scores to Find Group Educational Gaps

Once you have tested all your patients, you can begin to look at patterns in their answers that may indicate a knowledge gap that many patients share. If you have access to a computer program that can create bar graphs, it will be easy to see where the gaps are. Otherwise, a simple tally sheet for each question can provide helpful information.

Once you know what your patients' educational needs are, you can review your USAT scores for the Education "E." You will most likely be able to choose an educational strategy or activity from the USAT criteria list that will suit the material you hope to cover. When you first begin a renal rehabilitation education program, selecting a rehabilitation strategy from the USAT basic level is probably the easiest course. If you are adding to an existing program, you will find that the intermediate and advanced criteria have useful suggestions.

Assess and Address Special Learning Needs

Your patients may have special needs, such as sensory deficits, language or cultural differences, or learning styles, that influence their ability to learn. While you cannot change these characteristics, the strategies in this section will help you locate necessary resources or adapt your teaching methods to make them more effective for a variety of learners.

Stress of Chronic Illness

When a patient is anxious or experiencing stress, information overload is always possible. Easing into a learning experience slowly may be more satisfying for patients (McFadden, 1994) and may facilitate retention of the information.

Strategy for teaching during stressful periods:

- Be selective: Teach only what the patient will need to know until the next teaching session.
- Make important points in a clear and straightforward manner. Repeat key information.

Cognitive Changes During Dialysis

Patients often report trouble remembering information during dialysis. Fluid removal affects every cell in the body, including the brain. Rapid metabolic shifts may cause symptoms that make it difficult to concentrate, particularly in patients with large interdialytic weight gains. Other patients may not notice any difficulties.

Strategies for coping with cognitive changes during dialysis:

- Provide information early in the session if teaching must occur during dialysis.
- To reinforce the educational message, provide written materials that the patient can refer back to.
- Provide simple information and repeat it often (Harrington and Brenner, 1973).

Pediatric Patients

If your facility has a pediatric population, many of your educational efforts will be aimed at parents, but children also need to know what is happening. They are often quick to pick up the language of dialysis.

Strategies for teaching pediatric patients:

- Use educational materials that make learning fun, such as coloring books, anatomic dolls, computer programs, and other interactive methods.
- Watch for teaching opportunities, particularly as a patient matures and becomes able to understand information that was previously too complex.

Elderly Patients

Even healthy individuals over age 60 may have difficulty incorporating material from short-term memory into long-term memory, and recalling information (Schaie & Geiwitz, 1982). In general, expect them not to score as well as younger persons on paper and pencil tests (Barnason & Zimmerman, 1995).

Older dialysis patients may have additional special needs related to sensory deficits. Loss of taste and smell have implications for nutrition, hygiene, and safety (for example, smoke detection). Tactile deficits from peripheral neuropathy can lead to burns or infections. Loss of manual dexterity can affect the ability to take medications properly (King, 1990).

Visual impairments, present in as many as 90 percent of elderly patients (King, 1990), may influence learning. Older patients may suffer from macular degeneration or other vision-limiting problems that can reduce depth and/or color perception, peripheral vision, and ability to distinguish areas of reduced contrast. The colors blue, purple, and violet become difficult for older eyes to distinguish as the lenses of the eye yellow with age, so red, yellow, or orange may be preferable (King, 1990). The strategies listed below were recommended to address the specialized learning needs of elderly patients with limited vision (Jubeck, 1994). See also the section below on visual impairment.

Strategies for teaching elderly patients with limited vision:

- Remind patients who normally wear glasses for reading or general vision to put on their glasses before beginning any educational session.
- Ask patients to bring magnifying glasses, telescopic lenses, or their other assistive devices to the dialysis facility.
- Have a magnifying glass in the unit for patient use.
- Avoid fluorescent lighting and abrupt changes in room lighting.
- Limit glare from outside light.
- Use large posters or yellow paper with black lettering to enhance contrast.
- Use 14 point or larger type for materials you develop. The adjacent sidebar is in 14 point type.
- For patients who still have trouble reading these materials or watching a video, use one-on-one instruction from the staff, and have the patient practice procedures in front of the patient educator.

Helping Children Learn About Dialysis and Life

Texas Children's Hospital in Houston, Texas, winner of the 1996 *Exemplary Practices General Excellence* award for pediatric facilities, uses puppets, models of body organs, educational coloring books, and staff trainers to help children learn about kidney disease. This dialysis program focuses on keeping children in school, and offers peer tutors and provides computers with Internet access so patients can research topics of interest or pursue homework assignments.

(Renal Rehabilitation Report, Vol. 4 #5, 1996)

The Adult Learner

Adults learn primarily what they want or need to know to function in their environments. They tend to incorporate new information into an existing framework of knowledge. Therefore, they learn more if the information is relevant to their lives. Adults prefer to learn at their own pace; practice and repetition make teaching more effective. Organized information is learned more easily than random bits of information. Good intermediate rehabilitation interventions for adults include developing your own educational materials (ED-8) and holding in-unit sessions (ED-10). Both techniques personalize information to suit your unit's population. Such information is both easier to learn initially and easier to remember over the long run.

Strategies for teaching the adult learner:

- Plan brief teaching sessions (30 minutes or less), or plan for breaks.
- Repeat material often (Knowles, 1973) and assess knowledge by asking questions and requesting demonstrations of learning (ED-12). "Refresher" classes are useful, especially for complex material, so bad habits can be unlearned and good habits reinforced (ED-18).
- Devise analogies relevant to individual patients. For example, for a fisherman, relate interdialytic weight gain to the difference between a river that has a constant water level and a river that experiences floods and droughts. To use analogies successfully, you must learn what is most important to the patient.

Learning Styles

There are three basic styles of learning: Visual, auditory, and kinesthetic. Although most people use all these learning styles, one typically dominates (Markova, 1991). Very briefly, *visual* learners (the most common) learn mostly from what they see. They may read or take notes from oral presentations to allow them to see the material. *Auditory* learners learn mainly from listening; they may prefer to listen to

speakers or tapes or read things aloud to help them remember. Finally, *kinesthetic* learners learn primarily by doing, such as with hands-on practice sessions, and may point while they're reading or underline important passages. To maximize learning, use all three styles in your teaching.

Strategies to address different learning styles:

- Supplement written material with videotapes (ED-6) or practice sessions when incorporating learners of different styles into a group (ED-16) to ensure that you are using strategies that are effective for everyone. Supplementing written materials is an intermediate rehabilitation strategy.
- Encourage patients' active participation in your education program—an advanced rehabilitation strategy.

Literacy Level

Studies have shown that in the United States at least 10 percent of the adult population lack basic reading skills and another 20 percent have reading skills one to three years lower than the highest level of education they achieved (Jubelirer et al, 1994). Fear, anxiety, or an illness that impedes concentration can further reduce reading levels, as can materials that include medical jargon. In general, experts recommend that patient education materials be written for a fifth or sixth grade reading level (Meade et al, 1994).

If you suspect that a patient cannot read at a functional level, provide a paragraph to read and ask for the key points. Patients who can comprehend basic materials can move on to more sophisticated information. Meeting the needs of both ends of the educational spectrum is a challenge for health-care professionals. As suggested in the USAT, literacy testing is an advanced level component of an overall educational program, and potentially a very valuable activity.

Strategies for teaching patients with low literacy levels:

- Use videos to improve learning among low literacy groups (Gagliano, 1988) (ED-6).

- Look for materials with short sentences and simple words (two syllables or less), illustrations, clear organization, and writing in active voice. (“Take all your medication” versus “All your medication should be taken.”)
- Use one-on-one teaching sessions in which patients can ask questions (ED-16).
- Seek out literacy services in your community for testing and training programs. They can help patients learn to read or improve their reading.
- Determine the reading level of educational materials you use or develop. Tools to assess reading level include SMOG (McLaughlin, 1969), Fog (Gunning, 1974), and Flesch (Flesch, 1974). An example of a SMOG test is included as Appendix B. Grammatik® is the best-known computer software package that identifies the Flesch and Fog index and offers suggestions to adjust the reading level as needed. Look for it at your local computer store.
- Write consent forms and other health education materials at least three grade levels lower than the average educational level of the target population (Jubelirer et al, 1994).
- Assess patients’ literacy levels (ED-17).

Visual Impairment

Many dialysis patients, particularly diabetic patients, may have limited vision.

Strategies to teach patients with visual impairments:

- Contact the National Kidney Foundation (NKF) or your Network to request large-type publications or tapes. The NKF *People Like Us* series, for example, combines brochures and videotapes, which visually impaired patients can listen to.
- Develop your own large-type publications using desktop publishing software. Use fourteen to eighteen point type (ED-5).

- Audiotape educational sessions to reinforce learning for visually impaired, blind, or illiterate patients (McFadden, 1994; Meade et al, 1994) (ED-6).
- Look under “Blind” in your phone book for sources of volunteers to type educational materials into Braille if you have patients who can read Braille.

Hearing Impairment

You should provide interpreters for the deaf. Because of cost and scheduling, however, it may not be possible to have interpreters available for every dialysis session.

Many hearing-impaired patients, particularly elderly patients, have more difficulty distinguishing voices from background sounds in a noisy environment. Higher-pitched tones are more difficult to distinguish as well. The consonants B, F, G, M, N, S, T, and Z can be more difficult to identify. In addition, words that have a similar emphasis on each syllable (like “helpful”) may be harder to understand. Shouting does not help because it can distort the sound (Jubeck, 1994).

Strategies to teach patients with hearing impairments:

- Ask the patient and family whether the patient has a hearing impairment. Document the extent of the problem in the patient care plan.
- Ask the patient whether hearing is better in one ear than in the other.
- Write notes to the patient to assess learning needs and understanding.
- Request help from a family member or friend who understands the best methods of communicating with the patient, which may include repetition, lip reading, sign language, or other means.
- Seek assistance from local advocacy groups for the hearing-impaired.

Language Barriers

It can be very difficult to educate patients who speak a different language than the staff. Educational materials in languages other than English can be of great benefit, especially if your unit has a large non-English-speaking population. In many facilities, multilingual staff can help patients with language difficulties, or family members or community volunteers may be able to translate information.

Strategies to overcome language barriers:

- Call local hospitals to find out if they keep updated lists of foreign language interpreters that they could share with you.
- Contact your Network to seek educational materials for non-English speakers.
- Seek materials in other languages through the NKF, your local NKF affiliate, or NKF affiliates in another area where there are large numbers of patients who speak that particular language.
- Check non-English publications in *Bridging the Barriers for Patients and their Families*, a booklet with an extensive resource list, from the Rehabilitation Resource Center (800)468-7777.



Cultural Differences

In addition to language considerations, it is important to respect cultural and ethnic differences in your patient population. Illness may be stigmatized or viewed as a curse or punishment for bad behavior. Some cultures have little trust in traditional medical professionals, preferring alternative therapies and healers. Adult children of elderly patients from some cultures may feel uncomfortable discussing a parent's illness or making decisions. In some cultures, men make the important decisions.

Strategies to accommodate cultural differences:

- Ask patients about their cultural beliefs to devise methods for effective teaching.
- Seek assistance from a member of your patient's cultural community (Chachkes & Christ, 1996).
- Consider arranging to have a male staff person relay important information to the family of a patient from a male-dominated culture.
- Seek out patient educational materials that include pictures of different ethnic groups of the at-risk population to make the information more relevant and appealing. For example, hypertension is common among African-Americans and Asian-Americans, and diabetes is common among Native Americans and Hispanics.
- Learn about different cultures. Seek out journal articles and/or books on cultural differences and reactions to chronic illness and medical treatment.
- Make an active effort to respect cultural beliefs that differ from your own.

Organize Presentation and Materials for Each Topic

Dialysis is a complex treatment for a complex illness, and much of the learning that goes on is interconnected—topics can build on each other. Think about what you want to teach and how it fits with other information the patient has already learned or is yet to learn.

Divide Topics by Appropriateness for Group or Individual Instruction

Besides organizing your ideas, you'll need to organize your educational resources into a usable form. Patient videos, brochures, and other materials, as well as facilitator outlines and notes, must be easily accessible or they will not be used. Making such materials available for regular use is a basic but very useful element of a good educational program. Further, dividing materials for individual or group instruction will help pull together what you'll need for any teaching situation.

Strategies for organizing ideas and materials:

- Plan a logical sequence of ideas. Planning can pay off in better patient understanding and increased interest in learning. If you determine how best to present information, you'll be prepared if a patient asks an unexpected question or a “teachable moment” arises.
- Practice the sequence of materials you'd like to present, especially if you are uncomfortable with the idea of “teaching.” Trial runs will help you check the logical flow of your ideas, be sure timing is realistic, and polish your delivery so you can be fluid and confident, which will inspire confidence in your learners.
- Set aside a file drawer or space on a shelf to keep educational material organized and ready to use for group or individual teaching sessions.

Identify Appropriate Educators

Assigning a staff member to each component of your facility's patient education helps assure that teaching will actually occur as planned. You may find that either a single staff member or many different teachers will

work best for your facility and patients. Individuals who make good teachers are:

- Able to relate the material to patient concerns
- Patient with slow learners
- Encouraging of any signs of progress
- Organized and committed

Strategies to identify appropriate educators:

- Ask well-adjusted patients and/or family members to help teach new dialysis patients.
- Assess the individual strengths of your staff nephrologists, social workers, nurses, and patient-care technicians and assign them to patient education tasks that suit their interests and abilities.
- Draw upon the expertise of community volunteers, physical therapists, rehabilitation specialists, and other experts (ED-13). Having staff or local experts present materials is an intermediate level educational strategy that may give patients a new perspective and add an aura of importance to the topics that are presented.
- Hire a full- or part-time staff person as a designated patient educator.

Optimize the Learning Setting

Common sense suggests a relationship between the learning setting and outcomes of teaching. Provide a setting without noise or diversion, and ensure that the light and temperature are appropriate. For optimal learning, a trusting and non-judgmental emotional environment must also be provided.

Strategies to optimize the learning setting:

- Choose a pleasant, well-lit, quiet room with enough comfortable seating for all.
- Arrange privacy, as needed, for discussions of confidential or sensitive topics.
- Consider an off-site meeting if patients will not be able to speak freely at the facility (ED-15).
- Provide refreshments suitable for a renal diet.

Orientation Unit Gets Patients Off to a Good Start

The Northwest Kidney Center in Seattle, Washington, offers a supportive environment for new dialysis patients by creating a special orientation unit within the larger unit for the first few weeks of treatment. A comfortable, private setting allows staff to target new patients and family members for education and counseling interventions; it also allows meetings with rehabilitated patient volunteers. Patients' schedules are adjusted to accommodate their work or school needs. Patients and family members learn about options for dialysis, including home dialysis, and patients who are able to participate actively in their own care do so before falling into dependency. Twenty-five percent of new patients who go through the orientation unit choose a home dialysis modality, a figure much higher than the national average.

(Blagg & Fitts, 1994)

*B*egin the Program

When all the other pieces of your educational program are in place—assessment of educational needs, available resources, and staff assignment—you can begin to deliver your educational messages.

Schedule and Hold Group Education Sessions

Group education can be effective, especially when the group is facilitated by at least one rehabilitated patient. For example, education programs for adults with asthma that included peer support and group interaction helped motivate patients to make desired behavior changes (Wilson et al, 1993). According to Korniewicz and O'Brien (1994), who developed a group education intervention for dialysis patients, dialysis staff who plan group education programs should:

- Provide opportunities for patients to be active participants (ED-16).
- Provide regular one-on-one teaching sessions in addition to the group program.
- Include audiovisual materials (ED-6), patient diaries, peer teaching and support (ED-16).
- Allow chances for feedback on content learned in previous sessions, with practice time between sessions.

Strategies to schedule and hold group educational sessions:

- Survey patients to determine the best times to meet their schedules.
- Videotape or audiotape sessions for patients who cannot attend (ED-6).

- Publicize session times with posters, bulletin board flyers, or personal invitations (ED-1).
- Have an agenda and stick to it; begin and end on time.
- Offer sessions at a variety of times, if possible, to meet the needs of more patients.
- Invite speakers to make sessions more interesting (ED-13).
- Provide for group interaction and hands-on practice; use as many senses as possible (ED-16).
- Create clear, easy-to-read handouts or a binder of materials for each participant (ED-1).

Identify Teachable Moments (One-on-one Education)

One-on-one education has been found to be effective. In particular, it is well-suited for meeting special needs of patients with low reading levels or various sensory deficits (see pages 12-13). Since one-on-one education can be time-consuming, it may be best for complex information where the patient must demonstrate skills to be used independently, such as PD training.

Remember, however, that one-on-one education doesn't have to be a long, drawn-out affair. Use "teachable moments" while setting up the dialysis machine, inserting needles, or checking on patient progress to describe what you're doing and why, and to answer questions. You are *always* teaching. During dialysis, for example, patients may be most attentive to you and most receptive to learning.

Knowing when patients are most motivated to learn can be a challenge. Some patients will ask directly for information, while others new to ESRD do not know what questions to ask. Still others may be reluctant to admit that they don't know all they need to know. Some patients may have too much pride to admit they don't understand the material. If you pay attention, you can determine when your patients are ready to learn.

Strategies to identify and use teachable moments:

- Be alert to cues. Patients may joke about their concerns or ask indirectly about options. They may bring up something another patient is doing as a way to learn whether other behaviors or treatments might be appropriate for them (Greenfield et al, 1985).
- Offer a variety of educational materials in different formats. If patients are not initially interested in an important topic, don't give up—ask about their interest at a later time (ED-12).
- Use the patient care plan as a reminder to continually monitor patients' interests and status as treatment continues.

Document Education and Patient Response

In the patient care chart or other tracking document, note the patient's progress toward the educational objectives you identified earlier (ED-19). You may wish to develop a flowchart or checklist to help you determine for each patient which educational needs have been met, on what date, using what materials.

Evaluate Educational Interventions

Once you have implemented your educational intervention, periodic evaluation will allow you to assess the effectiveness of your educational efforts, both for individual patients and for your entire facility. As suggested in the USAT, evaluation is a key component of an advanced rehabilitation program (ED-19).

Administer the Post-test and a Patient Survey

Reassess your patients' knowledge by giving them the pre-test you wrote earlier as a post-test. In addition, periodically evaluate the educational process itself. Write a survey that asks patients to evaluate the content, format, teaching/learning style, teaching location, and timing of educational materials. This will provide you with a wealth of information to revise and improve your program.

Just as you did with the pre-test, graph or otherwise collect the results from your post-test, and survey and identify knowledge gaps. If your interventions were effective, you should see increased knowledge or skills in at least some areas. Some gaps will surely remain, since there is so much for dialysis patients to learn. Compare pre-test and post-test scores on each question. This can help you assess the patient's learning and the appropriateness of your test questions. For example, if scores *dropped* from the pre-test to the post-test on some items, you may need to evaluate whether those questions are confusing to patients.

On an individual basis, consider whether patients who learned successfully are ready to be encouraged to move up to the next level of self-care responsibility and knowledge. If some patients learned the material successfully and others did not, you may need to probe more deeply into the reasons by asking patients specific questions to help you improve your program.

Tally Individual Scores to Determine Group Educational Gaps

Again, part of the process of evaluation will involve looking at scores from all of your patients together to determine which areas of your program worked well and which areas have room for improvement.

Modify Teaching Methods and Learning Plan

Based on what you have learned from the evaluation of your educational program, modify teaching programs and educational objectives. Over time, as you continually improve your program, you will be helping your patients to benefit from increasing levels of knowledge and responsibility for their own care.

Assess the Costs of Your Program

Finally, cost tracking is an important activity for every rehabilitation program. The goal of making renal rehabilitation a routine part of ESRD patient care can only be realized when the costs of various activities are available. A good way to collect critical information about renal rehabilitation costs vs. benefits is for each unit to keep track of its own rehabilitation-related costs and outcomes. By sharing experiences, the renal community will eventually be able to project rehabilitation expenses and better plan strategies and initiatives based on available resources.



Case Study:

Satellite Dialysis Centers, Inc., East San Jose, Offers Education for Life

Dialysis patients encounter many barriers in the process of rehabilitation. The Satellite Dialysis Centers, Inc., of East San Jose, California, believe education is the key to overcoming many of these barriers, and the success of their EXCEL program certainly strengthens their case.

EXCEL, initiated in 1993, is a comprehensive program designed to help renal patients between the ages of 18 and 55 keep their jobs, enter the work-force or return to work, and obtain job retraining. EXCEL is a four-phase program that deals with the total person.

- During Phase 1, *physical satisfaction* is promoted through education, treatment, nutrition, exercise, and scheduling options.
- Phase 2 establishes *emotional security* by helping patients improve coping strategies and by providing education about work incentive programs and vocational services, insurance, disability, and compensation.
- Satisfaction with *social status* is fostered in Phase 3 through opportunities to meet with staff, vocational counselors, and prospective employers; participation in support groups; and socialization with other patients.
- *Achievement and mastery* is the goal of Phase 4, where patients become increasingly aware of employment benefits and their legal rights.

Program evaluation of EXCEL reveals excellent results. At program inception, only eight percent of 43 patients were working and five percent were in school. Two years later, 51 percent were employed, 14 percent were in school, and nine percent were in vocational training. The percentage of patients who were vocationally inactive, therefore, decreased more than three-fold, from 87 percent to just 26 percent.

There are other important outcomes. Patients report an improved understanding of their life choices, a greater sense of independence, and a heightened responsibility in decision making. The commitment to education displayed by Satellite Dialysis Centers, Inc., also resulted in their winning the 1995 *Exemplary Practices* award for *Education*, sponsored by the Life Options Rehabilitation Advisory Council. Perhaps the words of patient, Frank Perez, best describe the program's overall success: "It's made the 'old me' come alive. I'm on top of the world and I've got hope again."

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Appendix A: USAT Educational Criteria

BASIC REHABILITATION INTERVENTIONS:

Score 1 point for each "yes" answer

- ED-1 ___ Do you provide any printed educational materials (e.g., books, pamphlets, brochures, newsletters) for patients?
- ED-2 ___ Do you have a special orientation program for new patients?
- ED-3 ___ Do you have educational programs for patient families or other social support persons?
- ED-4 ___ Do you sponsor educational programs for members of the health-care team?
- ED-5 ___ Do you have any facility-specific educational materials?
- ED-6 ___ Do you have/provide any educational videos for patient use?
- ED-7 ___ Do you provide or have any other kinds of educational strategies/programs that were not covered in the above items?

INTERMEDIATE REHABILITATION INTERVENTIONS:

Score 1 point for each "yes" answer

- ED-8 ___ Do you sponsor or provide any educational programs for potential or present employers of dialysis patients?
- ED-9 ___ Do you have/provide any programmed learning modules (computer or booklet)?
- ED-10 ___ Do you hold any in-unit educational sessions or programs?
- ED-11 ___ Do you have any educational programs for the general public?
- ED-12 ___ Do you routinely and repeatedly offer educational materials to patients?
- ED-13 ___ Do you ever have any special "presentations" made by staff or guest speakers?
- ED-14 ___ Do you have any educational programs dealing with the other rehabilitation E's (Encouragement? Exercise? Employment? Evaluation?)

ADVANCED REHABILITATION INTERVENTIONS:

Score 1 point for each "yes" answer

- ED-15 ___ Do you sponsor/provide educational classes outside of dialysis time?
- ED-16 ___ Do you have regular/periodic educational sessions in which patients can participate?
- ED-17 ___ Do you provide any sort of evaluation for literacy level of your patients?
- ED-18 ___ Do you have a continuing educational program for established patients?
- ED-19 ___ Do you track the outcomes or results of your educational efforts?
- ED-20 ___ Do you track the costs associated with your education program?

_____ ***SUBTOTAL (20 possible)***

Explanations of USAT Education Criteria

BASIC: ED-1 TO ED-7

ED-1: There are many printed educational materials for dialysis patients, available from a variety of sources. Most of these can be obtained free of charge. Providing such materials for dialysis patients is an inexpensive, yet potentially effective, method of ensuring at least basic patient education.

ED-2: New dialysis patients have a special need for information. An educational program that introduces patients to the information that is essential to their successful transition to life on dialysis is a MUST!

ED-3: Patients who have the support and help of their families and/or other social support persons seem to adapt better overall. Educational efforts (in the form of printed information, formal or informal classes) for families/significant others are very important to ESRD patient rehabilitation.

ED-4: Abundant new information becomes available every day about the care and rehabilitation of dialysis patients. Members of the health-care team need to have ongoing education in order to stay current. Support or provision of in-house or outside continuing education opportunities for staff is a basic requisite of rehabilitation programming in the education category.

ED-5: Educational materials that have been developed within the unit have the potential to have more impact because they can be tailored to specifically identified patients' needs. Because they also can be made particularly relevant to the patients (for example, by using unit-specific examples), they are considered to be intermediate educational strategies.

ED-6: Video presentations might have more impact than printed materials because they educate patients through two senses rather than just one. For this reason, the use of videos for education is considered an intermediate rehabilitation initiative.

ED-7: There are many different ways in which to educate patients—too many to be specifically enumerated here. Other methods, audiences, or occasions related to education and ESRD that you have identified can be credited here.

INTERMEDIATE: ED-8 TO ED-14

ED-8: Employers who know about ESRD and understand its implications are more likely to hire ESRD patients. Any educational intervention that helps to teach potential employers about ESRD will contribute to patients' ability to live full and productive lives. As above, interventions can be provided in many different forms.

ED-9: Programmed learning modules use the technique of beginning with the simplest information and building on it. Since they have the potential to help patients learn and retain more of the essential information, they are also considered to be intermediate rehabilitation strategies.

ED-10: Educational sessions or programs held in-unit can be personalized to suit the population of the unit and also feel very "relevant" to patients. The convenience of the in-unit location is apt to help attendance and the familiarity of the surroundings is apt to induce learning and retention of information—thus they are intermediate strategies.

ED-11: Public attitudes toward ESRD have the potential to impact patients' quality of life, health, and well-being. Educational programs that help to educate members of the community about ESRD may ultimately help patients to find social support, jobs, services, etc. Education of the community may occur in many forms: printed educational materials, flyers, newspaper articles, newsletters, presentations, planned social events, etc.

ED-12: It is difficult for patients to learn and retain all of the essential information at a single session. Thus, information offered repeatedly and routinely has more impact than information presented only one time.

ED-13: Having staff prepare a special presentation or inviting guest speakers is an intermediate educational strategy for two primary reasons: it provides patients with a new/different perspective on what may be "old" information and also imparts a sense of the information's importance to all listeners.

ED-14: Since each of the rehabilitation "E" categories is important to patients' rehabilitation, education on any of the related "E" topics is a criterion of a good rehabilitation program at the intermediate level.

ADVANCED: ED-15 TO ED-20

ED-15: Educational classes sponsored outside of dialysis time can be carried out in whatever manner is most convenient to patients and involved staff. Times, places, schedule, and material covered can be “negotiated” by patients and staff together. Such programs are considered to be advanced interventions both because they are likely to have more impact (patients must be motivated to attend, staff must be very committed if they are participating, etc.) and also because they involve many more resources (in terms of time, place, staff, planning, etc.)

ED-16: In this criterion, active patient participation in the educational program is implied. Participation should be at the level of planning for materials covered, learning in a “hands-on” way, discussion groups, focus groups, or the like. Such participatory educational programs are considered to be advanced because they are relatively time-consuming and resource-intensive. However, they also have the potential to have increased impact on patients’ educational status.

ED-17: Because an effective educational program would include the potential for adapting educational strategies based on patients’ individual literacy levels, it is important that literacy, as well as visual acuity, be reviewed and/or assessed as necessary.

ED-18: A continuing or ongoing education program is considered to be a more advanced strategy than a dialysis orientation program because it indicates a concern with patients’ overall rehabilitation, as opposed simply to their smooth integration into the flow of the unit. Ongoing programs can be planned around any relevant topic and arranged in any way that will help to educate/rehabilitate established dialysis patients.

ED-19: Outcomes assessment is an essential component of any intervention. In order to know whether an intervention is worthwhile, its results or impact must be carefully evaluated. To meet this criterion, outcomes resulting from the intervention must be measured regularly using either a unit-developed or a standardized assessment tool.

ED-20: It is essential that the costs associated with facilitating renal rehabilitation be known. To this end, cost tracking should be performed whenever an intervention is undertaken. Any system of cost tracking or monitoring that allows an estimate of all expenditures associated with a particular intervention (time, materials, etc.) fulfills this criterion.

Appendix B: How to Test for Readability

The SMOG Readability Formula

To calculate the SMOG reading grade level, begin with the entire written work that is being assessed, and follow these four steps:

1. Count off 10 consecutive sentences near the beginning, in the middle, and near the end of the text.
2. From this sample of 30 sentences, circle all of the words containing three or more syllables (polysyllabic), including repetitions of the same word, and total the number of words circled.
3. Estimate the square root of the total number of polysyllabic words counted. This is done by finding the nearest perfect square, and taking its square root.
4. Finally, add a constant of three to the square root. This number gives the SMOG grade, or the reading grade level that a person must have reached if he or she is to fully understand the text being assessed.

A few additional guidelines will help to clarify these directions:

- A sentence is defined as a string of words punctuated with a period (.), an exclamation point (!) or a question mark (?).
- Hyphenated words are considered as one word.
- Numbers which are written out should also be considered, and if in numeric form in the text, they should be pronounced to determine if they are polysyllabic.
- Proper nouns, if polysyllabic, should be counted, too.
- Abbreviations should be read as unabbreviated to determine if they are polysyllabic.

Not all pamphlets, fact sheets, or other printed materials contain 30 sentences. To test a text that has fewer than 30 sentences:

1. Count all of the polysyllabic words in the text.
2. Count the number of sentences.

3. Find the average number of polysyllabic words per sentence as follows:

$$\text{average} = \frac{\text{Total \# of polysyllabic words}}{\text{Total \# of sentences}}$$

4. Multiply that average by the number of sentences *short of 30*.
5. Add that figure on to the total number of polysyllabic words.
6. Find the square root and add the constant of 3.

Perhaps the quickest way to administer the SMOG grading test is by using the SMOG conversion table. Simply count the number of polysyllabic words in your chain of 30 sentences and look up the approximate grade level on the chart.

*SMOG Conversion Table**

Total Polysyllabic Word Counts	Approximate Grade Level (±1.5 Grades)
0-2	4
3-6	5
7-12	6
13-20	7
21-30	8
31-42	9
43-56	10
57-72	11
73-90	12
91-110	13
111-132	14
133-156	15
157-182	16
183-210	17
211-240	18

**Developed by Harold C. McGraw, Office of Educational Research, Baltimore County Schools, Towson, Maryland.*

Employment

*Module 3:
A Practical
Guide to Renal
Rehabilitation*



Developed by
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The information in this Guide is offered as general background for the clinician who is interested in improving the quality of rehabilitation opportunities for dialysis patients. The Guide is not intended to provide practice guidelines or specific protocols and cannot substitute for the physician’s knowledge and experience with individual patients. The reader must recognize that exercise, in particular, involves certain risks, including the risk of severe injury or disability, including death, which cannot be completely eliminated, even when the exercise program is undertaken under expert supervision. Use of these materials indicates acknowledgment that Amgen Inc., the Medical Education Institute, Inc., and the authors will not be responsible for any loss or injury, including death, sustained in connection with, or as a result of, the use of this Guide.

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*K*ey Points

- *Employment and/or active engagement in life often improves dialysis patient outcomes.*
- *Positive facility policies are key to successful vocational rehabilitation.*
- *Patients who are working, attending school, volunteering, and keeping active should generally continue to do so.*
- *Early education and support are needed to improve employment outcomes.*



*D*ialysis Patients *Can Work*

Dialysis patients can often work—and many do so today in white- or blue-collar positions, full-time or part-time, in permanent, temporary, or seasonal jobs. Many studies have reported that between 11 and 24 percent of working-age dialysis patients are employed (Curtin et al, 1996).

Yet, it is clear that most dialysis patients have not yet achieved or cannot maintain their full employment potential. Approximately 73 percent of working-age patients (18 to 62 years old) in a recent study worked before starting dialysis, but only 24 percent worked afterward (Curtin et al, 1996). However, many patients want to work. Of the unemployed patients in the study, 67 percent were willing to work full- or part-time, 24 percent felt they were able to work, and 21 percent were both willing and able. Targeting these willing and able patients for return-to-work efforts would almost double the number of employed working-age patients.

Employment Benefits Patients

The advantages of work for patients are rooted in common sense and in the medical literature. For patients who are able and willing, working may enhance both psychosocial adaptation and financial status.

Psychosocial Adaptation

The majority of working patients (82 percent in one study) enjoyed their work and received benefits from their jobs; in fact, most said they needed to perform well on their job to feel worthwhile (Antonoff & Mallinger, 1989). Participation in community activities was higher for vocationally active patients, leading to better social and psychological adaptation. Working patients also reported higher self-esteem and quality of life than unemployed patients, and scored higher on medical, psychological, and social adaptation (Wolcott et al, 1988), factors that help predict dialysis patient survival (Gutman, 1983; Burton et al, 1986). Active involvement in life—such as working—helps patients live longer.

Financial Status

Money is an immediate concern for most patients facing dialysis, but less so for working patients. Employed patients may have group insurance that may pay part of

“I had it in my mind that I wasn’t sick. The mind is 80 percent of feeling good. I felt great and was able to lift equipment at work, keep up my volunteer work, and exercise.”

A 55-year old dialysis patient who works as a shop foreman.
(*Renal Rehabilitation Report*, Vol. 5 #1, 1997)

the costs of treatment and medications not covered by Medicare. Patients who work can more readily afford the renal diet, adequate transportation, safer neighborhoods, and entertainment.

Patient Employment Benefits Facilities

Patients are not the only ones who benefit from regular employment. Dialysis facilities benefit as well. Employment is associated with improved adherence to treatment, and patients who are more rewarding to work with; thus, dialysis units with high percentages of working patients will be more lively and fulfilling places. Further, providing the opportunity for working patients to share their successes with other patients can have a positive impact on the morale of all the patients in the facility.

Improved Adherence to Treatment

Because work requires a certain level of health, and missing work or appearing unproductive could jeopardize a job, most working patients are highly motivated to stay as healthy as possible. Patients who work may have fewer avoidance behaviors that could lead to compliance problems (Wolcott et al, 1988).

Increased Facility Revenues

Employed patients can benefit their facilities financially while their employer group insurance is the primary payer, as well as afterward. Because private insurance typically doesn’t require the discounted rates demanded by Medicare, employer group health

coverage may bring extra revenue into the facility. Even after Medicare becomes the primary payer, employer group coverage usually pays part of the 20 percent balance Medicare does not pay. Therefore, facilities with more working and insured patients may have more money to spend to provide quality care.

Perhaps more importantly, patients who stay healthy and out of the hospital bring in consistent revenue to the facility through uninterrupted scheduled dialysis.

More Rewarding Patients

Dialysis center staff report that working with patients who are leading productive lives is rewarding. Patients who participate in community activities have lower treatment stresses, and patients who are vocationally active—work, attend school, or do household chores—have significantly better relationships with dialysis personnel and other dialysis patients (Wolcott et al, 1988). These patients have hope, an undervalued commodity in health-care, and one that is contagious from patient to patient and between patient and staff.

Staff Support Facilitates Employment

Family members and dialysis team expectations can influence which patients work and which ones do not (Curtin et al, 1996). Physician assessments of patients’ ability to work often depend on perceptions of patients’ ability to perform physical functions needed on a job, such as lifting, standing, or walking (Kutner et al, 1991). However, patients can often do more than their doctors believe they can (Meers et al, 1995).

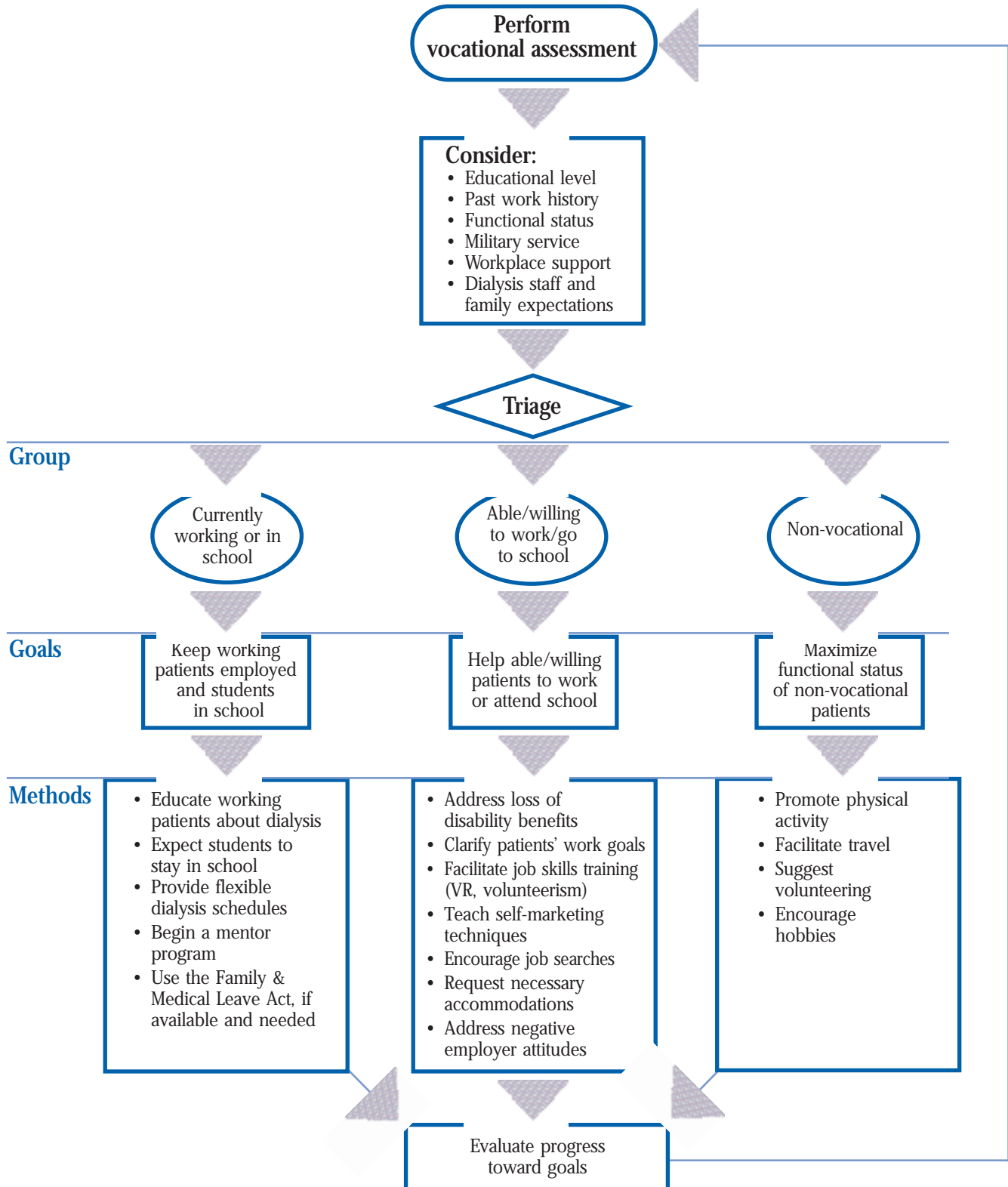
Nephrologists and other dialysis professionals with low expectations may discourage able patients from working and even encourage them to apply for disability unnecessarily. Routine completion of disability forms sends a negative message to patients. On the other hand, when everyone on the dialysis team expects working patients to continue working, and encourages the efforts of would-be employees to find jobs, patients will believe that a productive life on dialysis is possible. Educating patients, families, staff, and potential employers about the employability of dialysis patients can have far-reaching effects.

How to Begin Your Employment Program

The importance of employment for dialysis patients is clear. The remainder of this module will provide step-by-step information to help you perform a vocational assessment to triage patients into one of three vocational groups: currently employed or in school, able and willing to work or attend school, and non-vocational. These categories will help your facility to set rehabilitation goals that best suit your patients' needs and the resources you have available. Please refer to the *Renal Rehabilitation: Employment at a Glance Flowchart* on page 6 for an overview of key steps for pursuing employment and other activity goals. Each section includes strategies arranged in order from easiest and least time-consuming to most difficult and resource-intensive.

The Employment section of the Life Options *Unit Self-Assessment Tool for Renal Rehabilitation* (USAT) is included as Appendix A of this module. The USAT lists criteria for good rehabilitation programming for each of the five rehabilitation "E's." Like the strategies in this module, the *USAT criteria* are arranged by levels—basic, intermediate, and advanced—based on their complexity, resource use, and potential impact. You will find periodic references to the USAT criteria throughout this module, and specific criteria will be referenced by number in parentheses, such as **(EM-8)**, so you can find them in Appendix A. Additional information about use and interpretation of the USAT is available in the *Unit Self-Assessment Manual for Renal Rehabilitation* (USAM), which you can obtain by contacting the Rehabilitation Resource Center at (800)468-7777.

Renal Rehabilitation: Employment at a Glance



Perform a Vocational Assessment

A thorough patient assessment, including vocational and educational history, will help you determine how to allocate your facility resources. A comprehensive, multidisciplinary patient assessment should include information about the patient's past, current, and desired future vocational activities, including work,

school, homemaking, and volunteer activities. Other social activities should be noted as well. Ask patients about their goals and note them in the patient's record. The table below is an example of how to organize this information at a glance.

Table: Patient Vocational Status Checklist

Past Vocational Status	Current Vocational Status	Future Vocational Goal
<input type="checkbox"/> Employed full-time as _____ <input type="checkbox"/> Employed part-time as _____ <input type="checkbox"/> In school full-time for _____ <input type="checkbox"/> In school part-time for _____ <input type="checkbox"/> Full-time homemaker <input type="checkbox"/> Part-time homemaker <input type="checkbox"/> Volunteer _____ <input type="checkbox"/> Active Retiree	<input type="checkbox"/> Employed full-time as _____ <input type="checkbox"/> Employed part-time as _____ <input type="checkbox"/> In school full-time for _____ <input type="checkbox"/> In school part-time for _____ <input type="checkbox"/> Full-time homemaker <input type="checkbox"/> Part-time homemaker <input type="checkbox"/> Volunteer _____ <input type="checkbox"/> Active Retiree	<input type="checkbox"/> Employed full-time as _____ <input type="checkbox"/> Employed part-time as _____ <input type="checkbox"/> In school full-time for _____ <input type="checkbox"/> In school part-time for _____ <input type="checkbox"/> Full-time homemaker <input type="checkbox"/> Part-time homemaker <input type="checkbox"/> Volunteer _____ <input type="checkbox"/> Active Retiree
<input type="checkbox"/> On disability: <input type="checkbox"/> SSI <input type="checkbox"/> SSDI <input type="checkbox"/> Other	<input type="checkbox"/> On disability: <input type="checkbox"/> SSI <input type="checkbox"/> SSDI <input type="checkbox"/> Other	<input type="checkbox"/> On disability: <input type="checkbox"/> SSI <input type="checkbox"/> SSDI <input type="checkbox"/> Other
VR STATUS	VR STATUS	VR STATUS
<input type="checkbox"/> Applied ____/____/____ <input type="checkbox"/> Accepted <input type="checkbox"/> Enrolled <input type="checkbox"/> Denied ____/____/____ <input type="checkbox"/> Follow-up _____	<input type="checkbox"/> Applied ____/____/____ <input type="checkbox"/> Accepted <input type="checkbox"/> Enrolled <input type="checkbox"/> Denied ____/____/____ <input type="checkbox"/> Follow-up _____	<input type="checkbox"/> Applied ____/____/____ <input type="checkbox"/> Accepted <input type="checkbox"/> Enrolled <input type="checkbox"/> Denied ____/____/____ <input type="checkbox"/> Follow-up _____

Besides the checklist, a variety of other factors to help you assess your patients' vocational status are described below.

Consider Education Level

Patients with more education are more likely to be able to work. An associate, college, or advanced degree increases worth in the job market and improves earning potential. Specialized blue-collar skills are also a valuable commodity, as are a positive attitude and proven ability to learn. On the other hand, illiteracy is a detriment that must be addressed prior to vocational rehabilitation. Local literacy agencies may be able to help.

Review Past Work History

Past work history has been shown to predict future employment status for dialysis patients (Curtin et al, 1996). Workers whose skills transfer easily to other positions are more likely to stay employed or find new jobs, and "essential" workers, such as managers, may return to work sooner than other white-collar workers (Friedman and Rogers, 1988). White-collar workers may return to work more easily than blue-collar workers because their work is not physically strenuous and their higher incomes outstrip disability payments (Holley & Nespor, 1994). However, blue-collar workers can also return to work *if education and support are provided early enough* (Richardson, 1986; Rasgon et al, 1993).

Assess Physical Functioning

Many studies report that dialysis patients have physical functioning—strength, flexibility, and endurance—below that of the general population. A minimal level of fitness is required for even the most sedentary work. Dialysis patients with chronic anemia are too fatigued for normal activity—or for rehabilitation. One pre-EPOGEN® (epoetin alfa) study found that 23 percent of

non-diabetic and 60 percent of diabetic dialysis patients were incapable of doing anything more physically demanding than caring for themselves (Gutman et al, 1981). While many patients are now able to be more active with appropriate dosages of EPOGEN® and improved dialysis technology, you will need to match patients' physical functioning with their vocational goals. (See the Exercise module of this Guide for more information on assessing physical functioning.)

Check Military Service Record

Veterans of the armed forces receive additional points on many government civil service examinations, and may be eligible for additional vocational rehabilitation services as well.

Assess Workplace Support

Employed patients who are satisfied with their jobs are more likely to continue working. One study found that patients' coping ability, perception of their illness, and perceived support from their supervisors were positively related to how they viewed their jobs (Antonoff and Mallinger 1989). Ask your patients how supportive their workplace is.

Identify Dialysis Staff and Family Expectations

In a national survey of working and non-working dialysis patients, Curtin et al (1996) found that patients who believed that their *family and dialysis team supported their decision to work* were more likely to be employed after beginning dialysis. Physicians and nurses often rate patients' commitment to rehabilitation, energy, social functioning, and quality of life lower than patients rate themselves (Meers et al, 1995). Examine your own attitudes—and teach family members and staff that they are doing a disservice by discouraging patients from working.

Triage Patients According to Vocational Status

After you have assessed vocational status, it is helpful to triage your patients into three groups. Group one is *currently employed or in school*. This group is the top priority because they are continuing their usual activities, and thus may not require formal rehabilitation. When appropriate, encourage these patients to *keep working or stay in school*, even if accommodations are necessary, to maintain their quality of life and reduce the disruptive effects of kidney failure.

The second group of patients are not currently working but have past work experience and future goals compatible with vocational activities; they are *able and willing to work or attend school*. This group is priority two: they will need staff time for coordination and assistance, but their successes will likely make your efforts worthwhile.

Group three is non-vocational, due to poor or unstable health, advanced age, or lack of interest. These patients are unlikely to work or attend school, although they may be able to perform volunteer or community activities. Formal vocational rehabilitation is probably not appropriate for them. Instead, focus on improving

functional status to enhance their ability to live independently, allow higher activity levels, and renew life satisfaction. A marked increase in their quality of life can come through volunteer activities, travel, exercise, active pursuit of hobbies, community activities, and other activities.

Perform a Unit Self-assessment

Once you have grouped your patients into the three categories, decide what kinds of rehabilitation activities to implement. Completing the *Unit Self-Assessment Tool for Renal Rehabilitation* (USAT) for the Employment “E” (Appendix A in this module) will identify your current rehabilitation activities, and suggest additional activities that might fit into your overall plan. If you are just beginning a program to help dialysis patients improve their employment opportunities, choosing rehabilitation strategies at the basic level will probably be the easiest. If you are adding to an existing program, you will find that the intermediate and advanced activity levels of the USAT criteria have useful ideas.



K

Keep Working Patients Employed and Students in School

The paramount goal for patients who are working or in school is to keep them there. While some patients can keep working without interruption, uremia and adjustment to dialysis will require many working patients or students to take some time off. The longer patients are absent from work or school, the less likely it is they will return. Therefore, *time is of the essence*. Talk to patients about work and school plans as soon as possible, preferably before they begin dialysis. Providing early rehabilitation activities to maintain patients' employment through their period of adjustment to dialysis is a very important advanced rehabilitation strategy (EM-17).

Educate Working Patients About Dialysis

Some patients may not realize that it is possible for them to continue working after they begin dialysis. The possibilities of workplace accommodations, such as a change to a less physically demanding position, more break time, or even providing a chair instead of standing for an 8-hour shift may not have occurred to them. Patients with severe uremia may also not realize that they will feel better in a few short weeks. In addition, many patients believe that working may further jeopardize their health. Informing patients, families, and employers about the usual course of adjustment to dialysis and the possible accommodations that can be made for dialysis patients are solid basic rehabilitation strategies for the Employment "E" (EM-4).

Strategies to help workers keep their jobs:

- Reassure patients that they *will* feel better once they are no longer severely uremic. Patients should delay permanent decisions about their jobs until they become accustomed to dialysis and begin to feel better.
- Recommend that patients consider a *brief* period of disability (if necessary) rather than quitting their jobs and losing income, health insurance benefits, and self-esteem.
- Assure patients that Medicare benefits (once begun) are related to their kidney failure, not to disability. Working will not jeopardize these medical benefits.

- Offer to contact the employer (at the patient's discretion) to explain kidney failure and its effects (EM-12). Overcoming employer misconceptions can go a long way toward securing the positive support from a supervisor that makes the workplace a more pleasant place to be.
- Investigate work/school accommodations with your local Department of Vocational Rehabilitation, if necessary for the patient to continue working (EM-8). Patients may be covered by the Americans with Disabilities Act which requires "reasonable accommodations," which may include seating, extra breaks, flexibility in scheduling, or a clean room and time to perform PD exchanges.

Expect Students to Stay in School

Adult students have both a self-esteem and a financial stake in completing educational programs they begin. Some adult patients take classes to complete their GED, others attend college full- or part-time. Dropping classes for health or scheduling reasons is demoralizing, financially detrimental, can prolong the education process, and could reduce the patient's future earning capacity. As a dialysis professional, your positive expectations for student patients are key to their continued enrollment in school. Establish a facility expectation that dialysis alone is not a reason for permanent withdrawal from a school program, although temporary interruptions may be necessary. School-age children on dialysis should attend school regularly, avoiding homebound instruction unless it is absolutely necessary. Children derive both educational and psychosocial benefits from school, just as adults do from work. Getting behind in classwork places a child at risk of failing, which harms self-esteem and may reduce future educational aspirations and earning power. Psychological problems have commonly been reported among children on dialysis, particularly at adolescence. Support from family and dialysis staff to continue school is important for children and adolescents.

Strategies to expect students to stay in school:

- Suggest that patients use dialysis treatments as quiet time to complete classwork so free time can be used for recreation and other family responsibilities.

Case Study:

Promoting Patient Education and Understanding at Kaiser Permanente

At Kaiser Permanente in Los Angeles, an early education and support program helps patients keep their jobs. Each of the center's current 71 peritoneal dialysis and two home hemodialysis patients are seen monthly in clinic by a multi-disciplinary team that evaluates and adjusts their treatment and care plan. Patients receive educational materials prior to initiating dialysis and also participate in educational classes.

Flexibility is key to the program's success. Clinic visits are scheduled one month in advance to permit patients time to adjust their schedules, if necessary. Staff members have staggered hours to better accommodate patient needs, and phone support is available.

Patients are encouraged to exercise to promote well-being, help cope with stress, burn extra calories absorbed from the PD dialysate, and maintain fitness for employment. In addition, employers are educated about the likely needs of dialysis patients, and job site visits by the nurse

provide an opportunity for questions and examination of the worksite for suitability for PD exchanges.

Of the 71 patients on home hemodialysis in September, 1997, at Kaiser, 33 were working full time when they began dialysis. Twenty-eight of these patients maintained their jobs and schooling, for a job-retention success rate of 80 percent. The success rate is even higher if one considers that 3 of these patients became age-retired after onset of dialysis. According to Home Dialysis Coordinator Brenda Chemleski, RN, "The staff work together to breathe the expectation of success into patients. Often patients come to us with their confidence shaken, unsure of what they are capable of doing. The encouragement and support that is so integral to our program bolsters them and helps carry them through their period of uncertainty."

The center's Home Dialysis Program won an *Exemplary Practices* award for *Employment* from the Life Options Rehabilitation Advisory Council in 1995.

- Encourage adult students to communicate with you about their class and exam schedules, which may change each semester.
- Schedule dialysis and clinic visits to permit full-time school attendance (EM-18).
- Work with parents to educate school staff about the child's needs.
- Advocate for a child with the school system, especially if cooperation from teachers or school nurses is lacking. Under the Individuals with Disabilities Educational Act (IDEA), the educational system must serve children with disabilities in the least restrictive setting.

Provide Flexible Dialysis Schedules

Imagine the distress of patients who are beginning dialysis and worrying about how their lives will change. Imagine further how the fear and sense of loss are compounded when they learn that they must quit a job or school because there is no compatible time slot in the dialysis schedule. The purpose of dialysis is to enable patients to remain functional, yet some patients have complained that facilities operate more for the convenience of the staff than the patients. Providing a dialysis schedule that allows the flexibility necessary for patients to pursue employment or school is essential for patients' quality of life, and constitutes an advanced rehabilitation strategy for employment (EM-18).

Strategies to provide flexible dialysis schedules:

- Encourage patients to seriously consider medically appropriate home dialysis. Remind them that home hemodialysis and PD modalities are patient-scheduled (EM-2).
- Ask less active patients to trade dialysis times or establish a request list based on vocational priority. Patient packets should contain information about the shift prioritization process to reduce complaints from patients who are "bumped."
- Assign first priority for selection of in-center dialysis shifts to patients who are working or in school, and second priority to patients who have compelling transportation needs or other important life activities and responsibilities.

- Add early morning or early evening shifts (EM-18). Self-care shifts reduce staff time; motivated patients can learn to do machine set-up and clean-up, needle insertion, and treatment monitoring.

Begin a Mentor Program

Most new dialysis patients do not know anyone else on dialysis, and their impressions from the popular media may be dismal. Providing positive patient role models can be an effective way to keep employed patients working and encourage other patients to make vocational gains. Patients who see that other patients are successful in the workplace are more likely to believe an active lifestyle is possible.

Strategies to begin a mentor program:

- Feature employed patients on your facility's bulletin board so their successes can be shared and enjoyed by everyone (EM-1).
- Assign a successfully rehabilitated "buddy" to new dialysis patients. Try to match patients with similar vocational abilities.
- Form patient support groups (EM-11). (See the Encouragement module of this Guide for more information about patient support groups.)
- Invite working patients to speak to patients on other shifts at your facility.

Use the Family and Medical Leave Act

The Family and Medical Leave Act may cover certain brief sick leaves for patients who have worked long enough (1,250 hours in the last year) at a company site with 50 or more employees within a 75 mile radius. This law allows the patient up to 12 weeks off per year at one time or in increments without jeopardizing the job, benefits, or chances for advancement. Patients should inquire with their employer about the availability of leave and procedures for applying for leave. Individual arrangements must be made if the patient works for a smaller employer or has not worked enough hours to qualify.

Help Able and Willing Patients to Work or Attend School

Patients who are currently unemployed but are physically able and willing to work or attend classes may need assistance to address loss of disability benefits, clarify life goals (EM-6), obtain job skills training (EM-8, EM-13), market to prospective employers, answer employer concerns (EM-3, EM-4, EM-12), and use placement services (EM-16). Providing information to patients, families, and employers are basic rehabilitation strategies. Communicating directly with patients' employers and actually connecting patients with jobs are intermediate and advanced strategies, respectively. Realistic goal-setting will rely on a careful evaluation of each patient's overall vocational situation.

Address Loss of Disability Benefits

Loss of federal disability benefits is a primary fear of many dialysis patients who contemplate working. However, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits have work incentive programs to ease patients off disability gradually. The local Social Security office has numerous publications available on work incentives for disability recipients. Many larger Social Security offices also have a Work Incentive Liaison (WIL) who knows about programs appropriate for dialysis patients and may be willing to speak to patients or staff at your facility. An explanation of SSI and SSDI is included at the back of this module as Appendix B.

In addition, a number of dialysis-related costs, such as medications, PD supplies, and others can be deducted from a disabled patient's earnings as "Impairment-Related Work Expenses" that reduce the patient's loss of cash benefits. A list of Impairment-Related Work Expenses can be found at the back of this module as Appendix C.

Some dialysis patients incorrectly fear that they will lose their Medicare health insurance if they return to work. However, Medicare coverage under the Medicare ESRD program continues *regardless of employment status*, as long as dialysis is needed.

Strategies to address loss of disability benefits:

- Reassure patients that they do not risk loss of Medicare health coverage if they return to work.
- Invite your renal social worker or a Social Security expert to visit a group of your "willing and able" patients to discuss their benefit concerns.
- Help patients calculate their potential earnings and compare them to the amount of their disability checks. For more information on making this comparison, request the *Employment: A Guide to Work, Insurance, and Finance* booklet from the Life Options Rehabilitation Resource Center, (800)468-7777.

Clarify Patients' Work Goals

Once they are medically stable, some patients may need to re-evaluate and adjust their work goals. For example, a military or sports career may no longer be possible. Rebuilding a life affected by chronic illness can be difficult and painful. Although chronic renal failure and dialysis limit some options and require discipline, most of the individual's capacities remain. Patients who come to terms with their illness and move on may find a new appreciation for life—and a willingness to consider new employment or school options.

Strategies to clarify patients' work goals:

- Encourage patients to think about their ideal work lives and steps they can realistically take to move closer to that ideal.
- Have patients write down every job that sounds interesting or appealing, then help them look for characteristics the jobs have in common.
- Suggest that patients break down ambitious goals into manageable steps. For example, to eventually become a nurse, a patient might first try a refresher chemistry course.
- Refer appropriate candidates who still have difficulty clarifying their goals to your local Vocational Rehabilitation (VR) office for evaluation of employment or training avenues (EM-8, EM-10).
- Hold a "Job Fair" by inviting a number of presenters from various work fields (EM-14).

Facilitate Job Skills Training

Patients need to understand the employment market to determine whether their skills are in demand or if they need additional skills to obtain employment. Patients with job skill deficits may become more employable with vocational rehabilitation training or relevant volunteer work.

Vocational Rehabilitation

Offices of Vocational Rehabilitation (VR) are located throughout the country to help persons with mental and physical disabilities find and keep jobs, by providing assessment, training, placement, and adaptation. To obtain VR services, patients must have the potential to obtain work and be able to show why they cannot get work by themselves.

Dialysis patients are considered “severely impaired” by diagnosis, and therefore are a priority classification for VR services. However, very few dialysis patients have been referred to VR, and VR has historically underserved the patients who were referred. One reason for the underservice may be because VR counselors are evaluated based on numbers of successfully closed cases (patients employed for 90 days), and counselors may erroneously perceive dialysis patients as terminally ill (“end-stage”) or unable to be helped. A second reason may be a lack of understanding of renal failure and dialysis on the part of VR counselors, a problem that can be addressed through education.

Volunteering

Patients can gain valuable work skills, job connections, and socialization from volunteer positions, all while helping a worthy organization. Many communities have a volunteer coordination center or newspaper listing; if not, the patient can contact agencies that are of particular interest.

Strategies to facilitate job skills training:

- Develop a list of volunteer positions and post them on your facility’s bulletin board so patients can obtain skills.
- Invite the VR counselor to speak to patients and staff about services available to help them become more marketable.
- Contact your local VR office to learn how to make appropriate referrals and to determine what must be included in the referral to speed processing.
- Develop a list for VR of employment problems the patient has encountered.
- Understand the VR process and the patient’s motivation to follow through on appointments and recommendations before you make a VR referral.
- Learn how to help patients file appeals if VR rejects individuals you believe are good candidates.
- Develop a liaison relationship with the VR counselor in your area and offer to educate the individual about the special needs of dialysis patients (EM-8).

Teach Self-marketing Techniques

Patients who want to work may need to learn how to market themselves to potential employers, (e.g., by writing a resume or practicing interviewing skills). Patients with limited work skills or experience may need practice filling out job applications, but may not require a formal resume.

Strategies for teaching self-marketing techniques:

- Ask patients to list characteristics that would make them good employees.
- Recommend that patients role-play interviews with friends, family members, or other patients. Provide a list of commonly asked interview questions.
- Collect sample job applications for patients to practice on. Provide feedback. Make sure the patients are representing themselves in a positive accurate light.
- Refer the patient to a VR counselor, job placement service, or local college placement office to obtain help with a resume and job interview skills (EM-8).
- Suggest that patients with employment gaps consider writing “functional” resumes listing skills and where they were obtained, rather than chronological sequences of jobs (EM-9).

Case Study:

The Texas Rehabilitation Commission is Committed to Patient Employment

How did the Texas Rehabilitation Commission (TRC) win the 1994 Life Options Rehabilitation Advisory Council *Exemplary Practices* award for *Employment*? By combining a creative program for employment of dialysis patients with a dedicated counselor: Lucy Endermark.

Endermark has a general caseload that includes renal patients and is required to successfully close 50 cases a year. Despite this daunting task, she responded with enthusiasm, energy, and creativity when asked by Network 14 to become more involved with the patients in her region.

Endermark developed a successful strategy for identifying clients who may benefit from VR services. She regularly contacts 20 dialysis centers and the Dallas Transplant Institute, to talk with new staff, faxes referral forms, and provides information on TRC's services.

In addition, Endermark attends meetings of renal social workers and is available to answer questions. When patients show any interest in VR services, she requests that the social worker complete a referral and send it to her. She then contacts the client and provides facility social workers with regular feedback on progress.

Her counseling style focuses on a client's interests, abilities and ambitions. By focusing on the positive and helping them gain more control in their lives, clients again see themselves as productive and able to contribute to their families and communities.

During the past year, Endermark has helped over 30 renal patients become employed—giving these people a chance at an independent future. A future with hope.

Encourage Job Searches

Newspaper ads are not ordinarily the best way for dialysis patients to find employment; networking can be a more effective approach. Sources to use when networking include relatives, friends, acquaintances, business colleagues, federally funded employment resources, and social acquaintances.

Strategies to encourage job searches:

- Have patients develop a list of people to inform of their job search criteria.
- Suggest that patients research potential employers and write a letter to ask about job availability.
- Recommend that patients who worked in professional fields read journals or newspapers relevant to their area to look for job announcements.
- Advise would-be students to contact financial aid offices to learn about funding assistance.
- Contact your local federally-funded job service agency for assistance.
- Subscribe to state and federal job listings. Government jobs can offer excellent benefits, including health insurance that covers pre-existing conditions. A civil service test may be required; many libraries carry books to help with these exams.
- Contact temporary agencies about openings that may lead to jobs.
- Contact VR for assistance with job placement.

Request Necessary Accommodations

In some cases, patients who did not return to work cited the need for accommodations and the fear that their employer would not be willing to make them (Friedman & Rogers, 1988). However, even before the Americans with Disabilities Act, a study found that two-thirds of patients who returned to work had employers who made accommodations for their illness, such as adjusting hours, allowing more breaks, shortening the

work day, and changing job responsibilities (Friedman & Rogers, 1988). An IBM study found that 50 percent of workplace accommodations were free and another 30 percent cost less than \$500 (Frierson, 1990). This information should dispel the myth that workplace accommodations are costly.

Strategies to request necessary accommodations:

- Encourage patients to role-play requests for accommodations with family members, friends, or social worker acting as the employer before requesting accommodations of the real employer. Role-playing will help patients practice addressing possible employer concerns and may help them to be more assertive about their rights under the ADA.
- Accumulate information about the ADA, learn how it applies to specific situations, and provide it to interested patients.
- Request that VR act as a liaison for patients who are uncomfortable requesting accommodations from a prospective employer (EM-8).

Address Negative Employer Attitudes

Most working dialysis patients have reported few problems keeping their jobs—in fact, half the patients in one study were given more responsibility after starting dialysis (Antonoff & Mallinger, 1989). However, employers may fear that dialysis patients will not be productive employees. Concerns to address include absenteeism and the cost of health insurance.

Concerns about Absenteeism

Employers who were interviewed reported concerns about health setbacks and productivity of dialysis patients. They were more likely to re-hire a former worker who now has kidney failure than to hire a new employee with ESRD (Friedman & Rogers, 1988). According to VR data, however, only 5 percent of all workers with disabilities had worse-than-average absenteeism, while 55 percent had a *better* than average attendance record (Frierson, 1990).

In addition, 91 percent workers with disabilities had higher-than-average productivity (Frierson, 1990). Specific to dialysis, Friedman & Rogers (1988) found that in the first 6 months after returning to work, 47 percent of new patients had not missed a single work day. Patients who had missed work due to illness averaged less than one sick day per month. Patients may be so grateful to have a chance to prove themselves as employees that they may work *harder* than other employees.

Staff turnover is another typical employer concern. Many employers are reluctant to hire workers with disabilities, including dialysis patients, because they fear they will incur large training costs and then lose the employee. In reality, 88 percent of employees with disabilities had lower-than-average turnover rates (Frierson, 1990).

Strategies to address negative employer attitudes:

- Conduct a survey among your working patients on the number of days missed due to illness in the last year, work evaluations, and attitudes about working.
- Write a “fact sheet” to educate employers about dialysis patients as workers (EM-4).

Cost of Health Insurance

A General Accounting Office patient survey looked at the effects of requiring employer group insurance to be the primary payer for the first 18 months of dialysis. Some patients reported that they were discriminated against for insurance reasons, particularly if they worked for small companies. Patients who remained employed were more likely to work for companies with 100 or more employees (GAO, 1992).

The Americans with Disabilities Act forbids covered employers from discriminating against covered employees with a disability in the terms and conditions of employment including medical insurance and benefits. Patients who work for larger employers may have better health benefits and lower premiums because the illness risk for the insurer is spread across more employees.

Working or non-working patients over age 65 may be able to obtain Medicare supplement (Medigap) coverage because federal legislation limits waiting periods for pre-existing conditions and prohibits companies from refusing to insure the elderly. Medigap policies pay the 20 percent of Medicare-covered services that Medicare does not; some policies also cover services Medicare doesn't.

Some employed patients who would like to change jobs have been hampered by their fear of losing insurance benefits and not being covered under a new employer's policy. The Health Insurance Portability and Accountability Act of 1996 (PL 104-91) should provide patients with health risks similar flexibility in changing jobs as healthy individuals.

Strategies to address health insurance questions:

- Refer patients without health insurance to the renal social worker, who will review insurance options with the patient and family.
- Determine if working patients qualify for Medicaid under Section 1619(b) by calling your local Medicaid office.
- Call the State Insurance Commissioner's office to learn if the patient's state has high-risk insurance to cover medications and/or supplement Medicare coverage for dialysis. Ask about premiums and waiting periods. Check back periodically.
- Call the State Insurance Commissioner's office to obtain a list of companies that sell individual and group health insurance to persons under or over age 65 with pre-existing conditions. Share this list with patients and families.

*M*aximize Functional Status of Non-vocational Patients

Some patients, for a variety of reasons, do not want to or are unable to work full- or part-time. VR statistics frequently overlook patients who continue to function successfully in the unpaid but essential role of homemaker. Performing household tasks can give patients a sense of purpose in the family. Some retired or disabled patients perform childcare with or without pay, allowing other family members to work. Others volunteer regularly in their churches and communities. Maximizing functional status—the ability of patients to carry out their usual roles and activities—is the goal for this group.

Physical and emotional health can fluctuate from day to day in dialysis patients, depending on the level of toxins in their blood, effects of treatment, emotional adjustment, and other health conditions. Recognize that all these factors will affect a patient's activity level, but also remember that studies have shown that health-care professionals underestimate what patients can do, which can limit patients' expectations for themselves (Meers et al, 1995).

A recent study noted that elderly patients were less likely to participate in social activities after they started dialysis. Social isolation for diabetic patients was even worse than for other dialysis patients (Ifudu et al, 1994). Regardless of age or suitability for formal vocational rehabilitation, quality of life depends on patients' ability to participate in desired activities.

As suggested in the USAT, even vicarious participation in work-related activities such as grooming or “dress for success” presentations can contribute to the frame of mind and quality of life of patients who are not candidates for employment. Rehabilitation efforts for patients who are not VR candidates can include a number of possibilities, some of which are outlined below.

Promote Physical Activity

Most employment, school, or volunteer activities require a certain minimum level of strength and stamina. Dialysis patients may participate in a structured fitness program using a treadmill, weight-lifting, or exercise bike; take an aerobics or Jazzercise® class; or walk or play golf with a friend. Refer to the Exercise module of this Guide for ideas about improving fitness.

Facilitate Travel

Some dialysis patients enjoy traveling. Others probably would if they felt comfortable dialyzing away from home or away from their usual center. Patients may needlessly stop traveling because they worry whether the care at another facility will be comparable or whether they can pay for dialysis away from home. The social worker can relieve the patient's anxiety by explaining how transient arrangements are made and how dialysis prescriptions are shared with other facilities.

Strategies to facilitate travel:

- Ask facility patients who travel to share photos and their positive experiences with transient dialysis in your facility newsletter or on a bulletin board (EM-1).
- Teach patients how to arrange transient dialysis or have PD supplies shipped to their destination (EM-2).
- Inform patients about available lists of dialysis facilities worldwide that can help them plan trips outside their local area.
- Have the renal social worker or dialysis travel coordinator speak to patients or write a column in the facility newsletter about how to arrange trips (EM-14). Be sure to cover payment considerations for dialysis away from home.
- Collect and maintain a binder of current brochures about dialysis-friendly vacation sites, including cruises, and tell your patients about it.

Suggest Volunteering

Many community and non-profit organizations recruit volunteers to provide essential services. You may not be aware of how many of your patients already do some form of volunteer work. Patients may be active in parent-teacher organizations, school sports, churches, political organizations, local hospitals, or their AAKP or NKF affiliate. Patients report that these activities help them to feel worthwhile.

Strategies to suggest volunteering:

- Post photos of patient volunteers on a bulletin board to encourage other patients (EM-1).
- Maintain a list of community organizations seeking volunteers (EM-13).
- Call the United Way or Volunteer Center in your community about presenting volunteer options to patient groups (EM-16).

Encourage Hobbies

Both healthy and chronically ill people enjoy hobbies. Patients can perform many of their favorite activities while on dialysis in a facility or at home. Participating in a hobby can be a great way for a dialysis patient to interact with other family members and friends or to alleviate boredom. Patients receive satisfaction from completing projects and socializing with family and friends.

Strategies to encourage participation in hobbies:

- Talk to patients about reviving old hobbies or finding new ones.
- Suggest that patients work on portable hobbies during dialysis.
- Find a family member or volunteer to give simple craft demonstrations during dialysis and provide materials for patients to try the craft themselves.
- Arrange a craft sale of patient and staff creations. Target the money toward patient exercise equipment or some other mutually agreed-upon goal.

Evaluate Progress Toward Goals

The HCFA Conditions for Coverage for ESRD facilities charge the Networks with monitoring patient rehabilitation status and encouraging vocational rehabilitation in dialysis facilities. Patient care planning must occur every 6 months for stable patients, and every month for unstable patients. Vocational rehabilitation can improve social and psychological adaptation. Because poor social and psychological adaptation are predictors of mortality, dialysis teams should address social, psychological, and vocational rehabilitation as part of patient care planning to assure quality care.

Measure Individual Progress

Regularly assess progress toward patients' identified vocational and non-vocational goals. Discuss each patient's progress at regular team meetings and allow team members, including patients, to offer suggestions to improve progress. Praise patient accomplishments. Remember that patients may move from one group to another, so you will need to re-evaluate interest and ability for pursuing employment or non-vocational goals.

Evaluate Your Program

A very basic way to begin to evaluate your program is to examine your individual results across patients to look for patterns, for example, in the numbers of patients employed or in the outcomes of your VR referrals. If you learn that only a small number of patients you refer to VR receive appropriate services, you can develop steps to address the problem, in this case, perhaps by speaking with a VR supervisor to offer education about your patients' strengths and

needs, or offering a facility tour to VR personnel. Helping your patients to achieve their vocational and non-vocational goals will make your daily work more fulfilling while helping your patients live more fulfilling and active lives.

Since there are so many diverse barriers to employment for dialysis patients, you might want to use some other criteria to evaluate your program besides the number of patients who have found jobs since you began. Other appropriate outcomes to consider include patients' physical functioning, their social and role functioning, and their mental well-being. These dimensions of patients' health-related quality of life are measured by instruments such as the Kidney Disease Quality of Life (KDQOL™) tool. Although patients may not become employed as a result of your employment-related rehabilitation activities, they may still show improvement in other areas of functioning. Please refer to the Evaluation module of this Guide for more information and suggestions about program evaluation.

Assess the Costs of Your Program

Finally, cost tracking is an activity every rehabilitation program should undertake. Our goal of making renal rehabilitation a routine part of ESRD patient care can only be realized when the costs of various activities are available. A good way to begin to collect critical information about renal rehabilitation costs vs. benefits is for each unit to keep track of its own rehabilitation-related costs and outcomes. In this way, facilities will eventually be able to project rehabilitation expenses and better plan strategies and initiatives based on available resources.

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Appendix A: USAT Employment Criteria

BASIC REHABILITATION INTERVENTIONS:

Score 1 point for each “yes” answer

- EM-1 ___ Do you have a centrally located bulletin board featuring employed/rehabilitated patients?
- EM-2 ___ Do you inform patients about choices of treatment modalities to accommodate their work and life interests?
- EM-3 ___ Do you provide any kind of information about ESRD to your patients’ employers?
- EM-4 ___ Do you provide information to patients and their employers about accommodations that must be made in the workplace for ESRD patients?
- EM-5 ___ Do you provide information for families about patients’ potential to continue working and the benefits of working?
- EM-6 ___ Do you regularly conduct “informal” screening for employment status or potential?
- EM-7 ___ Does your unit have/provide any other employment-related activities that are not covered above?

INTERMEDIATE REHABILITATION INTERVENTIONS:

Score 1 point for each “yes” answer

- EM-8 ___ Do you have an ongoing relationship with the VR agency to facilitate patients’ retraining or job placement?
- EM-9 ___ Do you provide any job-seeking skills training, such as resume writing, interviewing techniques, or “dress for success” information?
- EM-10 ___ Does your unit automatically refer all working-age patients to VR?
- EM-11 ___ Do you have any in-center employment support groups?
- EM-12 ___ Do you sponsor or provide for any direct staff communications with patients’ employers?
- EM-13 ___ Do you have any relationship with a “temporary employment” service for potential training or jobs?
- EM-14 ___ Do you support/sponsor regular interactive sessions among staff and patients about the importance of employment?

ADVANCED REHABILITATION INTERVENTIONS:

Score 1 point for each “yes” answer

- EM-15 ___ Do you conduct formal screening of patients for employment status/potential?
- EM-16 ___ Do you have any mechanism or program to connect patients with jobs?
- EM-17 ___ Do you provide any early interventions (predialysis or within first 6 weeks) to help patients keep their jobs?
- EM-18 ___ Do you provide for individualized flexible dialysis scheduling (i.e., treatments beginning after 5 pm; weekend dialysis; self-care opportunities; separate shift for working patients; and/or priority scheduling for working patients)?
- EM-19 ___ Do you track the outcomes or results of your employment-related initiatives?
- EM-20 ___ Do you track the costs associated with your employment-related activities and program?

_____ ***SUBTOTAL (20 possible)***

Explanations of USAT Employment Criteria

BASIC: EM-1 TO EM-7

EM-1: Providing a bulletin board is a simple and basic intervention with the potential for positive patient impact with regard to employment and overall engagement in life. Job opportunities, volunteer work, community social activities, and unit-based activities can be posted in a central location.

EM-2: Many patients are accustomed to passively accepting whatever treatments are suggested by health-care providers. Simply informing patients that there *are* choices of modality and scheduling may improve the chances for them to seek/retain employment or participate actively in life.

EM-3: Educating employers of ESRD patients may mean the difference between continued employment and unemployment. If employers are aware of the true scope of ESRD patients' limitations and capabilities, they can formulate realistic expectations for their employees with renal disease.

EM-4: Employers have concerns about the potential impact of having an employee with ESRD. Providing information to employers about the necessary accommodations for dialysis patients may defuse such fears—the accommodations may not be as extensive or costly as employers might think.

EM-5: Educating families about patients' potential for employment is a useful strategy because research has shown that families' attitudes toward employment have a great deal of influence over whether patients are likely to be employed.

EM-6: Informal screening of patients for employment potential or status may uncover problem areas early enough to intervene before employment is lost, before activities are constrained, and/or before habits of inactivity are established.

EM-7: There are many other simple activities which might be undertaken to encourage employment/active lifestyle in dialysis patients. Any other methods or activities which you have identified can be credited here.

INTERMEDIATE: EM-8 TO EM-14

EM-8: Regular contact and an ongoing relationship between the dialysis facility and the local office of Vocational Rehabilitation increase the likelihood that patients will receive appropriate intervention and follow-up for employment. A designated unit staff person should make the effort to establish such a relationship and a continuing dialogue with at least one VR counselor.

EM-9: Having or sponsoring activities related to employment, such as grooming tips and resume writing, helps to make able patients "job-ready." Such activities also help other patients who might be unable to work feel like they are still a part of the mainstream—it helps to keep them interested and in touch with the world of employment.

EM-10: If an automatic referral system is in place, all patients will be guaranteed the chance to consider work or educational placement/assistance. Patients may surprise themselves and dialysis staff by doing more than was initially expected.

EM-11: A support group devoted to employment and related issues will provide the opportunity for employed patients to share their triumphs and their frustrations with others who understand. Patients who are unemployed can participate as well and can vicariously experience the workplace.

EM-12: Regular direct contact (authorized by the patients) between employers and dialysis staff can help to smooth over difficulties and nip potential problems in the bud. Contact helps to keep the employer committed to the employee and allows the chance for questions that arise about dialysis to be addressed.

EM-13: Temporary employment through an agency often provides flexibility for ESRD patients, allowing them to work variable hours, or at irregular times, without jeopardizing their disability status. An ongoing relationship between dialysis staff and a temporary employment agency facilitates the placement of patients in available positions.

EM-14: In addition to the obvious benefit of providing information for patients, planned opportunities or occasions for staff to talk with patients about employment convey a sense of the importance of employment as well as the real possibility of employment to patients.

ADVANCED: EM-15 TO EM-20

EM-15: Formal screening of patients for employment status/potential can identify their willingness and/or ability to be employed, their desires or preferences for types of work, and proficiencies and deficiencies, i.e., areas in which re-training is indicated.

EM-16: An example of a program or mechanism to connect patients with jobs would be a facility's relationship with specific employers who are willing to hire dialysis patients. To develop a connection of this type, staff might contact local employers to solicit their interest and then fill any positions obtained with dialysis patients who have expressed/demonstrated willingness and ability to work.

EM-17: Research has demonstrated that jobs held before dialysis can be maintained with early interventions. The interventions applied included such strategies as patient and family counseling and education, employer contact and education, etc.

EM-18: Providing flexible dialysis scheduling, evening or early morning shifts, or preferential shift choice individualized for workers and students goes a long way toward allowing and encouraging dialysis patients to maintain employment or school enrollment.

EM-19: Outcomes assessment is an essential component of any rehabilitation intervention. In order to know whether an activity is really worthwhile, its results or impact must be carefully evaluated. To meet this criterion, outcomes must be measured regularly using a unit-developed or standardized assessment tool.

EM-20: It is essential that the costs associated with facilitating renal rehabilitation be known. To this end, cost tracking should be performed whenever a rehabilitation activity is undertaken. Any system of cost tracking or monitoring which allows an estimate of all expenditures involved with a particular activity (time, materials, etc.) fulfills this criterion.



Appendix B: Work Incentives for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)

Special rules make it possible for people with disabilities who receive Social Security or Supplemental Security Income (SSI) to work and still receive monthly cash payments and Medicare or Medicaid. Social Security calls these rules “work incentives.”

The rules are different for Social Security beneficiaries and SSI recipients. Following are the rules that apply to each.

SSDI

Trial Work Period

For nine months (not necessarily in a row), the earnings of a disabled or blind Social Security beneficiary will not affect his/her Social Security benefit as long as the worker continues to meet the medical requirements for disability.¹

Extended Period of Eligibility

For three years after a successful trial work period (TWP), a disabled or blind Social Security beneficiary who continues to be medically disabled may receive a disability check for any month during which his/her earnings are not above the substantial gainful activity (SGA) level (in 1995, \$500 a month for a disabled person; \$940 for a blind person).¹

Continuation of Medicare

If Social Security disability payments stop because a person is earning at the SGA level and he/she still has a disability, Medicare can continue for up to 39 months after the TWP.¹

Impairment-Related Work Expenses (IRWE)

Certain expenses for things a person with a disability needs in order to work may be deducted when counting earnings to determine if he/she is performing at the SGA.¹

Recovery During Vocational Rehabilitation

If a person recovers while participating in a vocational rehabilitation program that is likely to lead to his/her becoming self-supporting, benefits may continue until the program ends.²

Special Rules for Blind Persons

Several special rules apply to blind beneficiaries who work. For example, in 1995, they can earn up to \$940 a month before their benefits are affected. Ask a Social Security office for details on work incentives for blind beneficiaries.^{1,2}

1. *Red Book on Work Incentives*
Social Security Administration
Office of Disability and Social Security
SSA publication # 64030, ICN 436900 Rev 8/95

SSI

Continuation of SSI Eligibility

Disabled or blind SSI recipients who work may continue to receive payments until countable income and resources exceed SSI limits.¹

Continuation of Medicaid Eligibility

Medicaid may continue for disabled or blind SSI recipients whose earnings may preclude payments if the person has earnings under a certain limit, cannot afford similar medical care, and depends on Medicaid in order to work.¹

Plan for Achieving Self-Support (PASS)

A disabled or blind SSI recipient may set aside income and resources for up to 48 months toward an approved plan for achieving self-support.¹

Impairment-Related Work Expenses (IRWE)

Certain expenses that a person with a disability incurs in order to work may be deducted when counting earnings to determine his/her continued eligibility or payment amount.¹

Recovery During Vocational Rehabilitation

If a person recovers while participating in a vocational rehabilitation program that is likely to lead to his/her becoming self-supporting, benefits may continue until the program ends.²

Special Treatment of Students

Parents' income and resources are no longer counted in determining the eligibility or payment amount of children reaching 18 years of age, regardless of their student status. Also, any scholarships, grants, or fellowships used to pay tuition, books, and other educational expenses are excluded as income.^{1,2}

2. *Working While Disabled: How Social Security Can Help*
U.S. Department of Health and Human Services
Social Security Administration
SSA publication # 0510095, Rev 1/94

Appendix C: Impairment-related Work Expenses for Dialysis Patients

- WHAT:** Impairment-related work expenses are costs of items or services needed for work that can be deducted from earnings before substantial gainful activity (SGA) is calculated. Items not specifically for work, but which *allow* the person to work, can be deducted if the working disabled person had to pay for the item and will not be fully paid back by any other source. Usually the costs must occur during a month when the patient is working.
- SSDI:** Approved expenses *not paid for by any other source* are subtracted from earned income before SGA is calculated.
- SSI:** Approved expenses *not paid for by any other source* are subtracted from earned income to calculate an SSI recipient's monthly benefit.
- WHO:** Social Security Administration field office decides what is allowed. They may ask for proof that the item is needed, and that it is paid for by the patient and not reimbursed.

According to the Red Book (1995) the following are some out-of-pocket costs that working ESRD consumers may be able to deduct.

- Medically necessary physician services performed in any setting—inpatient, outpatient, or home (p 21).
- Charges related to transplant or dialysis performed in any setting—inpatient, outpatient, or home (p 21).
- Regularly prescribed medications necessary to control a disabling condition (even if unsuccessful), including prescribed over-the-counter medications or nutritional supplements for ESRD-related conditions, and immunosuppressive medications for transplant patients (p 21).
- Services performed by a home dialysis assistant, allowing the ESRD consumer flexibility in dialysis scheduling, thereby increasing the number of hours he/she can work (p 21).
- Expendable medical supplies prescribed by a doctor, such as catheters (p 22).
- Physician-prescribed durable medical equipment, including diabetic monitoring equipment, hemodialysis equipment and supplies, and wheelchairs, prosthetics, or limb or back braces for the mobility-challenged (p 19).
- Hearing aids and TDD/TTY to help the hearing impaired, and electronic visual aids, braille devices or readers, and guide dog food and veterinary expenses for the blind (p 19).
- Physician-prescribed rehabilitation services (physical therapy, occupational therapy, speech therapy, cardiac rehabilitation, exercise, nursing services, social services, home health aide, personal care attendant) in any setting (pp 17, 21).
- Home modification to permit home hemodialysis, work at home, or access to the street or transportation (p 20).
- Shared cost of vocational rehabilitation services for evaluation, education, training, supported employment, or independent living (pp 17, 19).
- Transportation (vehicle modifications, mileage or driver) to and from work, or taxi fare if public transportation or personal vehicle are inaccessible or unavailable (p 18).

Talk to a *Work Incentive Liaison* (WIL) in your local Social Security Office to learn more about what impairment-related and blind-related work expenses might be allowable in your particular case.

Red Book on Work Incentives
 Social Security Administration
 Office of Disability and Social Security
 SSA publication # 64030, ICN 436900 Rev 8/95

Appendix D: VR Services Fact Sheet

Department of Vocational Rehabilitation

1. *What is Vocational Rehabilitation?*

The Rehabilitation Act of 1973, as amended, provides for awarding of Federal grants to help states set up comprehensive VR programs to assist eligible persons with disabilities. Persons are assessed by reviewing strengths, resources, priorities, concerns, abilities, and capabilities to help them prepare for employment.

2. *Who is eligible for VR services?*

An eligible individual must meet three conditions: Have a physical or mental impairment that substantially impedes employment; be expected to obtain employment through VR services; and require VR services to prepare for, enter, engage in, or retain gainful employment.

3. *How does an eligible individual obtain VR services?*

A VR counselor is assigned to each eligible person. The counselor gathers medical record information and information about work history, education and training, abilities and interests, rehabilitation needs, and possible career goals. The counselor and individual develop an individualized written rehabilitation program (IWRP) that identifies the individual's long-term vocational goals, steps to achieve them, services needed, and methods for determining successful outcomes. Services can be provided directly by the counselor or through purchase of services from community providers.

4. *What are the VR services an eligible individual may receive?*

Services include, but are not limited to, vocational counseling including assessment, guidance and referral, physical and mental restoration services, vocational and on-the-job training, transportation related to VR services, interpreter and reader services for the deaf and blind respectively, help for students in transition from school to work, personal assistance while in VR, rehabilitation technology services and devices, supported employment, and job placement services.

5. *Does every eligible individual receive VR services?*

If a state has insufficient resources to serve all eligible individuals, those with the most severe disabilities (including ESRD) must be served first. A waiting list is established if services cannot be provided immediately.

6. *Does the eligible individual ever have to pay for VR services?*

Sometimes individuals must help pay for some services; however, services that are free to all include assessments to determine eligibility and VR needs, vocational counseling, guidance and referral, and job placement.

7. *Are there other sources of payment for VR services?*

If the patient has Medicare, Medicaid, or other insurance, these sources of payment should be considered unless doing so would delay provision of services to someone at extreme medical risk or whose job placement could be lost by the delay.

8. *What is the Client Assistance Program?*

The Client Assistance Program provides assistance if the individual is dissatisfied with the State VR agency and can help explain rights and pursue legal, administrative, or other remedies.

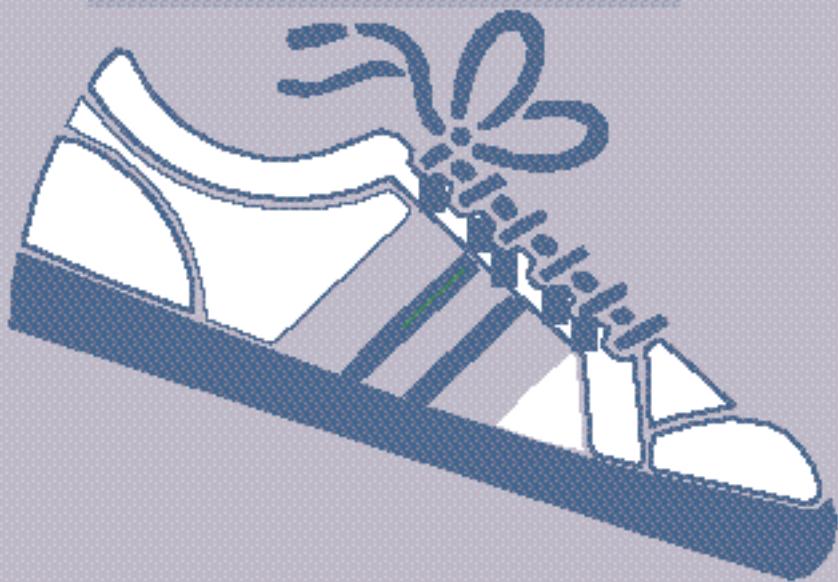
9. *What are the appeal rights under the VR program?*

A dissatisfied applicant or VR client can request a fair hearing before an impartial hearing officer. The hearing generally occurs within 45 days of the request. The director of the State VR agency can review the decision of the impartial hearing officer, but can only overturn the decision if he or she can prove by clear and convincing evidence that the decision is contrary to Federal or State law.

10. *How can an individual apply for VR services?*

Contact the State or local office of Vocational Rehabilitation. Look in the "State Government" section of the local phone book.

Source: *Rehabilitation Services Administration*
Washington, DC



Exercise

*Module 4:
A Practical
Guide to Renal
Rehabilitation*



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The information in this Guide is offered as general background for the clinician who is interested in improving the quality of rehabilitation opportunities for dialysis patients. The Guide is not intended to provide practice guidelines or specific protocols and cannot substitute for the physician’s knowledge and experience with individual patients. The reader must recognize that exercise, in particular, involves certain risks, including the risk of severe injury or disability, including death, which cannot be completely eliminated, even when the exercise program is undertaken under expert supervision. Use of these materials indicates acknowledgment that Amgen Inc., the Medical Education Institute, Inc., and the authors will not be responsible for any loss or injury, including death, sustained in connection with, or as a result of, the use of this Guide.

Life Options Rehabilitation Program



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Key Messages

- *Exercise improves physical and functional status, and psychological well-being.*
- *Dialysis patients can exercise safely.*
- *Given the low levels of physical functioning in dialysis patients, exercise may be even more important for dialysis patients than for healthy people.*



Improving Physical Functioning—A Challenge for Renal Professionals

In 1981, Dr. Robert Gutman reported that only 60 percent of non-diabetic renal patients and 23 percent of diabetic renal patients were capable of physical activity beyond self-care. He estimated that 50 percent of patients were too debilitated to work (Gutman et al, 1981). Today, more than 15 years later, many dialysis patients continue to have physical functioning that is lower than their potential. On average, dialysis patients have a peak exercise capacity only half that of healthy people (Painter, 1994). With reduced exercise capacity, dialysis patients have less energy to perform activities required for daily self-care, family and social activities, and work. Although cardiac medicine has traditionally viewed exercise as a critical bridge to rehabilitation, the renal community has only recently begun to include it as a component of a successful renal rehabilitation program.

Deconditioning of Dialysis Patients

Conditioning the body through exercise is the gradual process of improving flexibility, muscle strength, and endurance. *Deconditioning* is just the opposite—progressive loss of fitness. The human body operates on a “use it or lose it” principle. If a broken arm is immobilized in a cast for several weeks, the muscles in that arm will be smaller and the wrist and elbow will be stiff and inflexible from lack of use when the cast is removed. Anyone who is immobile can experience whole-body deconditioning. NASA studies of astronauts have shown that persons who are inactive (or non-weight-bearing) over time lose muscle mass, bone tissue, and experience significant deterioration in the functioning of many physiological systems. Additionally, they also experience psychological changes (Sandler & Vernikos, 1986).

Dialysis patients lose a considerable amount of exercise capacity for reasons that are not fully understood, leaving them with minimal functional reserve. Therefore, deconditioning—which gradually robs the patient of the ability to participate in desired activities—can have very serious consequences in dialysis patients. The less physical activity dialysis patients do, the less they will be able to do. But exercise can help patients regain a level of fitness that will enable them to participate actively in life.

***“Every patient should be asked,
‘What are you doing for
regular exercise?’”***

Patricia Painter, PhD, 1994

Benefits of Exercise to Patients

For patients, regular participation in exercise has the potential to improve overall health, physical functioning, financial status, and longevity.

Improving Health

The Surgeon General’s Report, *Physical Activity and Health* (1996), states that regular physical activity in the general population can reduce the risk of dying prematurely from coronary heart disease, or developing diabetes, colon cancer, and hypertension. Physical activity also lowers blood pressure for those with hypertension, helps maintain weight control, helps elderly people avoid falls by building strength, and helps build stronger bones, joints, and muscles.

In dialysis patients, exercise has also been shown to have a number of important positive physical effects, including:

- Increasing exercise capacity by 21 to 25 percent (Goldberg, 1983; Shalom et al, 1984; Painter et al, 1986; Ross et al, 1989)
- Stabilizing blood pressure (Goldberg et al, 1980) and reducing the number of episodes of low blood pressure during dialysis (Boettcher, 1989)
- Improving lipid and carbohydrate metabolism (Goldberg et al, 1980)
- Enhancing tissue oxygenation so patients can exercise longer without experiencing cardiac symptoms (Wizemann et al, 1992; Hase et al, 1993)
- Reducing fatigue and permitting higher activity levels (Brunier & Graydon, 1993)

Improving Physical Functioning and Adaptation to Illness

Physical functioning is one component of health-related quality of life, which also includes mental health, social functioning, and vocational activities. Exercise may, by increasing physical functioning, impact these other components of quality of life.

Mental health and outlook are important determinants of how individuals cope with chronic illness. Regular exercise can brighten moods: the Surgeon General’s Report (1996) states that exercise reduces depression and anxiety and increases the sense of well-being. Dialysis patients who exercise may have an increased sense of independence and control.

Social interaction can also be improved by exercise. Participation in team sports or classes exposes patients to new people, with whom they may share interests. Individuals who avoid deconditioning through regular exercise can avoid embarrassment, poor self-esteem, and associated depression that accompanies the reliance on others to perform personal hygiene and other activities of daily living. In addition, exercise may help patients structure their time, and provides a positive focus for conversation unrelated to the illness that may improve social acceptance in other situations. (For further information on how you can influence patient well-being and personal control, see the Encouragement and Education modules of this Guide.)

Vocational activities are directly related to improving functional status—the ability of patients to perform activities of daily living and other usual physical, mental, social, and role-related tasks—through exercise. Functional status predicts employment status (Curtin et al, 1996). To be able to work, patients must minimally be able to get out of bed, get dressed, prepare and eat breakfast, drive or negotiate public transportation, and possess sufficient stamina to be productive throughout a work day. Dialysis patients who are vocationally active in work, school, home, or community life have the additional benefits of being less isolated and may be less likely to become depressed. (For more information on enhancing employment and participation in other activities, see the Employment module.)

Adaptation to ESRD can be enhanced by levels of physical functioning that permit vocational activity. Wolcott et al (1988) found that patients who were physically fit enough to remain vocationally active adapted better to ESRD than inactive patients. The study examined 33 pairs of hemodialysis and peritoneal dialysis patients matched for sex, age, diabetic status, and interval since dialysis onset. (Vocational activity included employment, school, or household tasks.) Vocationally active patients participated in significantly more community activities; had less anger, anxiety, fatigue, and mood disturbances; less treatment-related stress; higher self-esteem, quality of life, and satisfaction with social support; and even had better relationships with dialysis staff.

Improving Financial Status

Patients who work derive income from employment (which may be more than disabled individuals would receive from disability) and may receive health insurance and other benefits. Patients who achieve full functioning after starting dialysis also do not have to pay others to do tasks or chores they can do for themselves.

Enabling the Possibility of Longer Life

Autonomy, independence, and personal control are related to individual well-being and quality of life (see the Encouragement module)—but they may also be related to survival. A study of disabled individuals living in their own homes showed that individuals who became dependent because they were unable to perform activities of daily living had a higher mortality rate (Warren & Knight, 1982). In hemodialysis patients, low functional status predicted increased mortality (Jones, 1990). Improving patients' physical functioning can improve their ability to care for themselves, and independence may prolong life.

Benefits of Patient Exercise to Dialysis Staff

Dialysis professionals may also benefit when patients are actively engaged in exercise, through improved patient relationships, time savings, and reduced risk of work-related injuries.

Saving Time

Patients who can walk or assist in transfers reduce the one-on-one staff time it takes to transport the patient from the waiting room to the dialysis chair. One study showed that hemodialysis patients with lower functional status had three times as many events requiring increased staff time and resources (Jones, 1990). Conversely, patients who exercised had fewer dialysis-related symptoms (Brunier & Graydon, 1993). Therefore, improving patient's functioning through exercise can lead to less staff time spent on symptom relief.

Reducing the Risk of Work-Related Injuries

Patients who require assistance to transfer to a dialysis chair place a physical burden on nurses. Back strain can cause injuries that require medical treatment and time off from work. Although appropriate body mechanics can help reduce the risk of injuries, it is better to help patients improve their strength so they can assist in transfers from wheelchair to chair, walk with a walker or cane, or walk without assistive devices. In addition, all the above physical and emotional benefits of exercise are very observable, allowing staff and other patients the opportunity to watch the progress.

Benefits of Patient Exercise to Dialysis Facilities

Further data collection is needed to examine relationships between exercise participation and hospitalization rates, nursing home admissions, in-home health services, and the need for mental health services; however, preliminary reports suggest a benefit. Patients who exercise during dialysis have fewer episodes of low systolic blood pressure that require treatment during dialysis (Boettcher, 1989). In another study, improving functional status reduced the number of unusual patient events. The same study found that the risk of hospitalization dramatically increased as functional level fell, and that improving functional status reduced the number of hospital days (Jones, 1990).

Reducing the need for these expensive services by improving physical functioning could turn out to be a cost-effective venture. If privately insured patients can maintain employment by avoiding deconditioning, their insurance covers the first 18 months of dialysis treatments, a benefit to facilities that receive higher private insurance reimbursement instead of the discounted Medicare rate.

How to Plan Exercise Interventions

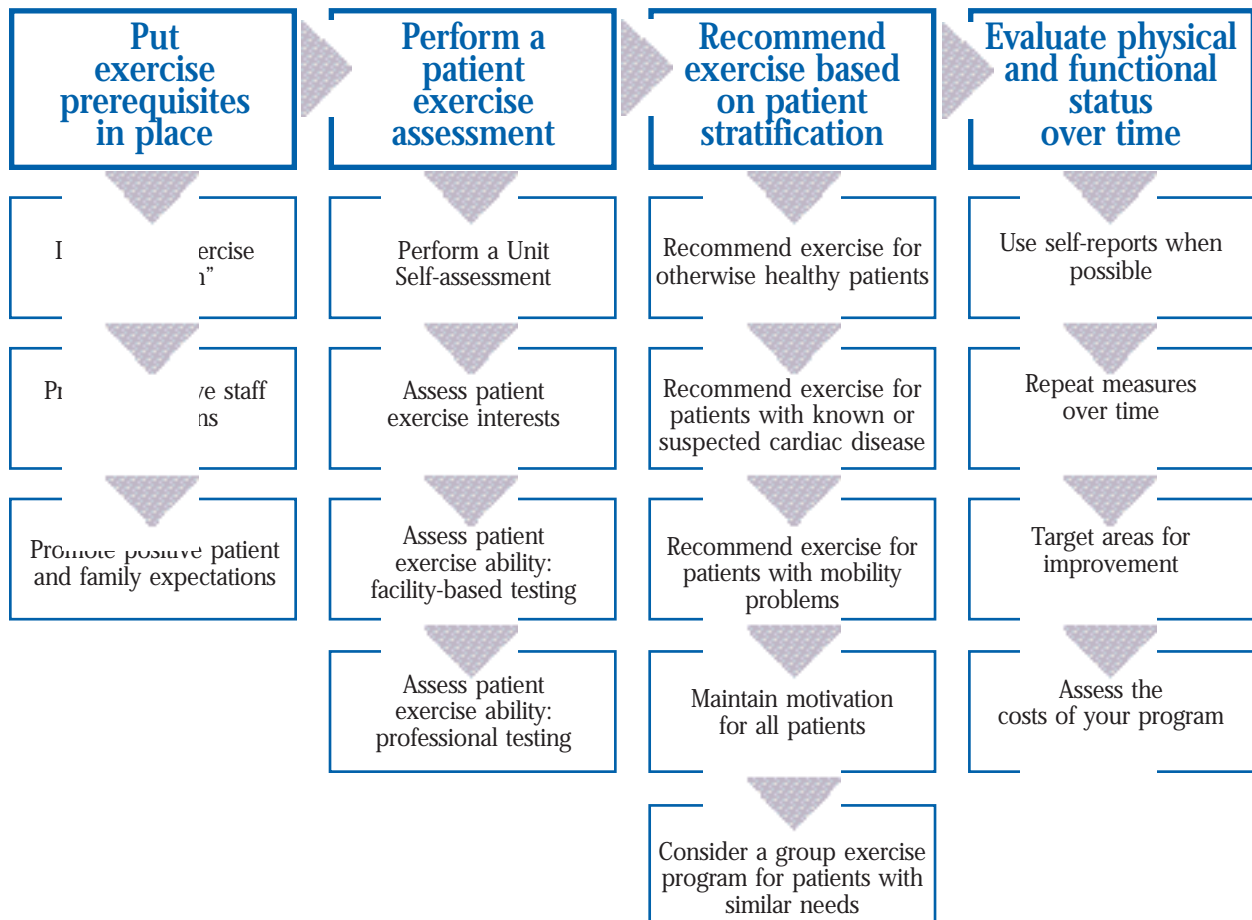
The remainder of this module is designed to help you help your patients improve their levels of physical functioning, both through individual assessment and planning and by considering a facility-wide program to enhance exercise participation. Strategies under each section are arranged according to resource use. Strategies progress from least costly and resource-intensive to more involved in terms of both cost and resource requirements. Please refer to the *Renal Rehabilitation: Exercise at a Glance* flowchart below to see how the rest of the module is organized.

The Exercise section of the Life Options *Unit Self-Assessment Tool for Renal Rehabilitation* (USAT) is included as Appendix A of this module, as an additional resource. The USAT lists criteria for good rehabilitation programming for each of the five rehabilitation “E’s”. Like the strategies in this module, the *USAT criteria* are arranged in order from basic to intermediate and

advanced level, based on their complexity, resource use, and potential impact. You will find periodic references to the USAT criteria throughout this module, and specific criteria will be referenced by numbers in parentheses (e.g., EX-12), so you can find them in Appendix A. Additional information about use and interpretation of the USAT is available in the *Unit Self-Assessment Manual for Renal Rehabilitation* (USAM), which you can obtain by contacting the Rehabilitation Resource Center at (800)468-7777.

You will want to be sure that your facility has a copy of *Exercise for the Dialysis Patient: A Comprehensive Program*, which is referred to throughout this manual. This program includes a physician manual, a staff manual, a prescribing guide, a patient manual, and a patient and professional video. Developed by the Life Options Rehabilitation Advisory Council, the program is available at no charge through your Amgen Professional Sales Representative.

Renal Rehabilitation: Exercise at a Glance



Put Exercise Prerequisites in Place

Before you can promote exercise for your patients, it is important to carefully consider both patient and staff attitudes. There are a number of myths and misconceptions to overcome about the exercise ability of dialysis patients. For example, some people erroneously believe that dialysis patients will harm themselves through exertion, or will damage their access sites. The staff, patients, and family must be re-educated about this and must hear a consistent message from all their care providers.

Identify an Exercise “Champion”

You will need an exercise “champion” or champions—one or more staff members, patients, or community volunteers—who will assume a leadership role among dialysis team members. (See the Getting Started module of this Guide for more information about rehabilitation champions.) The “champions” should be individuals who enjoy exercise and can inspire enthusiasm.

Strategies to identify exercise champions:

- Solicit interest from staff, patients, or community volunteers who might be interested in serving as exercise champions.
- Have a staff in-service and show exercise materials to inspire team enthusiasm (EX-2, EX-3, EX-4).
- Call a local college or training program about establishing your facility as an internship site for students studying physical or occupational therapy, or physical education.

Promote Positive Staff Expectations

Staff expectations are key to patient success in any rehabilitation endeavor, including exercise. Low staff expectations for patients are often fulfilled, placing a limit on patients’ efforts to improve their physical capabilities. Projections of future functioning *based on current patient status* may lead renal professionals to underestimate patient energy levels and commitment to rehabilitation (Meers et al, 1995). A proactive stance favoring exercise is essential to maintain and improve physical functioning.

Many renal professionals believe that encouraging patients to exercise could cause physical problems for which they would be legally liable. However, the exercise activities that dialysis patients take part in are, in general, less physically stressful than activities of daily living or even than dialysis itself, and therefore are unlikely to cause harm (Painter, 1994). See *Exercise for the Dialysis Patient: A Comprehensive Program* for information on risk factors.

Strategies to promote positive staff expectations:

- Contact the Rehabilitation Resource Center at (800)468-7777 for more information or to obtain a list of other facilities with successful patient exercise programs.
- Collect and distribute research articles on the benefits of exercise for dialysis patients.
- Encourage dialysis staff to participate in exercise, too.
- Include an exercise session as part of a regular staff meeting (Jagusch & Butchart, 1985). Use materials from *Exercise for the Dialysis Patient: A Comprehensive Program* to hold in-services for staff on the value of physical activity for patients.

Promote Positive Patient and Family Expectations

Patients and their families must understand that exercise is essential for patients to maintain or improve their current activity level. Yet many patients are routinely told to “take it easy” or not to “do too much” or are helped to do things they could do themselves, by well-meaning staff or family members. In particular, physicians who do not specifically discuss exercise with renal patients may be inadvertently giving the message that exercise is not important or not safe.

A classic example of this occurs after access surgery. When a surgeon or nurse tells a patient not to lift or even use the access arm, the surgeon or nurse expects the patient to restrict lifting during the healing period only. The patient hears that lifting items heavier than a gallon of milk should be avoided and assumes the restriction is permanent. This begins a cycle of deconditioning of the access arm and limits many activities of daily living.

A common myth for everyone—staff, family members, and patients—is that exercise is boring. Many interesting activities involve some degree of stretching, bending, lifting, or sustained effort that can improve flexibility, strength, and endurance. Gardening is excellent exercise. Picking up litter from a vacant lot or seashells at a beach, renting a paddleboat, or even walking the dog can all help patients to remain active or become more active.

Another common myth is that exercise must be done at a high level in order to be helpful. This myth must also be dispelled. Patients, in particular, seem to believe that they could not possibly participate in exercise at a level that would be adequate. In fact, increasing the level of physical activity—even in small increments—can benefit patients’ physical functioning and also their self-esteem so they are motivated to do more as they become more able.

Strategies to promote positive patient and family expectations:

- Teach patients that the more they do, the more they will be able to do.
- Inform patients and their families that people with cardiovascular problems routinely exercise using treadmills and exercise bikes in cardiac rehabilitation programs.
- Dispel myths about exercise by giving patients, family members, and staff the appropriate portions of *Exercise for the Dialysis Patient: A Comprehensive Program*, which provides rebuttals to a number of common exercise excuses. Extra copies of the patient guide can be ordered from your Amgen representative. Tell patients that dialysis patients who exercise feel better afterward, even if they occasionally report sore muscles and fatigue (Jagusch & Butchart, 1985) (EX-2, EX-3).
- Include family members in all educational efforts related to patient exercise.
- Consider referring patients who meet cardiac rehabilitation criteria for assessment, monitoring, and rehabilitation training (EX-16).



Perform a Patient Exercise Assessment

Once the attitudinal and physical prerequisites are in place, your rehabilitation team can design an appropriate exercise program for your facility, including assessing patient interests and abilities, recommending appropriate exercise, maintaining ongoing patient motivation, and considering an in-center exercise program.

Perform a Unit Self-assessment

Completing the Unit Self-assessment form for the Exercise “E”, found in Appendix A of this module, will provide you with an estimate of how well your unit is currently doing with its exercise programming. The USAT can also help you to generate new ideas for exercise-related strategies that might fit into your existing or future rehabilitation planning.

Assess Patient Exercise Interests

“Formal” exercise, like jogging, swimming, or riding a bicycle, is just one way to be active. Dialysis patients are all beginning at different levels. Any activity that regularly gets an ambulatory patient up out of a chair, a chair-bound patient actively using upper body muscles, or a bed-bound patient up into a chair is a step in the right direction, and will progress to improved physical functioning. Gardening, mowing the lawn, raking leaves, washing the car, hanging clothes on a clothesline, and vacuuming are often necessary chores that have a flexibility, strength, and/or endurance component. Participation in dance or in sports, such as bowling, softball, ice skating, basketball, tennis, badminton, golf, or soccer can also improve fitness—often with the added benefit of social interaction. Hunting, fishing, hiking, sailing, camping, canoeing, bird-watching, and other outdoor endeavors can enhance activity level at the same time that they improve mood and outlook. Teens may enjoy skateboarding, indoor rock climbing, in-line skating, or laser tag. New activities such as Tai Chi, low-impact aerobics, or yoga may be intriguing enough for patients to want to try them.

The key factor is for each individual to start slowly and progress gradually. Some sports and activities may be beyond the patient’s current capacity, so individuals

must work up to them by developing adequate muscle strength and endurance prior to starting more vigorous exercise. People (all of us) have problems with exercise and sports if they try to do too much too soon without taking the time to get into shape for safe participation.

Tell patients to be sensible in choosing exercise options. Don’t encourage them to do activities beyond the limits of their abilities.

Strategies to assess patient exercise interests:

- Give patients the Exercise Checklist in Appendix B and ask them to circle activities they have enjoyed in the past, are doing now, or think they would like to do.
- Encourage new patients to talk with other patients who exercise regularly.
- Be careful not to limit patient goal setting by communicating low expectations.
- Put up a bulletin board display of photos of patients engaged in their favorite activities (EX-1).
- Identify local programs and put together a binder of materials about as many different activities as possible. Include the activities listed above, with costs and times offered, and any additional activities your rehabilitation team can brainstorm. If your unit permits, patients can make calls during dialysis to request information and written materials (EX-4, EX-8, EX-13).

Assess Patient Exercise Ability: Facility-based Testing

The goal of an exercise program for dialysis patients is to help them to return to, or improve upon, the level of physical functioning they had prior to dialysis. To do so will require an assessment of the match between patients’ interests in physical activity and their abilities to carry out the activities they like.

Many patients can be tested for strength and endurance in the dialysis facility, although patients with more complex

physical rehabilitation needs may require further consultation with a rehabilitation expert. A later section of this module will discuss these outside resources. Besides helping you to determine the “fit” between a patient’s desired activities and abilities, this initial assessment also serves as a baseline measurement of fitness.

Keep a log sheet for each patient to facilitate ongoing evaluation. A sample Physical Functioning Log Sheet can be found in Appendix C.

Most patients feel best before dialysis. Thus, evaluation is best performed prior to dialysis. Following dialysis, assessment will depend on how a patient feels, and may be less consistent. For later comparisons, document the time and be consistent with each patient, e.g., always predialysis or postdialysis. Consistently re-assess at the same intervals, e.g., monthly, quarterly, or annually. The suggested assessment techniques below are common-sense measures of functioning. They have not been validated, and are not a substitute for a professional assessment. However, they can be useful for helping your facility to determine the levels of functioning of individual patients, and to monitor progress.

Free Weights

Purpose

Assess arm strength

Materials Needed

A set of several inexpensive small dumbbells or home-made weights (soup cans, milk jugs) weighing between one pound and eight to ten pounds.

Staff Requirements

During the evaluation, a staff person is needed to bring the weight to the patient, stand by for safety, and record the result.

Technique

Have the patient rest an elbow on the chair and with the arm out straight, palm up, grasp the smallest weight. Can the patient raise the weight to a vertical position easily? How many times can he or she raise it with each arm? Record the weight and number of repetitions (up to ten). Have the patient stop if lifting the weight

becomes at all painful, or muscle soreness may discourage further participation.

Interpretation

Patients who cannot easily lift a one-pound weight several times clearly have room for improvement! Fortunately, muscle strength can be regained relatively quickly, even in very elderly and frail individuals, and the rewards can be great. Patients who wish to participate in bowling, gardening, golf, sailing, hunting, fishing—or grocery shopping—may need to set higher goals for increasing their weight-lifting abilities. Patients who are able to lift a one-pound weight easily ten times may be ready to move on to greater challenges.

Sit-to-stand Test

Purpose

Measure leg strength in ambulatory patients

Materials Needed

A straight-backed chair (if the chair has arms, be sure the arms cannot move) and a stopwatch or timer

Staff Requirements

During the evaluation, a staff person is needed to time the patient and to stand by for safety.

Technique

Place the chair on a carpeted surface or against a wall so it will not shift with the patient’s movement. Have the patient sit down in the chair. Instruct the patient to stand up and sit down as many times as possible for one minute. Beginning on the word “go,” count every time the patient stands as a repetition. If the patient cannot rise to a full stand, document the patient’s position. Observe and document whether the patient begins to “push off” with the arms. The patient can stop and rest during the test, but keep the clock running. Record the results.

Interpretation

A healthy, sedentary non-dialysis patient with no joint problems can easily stand up between 20 and 30 times in one minute. Fatigue from lack of strength or difficulty with the knees, hips, or ankles would reduce the number of repetitions. Compare the result to the patient’s own results

over time, or to an average of all the eligible patients in your facility. Endurance is needed for sustained activities such as walking, vacuuming, swimming, dance, aerobics, racquet sports, hiking, bicycling, and skating. Leg muscle strength is needed to climb stairs, use a regular toilet, get in and out of a car, or visit a movie, concert, or sports event without a wheelchair.

Lift and Reach Test

Purpose

Measure flexibility and arm strength in ambulatory patients. **OPTION:** With lower shelves, this test could be adapted for wheelchair-bound patients.

Materials Needed

Two two-pound weights, a box with handles to hold the weights, and a table next to a bookshelf that has a shelf at knee height, a shelf at table height, and a shelf at shoulder height

Staff Requirement

During the evaluation, a staff person is needed to count repetitions and to stand by for safety.

Technique

Place the weights on the table in the box. Instruct the patient about good body mechanics while lifting: the patient should hold the box close to the body, and bend from the knees, not the waist, to avoid back strain. Remind the patient to breathe out when lifting the box to shoulder height. Ask the patient to stand next to the table and lift the box with both hands, move the box to the lowest shelf, the middle shelf, and the upper shelf, and then back to the table to start over. Count the number of repetitions in one minute.

Interpretation

There is no standardized figure for a “normal” result. The ability to use the arms to raise and lower different weights is needed for many activities such as lifting a child; activities of daily living, such as dressing; hanging up clothes in a closet; putting groceries on a shelf; washing a car; painting a wall; hanging wallpaper; or putting up curtains. These abilities are also called for in activities such as racquet sports, volleyball, and dance.

Two- or Six-minute Walk Test

Purpose

Assess overall endurance

Materials Needed

Non-slip shoes (for the patient), a timer, a chair for rest stops, and a measured length of tiled hallway (e.g., 20 feet) with a railing

Staff Requirement

During the evaluation, a staff person is needed to measure distance and stand by for safety.

Technique

Start the patient at one end of the measured hallway. Ask the patient to walk up and down the hallway at a brisk pace for either two or six minutes. Document the time and distance the patient covers.

Interpretation

Patients who have not been moving around for some time may be surprised and dismayed to find that they are now unable to walk very far or very quickly. Walking is a natural activity that does not require special equipment or unfamiliar movement. As such, it is within the grasp of any ambulatory patient. Measure progress by comparing the patient’s distance or time from one measurement to the next. Be sure to use the same test consistently for each patient.

Assess Patient Exercise Ability: Professional Testing

Professional assessments of musculoskeletal (including manual muscle testing and range of motion testing), neuromuscular, neurological, and/or mental status may be helpful for some patients. This may be particularly helpful for those who are already wheelchair-bound or have significant comorbidities. The ability to balance (sitting, standing, walking with and without shoes), eat, dress, transfer, and maintain personal hygiene—activities of daily living—can be assessed. Patients who cannot walk can be observed using their wheelchair to determine if they can move in a straight line and turn correctly (Cardenas, 1989).

Professional testing is also important for patients who are high-functioning (can complete a six-minute walk test, lift weights, formerly exercised regularly) but have stopped exercising and need support to begin again. These patients should be encouraged to go to a club and work with a personal trainer or take a class to gradually increase their levels of physical functioning until they can resume other desired physical activities.

A variety of physical rehabilitation professionals have expertise with medical conditions that limit physical functioning. The physician specialist who works to improve functional rehabilitation is a **physiatrist**. Physiatrists diagnose factors contributing to functional limitations and prescribe services to be provided by members of a multidisciplinary team. The rehabilitation team may also include a rehabilitation nurse, physical therapist, occupational therapist, speech therapist, recreational therapist, social worker, and dietitian. Like the renal team, regular rehabilitation team meetings are held to evaluate the course of treatment, modify the prescription, and assist patients and families in planning. Depending on their insurance payer, patients may or may not be able to receive physical rehabilitation services, either at home or in an outpatient or inpatient facility. Coverage varies by state and health plan, so it is important to verify what is possible for each patient.

Homebound patients, who leave home for dialysis and other medical appointments but not for social reasons, may be able to receive medically justified physical and occupational therapy services through a home health agency under Medicare. Home health agencies have administrative staff that will know applicable state and federal regulations and diagnoses for which these services are reimbursed.

If a patient needs specific equipment that cannot be transported to the home, outpatient rehabilitation services can be covered under Medicare. Inpatient admission to a rehabilitation hospital requires the patient to be evaluated by a physiatrist or physician.

Diagnoses that warrant inpatient admission for rehabilitation include amputations, stroke, spinal cord injury,

head trauma, major multiple trauma, neurological disorders (in some cases), burns, orthopedic disabilities (long bone fractures, joint replacement) if complicated by another medical problem, and rheumatoid arthritis.

Other members of the rehabilitation team that dialysis patients will most likely encounter are the physical and occupational therapist and their assistants. A **registered physical therapist** (RPT) diagnoses and treats problems related to physical functioning, and generally provides services that strengthen muscles in the lower extremities to address gross motor skills such as those needed in walking, standing, transferring, or sitting. A **certified physical therapy assistant** (CPTA) may treat problems after a RPT determines what treatment is needed. An **exercise physiologist** or a **personal trainer** can help higher functioning patients to resume their previous physical activities.

An **occupational therapist** (OT) evaluates and treats problems related to fine motor functioning. Services provided by occupational therapists may include fine motor skills, such as hand and upper body strengthening and re-learning how to do activities of daily living with assistive devices or effort-saving techniques. A **certified occupational therapy assistant** (COTA) may provide occupational therapy treatment based on the needs evaluated by the OT.

Strategies to obtain professional assessments of patient exercise ability:

- Establish a relationship with a variety of rehabilitation providers who treat patients in different settings to improve the ease of future referral.
- Determine which level of rehabilitation services is needed for each patient referred for professional services—home, outpatient, or inpatient. The rehabilitation provider knows or can find out the state regulations and/or insurance considerations regarding location and duration of services, and will help patients receive appropriate care.

R

ecommend Exercise Based on Patient Stratification

Determining the match between the patient's desired activities (and current activity level) requires common sense and creativity. Look over the results of the Exercise Checklist. A patient who is currently participating in physical activity three or more times per week may still require fine-tuning to be sure the three main areas of fitness are covered: endurance, strength, and flexibility. For example, a patient who golfs using a cart could be encouraged to walk instead.

Patients who are not participating in any activity now, but who would like to and have done so in the past, may be motivated to begin with encouragement on your part. You may be able to help them locate programs related to their favorite activities (EX-4, EX-8, EX-13).

Patients who have never been especially active are likely to be severely deconditioned, and will require more intensive basic intervention before it is possible to progress to higher levels of activity. Consider the debilitated patient who would like to go grocery shopping. For this to be possible, the patient will need to be able to:

- Walk at least two blocks
- Get into and out of a car
- Lift items off a shelf and into a cart
- Lift filled grocery bags out of the car and carry them inside
- Lift items up onto shoulder-height shelves

Any desired activity can be broken down into steps like this, and analyzed to see what types of exercise the patient should do in order to reach a goal.

The complete dialysis exercise binder, *Exercise for the Dialysis Patient: A Comprehensive Program*, describes a stratification scheme for determining the overall exercise needs of dialysis patients, once assessment has taken place. Patients can be stratified into the three main groups described briefly below: otherwise healthy, known or suspected heart disease, or mobility problems.

Recommend Exercise for Otherwise Healthy Patients

Patients who have few medical concerns beyond ESRD and who are generally mobile can participate in regular, unsupervised exercise at home, in the dialysis facility, or in the community.

Strategies for otherwise healthy patients:

- Consider, with the patient, what steps will achieve the desired level of functioning.
- Encourage the patient to choose an activity (or activities) toward the defined steps that he or she enjoys and can maintain.
- Determine, with the patient, a realistic frequency of participation in the activity that will help the patient achieve the goal.
- Encourage blind patients to swim or use stationary bikes for exercise, or to investigate special exercise opportunities through organizations for the blind.
- Suggest that patients make exercise a family affair by incorporating walking, dancing, or a visit to the gym into their regular routines.
- Suggest that patients work up gradually to more intensive exercise. Refer to *Exercise for the Dialysis Patient: A Comprehensive Program* for suggestions of how patients can gradually increase the intensity of their exercise activities.
- Help patients identify sources of information about desired activities and make the information available for patients to take home. If your unit permits this, make a phone and phone book available so patients can make informational calls during dialysis (EX-4).
- Try to negotiate reduced payments, if necessary, to increase patients' participation in desired but high-cost activities (EX-13).

Recommend Exercise for Patients with Known or Suspected Cardiac Disease

Cardiac rehabilitation can be a useful resource for dialysis patients with concurrent cardiac problems. The mild exercise usually undertaken by dialysis patients is not as stressful to the heart as dialysis (Painter et al, 1995). Cardiac rehabilitation programs consider exercise to be an essential component of rehabilitation.

Strategies for patients with known or suspected cardiac disease:

- Consider, with the patient, what the observable steps are to achieve the desired level of functioning.
- Determine, with the patient, a realistic frequency of participation in the activity that will help the patient achieve the goal.
- Encourage the stable patient to choose an activity (or activities) toward the defined steps that he or she enjoys and can maintain.
- Obtain an exercise referral from the patient's cardiologist.
- Encourage the stable patient to begin a regular program of progressive exercise prescribed according to the *Prescribing Guide in Exercise for the Dialysis Patient: A Comprehensive Program*.

Recommend Exercise for Patients with Mobility Problems

Patients with muscle atrophy, gait problems, arthritis, amputations, or other conditions that affect their mobility can benefit from a physical therapy evaluation and program of activity. In some cases, patients who begin a regular program of strengthening and endurance training may become able to transfer without assistance from a wheelchair to a dialysis chair, progress from a wheelchair to a walker or from a walker to a cane, or even to walk without assistance.

Strategies for patients with mobility problems:

- Consider, with the patient, what steps will achieve the desired level of functioning.
- Advise patients with renal osteodystrophy to avoid leg lifts and consider non-weight-bearing activities such as swimming and stationary biking.
- Start patients on the strengthening and stretching exercises in *Exercise for the Dialysis Patient: A Comprehensive Program*.
- Encourage patients with arthritis to consider gentle movement activities such as Tai Chi, ROM (Range of Motion) dance, water exercise classes, low-impact aerobics, or yoga to increase flexibility and reduce pain between flare-ups.
- Obtain exercise referrals from any other relevant specialists caring for the patient (e.g., rheumatologist, neurologist, endocrinologist).
- Encourage wheelchair-bound patients to assist in transfer, with the goal of progressing to a walker, unless this is physically impossible. Patients who can stand should push their wheelchairs. Patients with physical limitations should be evaluated for and trained to use assistive devices, which they should bring to the facility for every dialysis session.
- Refer patients who use wheelchairs because of fear of falling to physical therapy for gait training with a cane or walker.
- Evaluate psychosocial barriers that could impede rehabilitation, including emotional, financial, transportation, or conflicting family responsibilities.
- Determine if there are diagnoses that would qualify patients for evaluation and treatment by a rehabilitation professional. Refer to *Exercise for the Dialysis Patient: A Comprehensive Program* for more information about how to make a referral and obtain reimbursement for professional services.
- Discuss the patient's limitations and need for home, outpatient, or inpatient services with the nephrologist. Seek approval for a referral during patient rounds, by phone, or in the patient care plan meeting.

- Help the patient with managed care insurance to obtain a referral to a rehabilitation professional from the primary physician. Be prepared to point out the patient's limitations and potential costs and benefits to the patient and managed care organization.
- Schedule outpatient or home rehabilitation therapy visits or appointments on non-dialysis days or before dialysis.
- Request regular reports of the patient's progress from rehabilitation consultants.
- Request regular reports and contact the patient regularly during an inpatient rehabilitation stay to learn progress and reinforce your support.

Maintain Motivation for all Patients

Frequently, an individual decides to exercise but only does so for a short amount of time until fatigue, boredom, a viral illness, or a schedule problem disrupts the new pattern. Sometimes motivation is low because there is little hope that physical status will improve. Encouragement, incentives, and frequent, tangible measures of progress can help keep exercisers on track toward their goals.

Strategies to maintain patient motivation:

- Encourage the patient to consider what incentives will help maintain the activity.
- Ask each patient regularly about participation in the activity and praise continued activity (EX-5).
- Offer rewards or prizes for exercise achievements, such as a gift certificate for a sporting goods store; a special bulletin board display; a ribbon, medal, or certificate (EX-6).
- Chart progress toward defined exercise goals (i.e., count miles walked or bicycled toward a predetermined destination) (EX-6).
- Begin a "buddy" or team system to help patients encourage each other.

Trip to the "Beach" Motivates Patient Exercise Participation

The Kidney Center of Chester County, Ltd. in Exton, PA developed a program to encourage increased physical activity which was interactive (patients *and* staff participated) and promoted behavioral change. "Surfers," the more active patients and staff members and "Sunbathers," patients more severely restricted by disabilities such as blindness, inability to walk, etc., earned points which translated to miles they "raced" to the beach. Themes, teams, incentives, awards, a "Kickoff Party," and a celebration when all teams arrived, kept interest, enthusiasm, and participation alive during the three-month program. Funds were donated by pharmaceutical companies and a foundation created by one family in memory of their father, a patient at the unit.

Careful Taping Secures Bloodlines During Dialysis Exercise

Betty Murray, an RN at DCI Nashville, attributes her facility's excellent safety record for patients who exercise during dialysis to careful taping of the needles and bloodlines. Their policy is to:

1. Place a bandage directly over the puncture site. This aids in maintaining an aseptic environment.
2. Apply a piece of paper tape approximately 4" – 6" long directly over the wings. The tape acts as a stabilizer.
3. Back tape the needle by placing the paper tape behind the needle and bringing it up snug against the wings (criss-crossed if desired).
4. Tape the Luer-Lok[®] connection between the blood lines and the fistula needle. The extra tape provides added protection against disconnection.
5. Secure the blood line (not just the needle lines) to the access limb after the initiation of dialysis. This reduces stress on the needle connection and reduces the possibility of catching the lines on an object and disconnecting them accidentally.
6. Ensure that all blood lines will extend to the length necessary for the intended exercise. Blood lines must also be prevented from catching on objects such as side tables.
7. Secure extra tubing to the chair to decrease the risk of the lines getting entangled during exercise.

Caution: If a needle is in the bend of the arm or is sensitive to movement, either use that arm to stabilize a Thera-band[®] or skip exercises that use that arm.

Consider a Group Exercise Program for Patients with Similar Needs

If your patient assessments reveal that many patients will require a similar level of exercise intervention, an in-center exercise program may be a good choice. Facilities with in-center programs have found them to be fun, motivating, and effective. A variety of program designs are possible, depending on space, staffing, and financial resources. Many in-center programs use hand weights, Thera-Bands[®], or rubber tubes for strength training and exercise bicycles for endurance training.

Staff sometimes fear the effect of exercise on vascular access or interference with the machine if exercise is done during dialysis. The available literature reports no access injury or clotting due to exercise, even weightlifting. Facilities with exercise programs report no increase in machine alarms even when upper body exercises are performed during dialysis, nor have needle infiltrations or disconnections occurred. A common sense approach to weightlifting and exercise on dialysis (using a weight that is within the patient's comfort level, for example) is always necessary.

If a facility-based program is not feasible, for whatever reason, don't be discouraged. As noted, many other exercise options are possible for your patients. Now is a good time to review your *Unit Self-Assessment Tool for Renal Rehabilitation* (USAT) scores for the Exercise "E". You will most likely be able to choose some exercise initiative from the list provided by the USAT criteria into which you can fit the activities you hope to include. When you are starting out, selecting one of the rehabilitation strategies included in the *basic* level is probably the easiest course. If you are adding to an existing exercise program, you will find that the intermediate and advanced level strategies in the USAT criteria contain useful suggestions.

Strategies to consider a facility-based exercise program:

- Read *A Guide for the Dialysis Team in Exercise for the Dialysis Patient: A Comprehensive Program*.
- Assess availability of facility resources and determine costs for various types of additional exercise equipment before considering an on-site program.
- Evaluate sources of potential funding including pharmaceutical companies, individuals, bake sales, craft fairs, local or regional foundations.
- Determine whether facility resources allow purchase of new or used equipment. You may be able to find good used equipment at some sporting goods stores, garage sales, want ads, or staff members may have equipment they are not using. See *Exercise for the Dialysis Patient: A Comprehensive Program* for more information on exercise equipment or contact the Rehabilitation Resource Center at (800)468-7777.

Several Approaches to Exercise for Dialysis Patients

It is not possible for every facility to have an extensive, on-site exercise program—but your patients can still benefit from increasing their levels of physical activity. Below are several types of exercise programs your facility may want to consider:

PROGRAM TYPE	EXAMPLE
Patients exercise on their own, with staff motivation.	A “race to the beach” program where patients log their independent walking or biking time on a facility bulletin board chart.
Facility contracts for reduced-price classes for patients to exercise independently.	A facility arranges a kidney patient discount with the local YMCA.
Facility arranges outside consultation to get patients started, then motivates them in-center.	Patients are referred to an exercise physiologist or cardiac rehabilitation program to begin exercise; dialysis staff help the patient to follow through with the program.
Facility uses minimal equipment for an in-center exercise program.	One or two exercise bikes are donated to a facility. Patients sign up to use them during dialysis. The dietitian coordinates bike use and serves as the exercise “champion.”
Facility has exercise bikes in the lobby.	Patients are encouraged to arrive early for dialysis so they can ride the bikes first.

Evaluate Physical and Functional Status Over Time

Exercise may be, fortunately, one of the easier renal rehabilitation interventions to evaluate, because there are so many possible discrete outcomes, for example, strength, endurance, flexibility, ability to perform activities of daily living, socialization, employment, and attitudes. Staff outcomes could include perceptions of demands of the program, and satisfaction levels. Facility outcomes may include staff time involved, cost of equipment and supplies, and patient acuity changes resulting in changes in staffing requirements.

Use Self-reports When Possible

While simple multiple-choice or open-ended questions can assess staff and facility outcomes, patient self-reports on physical abilities, or staff or professional physical functioning assessments are preferable to observations by staff. The Evaluation module provides information on patient self-reports that measure physical functioning separately from the fitness assessments in this module. However, the fitness assessment in this Module can serve as crucial baseline information.

Repeat Measures Over Time

Choose a regular frequency of reassessment of your patients' exercise abilities. Charting patients' exercise participation combined with regular re-testing can provide you with valuable information you can use to fine-tune individual patient programs and to assess overall fitness at your facility. If your facility is not-for-profit and your efforts demonstrate improvement, you may also be able to use your results in a grant application to obtain outside funding for exercise equipment or rewards/incentives for your patients.

Target Areas for Improvement

Be alert to both individual and facility-wide areas for improvement when you repeat your patient exercise assessments to evaluate progress. If, for example, a number of patients improve to the point that they can participate in a regular walking group, it may be time to consider beginning a formal walking program (EX-11). In time, your efforts to improve patients' strength, flexibility, and endurance should pay off in improved fitness and an improved outlook on life.

Assess the Costs of Your Program

Finally, cost-tracking is an activity every rehabilitation program should undertake. The goal of making renal rehabilitation a routine part of ESRD patient care can only be realized when the costs of various activities are available. A good way to begin to collect critical information about renal rehabilitation costs vs. benefits is for each unit to keep track of its own rehabilitation-related costs and outcomes. In this way, facilities will eventually be able to project rehabilitation expenses and better plan strategies and initiatives based on available resources.

Case Study:

Dialysis Clinic, Inc., Nashville, Tenn. Fosters Positive Attitudes Through Exercise

Can an exercise program make patients more proactive in their treatment, increase independence, instill a greater sense of camaraderie, and improve coping skills? That's what happened at Dialysis Clinic, Inc. (DCI) in Nashville, Tennessee. The program also won them the 1996 *Exemplary Practices* award for *Exercise*, sponsored by the Life Options Rehabilitation Advisory Council.

Several stationary bikes at DCI had been gathering dust for years. Then, DCI staff responded to research that reported the significant benefits of exercise for dialysis patients by organizing a voluntary exercise program to improve patients' health status. The plan included setting target hematocrit goals, monitoring and educating patients about blood pressure values, and controlling interdialytic weight gain.

Staff provided one-on-one patient instruction and conducted initial assessments that included performance-based exercises, an exercise questionnaire and assessment form, and physical rehabilitation and quality of life measures. Based on the results, a realistic program was implemented that patients could enjoy.

Patients can choose to participate in any or all of these program components:

- Group chair-side exercises that focus on improving strength and flexibility
- Chair-side stationary bikes that patients use for five minutes and gradually increase their time to 30 to 60 minutes
- Outdoor walking groups
- An exercise room with a wide range of equipment

Initial outcomes indicate a 20 percent improvement in scores on the one minute Sit-to-stand Test and a 52 percent improvement on the Lift and Reach Test. Just as important, Betty Murray, RN, educational coordinator, has seen the program improve patient attitudes and markedly enhance relationships among patients. "The comradeship, encouragement, and praise that the patients have received from each other has been a positive influence for all involved."

The costs of exercise equipment and supplies at the DCI-Nashville program are listed below. Of course, costs vary over time, if different brand-name or used equipment is purchased, or if donations can be found for some equipment. Please note that not all of this equipment is necessary—the DCI-Nashville program might be considered a "Cadillac" program.

General Equipment

Fitness free weights	\$20.00
Hand, ankle weights	\$7.00
Thera-Bands®	\$1.30
Stationary bike	\$339.00
Pedal exerciser	\$42.00
Total	\$409.30+*

* +1 weights/Thera-Bands®

Exercise Room Equipment

Universal® machine	\$1400.00
Stepper	\$269.00
Recumbent bike	\$285.00
Air-O-Dyne bike	\$465.00
Treadmill	\$1300.00
Weight bench	\$39.00
Fitness mat	\$32.00
Total	\$3790.00

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Appendix A: USAT Exercise Criteria

BASIC REHABILITATION INTERVENTIONS:

Score 1 point for each “yes” answer

- EX-1 ___ Do you have a centrally-located bulletin board featuring patients who pursue fitness activities?
- EX-2 ___ Do you have brochures/literature about renal exercise routinely available?
- EX-3 ___ Do you have any videos re: exercise available in the unit or for home use?
- EX-4 ___ Do you provide information or make referrals to community exercise resources?
- EX-5 ___ Is *every* patient asked about participation in exercise activities?
- EX-6 ___ Do you sponsor or give rewards or other recognition for patients’ efforts toward improving physical functioning?
- EX-7 ___ Do you sponsor or provide any other exercise-related or activities-based interventions or programs not covered above?

INTERMEDIATE REHABILITATION INTERVENTIONS:

Score 1 point for each “yes” answer

- EX-8 ___ Do you make direct referrals to community resources for exercise/fitness programs?
- EX-9 ___ Do you sponsor group exercise programs that are offered during off-dialysis time?
- EX-10 ___ Do you have any fitness apparatus or exercise equipment available at the unit?
- EX-11 ___ Do you sponsor, support or have you organized any patient walking clubs/any other group exercise?
- EX-12 ___ Do you regularly refer patients for OT and/or PT evaluations and treatments?
- EX-13 ___ Do you have contacts with community fitness/exercise resources that provide discounts/access for patients?
- EX-14 ___ Is *every* patient formally evaluated for changes that could influence physical functioning (i.e., anemia, bone disease, muscle atrophy, etc.)?

ADVANCED REHABILITATION INTERVENTIONS:

Score 1 point for each “yes” answer

- EX-15 ___ Do you sponsor/support any local events for fitness among renal patients?
- EX-16 ___ Do you provide for any kind of exercise programming outside of the dialysis unit that includes evaluation and individualized planning?
- EX-17 ___ Do you have an in-center assessment and training program to improve patients’ ability to perform activities of daily living (ADLs)?
- EX-18 ___ Do you have in-center, organized group fitness activities during dialysis?
- EX-19 ___ Do you track the outcomes or results of your exercise-related efforts?
- EX-20 ___ Do you track the costs associated with your exercise-related activities and programs?

_____ ***SUBTOTAL (20 possible)***

Explanations of USAT Exercise Criteria

BASIC: EX-1 TO EX-7

EX-1: Providing a bulletin board is a simple and basic intervention which has the potential for positive impact on patient exercise habits. Patients' successful experiences with exercise activities, their solutions to common exercise-related problems, and other news and accomplishments can be posted in a central location to be shared by everyone in the unit.

EX-2: There are now several types of printed educational materials for dialysis patients regarding exercise. Many of these can be obtained free of charge. Providing such materials for dialysis patients is an inexpensive, yet potentially effective method of ensuring that dialysis patients know the basic information about exercise.

EX-3: Exercise videos directed toward patients on dialysis (such as the video available as part of Amgen's *Exercise for the Dialysis Patient: A Comprehensive Program*) may wield more impact than printed materials because they show real patients engaged in real exercise. Videos have the potential to inform and motivate simultaneously.

EX-4: Making information available about community-based exercise programs is a simple way to get patients to take the first step toward participation in an exercise activity. Staff might use the yellow pages listings as a starting point for learning about local exercise opportunities. As one or more programs are contacted, information usually begins to accumulate in "snowball" fashion.

EX-5: In addition to providing valuable information about each individual's exercising habits and aggregate information about the entire unit's overall exercise patterns, asking every patient what he or she is doing for exercise conveys the degree to which staff believe exercise is important for dialysis patients.

EX-6: Rewards can potentially have a big impact on patients' overall outlook and continued motivation for an activity. Even simple kinds of rewards can help to keep patients focused and enthusiastic about their exercise activities. Certificates, small prizes or gifts, public acknowledgment on a bulletin board or in a newsletter, a party or treat in the patient's honor—all such activities contribute to the likelihood of patients' continuation in an exercise program.

EX-7: There are many other simple activities which might be undertaken to promote patients' participation in appropriate exercise endeavors. Any other methods or activities which you have identified can be credited here.

INTERMEDIATE: EX-8 TO EX-14

EX-8: Some of the criteria listed at the basic level suggest the identification of community exercise resources for patients. At the intermediate level, this notion is expanded upon, with staff actually making direct referrals to exercise/fitness programs in the local community.

EX-9: Group exercise programs provide opportunities for patients to share the exercise experience, general information and helpful advice about exercise, accounts of their triumphs and frustrations, and common concerns about exercise and dialysis. Since this criterion specifies that group sessions be held during off-dialysis hours, these sessions can easily double as support group activities in which patients help each other to maintain positive attitudes about exercise and rehabilitation.

EX-10: Having exercise apparatus or equipment available in the unit serves several purposes: it conveys the staff's real commitment to the notion of exercise for dialysis patients, it serves as a constant reminder of the possibility of exercise, and it makes exercise convenient for patients who are motivated to participate. Exercise "equipment" can be as simple as rubber bands for stretching and soup cans for weight training, or as sophisticated as a modified exercise bike.

EX-11: Patient clubs for walking or other exercise offer social support outlets for patients at the same time that they provide an opportunity for regularly scheduled "institutionalized" physical activity. Clubs of this kind can contribute to the rehabilitation esprit of the unit overall and can help patients to maintain optimal physical functioning.

EX-12: Physical therapy for diagnosis and treatment of dialysis patients may be covered by Medicare and/or other insurance. Frequently, this potential resource goes unused. A unit policy of routine referral of patients to OT and PT for evaluation and treatment is a good rehabilitation strategy with clear potential to contribute to patients' improved physical functioning.

EX-13: Once staff have made the initial contact to request information about programming appropriate for dialysis patients, they can easily go one step further and ask if discounts might be provided for dialysis patients. Many patients are on a very tight budget; even a few dollars' savings might influence their decision to participate in an exercise activity.

EX-14: Exercise is feasible only for those patients who are enjoying good clinical management of all the physical changes that accompany renal disease. Formally evaluating every patient for such physical changes not only increases the likelihood that good clinical management will be carried out, but also makes it possible for exercise activities to become part of patients' everyday lives.

ADVANCED: EX-15 TO EX-20

EX-15: Local fitness events communicate the importance of exercise for dialysis patients to patients and their families, to staff, and to the public. They also provide opportunities for patients who exercise to compete and to be acknowledged publicly for their accomplishments. Races, “Olympic” events, or other participatory events or programs are considered to be advanced strategies because they are likely to be both time-consuming and resource-intensive. However, they also have the potential to have significant impact on patients’ physical functioning, motivation, self-esteem, and sense of empowerment.

EX-16: Providing individualized exercise programming for patients off-dialysis and off-site is another relatively cost-and-time intensive rehabilitation activity. Such a program might entail renting a fully equipped gym or other usable exercise room or facility, procuring appropriate equipment, hiring or otherwise engaging an exercise trainer to do evaluations and provide individualized training suggestions, etc.

EX-17: Patients’ capacity to carry out activities required for daily living (ADLs) is an aspect of their physical functioning which should not be neglected. Routine assessments of patients’ ability to live and function independently, and institution of appropriate interventions to improve such ability, constitute advanced rehabilitation interventions which are of paramount importance. If patients can no longer care for themselves, the degree of rehabilitation which is possible for them becomes very limited. Assessing and improving ADL skills for dialysis patients should always be a top priority.

EX-18: In-center group exercise programs which actively champion patients’ participation are advanced rehabilitation strategies. Such programs require some planning and resources and have the potential to significantly improve patient’s well-being. Educational and encouragement sessions focusing on exercise might be included as part of such a program.

EX-19: Outcomes assessment is an essential component of any rehabilitation intervention. In order to know whether an intervention is really worthwhile, its results or impact must be carefully evaluated. To meet this criterion, outcomes resulting from the interventions must be measured regularly using a unit-developed or standardized assessment tool.

EX-20: It is essential that the costs associated with facilitating renal rehabilitation be known. To this end, cost-tracking should be performed whenever a rehabilitation activity is undertaken. Any system of cost tracking or monitoring which allows an estimate of all expenditures involved with a particular activity (time, materials, etc.) fulfills this criterion.



Appendix B: Exercise Checklist

CATEGORY	I USED TO DO THIS	I DO THIS NOW	I WOULD LIKE TO DO THIS
<i>Formal Exercise</i>			
Aerobic Dance (or Low-impact aerobics)			
Bicycling (Exercise or Regular)			
Cross Country Ski Machine			
Rowing Machine			
Stair Stepper or Step Aerobics			
Swimming			
Tai Chi			
Walking, Jogging, or Running			
Weight Lifting or Body Building			
Yoga			
Other			
<i>Dance</i>			
Ballet			
Ballroom			
Country Western (Line Dance)			
Folk/Ethnic			
Jazz/Modern			
ROM (Range of Motion) Dance			
Square Dance or Clogging			
Tap			
Other			
<i>Outdoor Activities</i>			
Backpacking or Camping			
Bird-watching			
Canoeing or Kayaking			
Hiking			
Horseback Riding			
Hunting			
Fishing or Ice-fishing			
Rock Climbing (or Indoor)			
Sailing or Sailboarding			
Skating (Ice, In-Line, Roller)			
Skateboarding or Snowboarding			
Skiing (Snow, Water)			
Other			

CATEGORY	I USED TO DO THIS	I DO THIS NOW	I WOULD LIKE TO DO THIS
<i>Household Chores</i>			
Changing and Making Beds			
Cleaning and Dusting			
Cooking			
Gardening			
Grocery Shopping			
Hanging Clothes on a Line			
Laundry/Folding/Ironing			
Mopping and Sweeping			
Mowing Lawn or Raking Leaves			
Painting			
Snow Shoveling			
Taking Out the Garbage			
Vacuuming			
Washing the Car			
Washing/Putting Away Dishes			
Other			
<i>Team/Competitive Sports</i>			
Archery			
Badminton			
Basketball			
Bowling			
Fencing			
Football			
Golf			
Gymnastics			
Hockey (Ice or Field)			
Laser Tag			
Martial Arts (Karate, Judo, etc.)			
Skeet Shooting			
Soccer			
Softball or Baseball			
Tennis or Racquet Sports			
Volleyball			
Other			

Evaluation

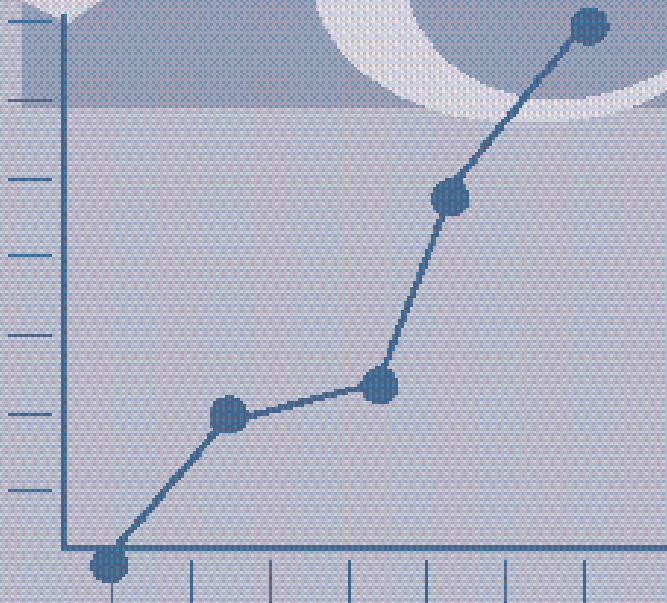
*Module 5:
A Practical
Guide to Renal
Rehabilitation*



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The *Practical Guide to Renal Rehabilitation* provides recommendations for individuals on dialysis regarding programming issues for the “5 E’s” of renal rehabilitation: Encouragement, Education, Exercise, Employment, and Evaluation. In using this Guide, the reader should be aware of certain limitations. First, the Guide may not cover all possible topics related to such issues, and it may not address aspects of such issues that may be relevant to you in light of your particular circumstances. Second, future legislation, regulations, administrative interpretations, and court decisions may significantly change the current law or the interpretation of current law cited in this material. Please note that neither Amgen Inc., the Medical Education Institute, Inc., nor the Life Options Rehabilitation Advisory Council intends to update the information contained in this Guide. It is based on information available as of the date of publication. Third, although the authors have used their best efforts to assure that the information contained herein is accurate and complete as of the date of publication, the authors cannot provide guarantees of accuracy or completeness. Fourth, practical suggestions provided throughout the text are based on the opinions of the Medical Education Institute staff. Suggestions may or may not reflect national experience and may instead reflect local experience. Finally, this Guide is provided with the understanding that neither the Guide nor its authors are engaged in rendering medical, legal, accounting, or other professional advice. If legal advice or other expert assistance is required, the authors recommend that the reader seek the personalized service of a competent professional.

The information in this Guide is offered as general background for the clinician who is interested in improving the quality of rehabilitation opportunities for dialysis patients. The Guide is not intended to provide practice guidelines or specific protocols and cannot substitute for the physician’s knowledge and experience with individual patients. The reader must recognize that exercise, in particular, involves certain risks, including the risk of severe injury or disability, including death, which cannot be completely eliminated, even when the exercise program is undertaken under expert supervision. Use of these materials indicates acknowledgment that Amgen Inc., the Medical Education Institute, Inc., and the authors will not be responsible for any loss or injury, including death, sustained in connection with, or as a result of, the use of this Guide.

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Key Points

- *Outcomes evaluation benefits patients, staff, facilities, and society.*
- *Patients and staff may need help understanding the rationale for outcomes assessments.*
- *Improving patient care requires systematic evaluation of the structure, process, and outcomes of care.*

Why Evaluate Patient Outcomes in ESRD?

“An outcome is defined as a change in a patient’s current and future health that can be attributed to antecedent health-care.”

Donabedian, 1980

Many people think evaluation is difficult and mysterious. However, the process of evaluation is not really difficult and it does not have to be mystifying. We all routinely engage in evaluation activities and use the conclusions we draw to make decisions in our day-to-day lives.

Today, evaluation of patient outcomes has become an integral component of all health-care delivery, including successful renal rehabilitation programming. According to Donabedian (1980), an outcome is “a change in a patient’s current and future health that can be attributed to antecedent health-care.” Evaluation helps health-care professionals determine whether patient outcomes are improved by changes in the delivery of care. Because evaluation is essential, it is our responsibility, as health-care providers, to become familiar with evaluation so measurement of outcomes can be routinely incorporated into dialysis facilities.

Outcomes evaluation is performed by different disciplines for different purposes. Traditionally, evaluation efforts have fallen into the realm of academic research. Researchers have developed methods, instruments, and protocols for collecting, analyzing, and interpreting outcomes data. Many evaluation activities performed by researchers are not immediately applicable to clinical settings. However, there are some research principles, tools, and techniques that can contribute to our ability to deliver optimal patient care, including rehabilitation (Meyer, 1994). In particular, evaluation can improve patient care and has the potential to influence public policy.

Evaluation Can Improve Patient Care

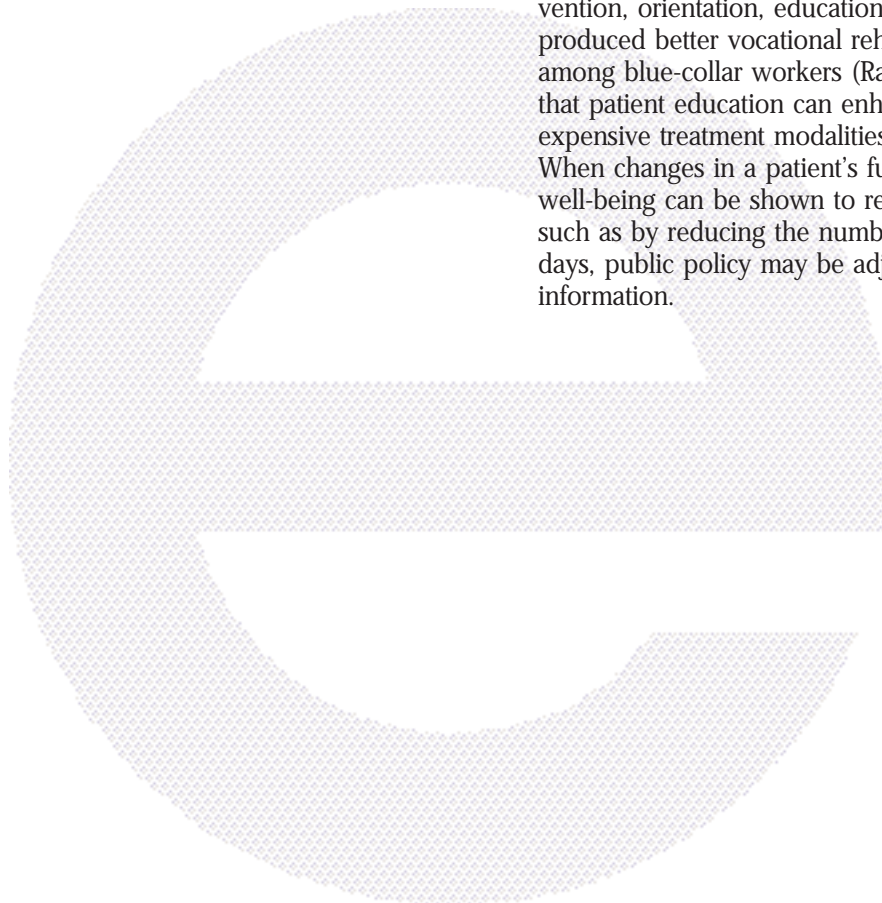
In clinical practice, evaluation can provide the impetus to help you adapt, revise, and improve care for your patients. For example, evaluation research has demonstrated that adequate dialysis can improve functional status and reduce morbidity and mortality (Rettig & Levinski, 1991; Held et al, 1990; Lowrie et al, 1994). This knowledge has led many facilities to routinely monitor dialysis adequacy and to modify their practice protocols to achieve better patient outcomes.

Additional research is needed to determine the exact relationships between clinical and rehabilitation interventions and improved patient quality of life (Curtin et al, 1997a). However, it is expected that rehabilitation activities will positively affect various aspects of ESRD patients' overall functioning and well-being.

Evaluation Can Influence Public Policy

Public concern about the high cost of medical care continues to grow. Insurers, providers, policy makers, government agencies, and patients are wondering how the increasing expense of quality medical care can be accommodated. As payers move toward limiting coverage to services that are cost-effective, the ability to demonstrate—through systematic evaluation—that a particular treatment provides a positive outcome in a cost-efficient manner is becoming more important. Demonstrating cost-effectiveness and positive outcomes may influence public policy and subsequent reimbursement.

If a certain rehabilitation intervention reduces the long-term cost of care, it is eventually likelier to be covered by Medicare or an insurer. We know that early intervention, orientation, education, and counseling have produced better vocational rehabilitation outcomes among blue-collar workers (Rasgon et al, 1993); and that patient education can enhance selection of less expensive treatment modalities (Grumke & King, 1994). When changes in a patient's functioning and well-being can be shown to reduce the costs of care, such as by reducing the number of hospitalization days, public policy may be adjusted to suit the new information.



Providing a Context for Outcomes Assessment

If you have read the other modules of this Guide, you will find that this module is a bit different. In order to help you understand how to do evaluation, we must first present some basic theory and then explain how the theory can be applied to evaluation of the outcomes of dialysis patients. Understanding this background will help you to design an evaluation plan that will suit the particular needs of your facility and your rehabilitation programming. Instead of a flowchart, this module has a step-by-step chapter, beginning on page 18, that will help you see the entire process from beginning to end.

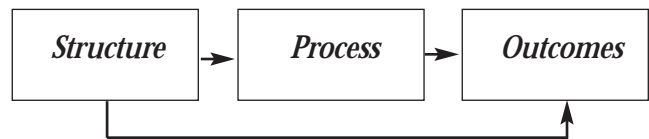
The evaluation section of the Life Options *Unit Self-Assessment Tool for Renal Rehabilitation (USAT)* is included as Appendix A of this module as an additional resource. The USAT lists criteria for good rehabilitation programming for each of the five rehabilitation “E’s,” and explanations of the criteria. The USAT criteria are arranged in order from basic to intermediate and advanced level, based on their complexity, resource use, and potential impact. You will find periodic references to the explanations of the USAT criteria throughout this module, and specific criteria will be referenced by number in parentheses (e.g., EV-6), so you can find them in Appendix A. Additional information about use and interpretation of the USAT is available in the *Unit Self-Assessment Manual for Renal Rehabilitation (USAM)*, which you can obtain by contacting the Rehabilitation Resource Center at (800)468-7777.

In the arena of research, *models* are often used to provide frameworks to organize thinking about how factors relate to each other. A particularly practical and widely applicable model for outcomes research was developed by Donabedian (1980), a clinician/researcher. This model, and a second model specific to the care of patients with ESRD, will be discussed in this section to help you understand the factors that go into selecting and assessing patient outcomes.

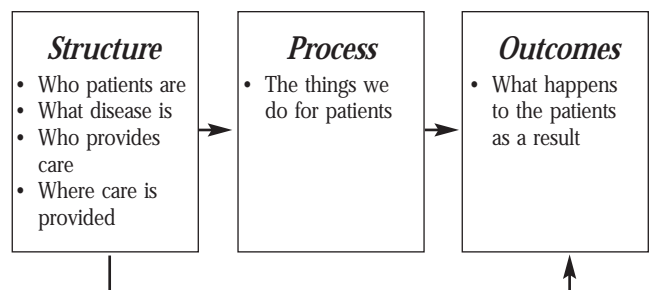
The Donabedian Model

The Donabedian model describes three major components of patient care: structure, process, and outcomes. *Structure* shapes and modifies the care provided. Structural elements include characteristics of patients, health-care providers, and the health-care system. *Process* includes factors related to how care is provided. Finally, *outcomes* are the levels and types of results that follow from the care provided (Rettig et al, 1997). Structure and process elements are inputs to all patient outcomes.

A practical demonstration of how the model works might help you understand it better. Here is the basic Donabedian model in graphic form:



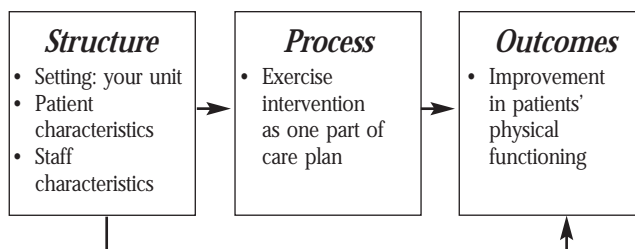
Events in the model occur from left to right in real time: structure influences process, while structure and process are both inputs into the outcomes. However, when you plan an intervention, such as a rehabilitation activity, you would *first* focus on the outcomes you want to accomplish, *then* on how to achieve your goals (structure and process). When we insert some of the elements from our definitions of structure, process, and outcome, the model looks like this:



The Donabedian model has real-life applications for outcomes evaluation in the dialysis setting. The following example may help demonstrate how it works: Perhaps in your facility, you notice (EV-1, EV-2) that some patients who used to walk into the unit independently are now using walkers or wheelchairs. What you are observing is an *outcome*, the result of things that came before—some elements of structure and some elements of process. The model suggests that the way to influence this outcome is by making changes to the structure and/or the process.

In our example, there are many structure or process elements that might be inputs to the deteriorating physical functioning of the patients. Perhaps it saves time to assist patients by offering wheelchairs rather than to help them walk into the unit. Perhaps the stairs are unsafe or inconveniently located, so patients take the elevator instead. Perhaps slippery floors in the unit make patients feel more secure in wheelchairs or with walkers. Perhaps poor weather contributes to less exercise in the winter months. Clearly, some of these

are more difficult to change than others. Some are impossible to change. Common sense tells us that an exercise-related rehabilitation activity might help to change the outcomes along with, or perhaps in spite of, all the other factors. With that in mind, the “blanks” in our model can be filled in to look like this:



This same basic model works for any need, or group of needs, you might identify and for any intervention or program you might conceive. The goals your team establishes for patient care and for rehabilitation programming will define the outcomes you will want to measure.

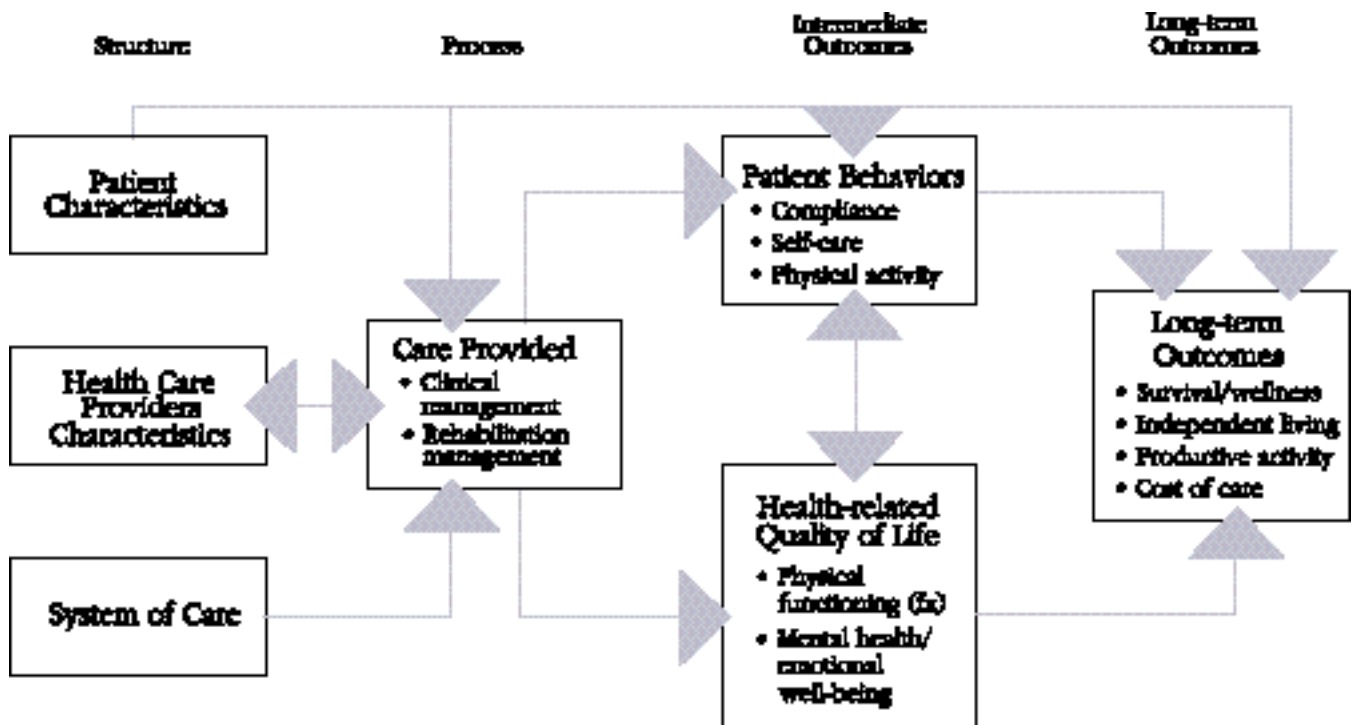


An ESRD-specific Model

Other models have been produced that focus on elements of structure, process, and outcomes, and which are particularly relevant to renal patients. One model was developed by Nancy G. Kutner, an emeritus member of the Life Options Rehabilitation Advisory Council (LORAC). Dr. Kutner's model identifies many

of the outcomes that are most meaningful for renal patients and specifies some of the important structural and process-related inputs to those outcomes (Kutner et al, 1997). Some minor adaptations of the Kutner model produce the version depicted below, which we will call the working model. We will refer back to this model throughout the rest of this module.

The Working Model of ESRD Patient Inputs and Outcomes



Adapted from a model developed by Nancy G. Kutner, PhD.

Outcomes of Care

The evaluation process *begins* at the *endpoint*, by looking at the outcomes of care—either outcomes that are occurring or outcome goals we hope to achieve. As you saw in both models, patient outcomes are results of the structure and process of care that precede them. So, the outcomes we measure should also be the goals we want to achieve.

For example, since keeping patients alive is a goal we want to achieve, mortality is an outcome we need to measure. Our goals for patient care can be intermediate or long-term. The outcomes we measure are correspondingly intermediate and/or long-term. As caregivers, we often focus on achieving intermediate goals, particularly with regard to renal rehabilitation, but always with a watchful eye to the long-term outcomes and implications.

Long-term or Health-care System Outcomes

Because the primary goal of health care is to preserve patients' lives, mortality and morbidity have traditionally been the priority long-term outcomes to measure (Lowrie, 1994). Mortality and morbidity continue to be important outcomes. But, now, *other* outcomes of care are known to be important as well. For instance, the ability of ESRD patients to live independently has important implications for their quality of life, as well as cost implications for the health care system and for society at large. The same is true for patients' continued ability to engage in productive activities (Kutner, 1997).

Productive and independent living, then, are important long-term outcomes of health care that must be repeatedly measured and monitored at some level (EV-2). Now, we will discuss long-term outcomes of care, including patients' survival/wellness, independent living and productive activity, and overall decreased health-care costs.

Patient Survival/Wellness

Keeping patients alive is the first long-term outcome of health care. Maintaining wellness is also an important outcome (EV-1). Recurrent symptom episodes, repeated hospitalizations, and the need for medical procedures greatly interfere with patients' normal lives. These incidents also have significant cost implications for the health-care system and for society. Reducing such events by enhancing or maintaining ESRD patients' wellness continues to be a desired long-term outcome of medical care. Fortunately, by altering some of the elements of process which will be discussed in the next chapter (i.e., by implementing good clinical and rehabilitation management), we can improve these long-term outcomes.

Independent Living and Productive Activity

The need for nursing home care or in-home assistance with activities of daily living can negatively affect patients' overall quality of life, while also adding to the cost of care. Preserving dialysis patients' ability to care for themselves and to perform productive activities are important long-term outcomes of care.

Cost of Care

A goal of our larger society is to contain costs for health-care. Monitoring the costs associated with achieving other long-term and short-term goals of the health care provided is very important for outcomes assessment (EV-20). Interestingly, rehabilitating dialysis patients and restoring their overall functioning might be the short-term route to the long-term outcome of containing the costs of caring for dialysis patients. (Jones, 1990)

Intermediate Outcomes of Care

Intermediate (or “intervening”) outcomes of care come between care provided and long-term outcomes. In the working model, the important intermediate outcomes are patient behaviors and health-related quality of life, each of which will be discussed in detail below.

Patient Behaviors as Intermediate Outcomes of Care

Patient behaviors are frequently overlooked, but are important, intermediate outcomes. Common sense tells us that structural elements (patient characteristics, provider characteristics, and system characteristics) are likely to influence how patients think, believe, and behave. Similarly, clinical management of their disease and the rehabilitation they experience are also likely to influence patients’ thoughts and actions—which can include patterns of compliance or noncompliance, self-care or passivity, physical activity or inactivity (Curtin et al, 1997b). These kinds of patient behaviors are closely interrelated with health-related quality of life, and even with morbidity and mortality (Meers et al, 1996), and should be monitored (EV-5, EV-14).

Compliance

Renal patients’ compliance with their complex therapeutic regimens is an important intermediate outcome of medical care, which has clear implications for their other health-related outcomes (Curtin et al, 1997b, Curtin et al, 1997c). ESRD patients’ adherence to their prescribed therapies can be influenced by both the structure and process of their care (Kutner et al, 1997). As is true for all patient behaviors, patients themselves have the greatest influence on these outcomes. Rehabilitation can also be instrumental in increasing the potential for patients to adhere to their regimens. The first step to improving patients’ compliance is to become sensitized to the problem of noncompliance and to obtain an estimate of the degree to which it is occurring. Only when noncompliance is seen as an outcome of the factors which precede it, and is systematically monitored, can a solution be found and implemented (EV-15).

Self-care

Recent research has shown that patients’ involvement in their own care affects other outcomes so positively that self-care is considered by some to be a “rehabilitation intervention in itself” (Meers et al, 1996). Involving patients in self-care can simultaneously be both a positive *input* to some desirable health outcomes, and a positive *outcome* of rehabilitation.

Helping dialysis patients to arrive at the point where even minimal self-care activities are possible requires both good clinical management of their disease and its symptoms and good rehabilitation management. Education, support, family programs, and many other activities can help patients move toward self-care. But before, during, and after such programming is instituted, regular assessments of patients’ levels of self-care will be needed (EV-9, EV-10, EV-11, EV-12). (See the Encouragement module for more information about self-care tasks).

Physical Activity

Patients’ participation in physical activities—which are necessary to their quality of life, wellness, and survival—can also be influenced by clinical and rehabilitation management. Performing activities of daily living contributes to patients’ feelings of autonomy and self-worth and preserves their ability to continue to care for themselves in the future (Painter, 1994). Measuring patients’ ability to perform activities of daily living constitutes a rehabilitation evaluation assessment at the basic (EV-1, EV-2), intermediate (EV-12) and advanced (EV-16) levels.

With good clinical management in place, good rehabilitation programs can support physical activities such as exercise, hobbies, recreational and competitive sports, as well as activities of daily living. In order to decide what program(s) might be indicated, you will need to evaluate patients’ *willingness* and *ability* to participate in physical activities. Once baselines are established and programs are conceived, monitor ongoing participation. (See the Exercise module for more information about physical activity for ESRD patients.)

Health-related Quality of Life

Health-related quality of life (HRQOL) is an intermediate outcome that has been shown to have an impact on the long-term health-care outcomes of survival and wellness (Kutner et al, 1997). HRQOL is a composite of measures of the patient's physical, social, and role functioning; mental health/emotional well-being, and perceptions of general health (Wilson & Cleary, 1995). HRQOL is the patient outcome most likely to be *directly* affected by rehabilitation programming. Because HRQOL is an outcome of great importance to patients, physical functioning and mental health/emotional well-being will be covered in more detail below.

Physical Functioning

In general, patients' functioning or "functional status" indicates how well they are getting along with their day-to-day lives despite ESRD. Patients' ability to continue functioning optimally in as many areas of their lives as possible is closely related to their quality of life. Further, improved physical functioning is linked, in varying degrees, with the long-term outcomes discussed earlier: survival, wellness, and independent and productive living (DeOreo, 1997; Painter, 1994).

For renal patients, physical functioning is especially relevant. The physical status of most dialysis patients is seriously compromised. Many dialysis patients are unable to do any activity beyond the most basic activities of daily living (Ifudu et al, 1994). Therefore, improved physical functioning is an important goal. Measurement of physical functioning as an outcome is the only way to ensure ongoing progress toward that goal (EV-1, EV-2, EV-3, EV-12, EV-16). Clearly, monitoring and improving physical functioning is a pivotal concept and activity for renal rehabilitation.

Mental Health/Emotional Well-being

Another dimension of health-related quality of life with particular relevance for renal patients is mental health/emotional well-being. Depression is a frequent by-product of chronic disease. Even when diagnosable clinical depression is not present, other mental health issues may arise. Diminished self-worth, loneliness, isolation, sense of loss and lack of motivation are just a few of the many problems dialysis patients face.

Improving dialysis patients' mental well-being begins with careful measurement of patients' current state. This can be done informally, as an ongoing process during regular care, or formally, through educational and support programs. In either case, unless the health-care team is aware of any problem (EV-5, EV-14), no help will be forthcoming.

Now that you have an overview of some of the more important long-term and intermediate outcomes of care, we will discuss process and structure in the next two chapters.

Case Study:

Kaiser Permanente Los Angeles Medical Center Dialysis Unit: Using Evaluation to Improve Patient Care

Months before a patient begins treatment for kidney failure at the Kaiser Permanente Los Angeles Medical Center Dialysis Unit, staff have already asked, “Who is this person?” They receive a good answer from a predialysis educational program that helps them begin to evaluate patients before they reach end-stage renal disease. This is just one component of an extensive evaluation program that won Kaiser Permanente the 1996 Life Options Rehabilitation Advisory Council’s *Exemplary Practices* award for *Evaluation*.

At Kaiser Permanente, which serves 800-1000 pre-dialysis and dialysis patients, evaluation is more than an afterthought—it is built into every part of a comprehensive rehabilitation program. Elements are tailored to evaluate the needs of each patient. Measurable rehabilitation outcomes such as rehabilitation potential, quality of life, self-esteem, compliance, and satisfaction with care are assessed repeatedly, and the information gathered is used to improve care.

Further evaluation occurs to determine the effectiveness of programming for each “E.” To assess exercise, the Karnofsky tool was used to measure patients’ physical functioning so patients could be appropriately referred for services. Pre-tests, post-tests, and informal assessments of the accuracy of patient knowledge are used to evaluate patient education outcomes from formal predialysis, home dialysis, and transplant classes, and one-to-one educational sessions. Literacy and comprehension are also evaluated.

With employment a major focus of rehabilitation, patients are screened for employment status. Flexible scheduling with priority for working patients, home dialysis modalities, referrals to community and vocational rehabilitation agencies, education, and job skills

training help Kaiser achieve notable patient employment rates. Encouragement interventions are evaluated with patient feedback forms, and questionnaires are used to measure patient satisfaction with care.

At Kaiser Permanente, evaluation activities continue around the clock. Informal patient monitoring by the nephrologist and nursing staff occurs during regular rounds. Each week, multidisciplinary patient care meetings are held. Each month, the continuous quality improvement team meets and patient care conferences are convened for pre-ESRD patients, home dialysis patients, and pre-transplant/transplant patients. Biannual rounds with patient participation are held to assess the progress of stable patients. Referrals are made at any time, as they are needed.

Despite the comprehensive nature of Kaiser’s rehabilitation program and its evaluation component, no outside funding or additional personnel are used. Further, the program works: patients who completed the pre-ESRD program before they began treatment had 4 times fewer hospital days. The annual hospitalization rate for the Kaiser Permanente dialysis population is an astounding low one-third of the national average, even though 43% of the patients have diabetes.

Kaiser Permanente has dedicated itself to ongoing evaluation. The focus of these efforts is to provide the highest quality of care possible for its patients. Kaiser’s commitment to quality is reflected in the words of staff nephrologist, Scott Rasgon, MD “We look at outcomes to see how we are doing. We’re always looking at ways to improve the center as a whole.”

E

lements of Process

The two basic elements of process in the working model and included here, are good clinical management of ESRD and good rehabilitation management. As you saw in the working model on page 6, health care providers and/or the system of health care can *only* affect patients through the care they provide. Obviously then, good clinical management and good rehabilitation management are crucial to achieving successful outcomes.

Clinical Management Prerequisites to Rehabilitation

In the Life Options' report, *Renal Rehabilitation: Bridging the Barriers*, several recommendations were made to enhance dialysis patients' overall well-being through optimal clinical management. These recommendations suggested that, in order to be true candidates for renal rehabilitation, patients must first have several prerequisites in place: appropriate anemia control, adequate dialysis, successful access placement and care, and sufficient nutrition. Measuring the fulfillment of these prerequisites constitutes an intermediate evaluation activity (EV-9, EV-10, EV-11, EV-12, EV-13). (See the Getting Started module for a more detailed discussion of the prerequisites.)

In-depth examination of the clinical prerequisites for ESRD patient care is beyond the scope of this guide. However, it is indisputable that these aspects of patient care can have an impact on patient outcomes. Attempting to begin renal rehabilitation before these clinical prerequisites are in place is nearly futile and likely to be frustrating for both patients and health-care providers.

Rehabilitation Management: The "5 E's"

The Life Options Rehabilitation Advisory Council's *Bridging the Barriers* report also defined renal rehabilitation in a way it had never been defined before—structuring it into five core principles: Encouragement, Education, Exercise, Employment, and Evaluation. Developing these 5 "E" categories was a major step that provided the renal community with a concrete and accessible framework for thinking about renal rehabilitation. The "5 E's" summarize the broad areas in which renal rehabilitation should be focused in order to obtain positive patient outcomes.

Rehabilitation activities in the 5 "E" categories, when taken together, comprise good rehabilitation management for patients with ESRD. As conceived in the modules of this Guide, activities related to the "5 E's" are *processes* which can positively affect patient outcomes. If good clinical management and good rehabilitation management are provided, both intermediate and long-term outcomes of care should be measurably improved.



*E*lements of Structure

You may remember that the elements of structure included in our model are characteristics of patients, health-care providers, and the health-care system. As you might imagine, these factors are far less easily changed than are process factors. Nonetheless, since they do have an impact on patient outcomes, we must at least be aware of their role in the overall scheme of things.

Patient Characteristics

The only characteristic renal patients have in common is that they all have renal failure. As you know, patients come from different socio-economic and racial backgrounds. They have different educational levels, personalities, health beliefs, attitudes, family circumstances, and different degrees of personal, environmental, and social resources. Even their symptoms may be different. In short, dialysis patients are far more dissimilar than similar, and generalizing about them is a risky business.

Each patient characteristic can have an impact on the health-related outcomes that can be achieved. If we are sensitive to patients' singularity (EV-5, EV-14), we may be motivated to individualize their care as much as possible. If we can work effectively with patients' unique strengths and weaknesses, we will be able to maximize their health-related outcomes.

Health-care Provider Characteristics

Several characteristics of health-care professionals can influence patient outcomes. Different disciplines bring different skills, abilities, attitudes, and orientations to their professions. For example, social workers, nurses, dietitians, and nephrologists may all see the same

patient issue in different ways. This can be an advantage or a detriment. Whether professional differences turn out to be a "plus" or a "minus" depends on how they are viewed in the care situation. If each health-care professional sees his/her approach as the "right and only approach", patient care might be fragmented and disjointed. If each views his/her unique input as one part of a complex care approach, the care is more apt to be unified and comprehensive (EV-16). Such comprehensive care would be more likely to contribute to positive patient outcomes.

System Characteristics

The system within which health care is provided affects patient outcomes. Individual dialysis facilities are organized, staffed, and managed differently, and such differences are reflected first in the care provided and then in the outcomes that result from that care. Similarly, policies, procedures, and approaches of payers differ, and these differences also affect patient outcomes. Finally, there is a culture-wide philosophy of health care in general and of renal disease care in particular that influences who is treated and what treatments they receive.

It is clear that these system characteristics are implicated in patient outcomes, but they are not factors that are easy to change. Being aware of them, however, helps keep us attuned to their influences and also may help us to account for otherwise unaccountable changes in the outcomes we are tracking.

C

hoices: Making Evaluation Decisions

Choosing Outcomes to Measure

The question of which outcomes to measure is best answered on a case-by-case basis. To date, there is no magic formula, no “best” approach, particularly for measuring outcomes of renal rehabilitation. There are, however, a few general principles that might help you decide where to start with outcomes assessment in your facility:

1. In every case, the outcomes you will choose to measure should reflect the goals you want to achieve. For example, since a primary goal of renal rehabilitation is to preserve patients’ ability to live independently, the outcomes you would look at would be their ability to independently perform activities of daily living.
2. The outcomes you measure should be specific and focused enough to provide you with useful information. At least in the beginning, do not collect information that you cannot use and interpret in your own facility. For example, measuring patients’ knowledge about what adequate dialysis is and what it has to do with cutting their dialysis time short is probably more practical and useful than measuring their knowledge about normal kidney function. Similarly, measuring patients’ health-related quality of life probably takes precedence over collecting Myers-Briggs personality types.
3. Instead of measuring “universal” outcomes, it might be better to begin by thinking of what you would like to change or improve about your patients’ functioning or behaviors. Although the working model on page 6 suggested several important intermediate and long-term outcomes for dialysis patients, these outcomes are broadly conceived, and may or may not be relevant to the goals you have for your patients’ rehabilitation.
4. Next, think of what you could measure that would verify when that achievement had been accomplished—and that is the outcome that you will want to measure.

For an even more “applied” discussion of how to begin an outcomes assessment, please refer to the section of this module entitled, “*Step-by-step Evaluation*”, on page 18.

Choosing Instruments to Use

Once you decide what outcomes to measure, you can determine what instruments might be useful for measuring the outcomes you have targeted. For example, several instruments are available to assess patients’ health-related quality of life. Some of these instruments are generic—designed for use with any kind of patient populations—while others are designed for use with kidney patients (Rettig, 1997). Also, different instruments may measure different domains of HRQOL, so you will have to know what you are specifically looking for. A table describing four of the most commonly used HRQOL instruments is provided at the end of this section.

Generic Versus Disease-specific Instruments

Which instrument you choose depends entirely on what you want to do with the information you collect. If you want to compare renal patients’ outcomes to cardiac patients’ outcomes, you will need to use a generic measure (Wiklund & Karlberg, 1991). If you want to measure outcomes unique to renal patients, you will want to choose a measure that was designed for use with renal patients. ESRD-specific measures have the obvious advantage of addressing the particular symptoms and problems associated with renal failure. As you will see in the table provided, there are a few of each of these kinds of measures available.

Performance-based, Self-report, or Observation Instruments

Similarly, there are different ways of obtaining the information that measures your targeted outcome. Which measure you choose will again depend on your specific aims for collecting the information. One type of measure is *performance-based*. As the name suggests, this type actually tests the patient's ability to perform a task or activity. Sit-to-stand, lift-and-reach, timed walk, or hand grip tests for evaluating physical functioning are performance measures. These tests for physical functioning are described in more detail in the Exercise module of this Guide.

The most practical advice that can be given about choosing an instrument is the following: know what you want to measure and make sure that the instrument you choose measures what you want to know.

Patient self-report measures have the patients answer questions instead of requiring them to perform an activity. A self-report measure might ask patients if they have a problem getting up from a chair, lifting and reaching, or holding on to objects. There is a wealth of information that can be gleaned via patient self-report. For example, self-report measures can be used to

assess such outcomes as physical functioning and well-being, functional independence, ability to perform activities of daily living, employment status, mental health and well-being, health perceptions, attitudes, and many others.

Observation instruments are those which are completed by observers. Assessments made by nurses, dietitians, or social workers are observation assessments. The Karnofsky scale is an often-used observation assessment that estimates patients' functional status (Karnofsky & Burchenal, 1949).

As mentioned earlier, the type of instrument you choose will depend on what you want to measure and why you want the information. For example, if you want to know whether an exercise intervention is increasing patients' strength, then a performance-based measure would probably be best. On the other hand, if you want to know whether your exercise program is helping patients with their day-to-day lives, you might want to use a measure that asks patients how much difficulty they are having walking up stairs, carrying groceries, and performing other daily activities (EV-15). Instruments such as the Medical Outcomes Short Form (SF-36) or the Kidney Disease Quality of Life Instrument (KDQOL™) ask practical questions like these. Each of these instruments is described in the table on page 15.

The most practical advice that can be given about choosing an instrument is the following: know what you want to measure and make sure that the instrument you choose measures what you want to know.

Table 1: Four Quality of Life Instruments—Summary Data

1. Instrument name	<i>Dartmouth COOP Functional Health Assessment Charts</i>	<i>DUKE</i>	<i>MOS SF-36</i>	<i>KDQOL</i>
2. Obtainable from	Dartmouth Primary Care Cooperative Practice Network, Dept. of Community Medicine, Dartmouth Medical School, Hanover, NH 03755-3862	Department of Community & Family Medicine, Duke University Medical Center, Box 3886, Durham, NC 27710; Attn: George R. Parkerson, Jr., MD	The Medical Outcomes Trust, 20 Park Plaza, Suite 1014, Boston, MA 02116-4313	RAND Corp, 1333 H St. NW, Washington, DC 20004-4792; Attn: Caren Kamberg, e-mail: caren_kamberg@rand.org
3. Conditions of use	@Dartmouth College; write Cooperative for permission to use	Duke University; reproducible by others with permission	@Medical Outcomes Trust Permission to use required but routinely granted	RAND; write Caren Kamberg for permission to use
4. Cost of instrument (in quantity)	Chart package (charts, manual, articles) available for \$20 for non-commercial use	Reproducible by others with permission	Reproducible by others with permission	Single copy free of charge; users permitted to make unlimited copies of instrument
5. Features:				
a. No. of items	7	17	36	KDQOL, 134 KDQOL-SF 1.2., 80
b. No. of domains measured (see Table 2)	7	11	8	19
c. Means of administration	Self-reported data by patient or clinician (physician, nurse, medical assistant)	Self-reported data by patient or trained interviewer	Self-reported data by patient or trained interviewer	Self-reported data by dialysis patient or trained interviewer
d. User's guide available? Other support materials?	Yes; translated into 20 languages	Yes	Yes; translated into many languages	Yes; KDQOL-SF translated into 5 languages
e. Estimated time for patient to complete questionnaire	5 minutes	5 minutes	12-15 minutes	KDQOL, 30 minutes KDQOL-SF, 16 minutes

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Table 2: Four Quality of Life Instruments—Domains Measured

1. Instrument name	Dartmouth COOP Functional Health Assessment Charts	DUKE	MOS SF-36	KDQOL
2. Domains measured	<i>Generic</i> Physical Emotional Daily activities Social activities Social support Pain Overall health	<i>Function</i> Physical health Mental health Social health General health Perceived health Self-esteem <i>Dysfunction</i> Anxiety Depression Anxiety-Depression Pain Disability	<i>Generic</i> Physical functioning Role limitations—physical Bodily pain General health Vitality Social functioning Role limitations—emotional Mental health	<i>Generic</i> SF-36 domains <i>ESRD/dialysis</i> Symptom/problems Effects of KD on daily life Burden of KD Cognitive function Work status Sexual function Quality of social interaction Sleep
3. Additional and supporting measures	Charts for domestic violence and health risks Integrated systems for adolescent, adult, geriatric, and dialysis patients	Duke Severity of Illness Checklist (DUSOI)	Physical Component Summary (PCS) Scale Mental Component Summary (MCS) Scale	Social support scale Dialysis staff support scale Patient satisfaction scale

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Choosing Activities to Implement

Remember that when you were choosing an outcome to measure, you first thought of what change or improvement you wanted to see in your patients. That goal became the outcome that you would ultimately measure. A simple extension of that line of thinking will help you to decide what rehabilitation activity to implement.

First, think about the goals you have established and the outcomes you have decided to measure. Next, try to imagine what activity, strategy, or program could help to bring about that outcome. You must conceive an activity that you believe will produce the outcome in spite of such structural constraints as reimbursement barriers, financial barriers, potential staff resistance, or possible patient apathy. If you can develop a strategy that might bring about the change you desire, then you will be successfully turning a theoretical model into a practical reality.

Step-by-step Evaluation

At this point, you probably feel like you know more than you did about *structure*, *process*, and *outcomes*, and how they all fit together in a theoretical model. But you may not feel that you know enough about the actual mechanics of *doing* outcomes evaluation to begin doing it yourself. This section will present a step-by-step plan for beginning an outcomes assessment effort.

1.0 Choose the Outcome(s) You Will Measure

The most crucial component in beginning an outcomes evaluation program is careful planning (Davies, 1994). As with any new program, mapping out your plan up front will help you determine where you are now, where you want to go, and how you will get there. As we discussed earlier, the first thing to do is to identify what outcomes are appropriate to measure in your unit.

1.1 Use the USAT evaluation forms for all 5 E's.

You can find the USAT forms for each E in the back of the corresponding module of this Guide. Use these forms to take inventory of the rehabilitation activities you are already doing in your facility.

1.2 Check to make sure that you are measuring the outcomes of the rehabilitation activities that are already in place. For example, if you are doing an exercise activity, are you measuring physical functioning? If you have a peer support program, are you evaluating mental health/emotional well-being?

1.3 Measure the outcomes that seem to be associated with *each* element of your rehabilitation program. Know that sorting out which rehabilitation activities are linked with which outcomes may be very difficult—but you should at least be able to gather useful information about whether your interventions are making a difference in patient outcomes.

1.4 Plan to measure outcomes you are not yet achieving, but would like to see happening in your unit. Perhaps you have noticed particular needs or deficiencies in your patients, or have observed some area of patients' functioning or well-being that could use improvement. In this case, you would have to plan a new program or initiative to produce the outcomes you desire.

1.5 Be sure to always measure the logical, projected outcomes of any new program or initiative. New initiatives may have new outcomes associated with them. Plan your outcomes evaluation at the same time that you plan any new activities—they are flip sides of the same coin.

2.0 Choose the Instrument(s) to Measure the Selected Outcomes

Become familiar with the outcomes evaluation instruments which are summarized in the tables on pages 15 and 16, as well as with any other instruments you may have heard or read about. Make sure you know what each instrument measures, where it is available, how it is administered, etc. A chart which may be helpful to you can be found in Appendix B. After you have accumulated that information, you might want to consider the following factors when you decide which instrument to use:

2.1 Be absolutely certain what you want to get out of your assessment. Once you know what information you are looking for, you can begin to determine whether the instrument you are choosing can accomplish that end. *Make sure the instrument you choose actually measures the outcomes you hope to assess.*

2.2 Consider the relative ease of use of your selected instrument. For example, the instrument must be relatively convenient for staff to use, it must be understandable to patients, it must be cost- and time-efficient. If an instrument is not all of these things, it is unlikely that you will continue to use it over time.

2.3 Determine *other* ways (besides your selected measurement tool) to obtain feedback from patients and staff about your evaluation program and about the outcomes. Information about the same outcome obtained from a different source helps to verify your data. Patients, families, and staff can offer valuable input into results or effects of rehabilitation activities that may not show up in your formal assessment process.

2.4 Resist the temptation to develop your own instrument or tool for evaluation. Experts in instrument development are much better prepared to develop a new evaluation tool than are health-care providers who are not trained in instrument development. Remember that if you do succumb to the temptation and design your own tool, you will never be able to compare your patients' outcomes with any other patient population.

2.5 Decide what you are going to do with the information. Be sure to use the information you collect. Incorporate the results of your outcomes assessments into care planning and/or discussions at patient care conferences.

3.0 Do a Baseline Assessment of the Selected Outcomes

Whenever possible, be certain to obtain baseline measures of your selected outcomes *before* you begin the rehabilitation activity. To perform a baseline assessment, administer the outcomes instrument(s) you have selected to your patients. This is the stage where you actually get to try out your outcomes evaluation plan. Now, in this next stage, you must:

3.1 Establish the procedure for administering the evaluation measures and for interpreting and using the information you obtain. After you have done the baseline assessment and actually have the results, you will want to closely examine what you have done and what you have obtained. If you don't have the information you want, re-assess and determine if the instrument is the problem, if the process is not as it should be, or if the timing of the evaluation was inappropriate.

3.2 Determine if the instrument administration went smoothly and was satisfactory to patients and staff. Again, if patients or staff are dissatisfied with the process of the assessment, it is unlikely that the evaluation process will ever be institutionalized. Take the time now to check in with staff and patients to make sure everyone is "in synch."

3.3 Determine if the instrument yielded the information you were looking for about the outcomes you targeted. After process concerns have been resolved, you will want to be sure you have actually obtained the outcomes information you were seeking. Do you know now if your exercise intervention is having an impact on patients' ability to walk into the unit rather than use a wheelchair?

3.4 Determine if you will be able to put the information you have gathered to good use. An important issue is whether or not the outcomes information you obtain is going to be really useful. Our main concern is patient care, and if our outcomes information isn't related to patient care, we are likely to soon abandon its collection.

4.0 *Implement, Modify, and Monitor Rehabilitation Activities*

Once you have completed a baseline assessment, you will be ready to begin the rehabilitation activities (inputs) you identified earlier. If you are implementing a new program or intervention, it is at this point that you would set it in motion. If you are assessing an ongoing program, now you would either continue it as is, or modify it based on your findings.

There is usually quite a bit of “lag time” before the outcomes you are trying to achieve with your rehabilitation activities will reflect any change. For this reason, outcomes evaluation becomes most useful when it is incorporated as a regular, ongoing, and long-term program. Over the long run, changes in patient outcomes can be observed and correlated with other laboratory findings, patient self-reports, staff observations, and the like. Often, when the information gathered from all of these sources is put together, an explanation for the change in outcome can be found (Curtin et al, 1996-97; Kutner, 1994; Meyer et al, 1994).

4.1 Be positive and enthusiastic. Emphasize the improved outcomes you are trying to help your patients achieve, whether you begin a new intervention, modify an ongoing one, or continue an existing program unchanged.

4.2 Based on your outcomes evaluation, set priorities for what needs to be changed or improved. Try to focus on changes that seem most likely to have a positive impact on patient outcomes. At times, you will be simply increasing or intensifying an activity—at other times, this step will involve initiating completely new activities (EV-15).

4.3 Integrate revisions into patient care planning. Look at each patient’s results over time in each of the areas you are measuring. Change your interventions as needed to promote progress. Continue to evaluate your interventions, communicate results to patients, family, and staff, and incorporate your data into ongoing care planning for individual patients.

4.4 Determine and implement facility-wide program changes. Tally and analyze the results in each measurement area for all of your patients. Look at these data to tell you which of your activities are most effective at producing the desired results. For example, after an intervention to improve mobility, are your patients engaging in more physical activities? These data are critical as you work to improve your rehabilitation program for your entire patient population (EV-15).

4.5 Monitor continuously. Although monitoring outcomes is the final phase in our step-by-step evaluation framework, a continual cycle of measuring, monitoring, and improving at both the individual patient and the facility level will be better able to help you determine if you are achieving your outcome goals.

Conclusion

By now, it should be clear that evaluation of outcomes is not as difficult as you may have thought. The key to evaluating outcomes in the dialysis setting is careful planning. At the outset, many of us try to collect too much information without any clear idea of how to use it. If you develop a workable plan with input from interested team members and follow the Step-by-step Evaluation section, you will be well on your way to an effective outcomes evaluation program.

To help other clinicians know that an activity you initiated has proven successful, it is important that you make your results public. You can accomplish this simply by talking with colleagues or by presenting in a more formal fashion at a local, regional, or national professional meeting. Another option is to submit an article to a journal for publication (**EV-8, EV-18**). Contact the Rehabilitation Resource Center at (800)468-7777 for

a list of journals and additional evaluation materials, or to report your intervention and results for possible publication in the *Renal Rehabilitation Report*. Be sure to share the findings from your evaluation project with staff, patients and families, and colleagues.

Finally, cost tracking is an activity every rehabilitation program should consider (**EV-20**). The goal of making renal rehabilitation a routine part of ESRD patient care can only be realized when the costs of various activities are available. A good way to begin collecting critical information about renal rehabilitation costs vs. benefits is for each unit to keep track of its own rehabilitation-related costs and outcomes. In this way, it will eventually be possible to project rehabilitation expenses and better plan strategies and initiatives based on available resources.



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Appendix A: USAT Evaluation Criteria

BASIC REHABILITATION INTERVENTIONS:

Score 1 point for each “yes” answer

- EV-1 ____ Do you perform regular assessment of patients’ overall functional status (physical functioning, mental health functioning and well-being)?
- EV-2 ____ Do you perform regular assessment of patients’ activities of daily living (ADL) status?
- EV-3 ____ Do you perform regular assessment of patients’ satisfaction with their levels of functioning or with their rehabilitation status?
- EV-4 ____ Do you perform assessments of patients’ literacy or educational levels?
- EV-5 ____ Do you perform any kind of informal assessment of patient, family, and/or staff attitudes toward rehabilitation?
- EV-6 ____ Do you perform assessment of patients’ job skills and/or suitability for vocational rehabilitation?
- EV-7 ____ Do you perform any other kinds of evaluation or assessment-related activities not enumerated here?

INTERMEDIATE REHABILITATION INTERVENTIONS:

Score 1 point for each “yes” answer

- EV-8 ____ Have any articles been written about your unit’s evaluation of patient outcomes or has information about the measurement of your unit’s rehabilitation outcomes been shared with the renal community in any other way?
- EV-9 ____ Does your unit regularly perform formal evaluations of dialysis adequacy and incorporate the information into patient care plans?
- EV-10 ____ Does your unit regularly perform formal evaluations of nutritional status and incorporate the information into patient care plans?
- EV-11 ____ Does your unit regularly perform formal evaluations of anemia and incorporate the information into patient care plans?
- EV-12 ____ Do you perform formal rehabilitation intake assessments of new patients, using standardized instruments?
- EV-13 ____ Has your unit developed or do you use a standardized rehabilitation assessment instrument on a regular basis?
- EV-14 ____ Does your unit perform formal assessments of patients’ or families’ overall attitudes/beliefs/health beliefs, etc.?

ADVANCED REHABILITATION INTERVENTIONS:

Score 1 point for each “yes” answer

- EV-15 ____ Do you use the information obtained from your outcomes assessment to modify/improve your rehabilitation programming?
 - EV-16 ____ Do you require periodic in-center progress evaluations by related services (PT, OT, Dietitian, VR, Nephrologist)?
 - EV-17 ____ Has your unit participated in any research efforts regarding rehabilitation outcomes and their evaluation?
 - EV-18 ____ Have any presentations been made at professional organizations (e.g., ASN, ANNA, NKF) or has information about your unit’s assessments of rehabilitation outcomes been shared with the renal community in any other way?
 - EV-19 ____ Do you track the effects or results of your evaluation efforts?
 - EV-20 ____ Do you track the costs associated with your evaluation program?
- _____ ***SUBTOTAL (20 possible)***

Explanations of USAT Evaluation Criteria

Basic: EV1 to EV7

EV-1: Assessment of patients' overall functional status, including their physical functioning, mental health, and well-being can be accomplished as part of regular care planning. At the most basic level, such assessment does not have to be formal or written—it must just involve a habit of taking a close look at how patients are getting along. Good questions to ask include: Does the patient seem better than usual? Same as usual? Quieter than usual? Weaker than before? Is the patient going downhill, holding his or her own, improving?

EV-2: Basic assessments of patients' ability to perform activities of daily living can be made informally. The ease with which patients are able to carry out spontaneous ADL's in the unit (e.g., outerwear removal, shoe tying, hair combing, make-up repair, etc.) should be noted and recorded in their charts and/or care plans. Patients can also be asked directly if they are able to do all of the usual day-to-day things they used to do. Any change (positive or negative) in their performance of such activities warrants further attention and intervention.

EV-3: Not surprisingly, patients are usually the first to notice declining functional status. However, although they might observe that their ability to do certain things is diminishing, they may not mention it to anyone. Simply asking patients, at regular intervals, if they are satisfied with their current level of functioning is a rehabilitation intervention at the basic level.

EV-4: Patients' ability to read and understand printed materials may influence their overall adjustment to dialysis. A good observer may be able to detect clues that a patient is having a problem reading, seeing, or understanding printed materials, without a formal assessment. If such indications are present, a more advanced rehabilitation activity, such as doing a formal assessment, might be warranted.

EV-5: Assessing patients', families', and unit staff's attitudes toward rehabilitation is a basic rehabilitation intervention. At this level, assessments can be as simple as asking what individuals think or know about rehabilitation for dialysis patients. Educational and/or motivational activities can be specifically targeted to needs identified through assessment.

EV-6: Informal screening of patients for employment status or potential may uncover problem areas early enough to intervene before employment is lost, activities are constrained, or before habits of inactivity are established.

EV-7: There are many other simple assessment-related activities which might be undertaken with dialysis patients. Any other methods or activities which you have identified can be credited here.

Intermediate: EV8 to EV14

EV-8: Sharing information obtained by evaluation procedures is an important rehabilitation intervention at the intermediate level. Only if such information is shared will the value of rehabilitation eventually become known so rehabilitation can become standard procedure in dialysis centers. Trade press articles, for example, are easily-accessible vehicles for information sharing.

EV-9: Patients whose disease processes are not stable will not be ready for rehabilitation. For example, patients suffering the effects of uremia may have difficulty concentrating, sleeping, and focusing on rehabilitation efforts. Thus, good clinical management is a prerequisite to any rehabilitation intervention, and formal assessment of patients' dialysis adequacy is an intermediate rehabilitation intervention.

EV-10: Patients who are malnourished are at increased risk of death, and may be less able to focus on rehabilitation efforts. Regular formal assessment of patients' nutritional status is another intermediate rehabilitation intervention.

EV-11: Patients who are anemic may be fatigued, weak, and have difficulty concentrating or focusing on rehabilitation efforts. Regular formal assessment of the quality of patients' anemia control is also an intermediate rehabilitation intervention.

EV-12: Routine formal rehabilitation intake assessments provide a baseline measurement of incoming patients' rehabilitation status. Since the progress of patients' debilitation is often slow and nearly unobservable, having a baseline rehabilitation status measurement allows even small degrees of deterioration to be observed and reversed before they can progress further.

EV-13: Regular use of a standard rehabilitation assessment instrument permits a uniform assessment to be made on all patients. This process will ultimately allow comparison of scores across patients, across units, and across the whole ESRD population. In this way, progress toward the goal of rehabilitation for individual dialysis patients and all dialysis patients can be monitored.

EV-14: The importance of patients' and families' attitudes and beliefs regarding renal rehabilitation can never be over-estimated. Regular attitude assessment provides information that can be used to plan educational and/or motivational interventions designed to convert negative attitudes and to instill hope, optimism, and a firm belief in the potential for renal patients' rehabilitation.

Advanced: EV15 to EV20

EV-15: Incorporating the results of the outcomes assessment process into rehabilitation program planning indicates a unit's understanding of and commitment to the concept of evaluation of renal rehabilitation.

EV-16: Requiring periodic in-center progress evaluations by related services is a good way to keep the whole team involved in the rehabilitation process and to make sure that every resource which can be brought to bear on the rehabilitation undertaking is being used. Evaluations themselves should identify specific areas of need and suggest remedies for the problems identified.

EV-17: Linking specific rehabilitation interventions to specific patient outcomes is an important component of evaluation. Facilities' participation in the research which will identify such linkages is crucial.

EV-18: As discussed in criterion EV-8, sharing information obtained through evaluation is an important rehabilitation intervention. The ultimate goal is for renal rehabilitation to be a routine part of every dialysis patient's care. Sharing information at professional meetings and other similar venues "legitimizes" rehabilitation, makes its methods known, and holds the key to its universal application.

EV-19: Outcomes assessment is an essential component of any rehabilitation intervention. In order to know whether an intervention is really worthwhile, its results or impact must be carefully evaluated. To meet this criterion, outcomes resulting from the interventions must be measured regularly using either a unit-developed or, preferably, a standardized assessment tool.

EV-20: It is essential that the costs associated with facilitating renal rehabilitation be known. To this end, cost tracking should be performed whenever an intervention is undertaken. Any system of cost tracking or monitoring that allows an estimate of all expenditures involved with a particular intervention (time, materials, etc.) fulfills this criterion.

Appendix B: Outcomes by “5 E’s” Categories

CKKT = Chambers Kidney Knowledge Test, available from Jeanette K. Chambers, PhD, RN, CS Nursing Education, Grant/Riverside Methodist Hospitals, 3535 Olentangy River Road, Columbus, OH 43214-3998, (614)566-5558

COOP = Dartmouth Coop Functional Health Assessment charts

DUKE = Duke Health Profile

KDQOL = Kidney Disease Quality of Life

QLI = Quality of Life Index, available from Carol Estwing Ferrans, Dept. of Medical-Surgical Nursing, College of Nursing (M/C 802) University of Illinois at Chicago, P.O. Box 6998, Chicago IL 60680

SF-36 = Medical Outcomes Short Form-36

<i>5 E Category</i>	<i>Outcomes</i>	<i>Instrument(s)</i>
<i>Encouragement</i>		
	Emotional mental health	COOP, QLI, DUKE, KDQOL, SF-36
	Self-esteem	DUKE, QLI
	Usefulness to others	QLI
	Stress or worries	QLI
	Social Support	COOP, KDQOL, QLI
	Emotional support	QLI
	Achievement of goals	QLI
	Spiritual	QLI
	Dialysis staff encouragement	KDQOL
<i>Education</i>		
	Cognitive function	KDQOL
	Knowledge, treatment	CKKT
	Knowledge, illness	CKKT
	Knowledge, unit services	
	Knowledge, financial issues	
<i>Exercise</i>		
	Physical functioning Daily activities	COOP, KDQOL, SF-36, COOP
	Energy/Fatigue	KDQOL, SF-36
	Physical independence	QLI
	Strength	Hand grip*, Lift/Reach*, Sit-to-stand*
	Endurance	Lift/Reach*, Timed Walk*, Sit-to-stand*
	Flexibility	

<i>5 E Category</i>	<i>Outcomes</i>	<i>Instrument(s)</i>
	Work Status	KDQOL, QLI
	Ability to meet family responsibilities	QLI
	Financial	QLI
	Social interaction Social activities, travel Social health	KDQOL, QLI, COOP, KDQOL, SF-36, QLI, DUKE
	Role limitations-physical	KDQOL, SF-36, QLI
	Skills inventory	
	Physical health	COOP, DUKE, QLI
	Pain	KDQOL, SF-36
	Symptoms/problem list	KDQOL
	Effects of kidney disease	KDQOL, QLI
	Problems of kidney disease	KDQOL
	Dialysis treatment	QLI
	Burden of kidney disease	KDQOL, QLI
	Sexual function	KDQOL, QLI
	Sleep	KDQOL
	Patient satisfaction	KDQOL
	Health care, general	QLI
	Potential for long life	QLI

**Items delineated with an asterisk can be found in more detail in the Exercise module of this Guide.*