What are the keys to living a long and productive life on dialysis? Renal professionals and patients alike continue to search for the answers to this question. In recent years, great strides have been made to this end. Still, much work remains to be done.

The Life Options Rehabilitation Advisory Council (LORAC) believes that optimal clinical care and rehabilitation management ultimately will help many dialysis patients to feel better and live longer. Numerous Life Options programs and initiatives have been developed based on this philosophy. One of the most recent of these is the Life Options Patient Opinion Study.

The Renal Care Continuum
Research has consistently shown that clinical practice patterns have a direct effect on patients’ survival and wellness. Until recently, however, only intuition and experience with other chronic diseases addressed the potential impact of rehabilitation on dialysis patients’ health and well-being. In the past few years, research has begun to establish that renal rehabilitation can affect survival and wellness indirectly through several dimensions of health-related quality of life.

A massing scientific evidence about the importance of clinical and rehabilitation management is an important first step toward achieving better patient outcomes. Once the medical community is convinced that this combination produces the best outcomes, comprehensive and high quality care will likely become more available.

Education and Empowerment
An equally important goal is to educate patients about the clinical care/rehabilitation continuum. With recent changes in healthcare management, it has become increasingly important to prepare patients to advocate for themselves. To succeed, people on dialysis must know how clinical care can affect the way they feel and how rehabilitation can improve their ability to function. They must know how to recognize good clinical care and good rehabilitation.

Like people with other chronic conditions, ESRD patients require rehabilitation to lead long and productive lives. Rehabilitation is not an option, but a crucial part of treatment. Patients’ decisions about their own disease management can directly influence how long and how well they will live. People on dialysis must be shown that they can control certain

(continued on page 8)
I didn’t know people could live as long on dialysis. I thought if I didn’t get a kidney within so many years, that that was going to be it, that dialysis wasn’t a long-term thing.”

—Patient Opinion Study participant

Communication Is Key

The Life Options Rehabilitation Advisory Council (LORAC) believes that renal rehabilitation philosophies and strategies are keys to improving longevity for people on dialysis. For renal patients, early education—about their disease, its treatments, and their potential to live long and productively—can aid in overall adjustment and decision making. Results of the recent Life Options Patient Opinion Study support this idea.

Interview Insights

Interviews conducted for the Patient Opinion Study helped to shed new light on patients’ expectations for a long life. While a number of the patients in the Life Options study hoped to enjoy longevity, most reported having no real expectation of living a long life when they started dialysis. Only 5 of the 31 patients felt they were almost certainly going to live for a “long time.”

Most of the patients were very ill when they began dialysis. Many felt death was imminent and reported preparing for it, both psychologically and practically. One respondent, only 27 years old at the onset of dialysis, wrote his last will and testament and made his own funeral arrangements shortly after beginning dialysis.

Over time, these beliefs changed as patients received information from several sources, including dialysis professionals and organizations such as AAKP, NKF, and Life Options. Several respondents observed other patients, and slowly concluded that they might not die immediately after all.

Analysis:

- When patients first begin dialysis, they don’t know what to think about their possibilities for a long life—they fear that death is imminent. Over time, patients learn from educational materials, from healthcare professionals, and from other patients that a long life is possible.
- Patient-defined keys to a long life include exercise, education, and a positive attitude.

Implications:

- ESRD is a chronic, not necessarily a terminal, illness. Education is needed to speed up the timeline and help patients learn immediately that a long life is possible.
- Education regarding the “5 E’s” of Encouragement, Education, Exercise, Employment, and Evaluation, as well as the clinical aspects of dialysis care, is needed to foster positive attitudes and enhance adjustment.

Focus on the Future

It is clear that the patients interviewed had little conviction that long life on renal replacement therapy is a possibility. Since patients who expect to die very soon are likely to make different life decisions than those who expect to live longer, the importance of informing patients of the potential for long life cannot be underestimated.

As such, patient-defined “keys to a long life,” including education about ESRD and its treatment, exercise, and a positive attitude, might be used to help change the expectation of imminent death to a belief in life.
After the first couple of dialysis sessions, I woke up and the sun was shining, and I was glad to be alive. I consider myself to be on borrowed time. If I'd been born in another era, I wouldn’t be alive.”

— Patient Opinion Study participant

The Quality Connection
Rehabilitation has often been referred to as “restoration of the whole person.” Indeed, the LORAC’s “5 E’s” of renal rehabilitation—Encouragement, Education, Exercise, Employment, and Evaluation—create a well-rounded approach to helping patients live long and well. As such, quality of life issues were a primary focus of the Life Options Patient Opinion Study interviews.

Interview Insights
When asked about quality of life and limits imposed by their illness, virtually every respondent in the Life Options study suggested that just staying alive with end-stage renal disease (ESRD) required a great deal of time and effort. This had a negative impact on patients’ overall quality of life, detracting from desired activities and proving to be somewhat wearing over time.

In addition, nearly every patient reported fatigue, lack of energy, and reduced stamina—

Analysis:
• Quality of life may be compromised by the time and effort needed for treatment, and by the fatigue patients experience.

Implications:
• Patients need to know that it is possible to live a long and high-quality life with ESRD, but that life will be different. The limits and constraints should be acknowledged up front, so patients can plan around them.
• Education is needed regarding practical solutions for fatigue: Exercise, good nutrition, adequate dialysis, and energy conservation techniques.
• Higher hematocrits (if medically justified) may be helpful for some patients.
• Better use might be made of the time on dialysis (e.g., planned educational or exercise activities) so this time is perceived as less “wasted.”

even at hematocrit levels of between 33 and 36. Most respondents believed that other patients shared these limits.

Difficulty associated with travel was another concern among the patients interviewed. Problems with impotence were mentioned by several respondents, and two patients on peritoneal dialysis also reported difficulty adapting to a changed body image.

When asked what might remove some of their disease-imposed limits, several patients noted that more exercise would likely improve the situation, while others said that only a kidney transplant would help.

Patients also cited the possibility of permitting higher hematocrits, having facilities with workout rooms and restaurants serving renal-appropriate meals, making it easier to dialyze while traveling, and increasing public education about organ donation as ideas for overcoming limits.

About half of the patients interviewed described the quality of their lives as satisfactory or better, even excellent. Many reported having a lesser quality of life than “healthy” individuals and than they enjoyed pre-ESRD—but a better quality of life than other patients they had seen.

Focus on the Future
In general, fatigue and the time needed for dialysis treatments were the factors most frequently blamed for diminished quality of life among the patients interviewed. Reducing these barriers and enabling a greater range of activities would presumably allow these patients to feel more “normal.”

Identifying and sharing coping strategies for fatigue may help such patients to feel they get an occasional break from the ongoing burden of chronic disease. ◆

The following comments have been excerpted from the Life Options Patient Opinion Study interview transcripts.

“Long life is not my goal. Proper life is my goal.”
“...you should live like it’s your last day today— then thank God the next day when you wake up so that you can live that one better than the day before.”
“If I eat right and exercise, I can live to be 100.”

“I haven’t asked much about longevity. That frankly doesn’t bother me. I’d be happy if I were struck dead tomorrow, as long as I feel good today. Quality of life is important.”
“It is a conscious decision and choice to do a lot of difficult things. I’m willing to invest hard work into my life so that I can have a higher quality of life.”
“...my idea is that I’ve got my life to live— I don’t let my life revolve around the dialysis center.”
s far as family goes, you live within what you can and can’t do. You adapt. And that pretty much goes for everything else in life.”

— Patient Opinion Study participant

Emotional Well-being
For many people on dialysis, the foundation for self-advocacy includes a strong support network of family and friends, as well as solid feelings of self-esteem. Both of these elements are closely related to a patient’s ability to carry out role activities— as husband or wife, father or mother, friend, co-worker, etc. This issue was one of several examined in the Life Options Patient Opinion Study.

Interview Insights
To help determine how dialysis patients’ lives are affected by their disease and its treatments, Life Options study participants were asked to describe their abilities in a variety of areas: Performing activities of daily living, fulfilling role responsibilities, pursuing a career, maintaining mental health, a “normal” social life, and an average level of happiness, etc.

Virtually every dialysis patient in the study reported being less able than before ESRD to meet role responsibilities—from cooking and yard work to marriage and employment. In general, respondents agreed: Living on dialysis takes a lot of time, leaving less time for optimal role functioning.

Most patients felt they were unable to work full time, since the symptoms of and treatment for ESRD interfered with their job performance. The problems they encountered included weakness and fatigue due to varying doses of EPO, fluctuating hematocrits, and other causes; lack of evening shifts or flexible dialysis scheduling; career interruptions due to illness; and perceived hiring discrimination against ESRD patients— despite the Americans with Disabilities Act.

Similarly, most respondents spoke of the importance— and difficulty— of maintaining a positive mental state in the face of ESRD. Many related experiences with depression and its negative effects on role performance.

Several patients noted the importance of getting out into the world and helping others for improving their own mental states. Many patients reported that strong spirituality or religious faith helped them to cope. Keeping up a normal social life with ESRD was difficult for several patients, who had cut back their activities due to lack of time and energy, dietary restrictions that limit restaurant and/or party attendance, lack of workplace friendships, feeling too ill to socialize, and not wanting to be a burden. Other patients, however, kept busy social calendars and refused to impose their own limits on others.

Focus on the Future
Opinions regarding self-advocacy were mixed among this group of patients. Most reported self-directed information seeking, and a few reported shopping around for satisfactory physician services— behaviors that fall distinctly into the category of self-advocacy.

However, some of the interviewed patients expressed a sense of helplessness with regard to their disease and its care. Empowering such patients through education about the areas of care in which some personal control is possible ultimately may help them to take other steps on their own behalf.

PATIENT VIEWPOINT

“I think you make your own limitations...If you want to do it and think you can do it, then do it.”

“I go out more with my wife now...you try to live the best you can today because you may not have a tomorrow.”

“I appreciate life more— the little things— my daughter laughing or smiling...things that really lift my spirit.”

“I’ve always taken the attitude that if you want to do something you will find a way.”

“My outlook is superb...I believe it takes faith to get that outlook and then to accept the things you can’t change.”

“The attitude is very important. I’ve always had a positive outlook...I don’t spend each day worrying about tomorrow...I have a calendar, I plan what I have to do, and I do what everyone else does. It’s integrated into my schedule.”

“I do what I want, I’m happy. I lead a normal life, I lead a full life. I’m satisfied at the end of the day. I feel I’m accomplishing something.”
“...having people who care and who you can talk to...is a blessing.”

“I interview doctors like you do lawyers. What's their attitude toward you? Are they looking to be helpful, or are you just a number...”

“...if you think your doctor knows what he is doing and you have the right kind of people to support you, then your attitude is better. Plus you have the knowledge that you’ve researched, then you’ve got it made.”

“...I got tired of being tired and of not being in control...I was feeling defeated. I was always in the hospital, I wasn’t working...and I decided to find those resources myself. I do not like to feel defeated. I have a tremendous desire to rise above my circumstances— to find some way around it.”

“You have to get to people right away and let them know this is not the end of the world. Get other dialysis patients to talk to them about how they survived it...that shows people that you can live with it.”
t never occurred to me not to work...I sense a ‘give-up’ attitude in a lot of folks I talk to. There are a few fighters, a lot more endurers, and most just slog through.”

— Patient Opinion Study participant

Rehabilitation in Action
For more than 5 years, the Life Options Rehabilitation Advisory Council (LORAC) has promoted the “5 E’s” concept of renal rehabilitation: A comprehensive framework based on Encouragement, Education, Exercise, Employment, and Evaluation. Getting a sense of how much information patients are receiving was one of the primary objectives of the Life Options Patient Opinion Study.

Interview Insights
Patients in the Life Options study were asked to discuss essential elements of rehabilitation in general, as well as for each of the 5 E’s. In most cases, the patients reported receiving surprisingly little in the way of positive messages or encouragement. Few felt they had experienced any specific “rehabilitation” at all, except what they had begun and carried out on their own.

Several patients cited return to previous life as the primary goal of rehabilitation, and mentioned the importance of empowerment, of staying flexible, and of fitting the disease into their lives, rather than fitting their lives around the disease.

Among the factors supporting rehabilitation, respondents noted flexible scheduling and evening dialysis shifts, patients’ acceptance of the diagnosis and compliance with the required regimens, a positive mental attitude, and as much education about the disease and its ramifications as possible. Patients almost universally agreed that exercise was among the most important keys to their well-being.

Patients in the study stressed the importance of information/education on the following:
• What constitutes good care

Analysis:
• Virtually all patients reported receiving no formal rehabilitation.
• Patients seem to be increasingly sophisticated with regard to seeking out their own healthcare information.

Implications:
• Continued education is needed for patients and healthcare professionals about the components of renal rehabilitation.
• Patients who are not offered access to the information they desire may go elsewhere and locate sources that may or may not be credible. Good care will include educational needs assessment and education to meet the identified needs.

Further, patients reported that they are no longer limited to the information they can receive from their own facilities. A number of respondents compared their facility experiences with other facilities or obtained insight from other patients or from Internet websites and mailing lists.

Focus on the Future
Overall, the patients interviewed acknowledged the importance of both good clinical care and rehabilitation. Though the sample was small, this seems to indicate that information about the continuum of clinical prerequisites and rehabilitation is beginning to get out. Continued emphasis of clinical care and rehabilitation messages will help promote penetration of these ideas into the remainder of the dialysis population.

“Keep as active as possible. That’s got to be stressed. It helps your mental attitude, your cardiovascular system, the whole body.”

“Through education and support, you can begin to take charge of your life—become more compliant, eat a proper diet, exercise, and work towards being functional in life, whether that be employment or volunteerism...”

“I had to go dig for education and encouragement when I started. But I’ve tried to be the source who volunteers it for new patients.”

“According to all my doctors, I can live with kidney disease for a long time, until a very old age...so I imagine I’ll live to be a very old age.”

“...good care is if your unit will form the four-person team: Dietitian, social worker, nurse, and physician. When you see those four persons, it’s right.”

“Exercise is important. You just have to figure out what you’re able to do.”

“I did lots of research...and then passed that information on to other patients and healthcare staff and anyone else who’d listen.”
The major thing for patients is that they must empower themselves...take charge of their healthcare...start on a course of education that will teach them what to do to care for themselves— to exercise, eat right, take medications, diet, get away from TV, and go to work.”

— Patient Opinion Study participant

The Clinical Care Connection
Patients’ satisfaction with various aspects of their care has the potential to affect their overall attitudes. As such, examining patients’ satisfaction with their care was one goal of the Life Options Patient Opinion Study.

Interview Insights
While most patients in the Life Options study reported being satisfied with their care, further observations brought specific problems to light. Some patients were unhappy with care that seemed depersonalized, too concerned with controlling costs and not enough with patient outcomes. Some believed they had received good care largely as a result of their own vigilance and effort. Others were disappointed and confused by erratic changing of EPO doses and resultant fluctuating hematocrits.

Several patients felt they received no services beyond medical care— no social services, physical therapy, dietary services, or vocational counseling. Although some thought that care received from nephrologists was satisfactory, many thought care provided by other dialysis staff was lacking.

Analysis:
• Some patients felt they needed to be active self-advocates in order to achieve satisfaction with their care.
• Despite the fact that they have a chronic disease, patients felt they were able to achieve at least an average level of life satisfaction.
• A realistic attitude, i.e., the ability to compare their situation to its likely alternative— death— rather than to their own lives prior to dialysis, was common among patients who seemed the most positive about their circumstances.

Implications:
• Dialysis patients need education to learn how to seek their own satisfaction by asking questions, selecting healthcare professionals that meet their needs, and advocating for themselves.
• Successful patients should be encouraged to serve as inspiration for others.
• For renal patients and professionals, the definition/parameters of renal rehabilitation may need to be more clearly articulated.
• Education is needed regarding the fact that if ESRD patients had another disease, their care would not be paid for by the federal government at all, and they would be much less likely to survive.

Despite these difficulties, many dialysis patients and almost all of the transplant patients reported being able to achieve an average level of life happiness. However, in various contexts and words, they also reported that being happy takes a lot of effort.

The overwhelming sentiment in this context seemed to be one of gratitude at being alive at all. The patients who seemed the most positive about their circumstances were those who compared their situation to its likely alternative— death— rather than to their own lives prior to diagnosis.

Focus on the Future
The majority of patients interviewed said that any rehabilitation achievements were largely due to their own efforts. When questioned more closely, a few patients did note the existence of specific elements of rehabilitation programming, such as newsletters, bulletin boards, or support groups. Thus, for dialysis patients and care providers, the definition and parameters of renal rehabilitation may need to be more clearly articulated.

If, as the Life Options Rehabilitation Advisory Council (LORAC) proposes, active rehabilitation can improve longevity and quality of life for people on dialysis, it will also be a key to improving dialysis patients’ satisfaction with their care.
aspects of their lives and health, and that they indeed have the potential to live long and productive lives.

**Spreading the Word**
More than ever before, through the efforts of many dedicated organizations and individuals, important messages about the successful management of ESRD are being transmitted. However, the crucial question remains: Are patients receiving the message? The LORAC’s Patient Opinion Study was developed to help answer this question.

The Life Options Patient Opinion Study provided a unique chance to learn about patients’ experiences and perceptions of their disease and its treatments, to identify content areas and messages to include in future education materials, and to suggest potential areas of further study. For more information about the project, please see About the Life Options Patient Opinion Study, page 1.

**Keys to a Long Life**
Insights gained from the Patient Opinion Study are being used to plan for upcoming Life Options programs and interventions, including a special Keys to a Long Life series of materials, which will be available later this year. In order to share the important information obtained from the Patient Opinion Study with as many dialysis patients, families, and care providers as possible, the LORAC is dedicating this special issue of the Renal Rehabilitation Report to the Patient Opinion Study.

If you would like more information about renal rehabilitation or about the Life Options Patient Opinion Study, please contact the Life Options Rehabilitation Resource Center (RRC) at (800) 468-7777.

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**About Patient Opinion Study Participants**

Of 31 total participants in the Life Options Patient Opinion Study, 29 provided demographic information, some of which is detailed below:

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<th>Gender</th>
<th>Male: 17</th>
<th>Female: 12</th>
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<td>Age</td>
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<td>Cause of Renal Disease:</td>
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<td>Diabetes: 6</td>
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<tr>
<td>Primary Modality:</td>
<td>In-center hemodialysis: 17</td>
<td>Peritoneal dialysis: 4</td>
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**About the Life Options Patient Opinion Study**
Taking a Closer Look at Life on Dialysis

**Gender:**
- Male: 17
- Female: 12

**Age:**
- 25-74

**Date of Diagnosis:**
- 1970-1979: 4
- 1980-1989: 5
- 1990-1998: 17

**Race/Ethnicity:**
- Caucasian: 20
- African-American: 5
- Hispanic/Latin American: 3
- Other: 1

**Primary Modality:**
- In-center hemodialysis: 17
- Peritoneal dialysis: 4
- Home hemodialysis: 3
- Transplant: 5

**Cause of Renal Disease:**
- Hypertension: 7
- Diabetes: 6
- Polycystic kidney disease: 2
- Glomerulonephritis: 8
- Unknown: 4
- Other: 12