

RENAL REHABILITATION REPORT

VOLUME 7 • NUMBER 1 • JANUARY/FEBRUARY • 1999

LIFE OPTIONS PATIENT OPINION STUDY

Taking a Closer Look at Life on Dialysis

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.

Amassing 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)



About the Life Options Patient Opinion Study

As part of the Patient Opinion Study, Life Options staff interviewed 31 renal patients by telephone. Participating patients were selected from the Life Options Rehabilitation Resource Center (RRC) database. For more detailed information about the participants, please see *About Patient Opinion Study Participants*, page 8.

The interviews allowed patients to discuss what they knew and did not know about their disease; what they believed, expected, and hoped in the face of their illness; what kind of care they thought they were getting; and what kind of care they felt they should receive.

Interviews ranged from 45 minutes to 2.5 hours in length, with open-ended questions structured around the following six themes: Expectations for a long life, overall quality of life, ability to perform usual role functions, components of good care for renal patients, perceptions of good rehabilitation programming, and satisfaction with various aspects of care.

Although the relatively small sample size and the respondents' self-selection through their contact with the RRC makes generalization of the findings to the entire ESRD population risky, many valuable insights were gained with regard to each of the targeted topics.

The LORAC's Patient Opinion Study provides important insights into the mindset of a small but relatively diverse group of ESRD patients. As such, it has important implications for patient education and rehabilitation. Each of the interview topic areas is detailed in this special issue of the *Renal Rehabilitation Report*. ♦

RENAL REHABILITATION REPORT

This publication is supported by
Amgen Inc.

LIFE OPTIONS REHABILITATION ADVISORY COUNCIL MEMBERS

Karen Daniels, MM
Nancy Gallagher, BSN, RN, CNN
Peter Howell, MEd, MPA
Karren King, MSW, ACSW, LCSW
Michael Klag, MD, MPH
Derrick Latos, MD, FACP
John Lewy, MD
Jill Lindberg, MD, FACP
Donna Mapes, DNSc, RN
Maureen McCarthy, MPH, RD, CS
Anita Molzahn, PhD, RN
Brian O'Moore
Rosa Rivera-Mizzoni, MSW, LCSW
Nancy Spaeth, RN
Sharon Stiles, BSN, RN, MS, CNN

EMERITUS MEMBERS

Christopher Blagg, MD
Kenneth Chen, MS
Ann Compton, RN, MSN, CNN
Peter DeOreo, MD
Nancy Kutner, PhD
Bruce Lublin
Anthony Messana, BSC
Spero Moutsatsos, MS
John Newmann, PhD, MPH
Patricia Painter, PhD
George Porter, MD
John Sadler, MD
Michael Savin, PhD
Theodore Steinman, MD
Beth Witten, MSW, ACSW, LSCSW

NEWSLETTER EDITORS

Roberta Braun Curtin, PhD, RN
Nicole Thompson

CONTRIBUTING WRITER

Nicole Thompson

*The Renal Rehabilitation Report is published bimonthly. Readers' comments and ideas are welcome. Contact the Life Options Rehabilitation Program, 603 Science Drive, Madison, Wisconsin 53711-1074
Tel: (800)468-7777
E-mail: lifoptions@medmed.com
Website: www.lifeoptions.org*

LIFE OPTIONS PATIENT OPINION STUDY

Theme: Expectations for a Long Life

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, NKE, 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.

Even after several years of dialysis, many of the patients reported viewing their futures in short increments and setting relatively short-term goals. A substantial number thought that they might live for "at least 10 more years." Almost every respondent reported believing that exercise was one of the most important keys to long-term survival.

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. ♦

LIFE OPTIONS PATIENT OPINION STUDY

Theme: Quality of Life for Dialysis Patients

“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. ♦

PATIENT VIEWPOINT

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.”

PATIENT OPINION STUDY

LIFE OPTIONS PATIENT OPINION STUDY

Theme: Patients' Ability to Perform Usual Role Activities

“As 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

Analysis:

- Nearly every dialysis patient reported feeling less able to meet their various role responsibilities than before ESRD.

Implication:

- Education is needed to facilitate dialysis patients' adaptation in such areas as daily living; workplace, family, and social roles; and mental health. It can be demonstrated to people on dialysis that “life options” are available to them—their lives may be different, but they can still be fulfilling.

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 like 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.”

LIFE OPTIONS PATIENT OPINION STUDY

Theme: Components of Good Care for Renal Patients

It takes time, it takes people to do this, but I think education is sadly lacking in general...in an area where the more you know, the better off you will be as a patient.”

—Patient Opinion Study participant

Quality Care Defined

An understanding of good dialysis care is crucial as patients prepare for self-advocacy. The Life Options Patient Opinion Study explored patients’ thoughts and perceptions about quality care.

Interview Insights

According to patients in the study, good nephrologists should be familiar with their cases, treat them as individuals, show sincere interest in their well-being, help teach them what to expect and how to take part in self-care, and be responsive to requests—even prompting them for questions if necessary.

Some patients said they would feel more cared for and respected by their doctor if they were seen in the office, like “regular” patients, and if the physician made physical contact to personalize the care. A few patients reported actively seeking out a nephrologist with whom a respectful partnership was possible.

The patients interviewed gave solid suggestions for good psycho-emotional care, including the need for support and encouragement to help

Analysis:

- Patients wanted better physician-patient relationships, and wanted their care to be personalized—and a few were willing to switch providers to obtain it.
- Patients expressed some dissatisfaction with facility activities that were purely social.
- In general, patients felt that many factors worked against their potential employment: Inflexible dialysis, fatigue, time for treatment, discrimination, etc.

Implications:

- Patients should be educated to identify and request what they want from their care providers.
- Facilities should be encouraged to offer opportunities for patients to have meaningful discussions with successful patients and with healthcare providers.
- Employment of ESRD patients is a problematic area that will require a multi-disciplinary approach.

them advocate for themselves, give the message that life goes on after ESRD, exposure to other patients who are doing well, no-cost counseling and treatment for depression, provision of as much information as possible, family involvement in the treatment plan, and evidence of caring from the staff.

Surprisingly, most did not consider the social activities and services sponsored by dialysis

facilities to be useful. Suggestions for alternative social activities and/or services included chances to interact with staff to develop trust and rapport, educational sessions in the facility, public education so ESRD patients aren’t made to feel isolated, permitting patients to have visitors in their facilities, and better dialysis services for traveling patients.

More than a few respondents suggested that the vocational needs of working-age patients could be met through education about the need to keep their jobs even after starting dialysis; keeping current lists of volunteer activities; making job and interview skills training and placement services available; educating employers about ESRD and advocating for flexible scheduling at the workplace; and building and maintaining better relationships between facility staff, vocational rehabilitation staff, and potential employers.

Focus on the Future

The patients in this study were very articulate about their notions of high-quality medical care, and some of them reported demanding quality. This type of awareness may become more important as competition in the dialysis marketplace builds and dialysis consumers are increasingly able to choose their own care. In such an environment, education about what factors or characteristics to seek in a care facility will become increasingly important. ♦

PATIENT VIEWPOINT

“...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.”

PATIENT OPINION STUDY

LIFE OPTIONS PATIENT OPINION STUDY

Theme: Essential Elements of Renal Rehabilitation

It 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

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.

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

- The meaning of lab values, causes of changes in lab values, EPO, iron management, dialysis machines and how they work, high flux, re-use, etc.
- Dietary choices and consequences
- Patient self-advocacy, self-confidence in question asking
- Consequences of actions, choices, and decisions made by patients
- Available resources for renal patients
- The role, function, action, and side effects of all medications prescribed
- That there is hope—ESRD does not mean the end of life

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. ♦

PATIENT VIEWPOINT

"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."

LIFE OPTIONS PATIENT OPINION STUDY

Theme: Patient Satisfaction With Care

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

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.

received from nephrologists was satisfactory, many thought care provided by other dialysis staff was lacking.

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. ♦

PATIENT VIEWPOINT

“When I went on dialysis, I felt that it would give me life that I would not have had—that I was being given a second chance.”

“The biggest thing that helped me out even before dialysis was the doctor. He took the time to sit down and explain and say not to stop living...”

“When you see someone with a caring attitude, who really wants to help and cares for the patients—that is a good doctor.”

“What really helps me is when people are honest, don’t sugarcoat the truth. If something’s going to happen, I may as well know about it so it’s no big surprise.”

“I always talked to my doctor and she said, ‘Don’t just sit there. Move, exercise, ride a bike. If you want to watch TV, then watch it on a stationary bike.’ Then later on I saw I did have more energy after exercise.”

“I had a reason to live and wanted to live as long as possible. My doctor told me what to do to help me live longer.”

PATIENT OPINION STUDY

LIFE OPTIONS PATIENT OPINION STUDY

Taking a Closer Look at Life on Dialysis (continued from page 1)

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. ♦

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:

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



RENAL REHABILITATION REPORT

Life Options Rehabilitation Program
603 Science Drive
Madison, Wisconsin 53711-1074
(800)468-7777

NONPROFIT ORG.
U.S. POSTAGE
PAID
MADISON, WI
PERMIT NO.278

The Renal Rehabilitation Report is dedicated to identifying effective programs, projects, and people who are helping dialysis patients realize their fullest potential.

RRR is a bimonthly publication of the Life Options program, which supports initiatives for renal rehabilitation in the vital areas of Encouragement, Education, Exercise, Employment, and Evaluation.