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Successful Adjustment to ESRD

The Emerging Role of Patient Self-management

It is no secret. The face of healthcare in the United States is changing. Improvements in technology, pharmacology, and medical practice are helping to extend the average lifespan and working to combat—even conquer—many acute medical conditions. At the same time, health management organizations and staff shortages are driving a delicate balancing act between quality care and the cost of treatment for an aging population.

Amidst these changes, chronic disease is emerging as a priority topic. One recent report states that chronic disease may be the “largest threat to health status and the largest cause of healthcare expenditures in the United States.”¹

SETTING THE STAGE

Chronic disease can be simply defined as disease for which there is no cure but for which, with proper medical care, a relatively long life is still expected. End-stage renal disease (ESRD) has only qualified as a chronic disease relatively recently. Before the availability of renal replacement therapy through dialysis or transplantation in the late 1960s and early 1970s, ESRD was a terminal illness.

Today, the numbers of patients with ESRD are increasing. In fact, the total number of ESRD patients is expected to exceed 660,000 by 2010. In the same period, the cost of the Medicare ESRD program is expected to more than double, surpassing \$28 billion per year.²

As these numbers increase, there is a growing interest in how the lives of people with ESRD can be extended as much as possible, how the quality of those lives can be maximized, and not surprisingly, how their required care can be provided in a cost-effective way.

BUILDING THE FOUNDATION

In general, the goal of treatment in chronic disease is to restore patients to their highest possible level of functioning.³ This includes optimizing medical, emotional, social, educational, and vocational functioning and bringing patients as close to full independence as their condition allows.⁴

Nephrologist and ESRD patient Peter Lundin offers this view. “From a patient’s perspective,” he says, “rehabilitation is simply the ability to get on with life, to see the possibility for

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Focus on Patient Self-management

It is a tribute to modern medicine that a focus on ESRD patient self-management is even possible. Not long ago, the diagnosis of ESRD was a terminal one—it carried no expectations of extended life, just the certainty of imminent death. Today, with dialysis, transplantation, and key medications, people with ESRD can expect to live for many years. Just how many years may depend, however, on the degree to which patients adjust by taking charge of ESRD.

In its fullest sense, patient self-management involves taking an active role in care and treatment, while also maintaining control over the signs, symptoms, and daily

effects of ESRD. This is no small task. And, although many people have achieved full self-management on their own, most patients could benefit from improved communication, as well as from more information, education, training, and support.

This issue of the *Renal Rehabilitation Report* is the first in a self-management “call to arms” for dialysis patients and professionals alike. Self-management can increase quality and quantity of life for people on dialysis. Let’s do what we can to help make it happen. For more information, contact the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777. ♦

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Application and Adaptation

Self-management is Key to Long-term Dialysis Success

A short time after being interviewed for this article, Walter Morant passed away, due to complications of long-term ESRD. With his loving wife Sandy's permission, we have printed this article in memory of Walter, and so that others may find inspiration and guidance in his story. Thank you, Walter, for touching the world by your wonderful example, your tireless good work, your unwavering courage, and your genuine spirit. We will miss you.



"To be a successful dialysis patient, you can't be passive," said 53-year-old Walter Morant. "You have to educate yourself and

become actively involved in your treatment. You have to fight. You have to want to succeed. And, you have to be willing to work." This is something Morant learned firsthand, from more than 32 years on hemodialysis.

THE EARLY DAYS OF DIALYSIS

Morant was 21 when he first experienced chronic renal failure due to glomerulonephritis. It was 1967, and dialysis was still in its infancy. "At that time, I didn't even know what dialysis was," Morant recalled. It wasn't long before he received a crash course in the subject.

Shortly after Morant was diagnosed, his nephrologist Dr. Julio Figueroa, explained that the only option for treating his condition was a fairly new process—one called hemodialysis. "I was feeling kind of poorly at the time," said Morant. "So, all I can remember him saying is 'it's kind of like a whirlpool.'"

"Well, I knew what a whirlpool was," said Morant. "So I thought 'I'll be getting in a bathtub.' I didn't panic—and I couldn't understand why everyone thought it was such a big deal."

It didn't take long, however, for Morant to realize that dialysis *was* a big deal. "After the second treatment, I asked about my life expectancy," he recalled. "Dr. Figueroa told me 'If you take care of yourself, you can live as long as anyone else.'"

ON THE ROAD TO ADJUSTMENT

It took some time for Morant to fully accept the changes he was about to face. "I had to come to terms with the fact that this was the way things were going to be for the rest of my life," he said. "Once I did, I stopped feeling sorry for myself—and I decided that I would do everything I could to make the best of my situation."

And so began Morant's commitment to managing his disease and his life—a commitment that proved to be instrumental in helping him adjust successfully to ESRD and dialysis.

THE ROLE OF EDUCATION

To a large extent, Morant credited education for helping him adapt to life with a chronic condition. "Education has played a big part in my success on dialysis," he explained. "Being informed has allowed me to take a more active role in my treatment."

This process began early for Morant, who started by learning the ins-and-outs of dialyzing at home. "I was Dr. Figueroa's first home hemodialysis patient, so the training was very rigorous," he recalled. "He told me, 'I won't do you any good from 175 miles away, so I want you to be able to take care of yourself.'"

This was no small task, since dialysis technology at the time was primitive, at best. In fact, Morant's first dialysis machine was a modified Maytag washing machine. The coils were handmade, the machine relied on gravity for flow rate, and the process of preparation and treatment involved many hours of dedication. "We were real pioneers back then," he said.

Morant's quest for information did not end, however, once he mastered home dialysis. He approached education as a lifelong process, and he learned to utilize a variety of informational resources.

Morant subscribed to several renal publications, participated in Internet dialysis discussion groups, and was an active member of the American Association of Kidney Patients and the National Kidney Foundation. "Even after 32 years, I still learn something every day—about dialysis, about how it affects you, and about how it affects your family life," he said.

CAUSE AND EFFECT

Being informed helped Morant approach his treatment with confidence and conviction. "A lot of patients talk

about how difficult things are—the dietary and fluid restrictions, showing up and staying for the full dialysis treatment, taking the binders and medications,” he said. “The way I look at it, you have a choice—either you follow the rules, or you don’t. It’s a choice that every person has to make, and then live by.”

The choice to follow the dialysis treatment plan was an easy one for Morant. “I don’t look at it as a punishment,” he said. “It’s just a means to an end—this is what I have to do to survive, so I do it.”

ACTIVE SELF-MANAGEMENT

As part of this philosophy, Morant took charge of his own clinical and rehabilitation management—something he believed is possible when patients have solid emotional support and positive partnerships with their healthcare team.

Morant said he felt lucky to have had a close network of family and friends throughout his time on dialysis. “My wife believes that successful dialysis patients are successful because of love,” he said. “I tend to agree, because I’ve always known that I have love—that people love and care about me.”

Having a good care team also helped. “Good healthcare providers will take the time to explain things, to give you all the information they can,” he explained. “Good healthcare providers will also treat you as an individual—and with respect. As a patient, all of these things help you take on responsibility for your own treatment.”

And, according to Morant, the more responsibility a patient takes on, the better. “There is a lot of satisfaction in feeling that you still have some control in your life,” he explained.

CLINICAL MANAGEMENT

In the dialysis unit, Morant himself readily applied the knowledge and skills he gained. “I weigh myself, I monitor my own machine, I do my own blood pressure, I insert my own needles,” he said. “I figure, this is my life—and nobody is going to care for me as well as I care for myself.”

Over the years, this active involvement helped Morant to understand dialysis treatment, as well as how his own

body reacted to it. “Since I’ve learned more about dialysis, I’ve learned how to be healthy,” said Morant. “If I’m not feeling well—if my URR or my Kt/V falls, then I know it might be the access, or that I’m not getting enough dialysis, or that I didn’t have the roller pump high enough.”

That is not to say that he knew all of the answers. Morant pointed out that part of managing any disease is knowing where to go to find the answers you need. He explained, “If I have a problem that I can’t work out myself, I don’t mind telling somebody, ‘Look, I’m having a problem with this. Can you help me?’”

REHABILITATION MANAGEMENT

Outside the dialysis unit, Morant worked hard to maintain a full and productive lifestyle. “When I began dialysis, I was in the college marching band, I played baseball and all kinds of sports,” he said. “Early on, Dr. Figueroa told me that staying active would help me, since the Maytag was unable to remove a lot of fluid.”

Over the years, Morant remained physically active by walking, jogging, and participating in a variety of sports, including tennis and basketball. In addition, he maintained employment in the accounting field until his retirement 2 years ago. Morant also volunteered for groups, including the Neighborhood Youth Corp for underprivileged children. “Staying involved helps me feel like I’m a useful part of society—that I can contribute something,” he said.

DAY-TO-DAY SELF-MANAGEMENT

Morant admitted that living with renal failure can often be challenging. However, he believed that adjustment is easier for patients who learn to self-manage. “You have to make a conscious effort to do it every day,” he explained. “And do it so much that it becomes part of you—so that you don’t even think about it.”

The results, Morant said, will pay off in the long run. “I know that if I take care of myself and continue to work hard, there is a good possibility that I can live as long as anyone else,” he explained. And that is what self-management is all about. ♦

“Even after 32 years, I still learn something every day—about dialysis, about how it affects you, and how it affects your family life,”

—Walter Morant

*Successful Adjustment to ESRD***The Emerging Role of Patient Self-management** *(continued from page 1)*

Engaging in self-management activities can empower patients by helping them to re-establish control over their own lives.

again striving for and achieving goals set before the onset of kidney disease.”⁵

The Life Options Rehabilitation Advisory Council (LORAC) combined various perspectives, formalized a more comprehensive way of thinking, and revitalized the concept of renal rehabilitation by structuring it around the “5 E’s”: Encouragement, Education, Exercise, Employment, and Evaluation.

NEW APPROACHES

Within this broad view of renal rehabilitation, much emphasis is naturally placed on the cooperative working relationship between patients and care providers. Since its inception, Life Options has promoted the idea that full partnership in care is an effective and efficient way to achieve positive outcomes for people on dialysis.

But what exactly does partnership entail? For health-care providers, it means providing the best medical care possible; supporting patients’ efforts to maximize their own health potential; cooperating with patients in developing

new approaches to their care and treatment; individualizing care to meet patients’ specific needs; and communicating with patients by offering information, education, and training, and by listening to patients’ perspectives.

For patients, partnership in care includes taking an active role in all aspects of treatment, as well as dealing with the effects of disease on everyday life. In practice, this process of taking charge constitutes *patient self-management*.

TOWARD SELF-MANAGEMENT

According to Dr. Kate Lorig, a pioneer on the subject, self-management is founded on 3 basic principles:⁶

- Dealing with the consequences of illness, rather than just the physiological disease
- Focusing on problem-solving, decision-making, and patient confidence, rather than just prescription and adherence
- Placing patients and care providers in partnerships, with providers primarily responsible for the medical management and patients responsible for the day-to-day management of the disease

As described in *The Goals of Patient Self-management*, at left, engaging in self-management activities can empower patients by helping them to re-establish control over their own lives. Research on the topic of self-management suggests that patients with chronic disease can successfully “shift to an alternative mind-set in which illness is perceived not as an insurmountable burden to which one must succumb but as a challenge that can be met head on and managed, if not vanquished.”⁷

SELF-MANAGEMENT SUCCESSES

Such an approach can produce many positive results. For example, self-management strategies have proven to facilitate successful adjustment in chronic diseases such as heart disease, diabetes, and arthritis—all of which are similar to ESRD with regard to self-management issues and disease-related tasks.¹

In one self-management program for people with arthritis, a 12-hour course was given over 6 weeks. The program, led by trained lay leaders, was shown to increase patients’ self-management activities such as exercise and relaxation, to reduce pain and depression, and to increase self-efficacy or confidence in their ability to manage their disease. Patients followed over 4 years showed a 19% reduction

Helping Patients Adjust to ESRD and Dialysis

The Goals of Patient Self-management*

Life on dialysis can present many challenges and obstacles. Self-management can aid in the adjustment to these changes by helping patients acquire the skills and confidence to:

Manage the work of dealing with ESRD

This includes activities such as taking medicine, exercising, going to the doctor, changing diet and fluids, and attending required dialysis sessions.

Manage the work of continuing their daily activities

This includes carrying out routine tasks, such as household chores, employment, and social events, and coordinating these activities with the addition of dialysis treatment.

Manage the emotions brought about by ESRD

These emotions may include anger, uncertainty about the future, changed expectations and goals, changes in relationships with family and friends, and sometimes depression.

* Adapted from Lorig K, Holman H, Sobel D, Laurent D, Gonzalez V, Minor M. *Living a Healthy Life with Chronic Conditions*. Palo Alto, CA: Bull Publishing, 1994

in their pain and a 43% reduction in outpatient visits related to their condition.⁶

Another recent study evaluated the effectiveness—measured by changes in health behaviors, health status, and health service utilization—of a self-management program for a diverse group of patients with chronic disease. The program proved beneficial, both in terms of improved health behaviors and improved health status.

At 6 months, study participants showed improvements in weekly minutes of exercise, ability to recognize and manage symptoms, communication with physicians, self-reported health status, health distress, fatigue, disability, and social/role activity limitations. They also had fewer and shorter hospitalizations.¹

Findings were also positive with regard to the program's feasibility. The 6-month healthcare costs for each control participant in the study were \$820 greater than for each treatment subject. Overall, the healthcare cost savings was about \$750 per participant—more than 10 times the cost of the self-management program.¹

These results suggest that patients can learn to take responsibility for the day-to-day management of their diseases, and that confident, knowledgeable patients who

practice self-management will have improved health status and will use fewer healthcare resources.¹

TOWARD THE FUTURE

By definition, chronic disease is lifelong. By encouraging healthcare partnerships that promote patient involvement and independence, self-management programs likely ease the adjustment to chronic conditions such as ESRD. There is little doubt that the results of such programs will prove to be beneficial on several fronts—in healthcare cost savings, and more importantly, in improved healthcare and quality of life for patients. ♦

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By encouraging healthcare partnerships that promote patient involvement and independence, self-management programs likely facilitate the adjustment to chronic conditions such as ESRD.

Q&A

SELF-CARE: A NURSING PERSPECTIVE

An interview with Dorothea Orem, BSN Ed, MSN Ed
Consultant in Nursing and Nursing Education

Q *In general terms, how would you describe the concept of self-care?*

A Self-care is a required activity in the everyday life of every person. There are universal self-care requirements that we all have—air, water, food, and others. To meet these requirements, a healthy person does self-care and never questions it. Children learn to do self-care as they grow and develop, with caring adults filling in as they learn to care for themselves. Illness and associated medical care produce new or adjust self-care requirements.

Q *How do chronic and/or acute illnesses affect one's ability to perform self-care?*

A Illness, whether chronic or acute, precludes or hinders some aspects of caring for the self. When someone has a medical

condition, the nurse or the medical care system steps in, acting as a care extender. The underlying goal, of course, is always to return the person to the highest level of self-caring possible. This, again, is the most natural circumstance.

Q *How does self-care fit in with the concept of self-management?*

A Self-management includes the oversight or the supervision of the various aspects of self-care that daily life requires. When able, you manage your own affairs in the interest of your own life and health—even when you're ill.

Q *What are some of the specific roles that health professionals play in self-care?*

A To start with, healthcare providers must assess where patients are—what patients need to do, what they can already do for themselves, what needs to be done for them by the healthcare team.

(continued on page 6)

Facilitating Adjustment for People on Dialysis

Putting the Self-Management Wheels in Motion

Whether we rely on research or common sense, our conclusion will be the same: self-management is definitely good for patients.

Healthcare self-management can be defined as individuals' active efforts to participate in their own healthcare to optimize health, prevent complications, control symptoms, marshal medical resources, and minimize the intrusion of disease into their daily lives. Full self-management implies patients' ability to oversee all aspects of their lives despite their medical conditions.

Research has shown that engaging in self-care and/or self-management can increase overall well-being and reduce symptoms for people with chronic illnesses—and that such involvement may be a rehabilitation intervention in itself.^{1,2} Common sense tells us that being in control feels better than being out of control, that being informed is safer than being uninformed, and that engaging in as “normal” a life as possible is the best life option.

Whether we rely on research or common sense, our conclusion will be the same: self-management is definitely good for patients. So, how does self-management work?

ABOUT SELF-MANAGEMENT

The foundation for self-management is built upon cooperative relationships between patients and their care providers. Without such relationships, patients' efforts to self-manage cannot possibly succeed. As such, the self-management

philosophy encourages full partnerships in care between health professionals and patients, with the goal of helping patients learn to manage daily life with one or more chronic conditions.³

BASIC ELEMENTS OF SELF-MANAGEMENT

For people with ESRD, the first step toward self-management is acknowledging or “owning” their illness. This means coming to accept their new status as persons with a chronic illness—persons who need special or extra care in their everyday lives. Being able to talk to dialysis staff about their condition and its effects on their lives can help ease patients' transition into their new life status—and help promote the acceptance and disease ownership that is necessary for self-management.

Similarly, peer counseling, or informal discussion with fellow patients who have had similar experiences, also helps people on dialysis find ownership and acceptance—as well as the mindset needed for self-management.

Once people on dialysis have begun to come to terms with ESRD and its meaning in their lives, it is time for education. Self-management requires information—and a lot of it. Living with renal disease requires patients to know what to do, when to do it, when not to do it, and why.

Q&A

SELF-CARE: A NURSING PERSPECTIVE (continued from page 5)

Providers can also help set goals—determining what patients need to know and do in order to care for themselves effectively and efficiently.

In addition, care providers can facilitate healthcare partnerships between themselves and patients. In such partnerships, health professionals provide the information and perform care that patients need, gradually reducing their role as patients learn and gain the skills and abilities to do more and more for themselves.

Q *What responsibilities do patients share with regard to their own self-care and self-management?*

A Patients must be willing to participate and to take on as much responsibility as their abilities permit. This ideally begins with information-seeking, which is a large part of self-care—you have to know what to do for yourself in order to care for yourself and understand the results sought. So, patients must become willing to look at themselves as in need of healthcare, and to learn what they have to do to take care of themselves. They have to be able to ask questions of the healthcare

team to get the information they need to do self-care, to develop the knowledge and skills, and then, ultimately, to self-manage.

Q *Are there specific things that can help patients in their self-care efforts?*

A A first step is for patients to accept the fact that they need to do certain things to care for themselves. In essence, they need to “own” a self with these needs, so that they can take charge of their illness and their care. They then need to be able to come to the point at which they have the right knowledge, skills, and mindset to do what is necessary to get themselves better—they must reach the point at which they can perform the greatest degree of self-care possible within their developing capabilities, and move toward self-management in daily life.

Providers must support the full continuum of these efforts, allowing patients to move from learning about and taking responsibility for individual self-care activities to the point at which patients are once again able to self-manage their lives and their health, seeking guidance and consultation as conditions and circumstances change. ♦

To help patients begin to identify subjects about which they would like to know more, Life Options has developed a series of *Patient Interest Checklists*. These checklists are divided into broad topic areas, including medical care, diet, family and social relationships, employment and insurance, the future, emotions, roles and responsibilities, and lifestyle.

The Life Options *Patient Interest Checklists* are designed to help patients tailor the information they get to their own individual needs. They are available free of charge through the Life Options Rehabilitation Resource Center at (800)468-7777, or they may be downloaded from the Life Options website at www.lifeoptions.org.

EXPLORING SELF-MANAGEMENT ROLES

Dialysis care providers play a big part in providing patients with information at all levels, on all topics—starting with the most basic and extending to the very technical—so that patients can grasp the whole spectrum of their care requirements and can envision their own roles in the self-management process. Further, care providers must present information repeatedly over time, so that details missed by patients at one point can be picked up at another.

For their part, people on dialysis must learn to seek information, to ask questions, and to persist until they get answers. They must learn also to use alternative sources—from the Internet and support groups, to healthcare organizations and publications—to find the information they need to successfully self-manage. They must be committed to the idea of self-management and willing to expend as much effort as is required to achieve it.

ACTIVITIES OF SELF-MANAGEMENT

Once patients have accepted ownership of their “altered selves” and have gained sound information, they will be ready to begin to perform self-care activities. As the term implies, self-care is simply caring for oneself—a process that is entirely natural in the healthy state and which must become natural in the altered or chronic illness state as well.

Self-management entails a range of health-related activities performed by patients. These can include such self-care actions as taking medications, managing diet and fluid, checking and caring for their access, tracking lab values, managing symptoms, and communicating with healthcare providers. The goal for every patient is to find

the level of self-care and/or self-management that works best for them, in partnership with their care team.

Ideally, people on dialysis should begin with basic self-care as required for life with ESRD, gradually add further self-care activities, and ultimately progress along the self-care continuum to active, comprehensive self-management of all aspects of their lives—physical, social, emotional, role, and financial.

There are frequent setbacks and/or acute episodes with any long-term illness. Even patients who ordinarily can fully self-manage all aspects of their lives with chronic disease will encounter times when they must turn over their care and its management to the healthcare team. However, when full partnership has been established, the “handoff” should be a smooth one—from patient to provider, and then back again when the patients are able.

SELF-MANAGEMENT PROGRAMS

The goal of self-management programming is to help patients adjust to the life changes that result from their condition and its treatment. This adjustment process is fostered through a coordinated, continued effort to encourage patient participation—and by a comprehensive, planned approach to patient education. Common elements of self-

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Once people on dialysis have begun to come to terms with ESRD and its meaning in their lives, it is time for education.

Planning and Preparation

A Plan for Self-management Education

Self-management education programs focus on building self-management skills, as well as the confidence to apply these skills in day-to-day life. Comprehensive programs to promote self-management include these elements.³

Criteria for Self-management Education

- Education, based on patients’ perceived needs
- Practice and feedback in new skills, including decision-making and problem solving
- Attention to emotional and role management, in addition to medical management
- Use of techniques to increase patients’ confidence in their ability to manage their conditions
- Emphasis on the patients’ active role in the physician-patient relationship

Facilitating Adjustment for People on Dialysis Putting the Self-management Wheels in Motion (continued from page 7)

management programs include those outlined in *A Plan for Self-management Education*, on the previous page.

Involving patients in their own care to the full extent of their abilities helps to reduce their fears and dependence and to increase their self-confidence and sense of control. To support these goals, healthcare providers must provide patients with the information and skills necessary to achieve independence in care.

Further, while self-management is something that is actually performed by patients, proper encouragement and support from staff allows patients to transition between periods in which they need more help and periods when they need less help. And a team approach works best.

While staffing resources are a concern at many dialysis units, a recent review of current programs suggests that self-management efforts “do not require a new cadre of health professionals.” They may, however, require some changes in current healthcare delivery, as well as in staff education and training.³ Programs centered on patients’ involvement in the

care process are, in fact, believed to make optimal use of healthcare *and* staffing resources.^{2,4}

A TEAM EFFORT

If patients and providers combine their efforts, form working partnerships, and set their sights on full self-management for ESRD patients, good things are bound to happen. Common sense dictates and research supports the notion that quality of life—the real measure of renal rehabilitation—will definitely be improved for patients who participate in self-care activities and aspire to/work toward full self-management of their lives with chronic disease. ♦

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