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Factors That Affect Patient Learning

Education Essential to Self-management Success

Life Options' research with hundreds of kidney patients has found two nearly universal questions: How long will I live? How well will I live? Early in their diagnosis, patients need to hear—and believe—that it's possible to have a long life with kidney disease, and that life can be good. These messages of encouragement are key to increasing patients' receptivity to self-management activities that may help them to build the lives they want to live.

The Life Options *Long-term Dialysis Survivors Study* found that the 18 interviewed patients who lived successfully on dialysis for more than 15 years were all active, comprehensive self-managers of their kidney disease and its treatment. That study defined self-management as "patients' positive efforts to oversee and participate in their healthcare to optimize health, prevent complications, control symptoms, marshal medical resources, and minimize the intrusion of the disease into their preferred lifestyles."¹

How did these patients learn what they needed to know to self-manage so effectively? Of the 18 patients studied, 17 had

extensive education and training: for peritoneal dialysis, home hemodialysis, or to become a dialysis technician or nurse. Education is the route to self-management—and self-management is the route to living long and living well with kidney disease.

THE IMPORTANCE OF EDUCATION

The chronicity of kidney disease first requires that patients learn a new role: that of informed partner in care, active information-seeker, and medical decision-maker. They are no longer served by the "acute" model of healthcare, in which patients assume the "sick role" and turn over their care to healthcare professionals until the illness is past.

Chronic disease requires a commitment from the patient and family, and mastery of information that alerts them to potential complications. Patients need comprehensive education to know which symptoms to report, which questions to ask, and which aspects of care to manage.

(continued on page 7)

Focus on Education

In 2001, the *Renal Rehabilitation Report (RRR)* has focused on patient self-management, first by exploring the meaning and importance of self-management for people with kidney failure. Next, the *RRR* examined the route to self-management: coming to terms with major life changes that come with life on dialysis, and affirming the basic elements of self that may be threatened by a serious chronic disease like kidney failure.

Information is an essential tool for patients as they struggle to adapt to their new self and circumstances. Education is the key that can unlock a long and productive life with kidney disease. How and where patients receive

information can affect the course of their future. But even when important messages are delivered, do patients receive those messages? Can patients understand and assimilate the information and use it to shape the new life ahead of them?

This *RRR* explores how patients learn, examines barriers to patients' learning, and discusses how healthcare providers and patients can improve the likelihood that information will be understood, retained, and put to good use by people with kidney failure. To learn more, please contact the Life Options Rehabilitation Resource Center at (800) 468-7777. ♦

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A Great Team

Education Helps Couple Cope with Two Chronic Conditions



Fred and Debbie Russell became high school sweethearts in the 1960s. More than 40 years later, married and with grown children of their own, they

find themselves in a whole new educational setting: learning to live with not just one, but two chronic illnesses.

INTRODUCTION TO CHRONIC DISEASE

In 1985, at age 39, Debbie was diagnosed with diabetes. Just 6 years later, Fred's kidneys failed from an undetermined cause, and he began dialysis.

"We began noticing unexpected changes shortly after Fred's diagnosis," Debbie explains. "He had elevated blood pressure, and he would become short of breath during gardening or other activities. We didn't know why these things were happening, and that was very scary."

For Fred, not knowing what to expect made the initial adjustment difficult. "I began to wonder 'Why me? Why now?'" he says. "Eventually, I came to realize the only thing I could do was to move ahead." For both Fred and Debbie, part of moving ahead meant becoming informed and involved in their healthcare.

EARLY EDUCATION

Education for both patients began in the doctor's office. "My doctor was a very 'get educated' person," recalls Debbie. "She encouraged me to subscribe to journals, she referred me to a diabetes educator so I could learn to control my illness and prolong my life, and she basically encouraged me to do as much as possible on my own."

Fred's experience was similar. "Early on, my doctor gave me a book for newly-diagnosed patients," he says. "It helped me understand and prepare for what was coming."

THE TEAM APPROACH

The Russells believe their united approach to education has also been very helpful. "In the beginning, Debbie was more prepared than I was," explains Fred. "If there were special issues, she was on them. She has always been good about asking questions and finding answers."

"I was good about learning the process, but Fred was good about understanding the theory," Debbie says. "Together, we've made a great team."

Together, the Russells have also used information to direct their decision making. "When I was first diagnosed, I was traveling a lot for work," Fred explains. "After seeing a video explaining all the options for treatment, we chose peritoneal dialysis (PD) so I could continue at my job."

When surgery to remove a failed transplant damaged Fred's peritoneal cavity, he was forced to try another option. Again, information became the Russells' guide, and they chose home hemodialysis.

EDUCATION LEADS TO SELF-ADVOCACY

The Russells believe it's crucial for patients to become informed and active in their own healthcare. "We've both learned that if you don't ask, you don't receive," says Fred. "That's why we've always been very vocal."

Fred is quick to point out that being assertive doesn't have to mean being nasty. "You have to decide for yourself what level of pain or discomfort you're willing to tolerate. When your limits are reached, you have to be able to say 'that's enough.'"

For Fred, this philosophy has led to a simple strategy. "I've made a rule," he explains. "No matter what it is—from needle sticks to lab tests—everyone gets two tries. If they can't get it in two tries, it's on to someone else."

ADVICE TO OTHERS

For newly diagnosed patients, the Russells have a few tips for gathering information. "Begin with your own unit," says Fred. "The written educational materials and videos are a great place to start."

According to the Russells, once the foundation is there, it's important to continue to build upon it. "As much as possible, learn from other patients," says Debbie. "Whether it's in your unit or on the Internet, talking to other people who have been through it will help you understand what you're facing."

The Russells stress the importance of using the healthcare team. "Ask all the questions you can think of—and then think of more," says Fred. "It's important to learn as much as you can, as early as you can."

"The more you know, the less fear you have of the future," Fred explains. "Once you understand the process, you can understand what will happen as you go down this road. Information will give you the faith to overcome." ♦

Barriers and Solutions

How to Apply What We Know About Patient Education

To effectively manage kidney disease, few can dispute the importance of patient education. Early in the treatment process, education is crucial to helping patients understand there is life after kidney failure—that they can live long and well if they commit to learning all they can about their disease and becoming active in its management.

Education helps patients begin the process of taking control. Education enables patients understand how to recognize and report symptoms, determine what questions to ask, and begin to manage as many aspects of their care as possible. In short, for people with kidney disease, education forms the basis of self-management and rehabilitation.

While we understand how important education is in treating kidney disease, many questions remain. For example, what are the most effective methods of teaching? And, how can education best be fostered and facilitated?

BARRIERS THAT INFLUENCE EDUCATION

Effective patient education focuses on what patients want—and need—to know. It involves patients as active participants and takes into account barriers that influence each patient's learning experience. Some potential barriers include facility characteristics, personal characteristics, and disease characteristics.

First, many elements of the dialysis facility itself can affect patient education. The main barriers are the workload of dialysis staff and the financial resources available for educational materials and programming.

A patient's personal characteristics make each educational experience different. These characteristics include age, gender, education level, ethnicity, health status, and personality traits. Personal resources such as family and community support, income, insurance, career and family responsibilities, and coping strategies also play a role.

Kidney disease is very complex, and its treatment is just as involved. As such, there is a lot to learn about living with kidney failure. In addition, fatigue, depression, confusion, and other common physical and emotional effects of kidney failure are a challenge for patient education efforts.

EDUCATE AND OVERCOME

To be optimally effective, patient education programs must take into consideration the factors that influence teaching and learning. Understanding and addressing these factors

will help prevent them from becoming barriers to education. For specific ideas about supporting the education process, see *Education Tips for Healthcare Providers*, below.

People with kidney disease can come to enjoy long, full lives. The foundation for doing so is effective education. The more patients understand about their disease and treatment, the better prepared they will be to take control of their health and their lives. ♦

Education Tips for Healthcare Providers

Developing a comprehensive patient education program can be a complex and resource-intensive undertaking. Still, there are ways in which every unit can support patient education. Here are some tips:

Start early.

Provide information as early as possible, even before the onset of dialysis, to help reduce patients' fears and prepare them for what is to come. This information can help patients make decisions about their options for treatment, their employment status, and maintaining activities they enjoy.

Create a common link.

Treat each patient with respect and dignity. Take the time to ask them about their lives away from dialysis. Consider what questions you would have if you were a patient—don't assume they'll ask about things they don't understand.

Build communication and self-esteem.

Introduce new patients to other patients they can talk to and learn from. Work with patients on depression or unresolved personal issues. After you've had a chance to evaluate their life experience, ask them to become mentors.

Use existing resources.

Use materials that have already been developed—many are available free of charge through groups such as Life Options, NKF, and AAKP. Provide patients with a list of resources, including dialysis support groups, organizations, and meetings. Encourage patients to get on-line—at home or at the library.

Focus on delivery.

Go at a pace that is comfortable for each patient. Evaluate patients' reading skills. Use a variety of tools, from printed and audiovisual materials to verbal instruction and hands-on demonstration. No matter what the teaching strategy, remember to ask, "Is there anything else you'd like to know?"

Provide ongoing support.

Provide encouragement toward goals and positive feedback for successes. Offer opportunities to educate families, employers, and other support persons. Have patient representatives call other patients to provide support.

Encourage patient self-advocacy.

Ask patients what activities they are maintaining. Discuss and explain test results, and help patients track their own. Encourage patients to be proactive, to ask questions, and to approach education as a lifelong process. ♦

*Patient Education in Action***Healthy Start Program Educates and Empowers**

...education restores hope to patients, giving them the best life possible with kidney failure...

The Healthy Start (HS) program at Ochsner Hospital in New Orleans has proven its worth in many ways—healthier patients starting dialysis, patients with hope for the future, and lower costs.

According to the program's co-founder Jill Lindberg, MD, FACP, education restores hope to patients, giving them the best life possible with kidney failure, "Patients often feel the wheel of control has been taken away from them," she says. "It's our job to give that wheel back."

Lindberg, who is also Director of Hemodialysis at Ochsner, contends that patients who receive early education are able to avoid some of the physical and emotional challenges other patients may encounter. In turn, these patients are often more prepared to self-manage.

"The Healthy Start program," she says, "provides the information and feedback to allow patients to be involved in their own medical care. We definitely see patients as an integral part of the care team."

EDUCATION'S POSITIVE OUTCOMES

What are the health benefits of this unit's education program? A research study looked at 29 HS patients and 29 non-HS

patients. Results showed that patients who went through Healthy Start had fewer hospitalizations, and shorter hospital stays. In addition, almost four times as many Healthy Start patients had permanent accesses when they began dialysis—a definite advantage.¹

"You can tell a Healthy Start patient from a non-Healthy Start patient right away," says Lindberg. "It's like night and day. The educated patients are more informed and relaxed—and they're healthier."

She believes the key to success is educating patients before they become uremic. "At the start of dialysis, some of our Healthy Start patients have never been in the hospital," she explains. "They are calm, and they are well-prepared."

There are benefits for the dialysis unit as well. Research data also showed hospital charges for the 3 months before and 3 months after the start of dialysis were \$41,676 for non-HS patients, but only \$28,934 for HS patients. Lindberg cites these data to maintain funding for the program.¹

PROGRAM COMPONENTS

The multidisciplinary Healthy Start team includes Lindberg, a nurse practitioner, social worker, dietitian, financial

Q&A**ASK THE EXPERTS: EDUCATION AND OLDER PATIENTS****An Interview with:**

Marilyn Diener, MS, RN

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Q *How is a chronic condition like kidney disease similar to the process of aging?*

A ANNE: With chronic disease, as with aging, people have different role expectations, physical expectations, fears, and concerns about what the end of life will be like. However, with normal aging, this is a healthy, lifelong process in which functional decline is progressive but slow.

MARILYN: People with chronic disease often go through stages similar to the stages of death and dying. They may experience denial, fear, anxiety, and depression. They may wonder: Why me? Who can help me now? Will I find a competent doctor? How will this affect my family? It takes a lot of information and support to deal with these issues.

Q *How do you build a foundation for patient education and involvement?*

A ANNE: I try to establish a relationship with patients from the very beginning. In my meetings with patients, I try to get as much information as possible about who they are as people. I also let them know that I will be their advocate. To do so, I need to understand who they are—their goals, the wishes they have in life, what hope means for them.

After that, part of the doctor visit is just that—a "visit." Over time, I learn about patients' children, grandchildren, and the stresses in their lives. This ongoing exchange is the foundation for trust and respect. It also helps me better understand how patients are coping with their illness.

MARILYN: I think we need to provide education about what it means to be a patient and what it means to be a doctor. When you buy a car, you kick the tires, you ask a lot of questions. A lot of times, patients are afraid. They hesitate to ask questions. If we educate patients to become advocates, they can make note of changes between appointments, they can bring a list of questions to each visit, or they can bring other family members along to ask questions as well.

administrator, nurse manager, administrative secretary, and patient care coordinator. Currently, the team conducts 12 Healthy Start clinics: four sections of an advanced session and eight sections of a basic session.

The Basic Session is for patients who may never need dialysis, but have evidence of renal insufficiency (GFR less than 60 cc/min,) microalbuminuria, or family history. This 3-hour program focuses on prevention and medication. Both patients and family members are welcome.

“In the Basic Clinic, we tell patients about the things that can protect or hurt their kidneys,” explains Lindberg. “The hope is that dialysis will be postponed—or never needed.”

The Advanced Clinic is for patients expected to start dialysis within 12 to 24 months. Most patients are already seeing a nephrologist. They attend the Advanced Clinic, which involves an hour each with the social worker, dietitian, and nurse.

The advanced session addresses many issues, including the transition to life on dialysis, the renal diet, kidney function and failure, anemia, bone disease, and lab values. It also covers exercise, community resources, treatment choices, and access care.

BENEFITS OF EARLY INTERVENTION

Because Healthy Start provides an education program rather than “ad hoc” teaching, the social workers, dietitians, and nurses have designated time for each patient. Lindberg says this format allows for a comfortable and productive learning environment—one in which patients and providers are less rushed and better prepared.

In addition, she says, team members make every effort to suggest what patients can do, rather than what they shouldn’t do. The Healthy Start nurse also follows up with each patient after class to answer additional questions they may have. These educated patients are taking control, according to Lindberg—getting involved, staying active, and keeping their jobs.

“Education is so important for patients and families,” she contends. “When patients are informed, they gain control. Then, if and when dialysis becomes necessary, it is simply part of their lives, not their entire world.” ♦

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Q *How can positive communication between patients and the healthcare team be enhanced?*

A ANNE: A lot of work can be done in the area of medical education. In addition to teaching patients how to work with their healthcare team, we need to educate the younger generation of clinicians—doctors, nurses, social workers—about how to work better with patients.

It’s quality versus quantity—and caring versus curing. We have to understand that the individual, not the disease, takes precedence. For example, I see myself first and foremost as an educator. Whether patients are young or old, my job is to help them learn to self-manage as much as possible.

MARILYN: It’s really about teaching doctor-patient communications skills, about relating human-to-human. Whether you’re talking about the elderly or those with chronic disease, we’re all individuals. We all want to be valued and respected for who we are and for our own life experiences. Coming to know patients as individuals can help them feel validated as people with decision-making abilities.

A curriculum could be developed, with real practice involving videos, role-playing, or mentoring. In addition, using stories—from a provider’s or patient’s experiences—can help illustrate points and tap into the patient’s emotional roots that form the basis of spirituality and hope.

Q *What communication strategies can reduce patients’ fears, support adherence, and encourage self-management?*

A ANNE: As a doctor, I feel it’s important to talk my way through an exam. I tell patients exactly what I’m doing and why I’m doing it. Sometimes, simply getting familiar with the sound of my voice can help patients become more comfortable.

It’s also important to remember that we can encourage patients and we can provide education, but ultimately it’s their right to decide what they want to do. Patients have a right to not participate, and we need to respect that right.

MARILYN: Everything we do makes an impact, from how we greet patients to how well we listen. Even our nonverbal cues make a difference: Do we stand or do we sit at eye level while we talk? Do we maintain eye contact? Do we allow time for silence? It’s important to give patients ample opportunity to ask questions. And we ourselves must ask the appropriate questions, not just the ones on the sheet.

Part of nursing philosophy is to put yourself in patients’ shoes. As a patient, what would you want to know? What will the needle feel like? How will I feel like when I get done? Providing this information can help reduce patients’ fears and anxieties. ♦

*On-line Dialysis Support***Defining the Essence of Patient-to-patient Education**

Forty-four year-old transplant recipient Dale Ester sees patient education as a lifelong—and life-saving—process. “You have opportunities to learn every day you’re on dialysis,” he says. “And education is the only thing that will get you to the finish line.”

EDUCATION AND EXPERIENCE

Ester’s belief in the power of education is, in large part, a result of his own experience, both as a patient and as an educator. He himself began dialysis in 1989, after diabetes caused his kidneys to fail.

Like most new patients, Ester quickly found he had a lot to learn. “I was so afraid,” he recalls. “Nobody can explain to you how it feels to see your life coursing through tubes, to hear alarms going off. It leaves you with a lot to wonder about.”

Ester says this fear of the unknown was very difficult in the beginning. He decided learning all he could was the best way to eliminate the fear. “I thirsted for information, but it seemed hard to come by,” he says. “My social worker was very overworked, and many of the patients sitting next to me didn’t know any more than I did.”

Instead of giving up, Ester went to the library and read technical manuals about his illness, he got involved in kidney organizations, and he started networking with healthcare professionals and other patients. “I’ve always believed that my life is what I make of it,” he says. “I knew I had to go out and find the information I needed to live the life I wanted to live.”

CONTINUED COMMITMENT

While Ester received his transplant less than a year after beginning dialysis, his commitment to education continued. For several years, he sent out patient information packets through the NKF of Arizona.

INFORMATION SHARING

Then, in 1995, Ester had a breakthrough—he decided to use the Internet to help patients find the information they needed. “At the time, the Internet was virtually untapped,” Ester explains. “Yet it seemed to have the most potential to reach the greatest number of people.”

Ester got on-line and started *Dialysis Support*, a free, Internet mail list for kidney patients and professionals. “*Dialysis Support* is basically an on-line bulletin board,” explains Ester. “It’s a place for people to share information, feelings, and experiences.”

According to Ester, this sense of sharing is what makes the mail list such a valuable resource. “Patients need support for what they’re feeling right now,” says Ester. “You can’t just give them something to read—they’re going to have questions. They need to be able to say ‘can you help me understand this?’”

The ongoing patient-to-patient dialogue of *Dialysis Support* is unique. “Nobody can talk firsthand about dialysis until they’ve been in the chair, until they’ve been through it themselves,” he explains. “That’s why some of the best information comes from patients themselves.”

Ester says patient-to-patient education turns raw information into practical application. “So what if 1+1=2,” he explains. “Patients need to know what to do with that information—they need to see how it applies to their own lives.”

A VALUABLE RESOURCE

Currently, about 340 people subscribe to the *Dialysis Support* mail list. “Nearly 17,000 messages have been posted,” says Ester. “It has become a wonderful resource for patients.”

Over the years, topics have addressed the full gamut of the dialysis experience, from hair loss, neuropathy, and sexuality to what’s going on in the unit and what can be done about it.

To this day, Ester has continued the work of managing the mail list. In addition to screening and archiving each posting, he researches and responds to many of the messages himself. In addition, he has compiled a large list of frequently asked questions (FAQ), which he sends to every new member.

Through it all, Ester hopes to help patients learn what they can do to manage life with kidney failure. “With dialysis, many patients give away control by coming to rely on other people to do things for them,” he explains. “*Dialysis Support* helps patients regain control of their destiny.” ♦

*Taking the First Step***Joining the Dialysis Support Mail List**

The *Dialysis Support* mail list is free to patients, family members, and healthcare providers. To subscribe:

- Send an e-mail message to:
dialysis_support-subscribe@yahoogroups.com, or
- Sign up at http://groups.yahoo.com/group/dialysis_support/ ♦

*Factors That Affect Patient Learning***Education Essential to Self-management Success** *(continued from page 1)***THE IDEAL**

Educating patients about self-management sounds straightforward: (1) patients learn it is possible to live long and well with kidney disease, (2) patients are taught and accept their role in maintaining their health, and (3) patients seek and absorb information, and become experts in their own care.

It's an ideal model. But if overcoming the challenges of kidney disease is difficult, it is no less difficult than finding the educational formula that will transform each kidney patient into an active and informed self-manager. Understanding the factors that affect learning and retention of vital information can help make education work.

EDUCATING ADULTS

Education can improve attitudes among patients with chronic illnesses, with long-lasting benefits. 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.^{2,3}

Adults approach learning differently from children: they learn primarily what they want and need to know, incorporating new information into an existing framework of knowledge. Adults learn more if information is relevant to their lives. Practice and repetition make teaching more effective for adults.³

Educating adults to self-manage, therefore, should focus on information and skills patients need to participate in their healthcare. According to Dr. Kate Lorig, effective self-management education for chronic illness:⁴

- Focuses on what patients need and want to know
- Provides hands-on experience with decision-making and problem-solving
- Teaches patients how to deal with emotional issues and medical problems
- Builds confidence in patients' ability to manage their conditions
- Convinces patients to take an active role with their physicians, i.e., asking questions

BARRIERS TO PATIENT LEARNING

Educating kidney patients is an ongoing challenge, due to the complexity of kidney disease, patients' varied educational and social backgrounds, comorbid conditions, lack of staff time, and a variety of other barriers.

Fear of dying, or of having a life not worth living, can make it difficult for patients to learn. Symptoms of kidney disease, such as fatigue and confusion, and unpredictable episodes of acute and chronic problems, can obstruct learning. Other barriers may be age-related, such as vision and/or hearing problems, or a long-held belief that patients should place total faith and control in the doctor or nurse. An article in this issue addresses barriers to successful education, with tips for healthcare professionals and patients.

READINESS TO LEARN

Another major factor in adult education is readiness for education, which can be affected by the imminence of dialysis, how sick a patient feels, or the patient's emotional ability to accept information at a given time. A patient just diagnosed with kidney disease, for example, may embrace medical information related to slowing the progression of the disease, but not yet be ready to hear about renal replacement therapies.

Some strategies for teaching, without overwhelming the patients' readiness to learn, include brief teaching sessions (30 minutes or less), planning for breaks, repeating material often, and assessing knowledge by asking questions and requesting that patients demonstrate what they have learned.

(continued on page 8)

Education can improve attitudes among patients with chronic illnesses, with long-lasting benefits.

*Keys to a Long Life***Patient Interest Checklists**

Life Options offers a free tool to help renal professionals assess kidney patients' educational needs, so that educational efforts can be more relevant—and therefore more efficient and effective. The Keys to a Long Life *Patient Interest Checklists* are available for four different levels of kidney disease: ESRD (soon to be revised for chronic kidney disease), Starting Dialysis (0-3 months), Early Dialysis (3-12 months), and Long-term Dialysis (1 year+). The *Patient Interest Checklists* can be downloaded from the Life Options website, www.lifeoptions.org, and reproduced as needed.

For more information and tips on patient education, download the free booklet: *Building Quality of Life: A Practical Guide to Renal Rehabilitation* in the Renal Professionals section of the Life Options website. You'll find the Education module on pages 47-73 of the *Practical Guide*. ♦

Factors That Affect Patient Learning Education Essential to Self-management Success (continued from page 7)

Demonstrations can include anything from pointing to the next access cannulation site to choosing a sample dinner from a restaurant menu.³

THE IMPORTANCE OF TEAMWORK

A final factor in learning—but perhaps most important—is how healthcare professionals and patients work together. Professionals who provide encouragement and education to patients may be rewarded by patients who are more involved, more likely to adhere to treatment, and more able to self-manage in a positive way. As a result, staff may be less stressed, more satisfied with patient outcomes, and have more time. Professionals can have partners instead of patients.

Patients, for their part, must come to see themselves as creators of their own best possible health and life. Gaining comprehensive knowledge of kidney disease can provide the background they need to make good medical and lifestyle decisions. The patient's contribution to education is to ask questions, search for answers, and partner with the healthcare team.

Education and hope can help transform more patients from frightened, sick victims into self-managers who grow in confidence, experience, and satisfaction as they go on with their lives. ♦

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