



# Renal Rehabilitation Report

## *The Hemodialysis Patient Experience*

### How Symptoms Affect Functioning and Well-Being

**D**ialysis patients' symptom management may have important implications for their future health and survival. A recent Life Options study suggests that how hemodialysis patients handle their symptoms can affect their functioning and well-being (FWB). In light of the well-established link between FWB and clinical outcomes—including morbidity and mortality—helping patients learn to manage their symptoms effectively may help them to live long and live well with kidney disease.

#### DIALYSIS SYMPTOM PREVALENCE

People with end-stage renal disease (ESRD) commonly have a wide range of symptoms associated with their loss of kidney function. Some of these symptoms, like swelling of the hands and feet, may indicate serious clinical problems. Others, like dry mouth or trouble falling asleep, may be bothersome, but less serious. The pervasiveness of symptoms in the lives of hemodialysis patients, however, undoubtedly has an impact on their quality of life.

"Dialysis patients experience a huge number of symptoms," reports Life Options research consultant Roberta Braun Curtin, PhD. "They live their lives around

their symptoms, and their experience of life is colored by their ability to manage those symptoms." Dr. Curtin and other Life Options researchers gained insight into the "lived experience" of hemodialysis patients over the course of years of research involving hundreds of interviews with dialysis patients. "Whenever we interviewed patients," says Curtin. "They always talked about symptoms."

During the course of several qualitative research studies, Dr. Curtin and her colleagues became sensitized to the serious issues that symptoms raise for dialysis patients. As a result, they decided to look more systematically at the effect of symptoms on hemodialysis patients' FWB.

#### SYMPTOM STUDY

In cooperation with Gambro Healthcare dialysis facilities, Life Options undertook a study to:

- Catalogue the symptoms commonly noted by dialysis patients.
- Examine the relationship between symptoms and functioning and well-being.

*(continued on page S4)*

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## Message from the LORAC Chair

**S**ymptoms experienced by patients with kidney disease—such as restless legs, itching, pain, swelling, and fatigue—have been found to negatively affect functioning and well-being and, therefore have implications for longevity.

Effective treatment of these and other symptoms is key to successful, long-term management of kidney disease. With encouragement and education from the care team, patients with kidney disease can learn to manage their symptoms and improve the overall quality of their lives.

This issue of the *Renal Rehabilitation Report* will discuss the importance of symptom management, ways to encourage patients to self-manage their symptoms, and personal stories of the benefits from active symptom management. ♦

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*Managing Symptoms*

**The Central Role of the Patient**

Living with a chronic disease like kidney failure requires that patients constantly make decisions about how to manage their symptoms and follow their treatment regimens. According to Betty Chewning, PhD, Associate Professor of Pharmacy at the University of Wisconsin, a researcher in the field of patient self-care and author of numerous publications on self-management in chronic disease, studies of patient behavior have shown that “selecting and managing [treatment] regimens can be as challenging as the chronic condition itself.”<sup>1</sup> Because dialysis patients must contend with so many symptoms, they must frequently make decisions about the seriousness of a particular symptom, whether or not to report it, to whom it should be reported, and what self-care strategies they might try on their own.

**DECISIONS, DECISIONS**

“People monitor their symptoms,” says Dr. Chewning, “and they generate hypotheses about what causes their symptoms to get better or worse. Then, they make adjustments to their self-care, and these adjustments can take many forms.” Based on the perceived benefits and side effects of medications, for example, patients often adjust their medication doses. They may also decide to augment recommended medications with other self-care therapies or over-the-counter medications.<sup>1</sup>

The fact that patients make so many decisions about their own care should come as no surprise. In any given week, a typical in-center hemodialysis patient spends only about 8% of his/her total time (about 15 hours) under the direct supervision of a medical professional. The remaining 92% of the week, they are self-managing their conditions essentially on their own—often with minimal preparation (see *pie chart*, at right). In a very real sense, “the healthcare system relies on patients to manage much of their own care,” notes Dr. Chewning,<sup>2</sup> who believes it is time for healthcare providers to acknowledge the importance of patient self-care in symptom management and adherence to treatment regimens.

**MONITORING SYMPTOMS**

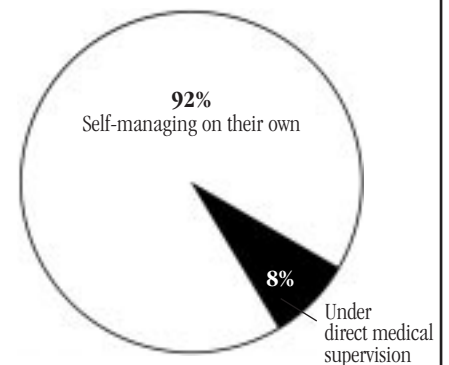
Patients’ decisions about symptom management and adherence can either reduce or raise their risk of negative health outcomes and hospitalizations. Providers have an opportunity to tap into people’s natural tendency to make sense of their treatment and their symptoms, and work *with* patients toward the goal of improving quality of life.

Better patient education about how to monitor, record, and report symptoms would be a good first step. Patients have a tremendous amount of information about their symptoms and reactions to medications and treatments. Providers who seek out that information can work more closely with patients to design effective, treatment regimens that patients can live with (see *The Write Track*, at right).

**A PARTNERSHIP**

When providers accept that patients have decision-making responsibility and power, and work more closely with them, an effective health care partnership can result. Dr. Chewning believes that such a patient-centered model of care offers a more realistic approach to symptom management in chronic disease because it acknowledges the importance of patient preferences in several important areas, including:

**Typical Week of a Person on In-center HD**



(Courtesy of Life Options)



- **Goals of care:** In a patient-centered model, ability to carry on with normal life activities and overall well-being are as important as clinical outcomes.
- **Prescribed regimen:** Patient preferences are assessed and incorporated into prescribed medical regimens.
- **Patient education:** Education focuses on increasing patients' ability to manage a treatment regimen, rather than on adherence alone.
- **Monitoring:** The healthcare provider actively seeks patient input about side effects and convenience to tailor treatment plans.
- **Self-care:** Patient autonomy and patient choices about care are recognized and valued.
- **Control and status:** Power and responsibility are conferred on patients so they can be actively involved in their own care.

Taken together, these attributes of the patient-centered model can help patients and caregivers forge effective health-care partnerships.

### CONCORDANCE: NEGOTIATED AGREEMENTS

Patients' ability to manage the symptoms of a chronic illness has enormous implications for living with any semblance of normalcy.<sup>3</sup> Research suggests that patients' need to maintain normalcy may take precedence over the need to follow a treatment plan. This need to be "normal" may result in inappropriate, patient-initiated changes to prescribed regimens—unless the patient and care team have worked together to negotiate a plan that respects the beliefs and wishes of the patient (concordance). The concept of concordance recognizes that each patient has unique expertise which the provider must identify, understand, and respect.

Perhaps the first step in achieving patient-provider concordance to improve patients' functioning and well-being requires a shift to a patient-centered model of symptom management. Such a model acknowledges that patient self-care is not supplemental to professional care—but rather, in the case of chronic illness, it is the center of the patient's day-to-day self-management efforts. ♦

## The Write Track: One System for Monitoring Side Effects

**W**hen University of Wisconsin professor Joe Wiederholt, PhD was diagnosed with colon cancer at the age of 45, his world was turned upside down. He had surgery, then began chemotherapy. Although he read everything he was given about his therapy, he wondered about what the effect of "chemo" would be on his daily life.

Doctors and nurses told Dr. Wiederholt that they would keep track of his blood counts during treatment. They asked him to monitor his symptoms, including nausea, loss of appetite, mouth sores, and diarrhea. What no one told him, however, was *how* to monitor his symptoms.

So Dr. Wiederholt devised a system of his own. Using a 10-point scale, he recorded symptoms, severity, frequency, and more in a diary. His diary helped him in several ways. First, it enabled him to see treatment-related patterns in his symptoms. Second, keeping the diary gave him an excellent tool for communicating with his health care team. Finally, and most important, the diary gave Dr. Wiederholt a sense of control. Using the information he learned by tracking his symptoms, he was able to make decisions and adjust his treatment schedule to preserve his quality of life.

Dr. Wiederholt was convinced that his side-effect tracking system could help other cancer patients. Eventually, with the support of Health Ed and Bristol-Myers Squibb Pharmaceutical Company, *The Write Track: A Personal Health Tracker* was published in book form and has been distributed to thousands of patients.

Although *The Write Track* is currently available on a limited basis, Peggy Wiederholt, Dr. Wiederholt's widow, is working on a new version of the book for national distribution. ♦

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*The Hemodialysis Patient Experience*

# How Symptoms Affect Functioning and Well-Being (continued from page S1)

**Table 1: Most Frequently Experienced Symptoms**

Symptom	N (%*) Patients Who Experienced
Lack of energy	248 (90.5%)
Feeling tired	244 (90.7%)
Dry mouth/thirst	221 (77.0%)
Itchy skin	216 (73.2%)
Muscle cramps	192 (69.3%)
Numbness	177 (62.3%)
Change in weight	171 (61.7%)
Constipation	161 (57.1%)
Waking in the night	161 (56.4%)
Trouble falling asleep	160 (56.5%)
Not enough sleep	159 (55.4%)
Food cravings	150 (53.8%)
Restless legs	150 (52.1%)
Muscle weakness	148 (54.2%)
Lack of appetite	148 (52.7%)
Trouble staying awake	148 (52.7%)
Muscle soreness	146 (51.8%)
Lack of interest in sex	141 (51.1%)
Bone/joint pain	130 (46.1%)
Changes in skin	118 (41.7%)
Difficulty/sexual arousal	115 (43.9%)
Inability to enjoy sex	111 (42.0%)

Adapted from Curtin RB, Bultman DC, Thomas-Hawkins C, et al. *Nephrol Nurs J* 29(6):562, 567-74, 2002

\* Percents vary due to response rate for each item

The study was conducted in 2001 with 307 in-center hemodialysis patients from 14 Gambro facilities.<sup>1</sup> Participating patients were given a list of 47 commonly experienced symptoms and asked to report how often they had each one (never, a little of the time, some of the time, most of the time or all of the time.) This list of 47 common symptoms was compiled based on a review of current literature and analysis of more than 100 transcripts of dialysis patient interviews conducted by Life Options over the previous 3 years.<sup>2-6</sup>

Patients were also asked to report on their functioning and well-being (FWB), measured using the Short Form-36 (SF-36)—a self-administered questionnaire. SF-36 scores include a Physical Component Summary (PCS) score, which assesses patients' physical abilities, and a Mental Component Summary (MCS) score, which assesses patients' mental health and ability to function in their usual roles. Low scores (a mean of 50 ± 10 is "normal" for the general U.S. population) suggest that patients' ability to perform routine activities of daily living—their FWB—is compromised.<sup>7</sup> The SF-36, including PCS and MCS scores, has been used successfully in the past with both hemodialysis and peritoneal dialysis patients.<sup>8-11</sup>

### RESULTS: SYMPTOM EXPERIENCES

Patient responses to the symptom survey revealed that 22 of the 47 symptoms on the list were experienced on average more than just "a little of the time" (see *Table 1*, at left). Lack of energy and feeling tired were the symptoms most often reported: more than 90% of patients had each of these symptoms in the previous 4 weeks. The other two most commonly noted symptoms were dry mouth and itchy skin.

Analysis revealed that 13 of the 22 most commonly felt symptoms could be grouped into three "clusters:"

- Fatigue/sleep concerns
- Sexual concerns
- Mobility concerns

Since the 13 symptoms in these three clusters, plus 4 other symptoms (dry mouth, itchy skin, lack of appetite, and restless legs) were found to be correlated with PCS or MCS scores on a first analysis, further analysis was done.



**RESULTS: FUNCTIONING AND WELL-BEING AND SYMPTOMS**

Not surprisingly, hemodialysis patients in this study had generally lower SF-36 scores than the normal U.S. population. While the average PCS score for normal U.S. adults aged 55–64 is 45.9,<sup>7</sup> patients in this study had an average PCS score of 32.9 ± 10.13. Similarly, the average MCS score for normal U.S. adults aged 55–64 is 51.1, while study patients’ mean MCS scores were 49.7.

Were the lower PCS and MCS scores among study patients related to their symptoms? Yes. Initial analysis found that 17 of the 22 most commonly-reported symptoms were correlated with lower PCS scores, MCS scores, or both. When the relationship of the three symptom clusters (fatigue/sleep symptoms, sexual symptoms, and mobility symptoms) to PCS scores was analyzed, all three clusters were negatively associated with PCS scores (see *Table 2*, at right): the more frequently these symptoms were experienced, the lower the PCS scores were likely to be. Three of the four miscellaneous symptoms (dry mouth, itchy skin, and restless legs) were associated with lower PCS scores as well. Finally, age and diabetes were also negatively associated with PCS. This was as expected, since previous research has shown—and common sense would predict—that normal aging and diabetes are generally linked with reduced physical functioning.

When the relationship between the symptom clusters and MCS scores were analyzed, the findings were somewhat different. Only two of the three symptom clusters (fatigue/sleep and mobility) and all four of the miscellaneous symptoms were negatively associated with MCS. None of the demographic characteristics were associated with MCS.

**A BETTER UNDERSTANDING**

The results of this study help us to better understand how hemodialysis patients’ symptoms affect their FWB. Frequently-experienced symptoms—even those that may not *seem* serious—have been shown to reduce patients’ FWB. This is an important finding, since past research has shown that reduced FWB predicts increased morbidity and mortality as reliably as Kt/V and serum albumin do.<sup>8-10, 12-13</sup>

**Table 2: Multiple Regression Analysis of Associations Between Symptoms, Patient Characteristics, and Quality of Life Measures**

Symptom Indices	Correlation with PCS Score	Correlation with MCS Score
Fatigue/sleep index	Negative	Negative
Sexual concerns index	Negative	—
Mobility index	Negative	Negative
<b>Miscellaneous Symptoms</b>		
Dry mouth	Negative	Negative
Itchy skin	Negative	Negative
Lack of appetite	—	Negative
Restless legs	Negative	Negative
<b>Patient Characteristics</b>		
Age	Negative	—
Diabetes	Negative	—
Gender	—	—
Race/ethnicity	—	—

Helping hemodialysis patients learn to manage common, non-acute symptoms may well have important long-term benefits—including avoiding hospitalization and prolonging survival. For this reason, patients’ symptoms, both large and small, warrant careful consideration by the healthcare team. ♦

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(continued on page S8)

*Day-to-day Life on Dialysis*

## Patient Practices Symptom Management

**“I know my body better than anyone. I tell my doctor what I need, and I do as much as I can for myself.”**  
—Eugene Willis



After 10 years on hemodialysis, Eugene Willis has become so adept at managing the symptoms of his kidney disease that he can almost predict the results of his monthly lab tests before he sees them. “I can pretty much tell you what they’ll be, based on the choices I’ve made,” says the 36 year-old.

Eugene not only understands his lab values, he knows what impact each has on his overall health. “This month, my potassium is probably a bit high,” Eugene explains. “That can be really bad—it can shut down your heart.”

For Eugene, this attention to the detail has evolved over time, but it all began shortly after he started dialysis. “I really started paying attention when I walked in, saw the machine, and knew that I had to get on it,” he says. “That was a real wake-up call—that’s when everything changed.”

### MEDICAL HISTORY

Eugene first became aware of his kidney disease about 12 years ago, when he was 24 years old. “I had gained a lot of water weight and was having some pain in

my left side,” he recalls. “I went to the doctor, and tests showed that I had high levels of protein in my urine.”

After a brief stay in the hospital, Eugene was able to return to his normal routine. “My doctor knew that my kidneys were failing and that I’d need dialysis at some point,” he says. “But I felt good enough continue my usual activities—going to work, playing basketball and football. My lifestyle hadn’t changed.”

About 2 years later, Eugene began to feel some cramping, which culminated in a severe episode at work. “I was taking out the trash and my whole body cramped up—my arms, my legs, and my chest,” Eugene recalls. “My boss found me on lying on the ground, yelling for help.”

Eugene was taken to the emergency room and was immediately hooked up to a dialysis machine, through a temporary access. “My kidneys were failing,” he explains. “I spent almost 3 weeks in the hospital.”

### THE START OF SYMPTOM MANAGEMENT

The seeds of Eugene’s symptom management were planted early, with his own informed decision-making. “When I was in the hospital, my nurse showed me a video

## Q&A

### ASK THE EXPERTS: SYMPTOM MANAGEMENT

#### **An Interview with Donna Mapes, DNSc, MS, RN**

A leading authority on issues related to the treatment of kidney disease, and a founding member of the Life Options Rehabilitation Program, Dr. Mapes recently retired from Amgen Inc. She remains professionally active as a part-time consultant.

**Q** *Why is symptom management so important?*

**A** People with chronic disease experience symptoms along a broad trajectory. At certain times, they may encounter many symptoms. At other times, their symptoms may be less pronounced. Because a chronic disease cannot be cured, the degree to which a patient’s symptoms are effectively managed will help dictate that patient’s overall quality of life.

In other words, most patients don’t wake up and think about kidney disease itself. Instead, they think about the symptoms they’re having as a result of that disease. Do they have a headache? Are they fatigued? Are they suffering from edema? Is the symptom a warning signal that requires further medical attention and treatment? While patients can’t manage the underlying kidney disease, they *can* learn to manage many of its symptoms.

**Q** *How does symptom management tie in to self-management?*

**A** If patients are going to manage symptoms, they must be able to recognize the symptoms they’re having and then implement some type of action. By definition, that’s the first part of self-management. The second part of self-management is for patients to recognize that action they choose to take or not take has a consequence that will ultimately impact their quality of life.

**Q** *What can healthcare providers do to help with symptom management?*

**A** Symptom management can be particularly challenging for people with kidney disease because they experience symptoms in every body system. To help with this monumental task, healthcare providers must respect the fact that patients *do* have symptoms as a consequence of their chronic disease.

Providers must also educate patients to recognize the various symptoms they experience, and to understand what options exist for managing these symptoms. Finally, and equally important, providers must help



about the different types of treatment, and I decided that hemodialysis was the best option for me,” he says. “I do get occasional cramps in my legs, but I relax, breathe, and stay in control. I’ve found that getting overexcited will have you seeing stars in no time! Other patients at my center now follow my method.”

Eugene continues his quest for information and for improved symptom management every day. “I used to take a prescription binder that caused me to have dry mouth,” he explains. “I decided to talk to my doctor about switching binders and, with his approval, began buying a natural, over-the-counter product that didn’t leave a film on my tongue.”

Over time, Eugene was able to feel even more comfortable making decisions that affect his symptoms. “To keep my appetite, I don’t eat anything before I go to dialysis,” says Eugene. “This way, when I get home after my treatment I’m hungry, and ready to eat!”

With the knowledge he has accumulated, Eugene has been able to take charge of many aspects of his treatment—weighing himself, providing input regarding the amount of fluid that should be taken off at each treatment, and determining the placement of his dialysis needles. “You have to learn to

assert yourself,” he says. “I know my body better than anyone. I tell my doctor what I need, and I do as much as I can for myself.”

### ADVICE FOR NEW PATIENTS

Eugene, who is a patient representative in his unit, has some symptom management advice for new patients. “To start, you need to get involved,” he says. “Pay attention to what’s happening around you. Ask questions—‘What are you doing? What is that? What does it do?’ Over time, you’ll pick it up.”

According to Eugene, the proper mindset is also important. “Try to keep a smile on your face,” he says. “Don’t let anything get you down. Even when I’m at dialysis, I’m laughing and joking.”

### THE FUTURE

Eugene feels that learning to manage the symptoms of kidney disease has allowed him to maintain a lifestyle that is rich and fulfilling. In fact, he spends a good portion of his free time fishing. In the end, he says, that’s what is important. “I believe in quality over quantity,” he says. “I’d rather live a full, active life than a long and bland life. Every day, I count my blessings because I’ve been able to do that.” ♦

patients understand the consequences of their decisions—that how they choose to manage their symptoms *will* impact their quality of life. As a team, we have the responsibility to teach patients to “safely adapt and modify their treatment regimen to their lifestyle.”

**Q** *How can patients become better symptom managers?*

**A** There are many ways patients can enhance their own ability to recognize and manage symptoms. To start, they must take responsibility for obtaining the information they need from their healthcare team. They must actively seek knowledge about their symptoms, come to understand how these symptoms relate to their disease and treatment, and learn how to recognize and manage them appropriately. When it comes to their own symptom experiences, no one else can be the expert. Patients must have the will and the motivation and take the responsibility to do it themselves.

**Q** *From the provider perspective, what are the biggest challenges for kidney disease symptom management?*

**A** When providing care, it is important to recognize and understand the uniqueness of each patient. As with any chronic disease population,

there are a great number of ethnic, cultural, age, gender, social, and psychological differences among people with kidney disease. We need to take these differences into account and tailor treatment to each patient, recognizing that individual responses to the treatment regimen will vary widely.

In my opinion, we have taken steps backward in this regard over the last decade. What I hear from professional nurses today is that they are so short-staffed—they simply don’t have time provide the information and support patients and families need. This has increased the burden on the rest of the health care team. While I don’t see this improving in the short-term, I do believe we have an untapped resource, and that is to engage patients to become peer counselors.

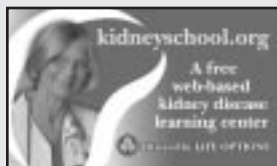
Most patients are hungry for information, and many will talk to other patients, even if they won’t talk with practitioners. I’d like to see trained peer counselors as members of the healthcare team in every unit, who could be a resource and a conduit for other patients. Of course, it would require a significant commitment from the kidney disease community as well as extensive resources to develop educational and training materials for this purpose. But, I think the opportunity to help patients and the results would be well worth the effort. ♦

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## How Symptoms Affect Functioning and Well-Being

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