Self-Management of Chronic Kidney Disease

Patients shoulder the responsibility for day-to-day management of chronic illness. How can nurses support their autonomy?

OVERVIEW: Living with chronic kidney disease usually involves management of other chronic conditions, such as diabetes or hypertension, and often requires a change in the patient’s way of life: medical and emotional aspects of the disease must be handled, symptoms interpreted and reported, partnerships with health care providers forged, and new resources used. Nurses can help patients maneuver this initially frightening and sometimes difficult terrain with strategies tailored to the stage of the disease.

The diagnosis of stage 2 chronic kidney disease has stunned 49-year-old Elizabeth VanDross. Two weeks ago she’d driven a neighbor to a screening for kidney disease—the Kidney Early Evaluation Program, a free, one-day program at a local clinic, and decided to get tested along with her friend. Although overweight and slightly hypertensive, Ms. VanDross felt great. Now, in her physician’s office for follow-up, she feels daunted by the diagnosis and the unexpected turn her life has taken—one that will entail routine testing, new dietary restrictions, several additional medications, and regular exercise.

She wonders: How will I manage it all?

In a world in which those with chronic illnesses spend about one hour a year in face-to-face conversation with health care providers, patients shoulder the responsibility for day-to-day management of chronic illness.1 This is no simple task. For example, the goals of treatment for people with chronic kidney disease include preventing or slowing disease progression, identifying and managing comorbidities and complications, and when necessary, undergoing kidney replacement therapies.2 Also, people with chronic kidney disease often simultaneously manage other chronic conditions, such as...
diabetes or hypertension (the most common causes of chronic kidney disease in the United States). Investigators have long studied the methods people use to live with illness and what “self-management” really means to those with chronic illness. Curtin and Mapes examined patients on long-term dialysis and defined self-management as “the patients’ positive efforts to oversee and participate in their health care in order to optimize health, prevent complications, control symptoms, marshal medical resources, and minimize the intrusion of the disease into their preferred lifestyles.” Lorig and Holman state, “One cannot not manage.” Accordingly, even a patient’s not managing a chronic illness reflects a decision about management.

Lorig and Holman reviewed trials involving chronic disease self-management programs, concluding that “significantly improved behaviors” were demonstrated, including increased time spent exercising; improved communication between patients and physicians; and reductions in pain, fatigue, distress, worry, and health care use. But when
Bodenheimer and colleagues reviewed clinical trials examining self-management of asthma, diabetes, arthritis, and unspecified chronic illness, they found that the strategies used to teach patients about self-management are so diverse that determining their effectiveness is difficult. They found that in “certain circumstances, self-management education is effective in improving outcomes.” And Haynes and colleagues found, in a review of randomized clinical trials on patients’ adherence to medication regimens, that the most effective strategies involved a combination of approaches including counseling, reminders, and supervision by a provider, but “even the most effective interventions did not lead to large improvements in adherence and treatment outcomes.”

Regardless of the fact that the evidence on whether self-management of chronic illness improves outcomes is inconclusive, nurses can agree that effective management of chronic kidney disease depends on recognizing that the patient is the principal illness manager, and that proficiency in specific skills and tasks is required to master this role—for which nursing support is vital.

CHANGING BEHAVIOR

Because many people with stage 1 or 2 chronic kidney disease are asymptomatic, early diagnosis can be difficult, as can encouraging asymptomatic patients to change lifestyles. (For information about identifying and screening for chronic kidney disease, see “Chronic Kidney Disease: An Overview,” Chronic Kidney Disease, February). Symptoms and medical complications are typically associated with the later stages of the disease.

Assessing the patient’s understanding.

Someone diagnosed with a chronic illness often

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**Sample Behavioral Change Action Plan**

**One technique for helping patients.**

<table>
<thead>
<tr>
<th>Name: Eloise Maines</th>
<th>Date: 09-26-05</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The change I want to make (be very specific: what, when, how, where, how often):</strong></td>
<td>I will work toward a goal of 30-minute sessions of exercise at home each day.</td>
</tr>
<tr>
<td><strong>My goal for the next two weeks:</strong></td>
<td>I will work up to 10 minutes of endurance exercise at least three times a week, five minutes of strength exercises twice a week, and five minutes of stretching exercises three times a week.</td>
</tr>
<tr>
<td><strong>The steps I will take to achieve my goal:</strong></td>
<td>• I will create a schedule of the types of exercises that I will do each week, including the days of the week I will do them. • I will keep a daily record of the exercises that I perform.</td>
</tr>
<tr>
<td><strong>The things that could make it difficult for me to achieve the goal:</strong></td>
<td>I’m tired when I get home from work. I don’t feel like exercising.</td>
</tr>
<tr>
<td><strong>My plan for overcoming these potential difficulties:</strong></td>
<td>I will do my exercises in the morning before I go to work.</td>
</tr>
<tr>
<td><strong>Support I will need to achieve my goal:</strong></td>
<td>• I’ll place written reminders of my exercise goal throughout my house (bedside table, bathroom, room designated for exercise). • I’ll talk with an exercise-support buddy frequently during the next two weeks about my progress.</td>
</tr>
<tr>
<td><strong>My level of self-confidence in achieving my goal:</strong></td>
<td>1 2 3 4 5 6 7 8 9 10 (not at all confident) (extremely confident)</td>
</tr>
</tbody>
</table>

Adapted from the Self-Management Support Patient Planning Worksheet by the organization Improving Chronic Illness Care (ICIC) (www.improvingchroniccare.org). ICIC is a national program supported by the Robert Wood Johnson Foundation, with direction and technical assistance provided by Group Health Cooperative’s MacColl Institute for Healthcare Innovation.
tries to make sense in concrete terms of the abstract concept of the diagnosis, usually by examining symptoms. This can mean that patients in the early stages of chronic kidney disease may have a hard time accepting the diagnosis and changing behaviors because there aren’t many noticeable physical cues. For example, in a seminal study of how people with hypertension perceive the illness, 46 out of 50 of those treated for three months to 15 years believed—erroneously—that physical symptoms (flushed face, headache, shakiness) indicated that their blood pressure had risen. In other words, they defined hypertension in terms of symptoms. Also worth noting was the fact that 17 of the 46 participants believed that their antihypertensive medication affected their symptoms; of these, 12 (70%) were taking their medication as prescribed. On the other hand, only nine (31%) of the 29 participants who didn’t believe that the medication affected their symptoms took it as prescribed.

Research has also shown that the absence of severe symptoms can lead people who have been diagnosed with chronic illnesses to underestimate the severity of the conditions and refuse therapy. For example, in a qualitative study of 25 HIV-positive men who refused antiretroviral therapy, many said that they didn’t need treatment because, among other reasons, they felt good and were not experiencing symptoms.

Assessing the patient’s perceptions is important; beliefs strongly influence self-management, and supportive approaches should be tailored accordingly. The following statements and questions may help:

- Describe what you think your illness is and how it should be treated.
- What concerns or problems do you have right now?
- What aspect of your illness is causing you the greatest and most immediate concern?

Building self-efficacy. The stronger a person’s confidence is in her ability to perform an action (“self-efficacy”), the more likely it is that she will do so. One study, for example, demonstrated that older adults who adopted and maintained a regular exercise program “believed they were capable of safely exercising.”

Enhancing a patient’s feelings of self-efficacy is an important component of supporting self-management. In the clinical setting, self-efficacy can be measured by asking the patient to rate how confident he is that he can perform a behavior on a scale of 0 (not at all confident) to 10 (completely confident). A score of 7 or higher indicates that the patient feels fairly confident and that the action plan will likely be successful. Scores of less than 7 indicate the need to alter the plan so that goals are more attainable.

Assessing the Patient’s Understanding

In addition to stage 2 chronic kidney disease, 56-year-old Jerry Nix has hypertension; this increases his risk of kidney disease progression, heart disease, and premature death. Because he’s asymptomatic, his nurse recognizes that he may find it hard to make the changes needed to control his hypertension. To understand him better, she asks him to describe his condition. He replies that his high blood pressure comes and goes based on his stress level—it’s not, he says, a chronic condition. He says that he takes his blood pressure medication only when he is stressed, and he doesn’t measure his blood pressure at home. She asks if he understands the risks. “What risks?” he responds. These answers make it clear that Mr. Nix requires further education. Through discussion, his nurse gives him information she hopes will help him understand the importance of blood pressure control.

Four essentials to building self-efficacy have been identified: performance mastery, modeling, interpretation of symptoms, and verbal persuasion.

Performance mastery. Helping patients to attain specific skills builds their confidence to move ahead. Nurses can help patients develop an action plan that covers a short period, such as one or two weeks, and is specific to certain behaviors. Goals should be realistic and the person should feel fairly confident in his ability to reach them; for example, a sedentary person could begin with low-intensity exercises (those that keep the heart rate below 60% of the maximum). It’s important to recognize that mastery of one task has to take place before the patient takes on new responsibilities.

Modeling. All teaching materials should reflect the age group, ethnicity, and when appropriate, sex of the population using them; this will enable patients to more easily identify with the messages. Peer-led self-management programs also provide an important

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A Patient’s Readiness to Change

Janet Downing received a diagnosis of hypertension on her 64th birthday. One year later, she is still having trouble monitoring her blood pressure. Her nurse practitioner suggests that they develop an action plan together. First, an assessment of Ms. Downing’s readiness to change is completed.

The nurse asks “Do you take your blood pressure and record it every day?” Ms. Downing can choose her answer from the following.

- No, and I do not intend to take and record my blood pressure every day (not contemplating a change in behavior).
- No, but I intend to take and record my blood pressure every day in the next six months (contemplating a change).
- No, but I intend to take and record my blood pressure every day in the next 30 days (preparing for the change).
- Yes, I have been taking and recording my blood pressure every day, but for less than six months (taking action).
- Yes, I have been taking and recording my blood pressure for more than six months (maintaining the desired behavior).

Based on Ms. Downing’s response, the nurse can determine how best to support Ms. Downing in becoming more ready to make desired changes.

opportunity for modeling, as do support groups, which allow participants to see how others cope.

Interpretation of symptoms in a negative way can result in feelings of vulnerability and difficulty in coping. In contrast, Lorig and Holman point out that when patients “have alternative explanations as to cause [of the symptoms], they also have reasons to try new self-management behaviors.”

Verbal persuasion involves supporting the patient with a you-can-do-it attitude—classes and support groups are two venues in which this can take place—and involves a credible source convincing the patient that she can perform an activity.

The transtheoretical model of change addresses behavioral change as a process rather than a discrete event. According to Prochaska and colleagues, it has five stages: precontemplation, contemplation, preparation, action, and maintenance. Each stage can predict a person’s success in effecting change; that is, people who are preparing for or taking action are expected to be more successful than those merely thinking about it. Efforts aimed at helping patients change should be tailored to the stage. For example, those in the precontemplation or contemplation stages may benefit from information aimed at raising consciousness. Those preparing for change or taking action may benefit from strategies such as completing a written plan or developing a system of personal reminders (such as placing notes throughout the house). (See Sample Behavioral Change Action Plan, page 42, for an example of one technique for helping patients change behavior.)

MANAGING MEDICAL ASPECTS

Chronic kidney disease is an independent risk factor for cardiovascular disease. People with chronic kidney disease have two to seven times the rates of hospitalization for congestive heart failure, ischemic heart disease, or arrhythmias than people with healthy kidneys. It’s therefore doubly important for patients to manage the medical aspects of kidney disease.

Compliance versus adherence. “Compliance,” a term often used to describe conformity to a treatment plan, suggests that patients passively follow orders; consequently, those who don’t follow orders are “noncompliant.” A better term for encouraging self-management is “adherence.” It acknowledges the patient’s role in making treatment decisions and living with an illness every day.

While it’s up to the patient to adhere to a regimen, nurses can make sure that the decision is informed by fact. In the early stages, patients need information about the illness, its treatment, and long-term consequences. They should also understand the importance of controlling blood pressure and blood glucose levels and reducing the risk of cardiovascular disease. For example, the proper use of medication for hypertension and diabetes requires an understanding of the medication, its purposes, benefits, and possible adverse effects; a method of remembering to take medication; and access to advice for problems or concerns.

In later stages of the disease, medical management and self-management become more complicated. Anemia, hypertension, congestive heart failure, protein-energy malnutrition, neuropathy, metabolic bone disease, and declines in functional status are all possible consequences. For example, increasing fatigue could be an early sign of anemia. Finally, people with stage 4 chronic kidney disease should thoroughly understand kidney failure and treatment options as they prepare for kidney replacement therapy (dialysis or transplantation or both). At this stage, referral to a nephrologist is imperative. Ideally, though, the patient should meet with a nephrologist before reaching stage 4. Research indicates that early referral and participation in predialysis programs result in fewer days of hospitalization during the first month of dialysis.
The Importance of Social Influences

When it comes to self-management, no patient is truly alone.

husband, daughter, health care practitioner—among factors that influence behavior change in people with chronic disease, the importance of social circles is increasingly recognized. “It is unreasonable to expect that people will change behavior easily when so many forces in the social, cultural, and physical environment conspire against such change,” states the Institute of Medicine report, Promoting Health: Intervention Strategies from Social and Behavioral Research.1 “If successful programs are to be developed to prevent disease and improve health, attention must be given not only to the behavior of individuals but to the environmental context in which people live.”

Because most chronic illnesses are managed within the home, significant others, spouses, and other family members almost inevitably influence a patient’s self-management regimen. For example, the spouse may feel that the consequences of chronic kidney disease are far less serious than the patient claims; this may curb the patient’s enthusiasm for changing. On the other hand, a concerned spouse will likely encourage her partner to adopt beneficial behaviors. Clearly, it’s important to include family members in all aspects of care and to assess a caretaker’s perceptions of illness. To do so, ask the caretaker (in private), “Describe what you think your loved one’s illness is and how it should be treated.”

A patient’s relationships with health care professionals are equally important. Although the majority of health care practitioners use the medical model to guide their actions and advice, the same may not be true for patients living with a chronic illness. Leventhal and colleagues found that, in fact, people living with chronic conditions base their self-management strategies on their day-to-day symptoms.2 In a study that compared the “illness beliefs” of people with diabetes or osteoarthritis to their physician’s beliefs, the patients believed that their illness was more changeable, less controlled by medical care, more painful, and less life-threatening but more progressive.3

Physicians, on the other hand, attached more weight to the severity of the illness. Indeed, the greater the differences in perceptions (between patient and practitioner), the worse the patient’s health, the greater the use of nonprescription drugs, and the greater the use of paramedical and alternative healers. These findings illustrate the importance of relationships between patients and health care professionals in shaping and supporting patients’ self-management skills and behaviors.

The patient’s cultural background is entwined in his perception of illness.4 When performing an assessment, ask about the patient’s use of traditional and nontraditional remedies (for example, use of herbs), beliefs about individual responsibility for health, and views of chronic illness. There are many books designed to guide nurses caring for patients from different cultures. Culture and Clinical Care is one worthy of note.5 In addition, multidisciplinary case conferences—perhaps including members from the patient’s church or people who share the patient’s cultural background—can also provide insight.

REFERENCES

KEEP-ing Kidneys Healthy
A free program for early identification of problems.

The Kidney Early Evaluation Program (KEEP) is a free kidney health screening program sponsored by the National Kidney Foundation and available through its local affiliates. Its goal is to “raise awareness about kidney disease, especially among ‘high-risk’ individuals.” During the program’s one-day events across the country, volunteers measure blood pressure and weight and test blood and urine. A health care professional reviews results with participants (hemoglobin levels and glomerular filtration rates, available within a few weeks, are sent to the participant and, with permission, to the physician). For more information and a schedule of screenings nationwide, go to www.kidney.org/keep/index.cfm.

For example, many chronically ill people reject as stigmatizing such diagnoses as depression,23 and some interpret emotions in physical rather than psychological terms—by admitting, for example, that they feel tired rather than sad. Also, they may pursue treatments such as a new medication rather than seeking psychological support and therapies. When talking to a patient about emotions, it’s helpful to listen to concerns, acknowledge beliefs, and help to clarify emotions.

Screening for emotional problems may involve, for example, a nurse asking, “How often have you felt sad in the past four weeks?” The patient then chooses from a set of quantifiable responses, “none of the time,” “some of the time,” or “all of the time”; if the patient chooses the second or third option, the nurse alerts the physician or nurse practitioner to the need for further intervention.

Support. Goal setting, problem solving, stress management, social support, and motivation may help patients with chronic kidney disease.24 In a study of approaches to teaching diabetes self-management, patients who received training in the psychosocial aspects of managing their disease had improved attitudes, more confidence in their ability to care for themselves, and significant reductions in glycosylated hemoglobin levels.25 Another study, of patients receiving hemodialysis, was designed to test a program that had three goals: to decrease depression, to change beliefs about the ability to manage emotions, and to increase confidence in caring for oneself.26 The nursing intervention involved teaching patients stress-management techniques, helping them to identify problem areas in their self-management, and allowing them to express their feelings. Participants who received the intervention showed improvements in each of the three areas.

USING RESOURCES
Even though it’s a nurse’s responsibility to help patients use a variety of resources, many people are unaware of the resources available to them. And although self-management programs often inform patients of Web sites, many neglect to explain how they’re used or provide Internet access. Nurses may need to help patients use the Internet, the library, toll-free numbers, or even phone books. There is ample information available; many organizations have launched educational initiatives. For example, the National Kidney Foundation’s Kidney Learning System (www.kidney.org/professionals/KLS), the National Institutes of Health’s National Kidney Disease Education Program (www.nkdep.nih.gov), and the American Association of Kidney Patients (www.aakp.org) all offer print and online resources for patients and providers. Another resource is
Kidney School, an interactive, online resource providing 20-minute modules designed to teach people with kidney disease about the disease and its treatment (see www.kidneyschool.org).

FORMING PARTNERSHIPS

Clinicians can and should encourage patients to be active in their own care—an idea central to self-management—by ensuring that patients feel comfortable during visits, avoiding brisk and insensitive interactions, keeping the patient informed of progress, and encouraging patients and their families to ask questions.27

The following steps may be taken to encourage partnership with patients:

- Listen to patients and ask them what they want from your interactions.
- Show that you care about the patient first and the illness second by asking how she feels (physically and psychologically) and whether she is reaching self-management goals.
- Spend more time listening and less time offering advice.
- Begin each visit by discussing the patient’s questions, concerns, and progress toward goals.
- Inform the patient of your assessment of her progress toward goals.

Concordance. The term “concordance” implies a shared understanding or agreement between patient and clinician on the nature of an illness and its treatment—a sign of a healthy partnership.3 But it’s not the same as adherence: concordance describes the outcome of the patient–clinician interaction, whereas adherence describes the patient’s behavior. Nonetheless, concordance doesn’t guarantee adherence. Although patient and clinician may agree about the necessity of taking medications, the patient may choose not to take them as recommended, for a variety of reasons that might include concerns about adding new drugs to an already complicated regimen.

No research could be identified that examines whether patient–clinician concordance affects self-management in people with chronic kidney disease. Yet findings from a study by Heisler and colleagues showed that patient–physician concordance on treatment goals and strategies was associated with higher levels of patient confidence in diabetes self-management and more positive assessments of self-management behaviors.28 This seems to suggest that achieving concordance may be one step toward successful self-management of chronic illness. But it’s not necessarily a simple step. In fact, although the majority of providers use the medical model to guide their actions and advice, Leventhal and colleagues found that people living with chronic conditions base their self-management strategies on their day-to-day symptoms and experiences.11 Clearly, more research is needed, yet these findings underscore the value of mutual goal setting and negotiations when conflicts arise.

For example, during an interview in which the first author asked an elderly patient receiving hemodialysis about his adherence to dietary restrictions, the patient responded that he understood and agreed with the need for dietary restrictions but believed that the restrictions were too rigid. He said that at his age he was not going to deprive himself of foods he enjoyed. His response indicates a need for a plan that includes some of the foods that he likes, which would, perhaps, encourage adherence.

Likewise, conversations with the nurse practitioner were essential to the success of Ms. VanDross’s self-management. With the help of a nurse practitioner, Ms. VanDross began a walking regimen and learned how to search the Internet. She also met with the nurse practitioner and other health professionals and the team created an action plan designed to halt the progression of her chronic kidney disease and ensure that she lived as long and productive a life as possible.

REFERENCES


