

Adequacy of Dialysis: The Patient's Role and Patient Concerns

John M. Newmann and William E. Litchfield

The patient's role in adequacy of hemodialysis is demanding and complex. It requires meticulous attention to initiating, accepting, and maintaining extraordinary behavioral change. This includes the following: (1) major alteration of dietary habits, often contrary to a patient's familial and cultural customs; (2) compliance with a new, voluminous medication routine, often straining personal finances; (3) reallocation of time for transportation, treatment, and partial recovery, frequently consuming a minimum of 6 to 8 hours 3 days each week; (4) psychologic adjustment to unaccustomed chronic dependency on, and accountability to, an array of variably experienced and competent renal care staff; (5) skills, seldom taught, required to communicate clearly and regularly with overworked medical professionals who are often much younger with less life experience; and (6) additional commitment to compensating for the physical fatigue that routinely accompanies hemodialysis. Reasonable behavioral modification in these 6 categories is likely to increase the chances of a patient fulfilling his role in adequacy of dialysis. Some patients, however committed the staff have been in assisting them, may show little interest in dialysis adequacy and the patient's role. Other patients periodically may fail in their role unless the renal care team recognizes the patient as an individual who is included as an important team member. The patient requires consistent and repeated education about their disease, treatment, and risks and benefits of adherence. The unique, unnatural requirements of adequate chronic hemodialysis require this patient support from the renal staff, enhanced by continuous sensitive attention, empathy, and persuasion. This will help the patient achieve success in their role.

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Hemodialysis, a complex, life-saving therapy, makes extraordinary demands on patients—all of which have major impact on the quality of their lives. Patients provide the dynamic element in the hemodialysis process. Their metabolic status is changing constantly, but without normal renal function to maintain homeostasis. Adequate hemodialysis is achieved through an integrated system of the patient (a dynamic, independent metabolic machine), the dialyzer, and the dialysis machine. Renal professionals (in conjunction with the patient) diagnose, prescribe, supervise, monitor, troubleshoot, support, and respond to the needs of this integrated system. If patients are consistently to achieve their prescribed dialysis dose, their cooperation and participation is essential.

The Patient's Role

The patient's role in adequate dialysis is complex: (1) they must carefully control the appropriate foods and liquids, medications, and quantities consumed; (2) they need to be sensitive to changing physical, mental, and psychologic symptoms and feelings, and communicate these regularly to their renal care professionals; (3) they are encouraged to be an active, preferably proactive, member of the renal care team, rather than simply a recipient of care, instructions, questions, compliments, reminders, or reprisals. They have no choice but to allocate considerable time to attending dialysis treatments and adjusting to the resulting fatigue. Psychologic and social adjustments also are required given the life-threatening nature of both kidney failure and chronic hemodialysis, and the behavioral change required to survive.

The patient's role is central and directly dependent on the patient's attitude, which can range from reckless to meticulous, in following the dialysis regimen. Successfully dealing with chronic kidney failure requires an optimistic attitude and a good measure of self-esteem. A high level of survivor

From Health Policy Research and Analysis, Inc., Reston, VA.
Address reprint requests to John M. Newman, PhD, MPH, Health Policy Research & Analysis, Inc., 1698 Chimney House Rd, Reston, VA 20190-4302. E-mail: johnnewm@aol.com

instinct and, for some, spirituality, help nurture a positive attitude.¹ A positive attitude also enhances the discipline necessary to adhere to the requirements of dialysis. A patient who (1) has reasonable knowledge of their disease and treatment, (2) understands dialysis patient responsibilities and their rationale, and (3) consistently, preferably meticulously, performs the responsibilities is likely to experience a reasonably good outcome.

The patient's role is no more and no less than the most important member of the renal care team. Although patient interest and willingness in assuming this role will vary, only a minority of nephrologists and renal staff may make the important, time-consuming efforts to enlist, engage, and encourage patients to assume this role. For the patient to contribute constructively, renal professionals must recognize and respect patients as individuals, their cultural backgrounds, and pre-renal failure life experiences. Patients also must be forthright in asking questions about issues important to them, and actively seeking answers and clarification.

Before kidney failure, the majority of chronic kidney disease patients will have spent decades living, eating, drinking, working, and playing in a manner easily maintained by 1 well-functioning kidney. Yet these same lifestyles cannot be supported by hemodialysis sessions 3 times per week. Without continuing sensitivity to, and respect for, individual patients by the nephrologist and renal care team members, patient to the extraordinary behavioral modifications required by chronic hemodialysis is unlikely. Not only do patients require excellent and continuous education about dialysis adequacy and their role, many patients really must be persuaded by staff to assume the numerous complex requirements.

Most hemodialysis patients, from the beginning of chronic renal care (independent of how late the patient was referred), need to be informed and educated repeatedly about their disease, treatment, and the reasons for the many patient responsibilities essential for successful care and the resumption of a near-normal lifestyle. They can benefit from continued encouragement to be engaged in shared decision making about the most reasonable ways to achieve adequacy targets. All renal care team members, from the nephrologist to the registered nurse, patient care technician, renal dietician, and social worker, increasingly will be frustrated, disappointed, and less than successful if they do not recognize the critical importance of the patient's need to have some degree of control when asked to adhere to an unnatural lifestyle that no one would choose freely.

Psychologic and Behavioral Research and Dialysis Adequacy

We do not adequately reference research of nearly 30 years on patient satisfaction, quality of life, and other important psychosocial parameters such as self-esteem and an internal and external locus of control. A limited number of the psychosocial studies specifically address the adequacy of dialysis.² However, much of what has been learned from investigations into patient behaviors when facing life-threatening, chronic disease (eg, kidney failure, asthma, diabetes, cardio-

vascular disease, some forms of cancer) may be very useful to revisit when attempting to increase patient adherence that is so critically important to achieving adequacy of dialysis.³ Educational interventions may result in positive behavioral changes among dialysis patients. One study by Schlatter and Ferrans⁴ targeted prevalent patients with chronically high serum phosphorous levels who had heard all the *do's* and *don'ts* previously. Modest improvement in serum phosphorous and calcium levels (only the latter reached statistical significance) was documented. We encourage reading widely in the chronic disease treatment literature, which evaluates educational interventions and behavioral change.

Patient Views on Achieving Adequate Dialysis

We include several patient responses to the question, "What are the most useful points patients can tell professionals how they, the professionals, can help patients consistently receive adequate hemodialysis?" We posted the query on the internet-based listserv: dialysis_support@yahoo.com; and received nearly 50 responses from new, medium-, and long-term patients. For confidentiality reasons we asked respondents to send their comments to us directly by e-mail, not via the list serv. The responses quoted are examples of serious patient concerns and understanding, or lack thereof. We included in our request: "We and they (renal professionals) know the following: (1) we need to show up for all the treatments; (2) we need to stay for the prescribed time for every treatment; (3) we need to not gain excessive fluid weight between treatments because removing it is so hard, and often makes us feel so bad, with low blood pressure, cramps, wanting to stop early, and so forth; (4) we need to know how important a good fistula or graft is; and (5) we need to know how critical it is to have consistent, effective placement of needles to get good blood flow for adequate dialysis.

We also asked the question, "From your point of view, what can professionals realistically do for patients to ensure the following. (1) To help us show up, stay the time, and not overeat and over drink? (2) To ensure our blood access functions well, and our needles are properly placed consistently? and (3) To make our lives easier to get adequate dialysis?" Most responses implicitly assumed the appropriateness of the 5 points listed, and therefore reflect personal comments, observations, and suggestions.

In describing the patient's role in adequacy of hemodialysis we include discussion of several adherence and behavioral issues, education needs, and staff responsibilities. We show the importance of positive patient and staff attitudes, discipline, and sensitivity. We consider mutual trust and respect critical to achieving hemodialysis adequacy.

Patients and Dialysis Staff: Some Obvious Assumptions and Explanations

Patients seem to be normally distributed with respect to their tolerance for inconvenience, discomfort, pain, being told to change their eating and drinking habits, and how they must now spend roughly 4 hours 3 times per week. The vast majority will be

about average; with small proportions either quite able, or barely able, to adhere to these very new and novel unconventional requirements demanding extraordinary discipline and behavioral change. One well-disciplined hemodialysis patient of 32 years stated:

“Fluid and diet restrictions are one of the toughest things about ESRD [end-stage renal disease] to come to grips with. Once your kidneys fail you must learn to say ‘no’ to a lot of things you formally just did without thinking. As soon as you are able to do the renal diet as easily as the normal diet (without thought), the better life is. After 32 years what is ‘normal’ for me is the renal rules.”

Nephrologists and dialysis staff members also are likely to be distributed normally if required to adhere to the requirements of hemodialysis. We have, however, often heard staff mention they would prefer transplantation to dialysis, if their kidneys failed, implying dialysis is just too difficult and undesirable a modality compared with a successful renal transplant.

Patients may understand the words used to describe adherence easily, but to the dismay of staff, understanding implies neither patient recollection nor action. Patients frequently are told about controlling diet and fluid, showing up for treatments, and staying the prescribed time. That does not mean they fully understand and will always remember all the *do*'s and *don*'ts. Staff may optimistically, but erroneously, assume patients' understanding the words translates into consistent adherence. Surprisingly, a 15-year veteran of in-center hemodialysis wrote:

“I, too, have often wondered why dialysis is not the perfect time to drink lots of good quality water. Wouldn't this flush our systems even further? Would that be especially useful when trying to get rid of colds or flu virus?”

Another surprise from a long-term in-center hemodialysis patient advised staff to

“Encourage a nutritious meal the first hour of dialysis and smaller snacks/drinks when needed by those who benefit from nourishment on dialysis, as most do.”

Patients must emotionally live through the physical and psychologic challenges that accompany all too common, unfortunate, hemodialysis experiences. When needles the size of 3-penny nails are inserted into an arm, the pain is sharp and lasting. That experience is likely to be repeated for several weeks until puncture sites develop considerable scar tissue. Even then cannulation still can hurt. When a needle misses the vessel, or goes through the fistula and infiltrates the arm, causing days of soreness and fear of using that spot and fear of the caregiver, one easily can empathize with the patient. A recent patient (on peritoneal dialysis for 6 months, now on in-center hemodialysis for 18 months) wrote,

“One thing I insist on is being ‘stuck’ by someone who is good at it. My vein wanders around my arm and has been infiltrated too many times for me to not pick who I trust to do the job right. Maybe those who are gifted at

this duty should do most or all the sticks and others can set up machines. . . etc.”

During a dialysis treatment when a patient gets headaches, severe calf or foot cramps, becomes short of breath, or hypotensive, one can empathize with the patient, especially the adherent ones. Although these scenarios can compromise achieving adequate dialysis, they also cause the patient considerable frustration, discomfort, anxiety, and pain. The attending renal professional may not take the opportunity to empathize because the patient may be nonadherent and must continue dialysis, blood pressure must be stabilized, and the caregiver must move on to the next patient in need of care.

Dialysis staff are unlikely to have been trained thoroughly, particularly concerning empathy while performing their duties. Some patients take this very seriously, as did this long-term patient, who said,

“I believe every member of the treatment team should have a thorough understanding of the operation of the machine and how it affects consumers' bodies. Maybe then, for example, the social worker would understand the consumer may be depressed due to physical, and not emotional, causes. Or the dietitian may realize it's not what the consumer ate or didn't eat that is causing a problem. And the nephrologist may see that the severe cramps the consumers have are due many times to his failure to properly assess and oversee the treatment. Is it any wonder many nephrologists don't stick around for more than 30 seconds to hear out the consumers' problems with treatments and can't look them in the eye?!”

Many staff may silently conclude that it is not their job and they simply cannot be bothered. Their workload is huge, their dialysis experience, expertise, and level of commitment to their profession are variable. This long-term home-hemodialysis patient explained,

“It's the demand that we all be the same. . .when we are all patently NOT the same that I find difficult to tolerate. That is why I continue doing home hemo.”

Patients may know needles must be placed properly to enable appropriate blood flow to achieve adequate dialysis—but they may not understand how to care for and protect their vascular access. Vascular access is the Achilles' heel in dialysis. Although the patient's role is substantial, many of the problems are physiologic, over which the patient has little or no control. The patient's responsibility is to protect the access, keep it clean, and free of infection. It is also the patient's responsibility to observe any changes or anomalies in the vascular access during and between dialysis treatments and report them to the dialysis staff immediately.

Standardized access care information appears either to be lacking or not well diffused throughout the dialysis community. The disturbing reality of frequent access site infection or failure can be extremely frightening to a patient, who may not have been educated about how to care for and protect their vascular access. Even meticulous experienced patients who work, travel, and maintain a very active life report confusion.

A patient with over 20 years of experience with all modalities wrote,

"I have received wildly varied information on how to take care of my access. In terms of postsurgery care, I've experienced everything from 'you don't have to do anything,' to a clear plan of exercise and wound care. I've also experienced great variation in how to take care of my access over the long term, and how to prepare for treatment. I'd like to see standardized care information for postsurgery and daily access care."⁵

Patients, sitting for hours in the dialysis chair, observe and make judgments about nephrologist and staff behavior, expertise, and how they treat other patients and each other. Patients often watch nephrologists making rounds in the center. They are well aware of the distance between themselves and the staff member or doctor often standing next to, and above them. They hear the commonly repeated, "How are you feeling today?" along with the "do's," "don'ts," and "why's?" expressed when patients come in fluid overloaded, or when important monthly laboratory results are far from the normal range. Although patients constantly may be aware of the fluid and dietary restrictions every time food or drink reaches their lips, this does not mean they are consistently able to follow these restrictions, particularly at celebrations or when an extra day is added between treatments over every weekend. Patients often wonder how the known smoker, or obese, or impersonal, or impatient renal professional would fare on dialysis, particularly when repeatedly reminded how they must eat, drink, and change their decades' old habits. This in-center HD patient since early 2002, who works full time, wrote,

"The most important issue for the RN/Techs/Directors: understand the feeling of sitting there. As one nurse once noted, she went through the process without really getting poked, etc., just sitting there for 3 to 4 hours was more than enough for her to understand our frustration."

These examples show the critical importance of staff technical and behavioral training for treating each patient as an individual (not a medical record number) and in a manner staff would prefer to be treated if the roles were reversed.

Adherence and Behavioral Issues

Consistently getting to and from the dialysis center on time always has been a problem depending on patient responsibility and flexible center scheduling for many patients, particularly the very active and those requiring special transportation. Attendance at all treatments for patients whose last treatment left them feeling terribly (whether from access, blood pressure, or even problems beyond the patient's control) can be seriously compromised and is related to both patient dietary and fluid adherence as well as staff competency. Few patients and staff may be aware of recently re-

ported results from the first phase (1996 to 2002) of the Dialysis Outcomes Practice Patterns Study (DOPPS).⁶ Patient data, for example, skipped treatments during the initial month of enrollment, were extracted from patient medical records. All patients were followed from enrollment until the end of phase I. Patient mortality during the several-year study was recorded for those patients who skipped 1 or more treatments during the first month, compared with the mortality of those who did not skip a treatment during the first month. Analyses were adjusted for several demographic and comorbid conditions. There was a 30% increased relative risk for death ($P = .01$) caused by 1 or more missed treatments per month, and 7.9% of US patients were reported to have skipped 1 or more treatments. Skipping 1 or more treatments per month also was shown to be associated with a 13% increased relative risk for hospitalization.

Decreasing the absenteeism seldom can be accomplished by one staff member alone. The entire renal care team, including the patient and an important family member or friend, may be needed to identify the primary cause or causes. If serious efforts are not made to correct clinical or transportation issues, additional treatments likely will be missed. Any patient or family misunderstanding of dietary and fluid restrictions and how to manage them must be addressed effectively. This may require additional sessions with competent dietitians and social workers, using patient and family peer counseling, educational tools, or outside mental health professionals. After a patient misses a treatment, it may be useful to take pre- and post-bloods during their next treatment; showing and explaining the laboratory results to the patient (and family member). This may reinforce patient and family education of the importance of attending all treatments. Sometimes, a thoughtful, informative, and empathetic session with the patient's nephrologist may stimulate needed behavioral change.

Shortening treatment time by 10 or more minutes during the first month of enrollment also has been shown in DOPPS phase I to be associated significantly with an 11% increased relative risk for death (95% confidence interval, .97-1.27) and a 9% increased relative risk for hospitalization (95% confidence interval, .99-1.19). Nearly one fifth (19.6%) of US patients shortened their treatment times.⁶ The reasons for shortened treatment time, whether owing to patient requests or staff or unit scheduling, were not explained. Patient requests or demands for treatment shortening are most common and are likely to reflect the very bothersome ultrafiltration side effects such as low blood pressure, headaches, cramps, and so forth. These may be present due to poor treatment monitoring, especially for small, low-weight, fluid-adherent patients, as well as fluid-nonadherent patients. If treatment time cannot be completed, regardless of the cause, we suggest it be added during the next treatment.

Transportation delays and time-consuming care for patients on the current or previous shift sometimes result in requiring staff overtime and/or units staying open later. Some patients will welcome shortening treatments due to staff/unit scheduling issues for which they are not personally respon-

sible, because the last half hour of every treatment for most patients is uncomfortable and seems interminable.

Given the known increased mortality and hospitalization risks, it is unconscionable for an individual's treatment to be shortened due to staff or unit issues, but no fault of the patient. Flexibility in staff and unit rescheduling are required to ensure patients receive their prescribed dialysis treatment time. This also will reinforce the importance of the patient's responsibility to stay for the prescribed time. Some units will arrange for the patient to either return the following day for additional time, or add the lost time to the next treatment.

Maintaining adequate nutrition and fluid intake without exceeding the renal diet is no small challenge. Initially, the renal diet drastically changes the normal social pleasures of eating and drinking. Effectively describing to the patient and their family how to balance restrictions of protein, sodium, calcium, phosphorous, potassium, and liquid without substantial muscle mass loss can be performed by excellent renal dietitians and adherent, experienced patients. Some useful teaching modules have been developed, for example, "Nutrition and fluids for people on dialysis" (Module #9 of the Kidney School, available at: www.kidneyschool.org). Several websites offer useful information for patients about adequacy of dialysis, many of which include links to other sites: www.kidney.org of the National Kidney Foundation (NKF), www.aakp.org of the American Association of Kidney Patients (AAKP), <http://kidney.niddk.nih.gov/kudiseases/pubs/eatright/index.htm>, Eat Right to Feel Right on Hemodialysis from the National Kidney and Urologic Diseases Information Clearing House (NKUDIC).

Renal dietitians often make the mistake of giving patients a list of foods they absolutely must not eat. This is misinformation. Even some very high potassium content foods such as avocados, bananas, and organ meat may be eaten infrequently and in small quantities if dietary trade-offs are made. Further, given time for digestion and metabolic absorption, these foods occasionally could be eaten 5 to 7 hours before the midweek dialysis session, enabling the excess potassium, calcium, and so forth, to enter the bloodstream during the dialysis treatment and be dialyzed out. In addition, food choices on a dietician's limited list may be eaten in moderation, with appropriate trade-offs before the midweek dialysis treatment. One patient expressed her approach as follows,

"Ahhh. . . how to get my Irish up. . . talk about renal rules. There are no renal rules, there are suggested parameters, within which you can flow. I met my 'new' dietician yesterday. I told her I am not on a renal diet. . . I am on the 'Debbie get a good laboratory result diet.' She was surprisingly supportive of that philosophy. I eat potatoes, tomatoes, drink orange juice (minimally, I admit) all while maintaining my potassium around 3.5 to 5.0, using a 2-K to 1-K bath depending on my diet."

Dry Weight

Estimating, achieving, and periodically confirming or re-estimating dry weight unfortunately remains an inexact science, and requires a knowledgeable staff member and a

very aware and sensitive patient. Over time, the knowledgeable staff member well familiar with the patient may know best how to establish a dry weight that will be comfortable for the patient and effective in achieving adequate dialysis. The patient or family member, knowledgeable about how the patient's body reacts to fluid gain and loss, the hint of cramps, headache, or low blood pressure, can be very helpful in guiding staff to agree on an appropriate *take-off* weight. Some patients may want to end their treatments a little on the light side. Others may prefer to be a pound or 2 greater than the calculated dry weight.

Interestingly, DOPPS phase I results show increases in interdialytic weight gain (IDWG) greater than 7.5% of dry weight tend to be associated with a 22% increased relative risk for mortality ($P = .002$).⁸ Nonadherence among US patients was 16.8%.⁶ This substantial increased risk normally may not be understood by patients and staff, but reinforces staff encouragement of sodium restriction as one way to decrease thirst and fluid intake. This increased risk is independent of dialysis dose, for which a single-pool Kt/V less than 1.2 is associated with a 16% increased relative risk in mortality ($P = .025$).⁷

It is very interesting to note the DOPPS findings of independent, higher relative risks for mortality from excessive IDWG (22%),⁷ and from skipping treatments (30%),⁶ when compared with that associated with inadequate dialysis dose (16%).⁷ Might the primary importance of traditionally emphasizing dialysis adequacy to patients be modified by bringing equal, if not greater, emphasis to IDWG and attendance adherence? Further studies are needed to replicate these findings. Analyses of phase II of the DOPPS, which ends in 2004, are underway, and a phase III is planned.

Given the intermittent nature of hemodialysis 3 times per week, we are particularly concerned about the reported increased risk for sudden death (20.8% versus 14.3%, $P = .002$) and cardiac death (20.2% versus 14.3%, $P = .0005$) on Mondays, when compared with the number of expected deaths.⁸ Potential causes mentioned, although not included in the analysis, include large IDWG, increases in serum potassium levels, and rapid ultrafiltration of large fluid volumes causing hypotension. Patients with underlying coronary artery disease and cardiac hypertrophy (common in dialysis patients) experiencing this postdialysis hypertension are particularly at risk.^{9,10}

For all patients, particularly those at high cardiovascular risk, predisposed to hypotension, or those chronically unable to control reasonable IDWG maintaining a reasonable dry weight, may require a 5- to 7-day cycle, rather than from one dialysis treatment to the next. Renal care staff often target ultrafiltration for each treatment to attain the patient's dry weight. Ending any treatment feeling extremely washed out, weak, cramps threatening, or thirsty from deliberately high sodium dialysate levels is not a recipe for fluid adherence between treatments. For such patients, we encourage staff to target reaching the desired dry weight to 2, possibly 3 treatments during the week, thereby avoiding or decreasing the vicious cycle of patient morbidity and staff frustration.

The patient's role is never-ending—the reality of receiving

chronic hemodialysis. Responsible staff recognition of patient preferences supports the patient in performing his role. Well-functioning renal care team interaction, which includes this support and understanding of patient preferences, may improve achieving adequate dialysis, laboratory values, satisfactory patient adherence, and general patient satisfaction. This combination of respect for the individual patient and teamwork requires patience and sensitivity. Occasionally, patients may need to be reminded of their adherence and clinical experiences with dialysis (good and bad) to fulfill their dialysis adequacy roles.

Might Role Models Help?

We recognize some patients never show any interest in treatment adequacy, their responsibilities, and the increased risks for hospitalization and death that accompany their behavior. Dedicated renal care professionals will try everything in an attempt to help the patient emotionally understand and accept the opportunity to improve the quality of their day-to-day lives by improving their adherence to the dialysis regimen. We encourage more use of peer counseling and patient role models. Identifying and training a knowledgeable, stable patient, preferably from a similar socioeconomic background, to assist other patients in need can make a difference.

Accepting the Minority of Patients Who do not Want or Care About Adequacy

We also recognize that there are patients who simply are unwilling and find it too difficult to make the sacrifices and behavioral changes required to achieve adequate dialysis. They may be convinced their role is merely one of showing up. Patient/renal team contracts have been signed and tried with the hope of improving patient adherence and clinical outcomes. Some succeed, others fail. If failure persists, it may be appropriate to consider recognizing the message the patient may have been sending: "Thank you for your commendable efforts, but I really would prefer to live as I am now, regardless of the consequences which you have explained to me." To them, their perceived quality of life may be more important than their longevity.

The sensitive renal care team, having exhausted all methods for persuading a patient to participate further, may schedule a special session with the patient and family to verify that this is what the patient wants, and jointly sign a simple statement of understanding. We are not suggesting withdrawal or termination of treatment, but mutual recognition that additional well-intentioned efforts may be neither effective nor desirable. We are not aware of published reports of this approach. It could result in considerable relief on both sides; as well as possible reconsideration by the patient. It also may result in eventual death, comparable with potentially and temporarily preventable deaths from chronic smoking, consuming heart-unhealthy diets, and so forth.

We realize this suggestion may meet opposition from those

concerned about improving center performance, reportable outcome data, and so forth. And some nephrologists may choose to no longer be responsible for the care for such patients. We hope a minority of cases such as these will bring staff, patient, and renal community recognition that, above all, dialysis really is for and about patients. Everyone is likely to have some self-destructive behaviors. The hemodialysis patient's role, by definition, increases the number and risk for such behaviors.

Finally, we provide some additional patient suggestions for staff to support the patient's role in hemodialysis adequacy (from patients with 3-32 years of ESRD experience dominated by in-center hemodialysis).

Regarding professionalism and education, one patient stated,

"The professionals should lead by example, which means being as EDUCATED and PROFESSIONAL as they can be. . . Consumers are irritated by and do not respect professionals who fake it because they can't answer questions, take short cuts with care, conceal necessary medical information, speak or act unprofessionally."

Another patient stated,

"Education is a key component, not just for professionals but patients as well. Professionals need not fear the educated patient either, but consider them a plus as part of their health care team. I have seen well-educated patients regarded as 'trouble' because they demand good care and know what good care is. These patients should be listened to with respect and taken seriously."

Regarding staff attitude and approach to patients, one patient stated,

"One thing that bothers me is the attitude I have found in several clinics. Staff needs to be aware that we patients are adults. We deserve respect and to be treated as adults and talked to as adults and not children. I think staff should require patients to learn the machine, what the alarms and the measures mean (blood flow rate [BFR], dialysate flow rate [DFR], venous pressure, conductivity, etc.), and give patients a sense that this is a part of their responsibility. We get information on what we can't eat, a limit to what we can drink, what time to show up, laboratory work. . .but, giving patients more insight and education; if this is an expectation of them, might help them take responsibility more seriously."

Another patient stated,

"Change takes a whole lot of time to occur—why should learning the renal rules. . .be an expectation anyone could pretend would take place any faster?. . .A kind word will help create change to come about a whole lot sooner than a scolding will ever hope to accomplish."

Patients feel that they should be respected as individuals.

"Each patient is different, and our individuality should be taken into consideration and the differences re-

spected. For instance, I know a lot about my diet and treatments, and am very compliant. Also, I'm very aware of how my body reacts. . . Often staff will turn a deaf ear believing that a patient can't possibly know so much. . . They try to squeeze everyone into a 'dialysis patient mold' because it's easier for them to see us all as cookie cutter patients. We're not! Sometimes I tease staff telling them it's my kidneys that aren't functioning at 100% but my mind is just fine. . . all too often decisions are made, medicine doses changed, tests ordered, etc., without discussing it with me. I was told 'relax, we know what we're doing.' No doubt, but as a patient, I deserve to know what is being done to my body."

Other patients stated,

"We are individuals and should not be treated all with the same protocols. We fall at both extremes. . . as partners in our health care should receive a full explanation of procedures being implemented, REASONS for being implemented, and offered alternative/elective options while adhering to standards." "I have trouble with an emphasis on compliance—the only reason that I survived for 12 years, 9 months on dialysis was by being reasonably noncompliant. Any diet-fluid restrictions need to be individually based. Working adults cannot be required to limit food and fluid intakes to the same extent as nursing home-bound elderly." Another patient stated, "Aside from feeling well, the most important thing patients want is respect and consideration. We aren't machines, we're just hooked up to one."

Regarding their appreciation for staff, one patient stated,

"When I was a respiratory therapist it was very frustrating for me at times to do a treatment and 2 minutes later the patient is out smoking on the patio; then calling for an early treatment because they are 'short of breath.' So it must get frustrating at times, for the kidney staff to have to remind their patients about the renal rules and have the person on dialysis come back next treatment overweight, feeling bad, and complaining." Another patient stated, "My nurse does all my sticks, is upbeat, positive, happy, sings on the job, jokes with the patients, and is a pleasure to be around. While it would be wonderful if all dialysis nurses had this attitude, it's simply not teachable. It's a personality gift and more should be hired who have it."

Regarding the importance of family and humor, one patient stated,

"Families and significant others need to be involved in the process—of course only with the consent of the patient. They need to know and understand dialysis, fluid and food intake, and the psychosocial aspects of dialysis. My final and perhaps most important comment is that it is important for humor to pervade the units. There has to be a relationship of trust between the staff and the patients, and a comradery [sic] between the patients."

Suggested Research

The major reasons for missing adequacy targets appear to be related to the wide variety of behavioral change required of patients. Expectations to consistently modify food, fluid, social, work, and recreational habits enjoyed for multiple decades regularly are frustrated. Additional research to improve understanding of how to bring about more consistent behavioral change is needed, perhaps by differentiating hemodialysis patients into normative subgroups representative of individual patient characteristics. The effectiveness of additional educational interventions designed to associate behavioral change, patient satisfaction, and quality of life with laboratory/hemodialysis adequacy outcomes are suggested.

Additional studies are likely to reflect strong associations between increased relative risk for mortality and failure to achieve Kidney Disease Outcomes Quality Initiative (KDOQI) Clinical Practice Guidelines, for example, serum albumin level, phosphorus and calcium levels, IDWG, occasionally skipping or shortening dialysis treatments, cardiovascular disease, and so forth. If so, might the primary importance of traditionally emphasizing dialysis adequacy to patients be modified by expanding the role of the dialysis patient and responsibilities of the renal care team? Patients normally are educated to know their numbers and emphasize performing the necessary tasks to ensure dialysis adequacy. The time appears ripe for developing comparative analyses to weigh the relative importance of several appropriate measures influenced by patient behavior and associated with improved quality of life, patient satisfaction, and longevity.

Summary and Conclusions

The patient's role in dialysis adequacy is multifaceted. As an active member of the renal care team, the patient must communicate clearly and continuously with the staff, explaining their changing physical, mental, and psychosocial symptoms and feelings. The patient must ask questions and push to seek informed, understandable, and reasonable answers. The patient must be open to understanding the dietary, fluid, and medication requirements and meticulously observe them; in addition to putting aside a good portion of 3 days per week to attend treatments. The patient and staff must gain each other's trust and respect. This requires staff assistance through education, patience, sensitivity, flexibility, and empathy.

Many patients yearn for meaningful staff time, attention, and comprehensive education. To emotionally accept and act out their role in dialysis adequacy, they require explanations about why adherence requirements are so important, and how flexibility can be weaved into these requirements to recognize each patient's individual characteristics, needs, and cultural background. Persuasion and use of the patient as a critical member of the renal care team largely remains an unmet but essential challenge. A patient who feels valued and respected by the staff, even in the presence of poor laboratory results, may be stimulated to carry on their demanding role. Too often, patients report, staff consider all patients more or less the same and therefore can be treated the same. If patients are to succeed in fulfilling their demanding role, recognition of them as individuals with differ-

ent levels of understanding, self-discipline, family support, and variable behaviors is necessary.

Some informed patients, through experience with the side effects and demands of dialysis at the unit, may lack interest in their role in dialysis adequacy. Eventually they may conclude their perceived quality of a potentially shorter life to be more valuable to them than what they have experienced by adherence to dietary and fluid guidelines and attending and staying for the length of prescribed hemodialysis treatments. The renal care team, including the nephrologist, must respect such patient choices, take the choices seriously, and act accordingly. Ignoring this likely will cause continued and unwanted frustration, anger, and disappointment on both sides.

It is not surprising that patients have difficulty accepting the many responsibilities for drastic behavioral change required to achieve dialysis adequacy. Improved methods to more easily achieve successful behavior modification are needed. However, it is refreshing and encouraging to be reminded of those patients and staff who remain intensely dedicated to improving and extending patients' lives through increased attention to making adequacy of dialysis easier for both patients and renal care professionals.

References

1. Kimmel P, Emont SL, Newmann JM, et al: ESRD patient quality of life: Symptoms, spiritual beliefs, psychosocial factors, and ethnicity. *Am J Kidney Dis* 42:713-721, 2003
2. Kimmel PL, Peterson RA, Weihs KL, et al: Behavioral compliance with dialysis prescription in hemodialysis patients. *J Am Soc Nephrol* 5:1826-1834, 1995
3. Lopes AA, Bragg-Gresham JL, Satayathum S, et al: Health-related quality of life and associated outcomes among hemodialysis patients of different ethnicities in the United States: The Dialysis Outcomes and Practice Patterns Study. *Am J Kidney Dis* 41:605-615, 2003
4. Schlatter S, Ferrans C: Teaching program effects on high phosphorus levels in patients receiving hemodialysis. *Am Neph Nurs Assoc J* 25: 31-36, 1998
5. Newmann JM: The vascular access: A long-term patient's considerations and reflections, in Ronco C, Levin NW (ed): *Hemodialysis Vascular Access and Peritoneal Dialysis Access*, Karger, 2003, pp 363-375 (Contrib Nephrol:142).
6. Saran R, Bragg-Gresham JL, Rayner HC, et al: Nonadherence in hemodialysis: Associations with mortality, hospitalization, and practice patterns in the DOPPS. *Kidney Int* 64:254-262, 2003
7. Port FK, Pisoni RL, Bragg-Gresham JL, et al: DOPPS estimates of patient life years attributable to modifiable hemodialysis practices in the United States. *Blood Purif* 22:175-180, 2004
8. Bleyer JB, Russell B, Satko SG: Sudden and cardiac death rates in hemodialysis patients. Analysis of United States Renal Data System (USRDS) patients enrolled in the Case Mix Adequacy Study, covering years 1977-1977. *Kidney Int* 55:1553-1559, 1999
9. Parfrey PS, Foley RN, Harnett JD, et al: Outcome and risk factors of ischemic heart disease in chronic uremia. *Kidney Int* 49:1428-1434, 1996
10. Huting J, Kramer W, Schutterle G, et al: Analysis of left-ventricular changes associated with chronic hemodialysis. *Nephron* 49:284-290, 1988