

Dialysis options education: Is 'modality neutrality' fair to patients?

By Dori Schatell, MS and Paula Stec Alt, MBA

No single factor in the treatment of end-stage renal disease is more central to how patients will live from day to day than their choice of treatment. This impacts their diet, medications, symptoms, the frequency of hospital visits, and how long they will live. Most patients never learned about any treatment options other than standard in-center hemodialysis. To have life options, patients must have treatment options, but in the most recent U.S. Renal Data System Annual Data Report, 91.6% of U.S. dialysis patients were using standard in-center HD.¹

The new Conditions for Coverage for End-Stage Renal Disease Facilities, which became effective Oct. 14, include at least one historic advance for people with Stage 5 chronic kidney disease. The new Patients Rights Condition specifies that patients must be informed of all possible dialysis modalities and where those modalities are offered.²

For the first time ever, dialysis providers are required by law to tell every patient about all of the ways this lifesaving treatment can be offered (whether or not they offer all of the alternative therapies). A list we have assembled includes:

- ▶ Continuous ambulatory peritoneal dialysis (CAPD)
- ▶ Continuous cycling peritoneal dialysis (CCPD)
- ▶ Conventional in-center HD (three times per week for three to four hours per treatment)
- ▶ Nocturnal in-center HD (three to four times per week for six to eight hours per treatment)
- ▶ Nocturnal HHD (three to six times per week for eight to 10 hours per treatment)
- ▶ Short daily HHD (five to seven times per week for two to three hours per treatment)
- ▶ Transplant
- ▶ No treatment

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Good news for patients

For several reasons, the new Conditions are good news for people who need renal replacement therapy. First, studies have shown that most patients have not received education about the full range of treatment options. The only national, random study of modality awareness, conducted among 4,025 new patients as part of the Dialysis Morbidity and Mortality (DMMS) Wave 2 study and published in the 1997 USRDS Annual Data Report, found that only 24.6% of in-center HD patients were aware of HHD; just 25.3% knew about CAPD; and only 20% knew about CCPD.³

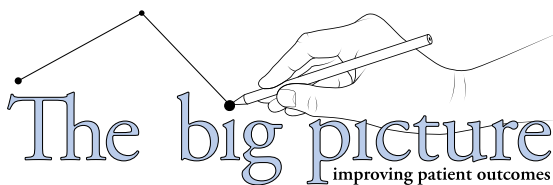
More recently, a survey of 1,365 patients who started dialysis in April and May of 2002 in ESRD Network 18 revealed that 66% were not told about peritoneal dialysis, 88% were not told about HHD, and 74% did

not even receive information about transplant.⁴ The new Conditions should help to ensure that all patients learn about their options.

Second, obtaining information about treatment options has a potential to improve patients' lives.

Increased autonomy—Several studies have concluded that patients who are educated about all of their options are significantly more likely to choose a home dialysis treatment.⁴⁻⁷ This suggests that the prevailing lack of education has been, up until now, systematically depriving patients of their autonomy. Information empowers patients to actively choose a dialysis treatment. One study found that patients who chose their own treatment option were significantly more likely to have received a transplant and had significantly lower unadjusted death rates five years later than patients who reported that their modality was selected for them by their doctors—or even those who chose an option in partnership with their care teams.⁸ This finding is entirely consistent with Self-Determination Theory, which holds that autonomy is a core psychological need that must be met for human beings to develop in a positive way.⁹

Increased employment—In-center HD is intrinsically work-unfriendly due to scheduling issues and a higher burden of symptoms and hospitalizations than other treatment options. Access to work-friendly treatments with less rigid



schedules, such as transplant, PD, or some form of HHD, may help the 50% of incident patients each year who are of working age keep their jobs. A patient who continues to work may also be able to keep employer group health plan (EGHP) coverage, improving the payer mix for their centers while they help maintain their own family's standard of living.

Delivering the message

Clearly, giving patients the information they need to make choices is the right thing to do. The controversy arises from just how to do it.

The "ESRD Interpretive Guidance Update," issued by CMS in October 2008, provides some direction. It requires documentation that "facility staff provides unbiased education to patients/designees about transplantation and all dialysis treatment options (modalities and settings) offered for kidney failure."¹⁰

The key word is "unbiased." What does it mean? Some of the directive's readers have interpreted it to mean "neutral presentation of multiple modalities."¹¹ If they are suggesting that modalities be presented as equivalent options, we disagree. Why? Because the data show that some choices are better than others in terms of outcomes and survival. Thus, to be truly fair, modality education information needs to give patients the relevant facts—the upside and the downside of each choice, both in-center and at home—particularly as they relate to day-to-day lifestyle on each therapy and long-term outcomes.

Current knowledge

Presenting all dialysis options as equal without clarifying the impact of each choice on lifestyle, morbidity, and mortality does not accurately convey current knowledge about dialysis. A presentation that would equate all modality options may have been acceptable in the past, but the availability of new data and new treatment options have changed that equation. Given patients' widespread lack of awareness of home modalities—and their lesser availability versus in-center care, our concern is that the downsides of these therapies may be emphasized by presenters who are not fully familiar with them, while the upsides are minimized.

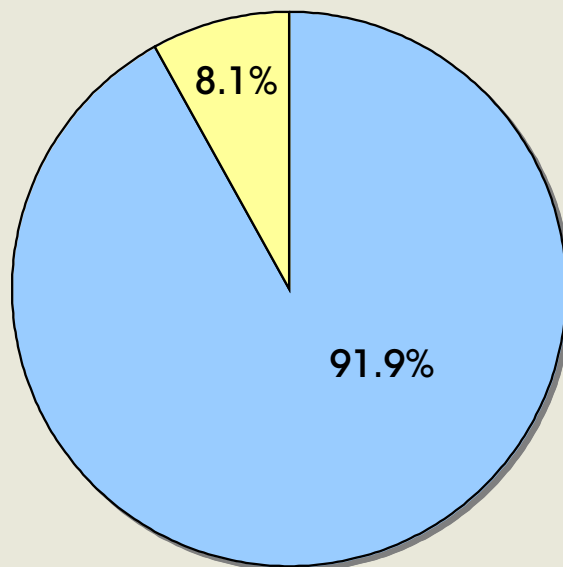
PD offers numerous benefits as a first treatment, for example. It maintains residual kidney function longer.¹² It can be learned in just a week, and can be done on the patient's schedule, which makes it easier for working-age patients to keep their jobs. A PD catheter can be placed and used almost immediately,¹³ avoiding the use of central venous catheters for late-referred patients, and buying time for placement of an arteriovenous fistula. As a self-care modality, PD patients retain their autonomy from the start, avoiding the dependence and depression that so often char-

acterize in-center HD patients. And, for the first two years, PD offers a survival advantage over standard in-center HD for those without diabetes.¹⁴ On the flip side, most patient educators are well aware that PD can create body image issues, each exchange must be done using aseptic technique to avoid peritonitis, the PD prescription must be adjusted upward as residual renal function declines, and the peritoneal membrane can eventually burn out.

Data from studies of short daily and nocturnal HD clearly show that these modalities confer lifestyle as well as survival advantages. Kumar and colleagues at Kaiser Permanente in Los Angeles demonstrated that daily (five to seven) short-duration HD treatments per week improved nutritional status and decreased hospital admissions.¹⁵ Blagg et al. studied 117 U.S. patients treated with short daily dialysis in 2003 and 2004, and found 61% bet-

Point prevalent ESRD patients on dialysis at the end of 2006, by treatment modality

Ingredients: Total patients* 354,754
One slice: In-center hemodialysis 325,299 (91.9%)**
Second slice: Home dialysis* 28,569 (8.1%)**



* includes 866 unknown dialysis (.02%)
 ** Among the in-center hemodialysis patient population, 111 were self care (0.3%).
 *** Includes CAPD, CCPD, other PD. Among the home patients, 2,455 (.7%) were on home hemodialysis.

From Table D.11, USRDS 2008 Annual Data Report

ter survival than among conventional HD patients in the United States.¹⁶ Just this year, Kjellstrand et al. found that survival of patients on short daily HD was two to three times better than that of matched U.S. (conventional) HD patients—and, in fact, rivaled that

outcomes, daily lifestyle, and survival itself. Patients need to understand that certain modality choices will substantially improve their ability to work, eat and drink normally, take fewer medications, stay out of the hospital, and perhaps live longer as well. And, patients

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of age-matched transplant patients.¹⁷ A study by Pauly et al. presented at the 2008 Transplant Congress found survival on nocturnal HD was also equal to deceased donor transplant.¹⁸

Skeptics have suggested that the dramatic results of these studies can be attributed, in part, to patient selection. In many cases, study methodologies were designed to correct for that possibility. But, even if patient selection was a factor, the same argument applies to transplant survival rates. Yet, transplant has the greatest potential for long life with ESRD. Incidentally, survival rates for patients with transplants are better—in the aggregate—than average survival rates for patients using standard in-center HD. However, transplant also comes with risks. Individual patients who are doing well on dialysis may actually experience more difficulties with a transplant, and a recent study suggests that pre-transplant patients substantially overestimated the positive impact a transplant ultimately had on their quality of life.¹⁹ A factual presentation of the options includes presenting the downside and upside of transplantation.

The case against modality neutrality

Can we present all the dialysis modalities as equivalent in the face of this data? We think not. Unbiased presentation of the facts about dialysis options demands that we honestly and truthfully convey what we know about the impact of treatment choice on

also need to understand the tradeoff that home therapies require: an investment in time (both upfront and ongoing), an appropriately prepared place to dialyze, and an active involvement in self-care. Patients need those facts to make truly informed decisions about their life options. **N**

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[REHABILITATION UPDATE, continued on page 30]

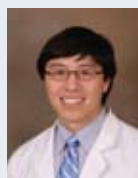
Patient-centered dialysis care: The argument against modality neutrality

By Lesley Wong, MD

The onset of end-stage renal disease is a profound event for patients, imposing a set of physical, emotional, and social changes that impact their lives. The great majority of these patients are treated with in-center dialysis despite agreement that home dialysis modalities (peritoneal dialysis and home hemodialysis) are underutilized.¹⁻² Lack of adequate predialysis education and in many instances, failure to offer patients a choice of modality, are factors limiting home dialysis prevalence.¹⁻⁴ Likewise, the pervasive thrice-weekly culture and existing dialysis infrastructure is biased towards in-center care. Home dialysis, with its requisite investment in training, smaller infrastructure, and added demand for patient responsibility, is often less easy to initiate for patients and nephrologists.⁵

Patients often feel overwhelmed when faced with impending dialysis. Fear of the unknown and unfamiliarity with self-care reduces willingness to pursue home therapy.² These apprehensions are frequently more important than physical limitations when analyzing the reasons why patients do not choose home dialysis.² Predialysis education can help assuage concerns and misconceptions about home therapy. By providing objective information, promoting self-care, and helping patients make an informed modality decision, predialysis education programs have been shown to dramatically increase patient choice of home dialysis.^{1,6}

Home dialysis is centered on patient independence and lifestyle.⁴ The two



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types of home therapy, PD and HHD, are different but complementary treatments.¹ PD patients who are more likely to have chosen their modality, are employed at higher rates, possess more autonomy, and have greater social support and likelihood of being married than patients undergoing in-center HD.^{4,7} Recent data also suggests that PD outcomes are improving, with reduced early mortality and lower rates of treatment failure.⁸ HHD patients possess similar advantages: improved well-being, greater flexibility of schedule, and better satisfaction with care compared to patients in-center.⁵ HHD may also improve patient survival compared to other forms of dialysis.⁵

Unfortunately, increased understanding of the importance of predialysis education, and data demonstrating equal, if not superior clinical outcomes for home dialysis, have not yet translated into a substantial change in practice patterns. In fact, the incident PD patient population has actually decreased from 11% to 7% for reasons not attributable to age, comorbidities, or body size.⁸ While HHD prevalence has grown 40% since 2002, approximately 99% of HD patients still receive treatment in-center.⁹

How then should we approach the issue of modality neutrality with patients? Should in-center and home dialysis be presented as equivalent therapies? There are several reasons we should not. In-center dialysis does not emphasize nor promote patient choice, foster autonomy nor encourage self-determination. Home dialysis provides patients with a better opportunity to achieve a lifestyle that fits with their individual goals and needs. Home dialysis outcomes are favorable and quality of life can be improved.^{2,8} The disparity in prevalence between in-center and home dialysis reflects in part

our failure to adequately promote and advocate the option of home therapy for our patients. While many patients will still choose in-center dialysis, many more patients would select and benefit from home dialysis if given better education and perhaps just some well-needed encouragement.^{1-4,6} **N**

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