In CONTROL
A Medical Education Institute/Life Options Publication

VOL. 4 | NO. 4
DECEMBER 2007

Coming in 2008!

In Control is getting an extreme makeover! After 4 years and 16 issues, we're going to streamline our format to better meet the needs of busy dialysis professionals. Instead of an 8-page, 2-in-1 newsletter, we're going to publish a regular column—with news about bringing the concepts of research and theory into the real world of clinical practice.

All about rehab. We will continue to focus on renal rehab—and how to make patients' lives better by helping them learn how to manage and live with chronic kidney disease.

Connecting the Dots. We'll help you make sense of the findings of academic inquiries and research papers by looking at the big picture and "connecting the dots" to help you draw practical conclusions that you can apply in day-to-day clinical caregiving.

Look for *Connecting the Dots* in March 2008.

Until then, we encourage you to make copies of *In Control* and use it to supplement your own education materials. You can find all past issues at **www.lifeoptions.org**.

In Control is supported by Amgen Inc.

AMGEN

and published in cooperation with

Integrated Care: Planning for Change

Patients and healthcare professionals may focus considerable time and energy on choosing a dialysis modality, and rightly so. The choice of a treatment affects every aspect of a patient's lifestyle. While the decision should not be made lightly, neither should it be viewed as a permanent, either/or choice between competing options with changes regarded as "failures." Instead, experts recommend a long-term "integrated care" approach—in which patients may be anticipated to transfer from one option to another over time, to meet their individual needs.

Complementary Treatments

"It should first be acknowledged that there is no single perfect form of renal replacement therapy, and that each of the existing options has its own inherent strengths and limitations," notes nephrologist David Mendelssohn.[1] He and colleague Gihad Nesrallah, MD, have published recommendations proposing the use of peritoneal dialysis (PD), in-center hemodialysis (HD), and various home HD regimens in a complementary, serial manner that has been called integrated care.

Dialysis teams who practice integrated care make use of the "whole renal replacement therapy arsenal,"[2] and help patients select the treatment(s) that will work best at different phases of their lives.

Compelling Rationale

Proponents believe that applying integrated care concepts helps nephrologists accommodate patient preferences, meet their medical needs, *and* reduce the cost of providing quality care to a growing number of people with chronic kidney disease. Here's why:

Patient preferences: Surveys of nephrologists in Canada, the United States, and the U.K. find that doctors believe patient preference should be the primary determinant of dialysis choice.[3-5] Studies of patient preferences have shown that—educated about all of the choices—about 50% of patients will choose a home treatment.[6] Since most patients will not have an absolute indication or contraindication to a particular modality,[1] practicing integrated care should lead to a significant increase in the use of cost-effective home modalities, including PD.

Medical benefits: There is ample evidence in the literature to support the claim that survival on PD and in-center HD are at least comparable, and PD even appears to have an advantage in the first 2 years.[2] In fact, there are many benefits to using PD first, including preservation of residual kidney function, a more liberal diet, less risk of

(continued on page S4)

Focus on Patient Choice: DCI-Oakland, PA

In her work with dialysis patients, Beth Piraino, MD focuses on patient choice, rather than integrated care concepts per se. "I am not driven by registry studies that promote one treatment over another," explained Piraino. "I am more a believer in patient choice."

Helping patients get what they need to make truly informed choices takes a concentrated effort, however. Here are some insights from Piraino about what it takes to make patient choice a reality in clinical practice.

Education

Everyone talks about patient education, but it is hard to give patients a proper education about dialysis and their choices. As a result, Piraino has found that many patients are not well informed. "They can't really make a choice because they don't get enough information," she noted. "I have seen patients come for their first hemodialysis treatment who don't know that there are needles involved."

"People will not choose a home modality unless they feel comfortable with it," Piraino advised. In her opinion that requires "hands-on" education that includes showing patients exactly what is involved. "Good education takes a lot of time," said Piraino. "We realized a long time ago that we needed to provide funding to support good CKD education, so we have a dedicated nurse educator."

So-called "unbiased" patient education is not the same as good education, according to Piraino. "I used to think that expressing an opinion was putting too much pressure on my patients," she said, "but now I think that if you're not *selling* a treatment option, you're not giving your patients the freedom to make that choice."

Back-up Planning

Whenever she talks to her patients, Piraino emphasizes the need to have a back-up treatment plan for kidney replacement therapy. "We talk about the fact that no treatment choice will last forever, and that we always have to be thinking about the next choice(s)," she said. She credits Martin Schreiber, MD, Cleveland Clinic, with describing this view best, calling it a "life plan for the person with end-stage renal disease."

"Some of my young patients are likely to use every treatment modality during their lifetime," she noted. Even with a transplant, there is no cure and no final treatment choice. "It's my job to help patients understand that there are no guarantees and to guide them in developing their life plan," said Piraino.

Patient Decision-making

Piraino describes herself as being "passionate" about patient choice. Why? "Because it is such a terrible, life-changing position to find yourself in," she explained. "With all that is at stake, it is just not appropriate for me to make these (treatment) decisions," she claimed. Nevertheless, Piraino admits that some patients want the nephrologist to tell them what to do. Or, refuse to consider a change when one is needed. "You cannot allow patients to let you practice bad medicine," she explained, "you must work on offering choices that meet their medical needs."

Piraino and staff work hard to make patient choice a reality. And, they practice what they preach. "In our clinic," she said, "we do not tell patients which treatment option is best, we work with them to make a decision about which treatment choice is 'right for you.'"

Dr. Beth Piraino is former medical director of the DCI-Oakland home program, and still sees patients there. She is currently Professor of Medicine and Associate Dean of Admissions at the Univ. of Pittsburgh School of Medicine.

Dr. Piraino on Dialysis Modalities

Transplant—Most of my patients get transplanted. (Note: Univ. of Pittsburgh is a transplant center.) I make it a point of asking about transplant first, especially if they have a donor. If not, many patients will accept even suboptimal cadaver donors. I make sure they understand that transplant is not a cure; it may not work, it may not last. They need to have a back-up plan.

PD—I find this is a great bridge to transplant. It interferes the least with your life. It usually works well for a few years. The access is less of a problem and much safer than most vascular access. Elderly patients often like the comfort and convenience of dialyzing at home with CAPD.

PD failure—Home HD is great for people who are not making it on PD. The biggest problem is coaxing them to agree to a fistula or graft. Sometimes it takes quite a while. People talk about "body image" and PD, but I find that more patients dislike the look of a vascular access.

Home hemo—Patients rarely start out on home HD. It's just too scary for most people as a first therapy. They need time to adjust to dialysis, and then they may be willing to try it.

In-center hemo—Some people do make this choice. It is our job to give an honest picture of what it will be like. Yes, you'll have someone there to do your treatment, but you may not have a nurse and he or she will be taking care of other patients, too.

Q & A:
Ask the Expert

An interview with David Mendelssohn, MD, FRCCPC

Dr. Mendelssohn is chief and physician director of the Department of Nephrology at Humber River Regional Hospital in Toronto, Ontario, and an Associate Professor of Medicine at the University of Toronto. He is currently one of two Canadian principal investigators for the multinational Dialysis Outcomes and Practice Pattern Study (DOPPS).

Q: How has the concept of integrated care evolved over the years?

A: Prior to 2002, integrated care was primarily a PD-first approach to dialysis that was promoted mainly by European practitioners. In 2002, Dr. Pierratos and I published an editorial in *Peritoneal Dialysis International* advocating a broader approach—with more emphasis on aggressive predialysis care and patient choice, as well as the promotion of all types of home dialysis (PD and home HD) and preemptive transplant as first choice treatments. In other words, we shifted the focus away from PD first to transplant and home (including PD) first.

I should note that Canada's strong preference for home dialysis treatments is not new. As far back as 1997, the Canadian Society of Nephrology (CSN) adopted a policy stating that renal practitioners should encourage—but not require—the use of home and self-care therapies for suitable patients. I find it hard to understand why no USA-based organizations have advocated a similar policy.

Q: Would the adoption of integrated care concepts change how dialysis is provided?

A: Absolutely. Because, I believe, it would significantly change the utilization rates of the different types of dialysis. The result would be a more optimal distribution of treatments, with about 40% of patients choosing PD or home HD, and 60% choosing HD.

I refer to such a distribution as optimal because it is likely to yield the best patient outcomes at the lowest cost. Note that this distribution (surprisingly similar!) was recommended by nephrologists from Canada, the US and the UK in response to a survey questionnaire. (Nesrallah G and Mendelssohn D, *Hemodialysis International*, 2006).

Q: Integrated care calls for early referral and aggressive management of CKD. How do you manage patient volume?

A: In Canada the government provides funding for both predialysis and dialysis care for anyone with chronic kidney disease (CKD) and an eGFR <30. Still, there is concern that referrals of all elderly patients with an eGFR between 45-60 (especially those with non-progressive CKD and who don't need predialysis care) would overwhelm the system. So, the CSN is working on a set of patient management guidelines that primary care providers can follow to provide appropriate care as needed, and refer only the patients who need predialysis education and treatment.

Q: In your opinion, what is the biggest obstacle to implementing integrated care in the US?

A: In the US, the funding situation—specifically the lack of funding for predialysis CKD education and treatment—often creates a disconnect between CKD care before and after dialysis. Therefore, it is difficult to manage a smooth transition through the various stages of treatment, especially at the initiation of dialysis. Fortunately, this problem has been recognized and there are many in the US nephrology community who are working on a solution.

I think the large dialysis organizations could play an important role by adopting integrated care concepts and participating in policy discussions about how to create a continuum of CKD-dialysis care. Some are already taking steps to encourage the use of home modalities.

Q: Speaking of home dialysis, do you really think a significant number of patients can manage their own treatment at home?

A: Yes, I do. And, I am not alone. Fairly large studies in North America and Europe have shown that as many as 50%-60% of all dialysis patients could manage some form of home therapy, even if it is home assisted PD. We are missing a big opportunity if we do not help more patients take advantage of the medical and lifestyle benefits of home dialysis.

(continued from page S1)

Integrated Care: Planning for Change

hepatitis and other infections, greater patient independence, and improved ability to keep a job.[7] Training is usually quick (about one week) and a PD start allows time to create an arteriovenous fistula for HD later.

Reduced costs: In both North America and Europe, the costs of PD and home HD (including nocturnal home HD) are less than the costs of providing in-center HD.[8] A shift to higher utilization of PD and other home treatments should reduce costs system-wide—a key consideration when every dollar is stretched to the limit.

Making It Work

Implementing integrated care requires a multidisciplinary effort, and depends upon:

1. Timely referral to a renal care team
2. Timely preparation, including modality education, for dialysis
3. Timely initiation of dialysis—with preemptive transplant or home dialysis as first choice for suitable patients
4. Timely transfer to a form of HD when residual kidney function declines or PD-related problems arise[7]

Each of these elements is needed for success, but an emphasis on modality education is critical. A complete presentation of *all* options is an absolute must for patients to make informed choices.

Recent growth in home HD options and expanded access to daily and nocturnal HD have prompted Mendelssohn and others to modify their recommendations for integrated care. First, they would like to see preemptive transplantation as a first option. "It offers patients the best possible outcome; thus, it should be promoted as the first-line treatment."[1] And second, they would like to see *all* home options—including PD and the various forms of home HD—acknowledged and presented as choices that are preferable to in-center HD in terms of both outcomes and costs.

Quiz Answers

1. True
2. False. Most people who have kidney failure for a long time will use more than one treatment.
3. True
4. True
5. True

References

1. Nesrallah G, Mendelssohn D. Modality options for renal replacement therapy: the integrated care concept revisited. *Hemodial Int* 10(2): 143-151, 2006.
2. Van Biesen W, Vanholder RC, Veys N, Dhondt A, Lameire NH. An evaluation of an integrative care approach for end-stage renal disease patients. *J Am Soc Nephrol* 11:116-125, 2000.
3. Jassal SV, Krishna G, Mallick NP, Mendelssohn DC. Attitudes of British Isles nephrologists towards dialysis modality selection: a questionnaire study. *Nephrol Dial Transplant* 17:474-477, 2002.
4. Jung B, Blake PG, Mehta RL, Mendelssohn DC. Attitudes of Canadian nephrologists toward dialysis modality selection. *Perit Dial Int* 19:263-268, 1999.
5. Mendelssohn DC, Mullaney SR, Jung B, Blake PG, Mehta RL. What do American nephrologists think about dialysis modality selection? *Am J Kidney Dis* 37:22-29, 2001.
6. Golper T. Patient education: can it maximize the success of therapy? *Nephrol Dial Transplant* 16(Suppl 7):20-24, 2001.
7. Mendelssohn DC, Pierratos A. Reformulating the integrated care concept for the new millennium. *Perit Dial Int* 22(1):5-8, 2002.
8. Lee H, Manns B, Taub K, et al. Cost analysis of ongoing care of patients with end-stage renal disease: the impact of dialysis modality and dialysis access. *Am J Kidney Dis* 40: 611-622, 2002.

In Control

Contact:
Life Options Rehabilitation Program
c/o Medical Education Institute, Inc.
414 D'Onofrio Drive, Ste. 200
Madison, WI 53719
Tel: (800) 468-7777
Fax: (608) 833-8366
E-mail: lifeoptions@meiresearch.org

www.lifeoptions.org
www.kidneyschool.org

Patients In CONTROL
A Medical Education Institute/Life Options Publication
VOL. 4 | NO. 4
DECEMBER 2007

Planning for Changing Dialysis Needs

If you have kidney disease, taking care of yourself and looking at your future treatment options is key—knowing that the treatment you choose is not set in stone. Knowing what to do *before* you start dialysis can help you to have a long life. Learning your options will allow you time for future changes if a treatment no longer works for you.

Early Choices

The choices you make in the months or years before you start dialysis may have long-term benefits. The most important things you can do are:

- See a nephrologist as early as possible to discuss ways to prolong your kidney function
- Take care of high blood pressure, diabetes, your heart, and other health problems
- Learn about your treatment options and think about how they would fit your lifestyle with as few changes as possible

In Control is supported by Amgen Inc.
AMGEN
and published in cooperation with

Looking at Your Options

Educating yourself about *all* of your treatment options will help you make a good choice. Look at your life now and think about things that might affect which treatment you choose, such as:

- Do you have a job that you need to keep?
- Do you live alone?
- Are you willing and able to follow strict diet and fluid limits?

Each option has pros and cons. *The choice you make is not permanent*. Most people who have kidney failure for a long time will use more than one type of treatment. (See Nancy's story on page S4).

Preemptive Transplant

Getting a transplant before you need dialysis (preemptive) has some real pluses. Studies have found that the kidneys were less likely to reject, so they last longer, and the patients live longer as well. Talk with your nephrologist about preemptive transplant with a living or deceased donor kidney—it's a good option that is not used as often as it could be.

(continued on page P4)

Nancy: a 40-year Survivor

Sixty-year-old Nancy has lived with kidney failure for more than 40 years—making her one of the longest living kidney patients in the world. In that time she has used many types of dialysis and had four transplants, switching treatments as her life and illness dictated.

Chosen for Dialysis

Nancy learned she had glomerulonephritis in 1959 when she was just 11. "At the time, I got the impression that I wouldn't live past the age of 20," recalls Nancy. Not much was shared with Nancy about her disease, but she was told not to eat salt—advice she still follows today.

It wasn't until 1966 that Nancy's kidneys failed, while she was in college. She was lucky to live in Seattle, which had the first chronic dialysis center in the world. "Because the center had just 24 beds, we had to be *chosen* for treatment by a 'life or death' committee," explains Nancy. "Luckily I was chosen." Nancy went to college full-time, dated, snow skied, and lived a mostly normal life on dialysis.

Nancy on home dialysis with a Kiil dialyzer in 1969.

Switching Gears

After 2 years of in-center care, Nancy decided to try home treatment. "I spent the entire summer training to do home dialysis, and learning how to repair the machine and take apart, scrub, and rebuild the dialyzer," recalls Nancy. "I dialyzed overnight three times a week and went to school during the day." In 1970, she graduated with an education degree and got a full-time job.

Since Nancy was young and active, her nephrologist suggested that a kidney transplant might be a good option. In March of 1972, the youngest of Nancy's three brothers gave a kidney to her. "The following summer I got married and had two children in the next four years."

More Changes

In 1979, Nancy got divorced. Unable to find a teaching job, she began nursing school—and her kidney rejected from food poisoning. "I started doing in-center hemo again, but now they were using new and 'improved' dialyzers and shorter treatment times," reports Nancy. "But I didn't feel as well as when I did overnight home hemo, and I hated taking time out

of my day—I liked 'sleeping away' my time on dialysis!"

With two children under five plus nursing school, Nancy again chose home dialysis. "I started to train for home hemo and couldn't believe how small the machine was compared to the one I was on before!" explains Nancy. "I didn't have to wash and clean it, and it only took about five weeks to train."

A Second Transplant and Epogen®

In July of 1981 Nancy had a second transplant, and she graduated nursing school the next year. She worked full-time as a nurse until her transplant failed five years later. "I was very weak and my hematocrit dropped to 15," recalls Nancy. "I had to quit working, go on disability, and started in-center hemo," relays Nancy. "Shortly after, I switched to home hemo again in an attempt to feel better."

The next year, Nancy took part in a study for a new drug now known as Epogen. "I went from a hematocrit of 15 to 40!" she explains. "I had more energy for my children but wasn't getting enough treatment to feel well enough to work—I longed to do overnight dialysis again but it wasn't being done at the time."

A New Approach

In 1989, Nancy had a third transplant, which she kept for 6 years. When it failed, Nancy's doctor suggested continuous ambulatory peritoneal dialysis (CAPD). "I was worried about infection, but my doctor alleviated my worries and convinced me I'd like this over time," explains Nancy. "Turns out I *really* liked it! I could do it at work, on airplanes, in meetings—and I felt much better. I liked CAPD just as well as the overnight dialysis I had done years ago."

Nancy today (far right) with son Josh, grandson Eli, daughter-in-law Karen, and daughter Sarah.

Today, Nancy is still working as a nurse and living happily with a fourth transplant she received in 2000. Does she think about her transplant failing? "I think about the future, but I know what it feels like when my body is rejecting, and if that happens I will look at what's going to serve me best at that point in my life," says Nancy. "Denying anything won't make it go away, so I say 'that's what I've got and I'm going to make the best of it.'"

(continued from page P1)

Planning for Changing Dialysis Needs

PD: A Good First Dialysis Option

Experts believe that choosing peritoneal dialysis (PD), or other home options, as a first treatment has many benefits such as:

- Keeping the kidney function you still have longer
- Much better ability to keep a job or an active lifestyle
- A better chance of getting a transplant
- Fewer diet and fluid limits
- No "ups and downs" in how you feel from day to day

Thinking Ahead

Being armed with knowledge about your options will help you see changes as normal transitions, not failures. Think ahead about your next choice and what treatment will benefit you the most at each stage of your life with kidney failure.

For More Information

For information about all five home dialysis treatments—with the pros and cons of each in a handy chart—visit www.homedialysis.org/learn/types/.

Planning for Change Quiz

Now that you've read about planning for change with kidney failure, try to answer the true/false statements below to see how much you've learned (answers are on page S8).

1. Knowing what to do *after* you start dialysis can help you to have a long life, and knowing what to do *before* you start dialysis is even better, when possible. ❒ True ❒ False
2. Most people who have kidney failure for a long time stay with the same type of treatment and don't make changes. ❒ True ❒ False
3. Getting a transplant before you need dialysis has many pluses. ❒ True ❒ False
4. Choosing PD or other home dialysis as a first treatment has many benefits. ❒ True ❒ False
5. Changing your dialysis treatment should be seen as a transition, not a failure. ❒ True ❒ False

In Control

Contact:
Life Options Rehabilitation Program
c/o Medical Education Institute, Inc.
414 D'Onofrio Drive, Ste. 200
Madison, WI 53719
Tel: (800) 468-7777
Fax: (608) 833-8366
E-mail: lifeoptions@meiresearch.org

www.lifeoptions.org
www.kidneyschool.org