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Challenges and opportunities in modality options education

Editor's Note: One of the keys to increasing the number of patients on alternative therapies is providing comprehensive modality choice education in the early stages of chronic kidney disease, so patients understand their options. We asked the authors, both veterans in developing patient education programs in dialysis, if we have made progress.

NN&I Overall, do we do a good job now with modality choice education?

Campbell, Witten It's hard to say. While we believe that some progress has been made, we have no real benchmarks yet to quantify how much modality education is being done and, if so, whether it is being done effectively. A number of studies have all found that when patients receive unbiased modality education, 40-60% will choose a home treatment option—but in the United States, 91.7% of patients are on standard in-center hemodialysis. This would suggest that modality education is not yet optimal.

NN&I With a government mandate to improve modality education for CKD patients, have we seen major changes in how this education is offered?

A.C./B.W. While it had good intentions, there are major shortcomings of the Medicare CKD education benefit approved by Congress. They include:

- Education is only reimbursed for individuals with Medicare, leaving a large percentage of CKD patients under age 65 without access to education or potentially having to pay for it.
- It does not reimburse dialysis providers for educating CKD patients, which could allow the hiring of more experienced educators to teach about modality options.
- It will not reimburse for education provided by any disciplines other than physicians, advanced practice nurses, or physician assistants and requires no experience in the treatment of kidney disease.

It would be fair to state that there is much more emphasis now on education for individuals with kidney disease than at any preceding time. However, issues still remain in terms of access to education, qualifications and knowledge base of education providers, timing of the education, and how to evaluate the myriad of educational interventions that exist.

NN&I Is there a way to track improvements in modality choice education?

A.C./B.W. It's not possible to know at this time whether patients know more now than before the CKD education benefit took effect because no data have ever been collected or reported nationally. We don't know how many patients have been educated under the CKD benefit, how many of the six modules they have received, what the costs have been to Medicare and patients thus far, and most importantly, what the impact has been on patient knowledge of CKD and their selection of what modality would be best for them. We don't have any means yet to know whether the content required in the Medicare CKD education benefit is helping patients. Nor do we know how to compare the education given to Medicare patients under this benefit with that given by industry or by dialysis providers. We think that it's safe to assume that while there is more education being delivered, the quality and outcomes of modality choice education still needs to be

evaluated further.

We can comment on some figures on CKD education gathered before the initiation of the The Medicare Improvements for Patients and Providers Act. In 2008, before the Medicare CKD benefit took effect, the American Association of Kidney Patients conducted a study of 977 patients. In this group, 38% were on in-center HD (ICHD), 10% on peritoneal dialysis, 5% on home hemodialysis (HHD), and 47% had transplants. Of these:

- 40% of the ICHD patients, 52% of the HHD patients, and 23% of the PD and transplant patients said they did not believe treatment options had been presented fairly in the CKD education they received.
- Most patients in the AAKP study were educated in their doctor's office by the doctor or nurse.
- Most said they had been told that ICHD was the better option for them.
- Only 43.5% of PD patients were told that PD was their best option.
- 74.7% of those on ICHD were told ICHD was their best option.
- Of those who chose transplant, 58.8% said this was presented as their best option.
- Only 3.8% of patients on HHD were told that option would be best—while 57.7% of HHD patients were told ICHD would be the best option for them.¹

NN&I How do you evaluate a good modality education program?

A.C./B.W. The best way to evaluate

the quality of any educational intervention is by measuring knowledge gained and satisfaction with the education received, along with follow up to learn what modality was chosen, and how satisfied patients are with the choice. To know whether

with and without the educational intervention is another excellent form of evaluation.

Above all, a good program must have provider(s) who are well educated and experienced in all content areas, provide research-based information regarding the

It is quite possible that the law opened the door for those motivated by Medicare reimbursement who have the right qualifications but questionable teaching skills or knowledge about ESRD to provide education that could be based more on their own biases and/or misconceptions than facts and that could steer patients to modalities that would be less than optimal for them. Lack of time for proper assessment of patients and answering complex questions are other areas that are of concern.

Therefore, the survey...should ask core questions related to each treatment option, including but not limited to what is required and how the modalities compare in terms of variables such as hospitalization, survival, access, symptoms, potential side effects or problems, health-related quality of life, diet, medications, schedules, and costs.

the education has imparted basic information requires a pre- and post-test, preferably using a standardized survey. This would identify what patients knew prior to receiving the education and what they learned during the education program. Health literacy has a tremendous impact on educational satisfaction and outcomes that is only recently becoming more appreciated in health care. A recent study found that only 68% of HD patients had adequate ($\geq 9^{\text{th}}$ grade) health literacy. Limited health literacy was associated with a 54% higher relative risk of death even after adjustment for age, race, sex, and diabetes status when compared with adequate health literacy.² Therefore, the survey should be short—one page if possible—written in simple easy-to-understand language (6th-8th grade reading level). It should ask core questions related to each treatment option, including but not limited to what is required and how the modalities compare in terms of variables such as hospitalization, survival, access, symptoms, potential side effects or problems, health-related quality of life, diet, medications, schedules, and costs. If the survey is administered prior to ESRD treatment, it should ask what modality the patient would choose. In addition to the patients, feedback from nephrologists and nurses in all modalities, including ICHD, HHD, PD and transplant programs, on the knowledge and adjustment of patients

positive and negative impact of each treatment modality on various elements of lifestyle that are important to patients—not personal opinions, and give adequate time and attention to each modality to achieve patient understanding. Educators should have a close working relationship with involved nephrologists and other team members and should possess a thorough comprehension of the frequent complexities and emotional/mental challenges of modality decision-making.

NN&I Who ideally should be teaching about modality choice options?

A.C./B.W. Educators should be knowledgeable about kidney disease and treatment options. The Medicare CKD education benefit limits who can provide education to “qualified providers” that the law defined as a physician (not necessarily a nephrologist), advanced practice registered nurse or physician assistant. The law sets no requirement that the qualified provider had to have any experience or expertise in either education or in treatment of kidney disease. It bypassed professionals who work in dialysis or transplant facilities and also bypassed individuals from other disciplines who might be well qualified to provide education on certain topics (i.e., nutrition and psychosocial/financial issues) better than physicians or nurses.

NN&I At what stage should we be talking to CKD patients about modality choice?

A.C./B.W. The National Kidney Foundation’s KDOQI guidelines recommend that patients in Stage 4 CKD be offered modality education. Medicare only covers CKD education for patients in Stage 4. Ideally, we should discuss modalities in overview and then in more detail as eGFR decreases through Stage 4 and 5 and as symptoms and discussion begin to make the need for modality decisions more important to patients. Prior to Stage 4 some patients are interested in learning about treatment for kidney failure and they should have access to education when they want it (any “teachable moment”). However, many who learn they have earlier stage CKD are seeking answers to how to improve or maintain kidney function, how to slow the progression of kidney damage, or to prevent kidney failure. Therefore, CKD education has different goals and content at different stages.

The general population, particularly individuals at high risk of CKD, also has vital educational needs. The NKF’s Kidney Early Evaluation Program found that 29% of the 55,000 screened have CKD and most did not know it.³ Therefore, the major focus of educational efforts to the general public should emphasize symptoms of kidney disease and what actions to take to slow or stop the progression of CKD. Scare tactics about kidney failure and dialysis are best avoided. There are many efforts underway for better screening for CKD in primary care through testing such as eGFR and urine protein. This is an area that could

be tied to educating patients, particularly those with hypertension and diabetes, who are at a higher risk of kidney failure and need to know how to control risk factors and avoid anything that could harm their kidney function.

NN&I | We have about 90% of individuals with kidney failure on ICHD. Is that a failing of pre-dialysis education?

A.C./B.W. | It is not a failing of CKD education itself that so few patients are on home therapies. When patients receive unbiased CKD education, more of them do choose home modalities. It is more likely a failure to reach enough patients with CKD education. Other factors are also important barriers to home therapies, some of which we know, others we can speculate about and still others may not have yet been identified. Late referrals and the lack of nephrology care pre-dialysis causes more people to be started in-center, though several studies have reported that it is possible to initiate late-start patients on PD. It can be difficult to convince some patients to consider self-care once they stay on ICHD for any length of time.

Advanced age and co-morbidities are often cited by renal professionals as another rationale for why so many patients do ICHD. The dramatic increase in dialysis facilities closer to patients' homes may be another factor in the large numbers of patients who go to facilities rather than choose home modalities. We have also observed over the last few decades that patients have changed as our American culture has changed. As we have become used to doing less for ourselves and receiving faster, more convenient services from others, fewer patients seem to be as inclined to take on the responsibilities of self-care.

There are also other reasons for the 90% ICHD figure beyond patients and their culture. Most patient contact during nephrologist training is with ICHD patients. This may lead nephrologists to be biased in favor of the modality with which they have the most experience and comfort. Nephrologists who do not have experience with home patients may believe that these patients will require more of their time or

ask questions they can't answer. They may not realize that an experienced home training nurse will provide most of the support that home patients need. They may underestimate their patients' abilities and ignore the substantial burdens of ICHD when discussing treatment options with patients.

Physicians may not take the time to allow the patient to cope with the initial shock that he/she has kidney failure and will require ongoing treatment before suggesting that the patient can be cared for in a dialysis clinic. Patients who are frightened may feel incompetent to take on medical care they know nothing about and that dialysis staff are trained to do. They may not understand that if they choose to do any type of home dialysis, they and/or their care partner will receive training similar to what a dialysis patient care technician receives. They may not know enough to compare dialysis options.⁴

Currently there are insufficient numbers of nephrologists to care for the number of patients with CKD. A 2005 study showed that while the number of CKD patients was growing at a rate of 5-7% per year, the number of nephrologists was only growing at 2%. Nurse practitioners' strong suit is patient education.⁵ If more nephrology practices hire more nurse practitioners, perhaps there will be a greater focus on CKD education in the practitioner's office and/or referral to education in the community. In areas where there are CKD education programs, it is important for nephrologists and nurse practitioners to be made aware of them and for those offering the CKD education programs to help these caregivers feel comfortable to make referrals.

One way to improve the comfort level and increase referrals is to involve nephrology fellows, community nephrologists, and nurse practitioners in community-based or dialysis provider-based education.

NN&I | So what lessons have we learned for the future of modality education?

A.C./B.W. | It would seem that CKD education has grown in scope and emphasis since the 1970s, but there is not one perfect way to provide this service. Attempts

by individuals, industry, dialysis providers, renal organizations and now Medicare all have pros and cons. The Medicare CKD education benefit offers one more way to reach patients with education and creates incentives for it by reimbursing qualified providers. Yet there remain issues with access to education even for some CKD Stage 4 patients.

The effects of bundling may lead to the growth of more self-care modalities, but some patients will not be able to do self-care and others will choose ICHD for a variety of reasons. It is clear that dialysis and transplant providers and the federal government are finally seeing the need for more education. Studies are needed to determine how patients and providers are using and experiencing Medicare-covered CKD education. Well designed studies are also needed to determine the best ways to provide education and to ensure that patients are equipped to choose a treatment option that is right for them when the time comes.

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