

# The Missouri Kidney Program's Patient Education Program: A 12-year retrospective analysis

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## Abstract

Unbiased patient education for individuals with chronic kidney disease can result in a multitude of positive benefits. The current study reviewed 1,844 participants in a six-topic patient education program over a 12-year period from June 1994 to July 2006, examining patients' level of knowledge about CKD, preferences for treatment, and feelings of hope and fear before and after the educational intervention. After the educational intervention, patients scored significantly higher on knowledge tests of all topics than they scored on the pre-test ( $p < .05$ ). Overall, there were no significant differences from pre- to post-test on self-ratings of being "scared" or "hopeful," although on the post-test, females were significantly more hopeful than males ( $p < .01$ ). More patients were interested in peritoneal dialysis as a treatment option after class attendance ( $p < .001$ ). Multivariate logistic regressions indicated that patients who were older, black, or who had a high school education or less were more likely to prefer center hemodialysis ( $p < .007$ ). Although overall interest in the transplant option did not change significantly from pre- to post-test, younger patients (52 vs. 67 mean years,  $p < .001$ ) and males (59% vs. 54%,  $p = .02$ ) were more interested in receiving a transplant.

## Introduction

Individuals with CKD face a lifetime of complicated involved treatments, which not only includes dialysis or transplantation but also medications and dietary restrictions. Health care providers have a professional and ethical obligation to insure that those who experience CKD are educated about their illness and all treatment options. Not doing so would potentially deprive them of the many benefits derived from patient education. The purpose of this paper is to outline a model of CKD education for patients with kidney disease, and to examine patients' level of knowledge about kidney disease, preferences for treatment, and feelings of hope and fear before and after the educational intervention.

The National Kidney Foundation and the Renal Physicians Association

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have recognized the benefits of informing people with CKD about treatment options and living with kidney disease. Each has established guidelines for physicians and other allied health professions to encourage them to educate patients prior to kidney failure.<sup>1-2</sup>

## Benefits of CKD patient education

Enhanced psychological functioning has been associated with receiving patient education. Anxiety may result from worry about the unknown; thus, it is not surprising that multiple studies have demonstrated lowered anxiety levels for dialysis patients who participate in an educational program.<sup>3-7</sup> Other psychological benefits associated with dialysis-related education include improved mood, decreased loneliness,<sup>8</sup> and enhanced psychosocial adaptation.<sup>9</sup>

Educating patients about their disease may also positively impact vocational and social functioning. Researchers assessed the impact of predialysis intervention-including patient education-on blue-collar workers' vocational functioning both prior to initiation of dialysis and at least six months after beginning dialysis. The findings demonstrated that those who participated in the program were 2.8 times more likely to remain employed

than those blue-collar workers who did not participate.<sup>10</sup> Another study documented that educated patients were more likely to be involved in work, recreation, and pastime activities, as well as have increased social interaction.<sup>11</sup>

Education has also been associated with improved medical outcomes. Research studies evaluating the impact of education on CKD patients have demonstrated better control of blood pressure, calcium, phosphate, and anemia and decreased interdialytic weight gain.<sup>12-14</sup> One health care provider attributed 80% of its patients having a Kt/V of 1.4 and higher, as well as 83% with a urea reduction ratio of at least 65%, to its predialysis education program.<sup>15</sup> Patient education has also been found to positively impact survival.<sup>16</sup> Decreased physical dysfunction and significantly more positive physical adaptation was an additional benefit for dialysis patients who had received education.<sup>17-18</sup>

Medical cost is a necessary consideration in today's health care environment. A Canadian study documented that its education participants were less likely to initiate dialysis emergently, had more outpatient dialysis training, and were hospitalized less often during the first month of dialysis when compared to those receiving standard care. Those

results provided an estimated cost savings of more than \$4,000 (Canadian) per patient.<sup>19</sup> Other investigators found that patients in their predialysis education program delayed dialysis initiation

not receive any predialysis education and approximately 50% reported they did not receive adequate information early enough in the course of kidney disease.<sup>32</sup> An NKF study of 844 CKD

vices and programs. One of its goals is to encourage and support research designed to reduce the cost of care or delay the onset of CKD. It was out of this goal that the PEP was born.

The initial intent of the PEP was to educate individuals with CKD prior to the initiation of dialysis to facilitate their full participation in treatment decisionmaking. While that remains the goal, the program has also realized it has a role in further educating those who, although already on a treatment modality, are in need of further education about treatment options. The PEP has been offered in four loca-

Those who selected peritoneal dialysis as their initial treatment modality and remained on that treatment cost Medicare \$44,111 per year compared with a Medicare cost of \$72,185 for those who initiate and remain on hemodialysis.

three months longer than non-participants. The estimated cost savings per patient was \$13,353.<sup>20</sup> A predialysis education program demonstrated that 78% of those who participated began dialysis on their preferred mode of treatment with a permanent access compared to 55% of those who did not receive the education. Of the educated group, only 22% required more than one access procedure to begin their primary treatment compared to 45% of the control group. It was predicted that having fewer access procedures would result in a cost savings.<sup>21</sup> Multiple studies have found that persons who are educated about all of their treatment options prior to beginning dialysis frequently select a method of home dialysis, most often peritoneal dialysis (PD).<sup>22-30</sup> It has been documented that those who selected PD as their initial treatment modality and remained on that treatment cost Medicare \$44,111 per year compared with a Medicare cost of \$72,185 for those who initiate and remain on hemodialysis (HD).<sup>31</sup>

While most would champion use of patient education based on its many benefits, there is considerable research demonstrating that all too frequently comprehensive patient education, particularly focusing on dialysis treatment options, does not occur. It was found that approximately 67% of participants in one study reported they did

patients found that approximately 25% of those participating indicated they had initiated dialysis prior to having a one-on-one discussion about treatment options. The study also documented that while 83.6% of participants were presented the option of in-center HD, only 49.4% were offered continuous ambulatory PD, 27% were offered HHD and 23.3% were offered automated PD. Respondents who began treatment with in-center HD were more likely to believe that they had received inadequate information about their treatment options (14.3%) than those who had initiated on PD (4.6%).<sup>33</sup> Another study reported that 40% of patients knew about both HD and PD, while just 16% were aware of only HD, less than 1% knew only of PD, and 43% were not familiar with kidney transplantation as a treatment option.<sup>34</sup>

### Missouri Kidney Program's Patient Education Program

The Missouri Kidney Program (MoKP) demonstrated great vision when its statewide Patient Education Program (PEP) was initiated in 1984. The MoKP, a state kidney program affiliated with the University of Missouri, was established in 1968 with the mission of assisting eligible Missouri residents with CKD meet their medical, social, psychological, and educational needs, and it provides a variety of ser-

### PEP Talk: A list of the Patient Education Program's goals

1. To provide comprehensive, objective information about treatment options for kidney failure to patients who have not yet started treatment.
2. To provide comprehensive, objective information about treatment options for kidney failure to patients who may be interested in changing treatments or learning more.
3. To provide a brief orientation for new dialysis and transplant staff.
4. To promote information seeking and sharing of experiences among patients, loved ones, and staff.
5. To empower patients to become active partners in their care, to make informed treatment decisions, to manage their illness, to adhere more closely with their treatment prescription, and to resume their usual activities.
6. To prepare patients and families emotionally to deal with kidney disease and its treatment by serving as an informal support group for patients and their loved ones.
7. To reduce the cost of treating kidney failure.

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tions throughout Missouri, including St. Louis, Kansas City, Springfield, and St. Joseph. The PEP had dialysis professionals serving as staff coordinators in Kansas City and St. Louis during the study period.

There are multiple reasons for the successful longevity of the PEP. Emphasis on objectivity and neutrality has been central to its success, seeing as the MoKP and its staff are not affiliated with a specific dialysis or transplant facility and that the PEP classes are held at neutral, informal sites, such as the area office of the NKF affiliate or organ procurement organization. The content, including the presentation outline and slides, of the program's six classes, are developed by the staff coordinators with input from the class presenters to assure that information is up-to-date and every important issue, including the advantages and disadvantages of each treatment option, is addressed. The handouts are also selected by these professionals based upon their ability to provide unbiased, accurate information. Every dialysis and transplant facility and nephrology practice in the four areas were notified of every class series and invited to refer CKD patients and their family members or guests. Efforts have also been made to inform primary care practitioners, endocrinologists, and diabetes educators about the program. Individuals with CKD and their families may also self-refer.

The six classes and the order in which they are presented in each series are shown in Table 1. The schedule of classes varies, most recently featuring six classes, each 60 to 75 minutes, being held during one weekend or over a two-week period. The entire series of classes is moderated by a social worker with a master's degree in social work who practices in a dialysis or transplant facility.

This individual is generally the presenter for the class on finances and

Table 1: Patient Education Program Class Topics

- Class 1:** Introduction to Kidney Disease
- Class 2:** Diet and Kidney Disease
- Class 3:** Financing and Coping with Kidney Disease
- Class 4:** Hemodialysis
- Class 5:** Peritoneal Dialysis
- Class 6:** Kidney Transplant

coping. The introduction to kidney disease class and the three classes on treatment modalities are each presented by a different registered nurse with expertise in that particular area. A registered dietitian who is practicing in a dialysis facility is the presenter for the diet class. In addition to the professional presenters, there are patient presenters, who are sometimes accompanied by family members, for the treatment option classes. Again, PEP coordinators strive to assure that presenters represent different dialysis and transplant facilities in the area so that partiality is not shown to any facility.

## Methods

### Survey Administration

In addition to providing demographic data, participants are asked to complete a variety of scales that were developed by the PEP. One scale is a 24-item true or false test, with four items specific to each of the six topics, to ascertain knowledge. Participants indicate their dialysis treatment choice (in-center or HHD, PD, undecided, or none), as well as whether they are interested in kidney transplantation, on two additional scales. Another measure assesses fear (assessed by a self-rating on "scared") and hopefulness. When completing this assessment, patients rate themselves on a scale of 1 to 4 (with 1 being less and 4 being more) as to being scared and hopeful. Each of these scales is administered both prior to and after participation in the classes. Participants are also asked to evaluate various aspects of the PEP.

### Sample Selection

Although 1,918 patients diagnosed with CKD attended at least one class in a six class PEP series from July 1994 to June 2006, only data collected from the 1,844 patients who completed all or at least some portion of the surveys was analyzed. Not included is data obtained from the 1,840 guests of the patient participants who attended at least one class in a six class series during this timeframe. Participation in the PEP classes is voluntary, thus patients attending were not selected at random from the population of all individuals diagnosed with CKD in Missouri, Kansas, or Illinois.

### Missing Data

Data is missing for several reasons. First, since some questions were modified, added, or eliminated across different survey years, data for every question is not included for every year. Data on demographic characteristics and the classes' impact on knowledge, treatment choice, and emotions were collected from July 1994 through June 2006, while program evaluations were collected from July 2002 through June 2006. Second, some individuals did not attend every class session or skipped questions when completing the various scales or forms and some returned blank surveys. Every patient who completed a particular question was used in the analyses.

### Data Coding

The majority of the questions were coded identically to the actual sur-



vey instrument. However, the continuous variable, age, was recoded into age categories consistent with the United States Renal Data System. For the univariate and multivariate analyses, demographic variables were dichotomized where sample sizes in some cells were low (less than 10 individuals) to create better statistical models. Questions that varied in their presentation across different survey years were recoded for improved consistency.

### Statistical Analysis

All statistical analyses were performed using the statistical analysis software SPSS 13.0 (SPSS, 2005). All figures and tables were prepared using SPSS and Microsoft Word 2003. Frequency and descriptive statistics were conducted to summarize data into categories to examine key relationships.

### Results

#### Patient Demographic Data

The average age of the patients attending the classes ranged from 57 to 61, with the median age of 61. Those patients attending the classes ranged in ages from 16 to 88. Males comprised 51% of attendees; whites accounted for 58% of participants (compared to 26% black, 2% Hispanic, and 1% other). Participants were more likely to reside with someone (80%) than live alone (20%). Only 26% of patients were college graduates, while 27% had attended some college and 47% had a high school education or less. Those attending classes in the more rural areas of the state were significantly more likely to have a high school education or less. Participants in these areas were also significantly less likely to be employed. Overall, 69% of those who attended statewide classes were unemployed.

Forty-four percent of patients had been diagnosed with CKD between one and five years, with 28% being diagnosed less than one year and 28% receiving their diagnosis more than

five years. There was no significant regional variance. The majority, 82%, had not initiated dialysis at the time of their class attendance. Although 73% of Kansas City, Mo. participants were not yet on dialysis, those in that city were significantly more likely to have initiated dialysis when compared to those in the other areas. Participants were asked whether they had a dialysis access, as it was hypothesized this might influence their pre-class choice

of treatment. Most patients did not have a dialysis access (71%). Of those who did have an access, 57% reported it was located in their arm, 20% in their chest or neck, 20% in their stomach and 3% indicated "other." Access location varied significantly by where the person resided. Those in the St. Louis and Kansas City, Mo. areas were more likely to have a dialysis access in their chest or neck, whereas those in Springfield, Mo. were more likely to



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Table 2: Location of Dialysis Access

	Arm	Chest/Neck	Stomach	Other
2006	48%	48%	0%	4%
1994	64%	11%	25%	0%

have a stomach access and those in St. Joseph, Mo. an arm access. Type of access placement has varied over time. Table 2 compares the differences in 1994 to 2006. Typical of the U.S. dialysis population, the majority (79%) of PEP attendees who had begun dialysis were in-center HD patients. Twenty percent were on some form of PD and only 1% did HD at home. There was no significant difference between the geographical areas of the state, although those in the more rural areas did show a higher prevalence of PD. The number of those reporting being in-center HD patients was higher in 2006 than it had been during the entire reporting period.

#### Attendance

The total attendance for the PEP from July 1994 through June 2006 included 1,918 individuals with CKD. Class sizes in St. Louis were the largest, averaging 80 patient participants per year compared to Kansas City's 50. With the St. Louis area's population approximately 1 million larger than Kansas City's, this would be expected. The classes in the other two less populated areas of the state averaged from 17 to 21 annual patient participants.

Throughout the 12 years of the education program, the statewide attendance at the six different classes ranged from 65% to 91%. The kidney transplant class consistently ranked as the least attended of any class. This might

be explained by individuals perceiving that they are not eligible for a transplant, patients not being interested in learning about transplantation or, since the transplant class is the last of six classes, fatigue from attending the class series.

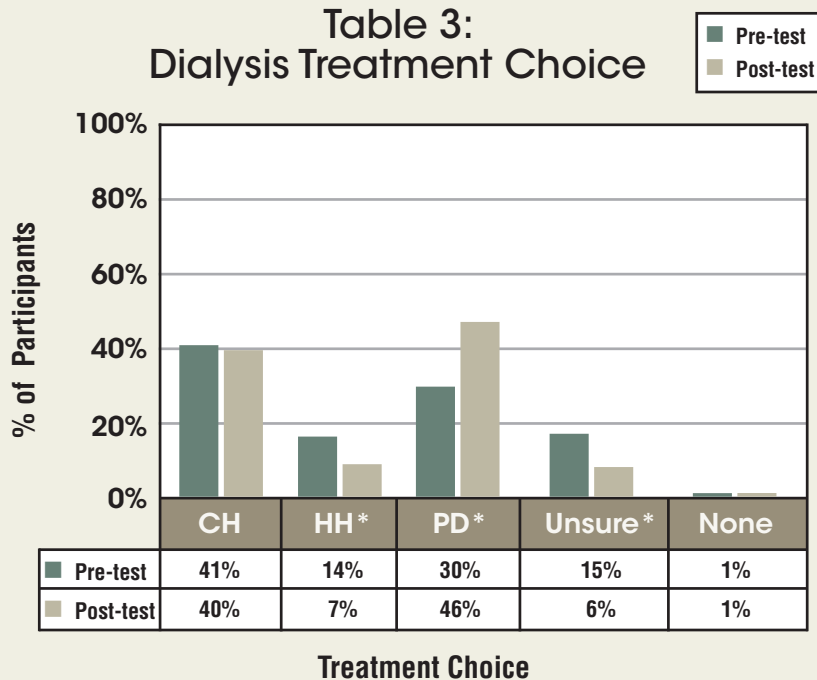
#### Impact of Education

The majority of patients selected in-center HD as their preferred mode of dialysis both before (40%) and after (41%) attending the classes. Those who choose HHD declined from 14% pre-class to 7% post-class. The only significant difference in dialysis treat-

ment choice prior to and after attending PEP classes was in those selecting PD. While only 30% of participants indicated that PD was their preferred mode of treatment prior to attending the classes, 46% preferred PD after attending, showing a significant difference ( $p < 0.001$ ). Table 3 shows the pre- and post-test dialysis treatment preferences of participants. Individuals who were older (ages 57 vs. 60,  $p < 0.001$ ), black (54% vs. 36%,  $p < 0.001$ ) and had a high school education or less (52 vs. 48%,  $p < 0.002$ ) were significantly more likely to select in-center HD than other participants. Patients who were younger (ages 56 vs. 59,  $p < 0.002$ ), non-blacks (52% vs. 32%,  $p < 0.001$ ) and had more than a high school education (59% vs. 41%,  $p < 0.007$ ) tended to choose PD more frequently than others who attended the PEP classes. The participants' gender and living situation did not significantly affect dialysis treatment choice.

Interest in kidney transplantation did not change significantly prior to and after attendance at the transplant class. Prior to class, interest was 56%, and after attendance, inter-

Table 3: Dialysis Treatment Choice



est remained nearly the same at 57%. Attendance at the class did little to change the opinions of those who were uncertain about transplantation, as the pre- and post-class percentages were 11% and 12% respectively. Males (59% vs. 54%,  $p=.02$ ) and younger (52 years vs. 66 years,  $p<.001$ ) patients were significantly more likely to favor having a transplant than women and those who were older. Participants' race, education level or dialysis status did not significantly affect their desire to receive a kidney transplant.

While only 47.6% of the knowledge pre-test questions were answered correctly, 76% of the questions were answered correctly after class attendance. Knowledge in all six class topics showed significant increases ( $p<0.001$ ). The largest gain in knowledge from pre- to post-test was with the PD class, followed by the class on HD.

Although PEP attendees reported feeling slightly less frightened and slightly more hopeful after attending the class series, the change was not significant. Females, however, were significantly less afraid at post-test than males ( $p=0.01$ ). There was no significant emotional difference pre- and post-test due to age, race, educational level, living situation, whether a participant had initiated dialysis or the number of classes attended.

#### Program Evaluation

Among the individuals who participated in the class, 99% reported they would recommend the PEP program to others with CKD. At least 90% of all participants throughout the state rated the following characteristics of the program as either good or excellent:

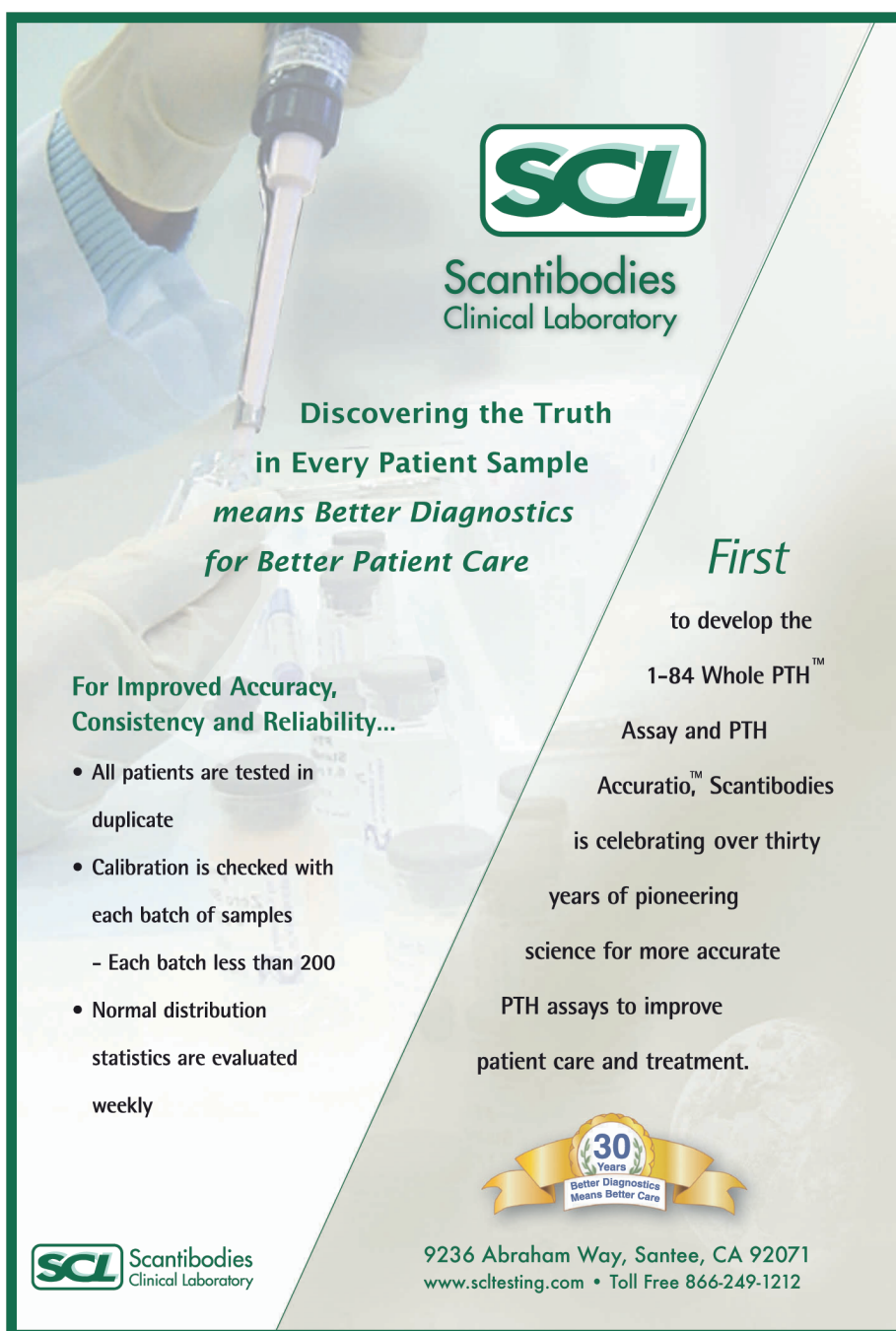
- ▶ Length of the program
- ▶ Length of the class topic
- ▶ Number of topics covered per day
- ▶ Time for questions and answers
- ▶ Time to speak to others with CKD, as well as their families
- ▶ Speaker quality
- ▶ Handout materials

- ▶ Educational experience's overall quality
- ▶ Ability of class to aid with treatment decisions
- ▶ Ability of class to facilitate coping with CKD

#### Discussion

This study supports the earlier findings that those who are educated about all treatment options tend to select PD as their modality of choice. And 46% of

these patients who received education about treatment options selected PD compared to 6.6% of incident patients in the United States who selected PD as their initial treatment option.<sup>35</sup> While those who would choose the options of center HD and no treatment remained basically unchanged, there was a non-significant decrease from 14% to 7% in those who would elect to do HD at home after attending the PEP classes. Regardless, the 7% of participants who



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continued to prefer HHD is much higher than the 0.4% of incident patients nationally who chose this modality as their initial treatment choice.<sup>36</sup> One might speculate that some individuals might have shifted from HHD pre-class to PD post-class because they learned that while both can be done at home, PD can be done without a partner, can be mastered in less time, and may be more mobile. If so, this may change as more clinics use smaller, portable home dialysis equipment that involves no costly home modification and requires only slightly longer training that required for PD. While the classes did seem to assist some who were undecided in making a treatment

providers better prepared to participate as active, informed team members.

While the scales assessing fear and hope did not demonstrate an impact from class attendance, patients did indicate that the classes facilitated their ability to cope with their kidney disease. It is possible that the scales, which were developed by the PEP staff, were not reliable and accurate enough to evaluate the classes' emotional impact. It might also be questioned whether the short timeframe during which the classes are held allow adequate time to measure emotional change.

There are possible limitations to this study. The study participants may not be typical of the average person with

treatment, the person may be unlikely to indicate a differing treatment preference. The primary disease contributing to their CKD was unknown, as were other co-morbid conditions that may impact treatment selection. Also, there is no information as to what treatment decisions participants made when faced with the actual choices of mode of dialysis and whether to seek transplantation.

## Conclusion

The Missouri Kidney Program's Patient Education Program will soon be celebrating its 25th anniversary. This 12-year review of the PEP contributes to the body of literature documenting that those who receive education about all dialysis treatment modalities are more likely to select PD. There is no doubt that class attendance resulted in increased knowledge about kidney disease, dialysis treatments, transplantation, diet, finances, and coping. Participants viewed the program as valuable in facilitating coping and treatment decision making. While every state does not have a state-funded kidney disease program to initiate CKD education, hopefully the findings of this study will motivate professionals who work with CKD patients to provide objective information about all treatment modalities, preferably before the individual initiates dialysis. **N**

90% of participants indicated that the PEP did aid them in making treatment decisions.

selection, even after receiving extensive education, 6% of participants were still unable to make a choice.

Attendance at the PEP classes did not have a significant impact on transplant interest. Again, even after attending the classes, 12% of the participants indicated they were unable to decide whether they were interested in transplantation. This might be partially explained by the fact that the kidney transplant class was the least attended of the six classes. It should also be noted that 90% of participants indicated that the PEP did aid them in making treatment decisions.

The format and content of the classes appear to facilitate learning, as all six classes resulted in significant increases in knowledge of the specific topic. Armed with this knowledge, it is anticipated that participants will return to their dialysis facilities and health care

CKD; therefore, the findings may be unable to be generalized to the CKD population. These individuals were motivated and physically able to attend two half-days of classes to learn about their disease. They were also typically referred by their physician, thus indicating that these care givers encouraged patient education. There was no control for prior knowledge, thus some participants may have entered the classes already informed about CKD.

It is possible that attending class while already on dialysis treatment or with an access may have influenced both pre- and post-treatment selection regardless of class education. A qualitative research study found that prior placement of a vascular access influenced the dialysis selection process.<sup>37</sup> If an individual is on a specific treatment or has an access that would lend itself to a particular method of

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January 18

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Sherman Oaks, Calif.  
[www.rsnhope.org/programs/renal\\_teen\\_prom2.php](http://www.rsnhope.org/programs/renal_teen_prom2.php)

#### Symposium for the Advanced Transplant Professionals

January 16-18

Marriot Marco Island Resort & Spa  
Marco Island, Fla.  
913.895.4612  
[www.natco1.org](http://www.natco1.org)  
[natco-info@goAMP.com](mailto:natco-info@goAMP.com)

#### ASTS 9th Annual State of the Art Winter Symposium

January 16-18

Marco Island Marriot Resort  
Marco Island, Fla.  
703.414.7870  
[www.asts.org](http://www.asts.org)