

# ***Missouri Kidney Program***

## ***Center for Renal Education***

### ***Patient Education Program Summary Report For Years 1994-2006***



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# METHODS

The Missouri Kidney Program's (MoKP) Center for Renal Education Patient Education Program (PEP) classes began in 1983 with the goal of educating patients diagnosed with chronic renal disease and their families. From 1994 to 2006, 1918 patients diagnosed with chronic renal disease attended PEP classes.

This report presents data from these patients, divided into three sections:

1. Demographic Characteristics of PEP Patients (Includes Data from 1994-2006)
2. Impact of Education on Knowledge, Attitudes, and Emotions of PEP Patients (Includes Data from 1994-2006)
3. Overall PEP Program Evaluation (Includes Data from 2002-2006)

## **Survey Administration**

Surveys were completed before and after the PEP classes to assess changes in patients' knowledge and attitudes about renal disease and their dialysis and treatment options. The surveys measured individuals' demographic characteristics, dialysis use, interest in transplantation, and their knowledge about chronic renal disease-relevant topics. The final survey also assessed their satisfaction with the class and their emotional state after attending the class.

## **Sample Selection**

This report summarizes data collected from the 1844 patients with chronic renal failure who completed all or at least some portion of the surveys. Seventy-four patients with renal disease attended the class but did not complete any survey questions. This report does not summarize any data collected from family members. Participation in the PEP classes is voluntary, thus patients attending were not selected at random from the population of all individuals diagnosed with chronic renal disease in Missouri or Kansas.

## **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. Throughout the report, data is reported for each year that it was available. Second, some individuals did not attend every class session or skipped questions. Every patient who completed a particular question was used in the analyses.

## **Data Coding**

The majority of the questions presented in this report were coded identically to the actual survey instrument. However, the continuous variable, age, was recoded into age categories consistent with the United States Renal Data System (USRDS). For the univariate and multivariate analyses, we dichotomized demographic variables 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 ANALYSES

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. We conducted frequency and descriptive statistics to summarize data into categories to examine key relationships. We conducted inferential statistics to explore certain hypotheses, specifically:

1. Did the renal disease knowledge of PEP class participants significantly improve from pre- to post-class?
2. Did patients' interest in different types of dialysis change from pre- to post-class?
3. Did their interest in receiving a transplant increase from pre- to post-class?
4. Did patients' willingness to receive a transplant vary by any demographic characteristics?
5. Did the type of dialysis they would choose vary by any demographic characteristics?
6. Did post-class fear vary by their demographic characteristics or by how many classes they attended?

**PATIENT  
DEMOGRAPHIC  
CHARACTERISTICS  
(1994-2006)**

## I. Class Attendance and Demographics

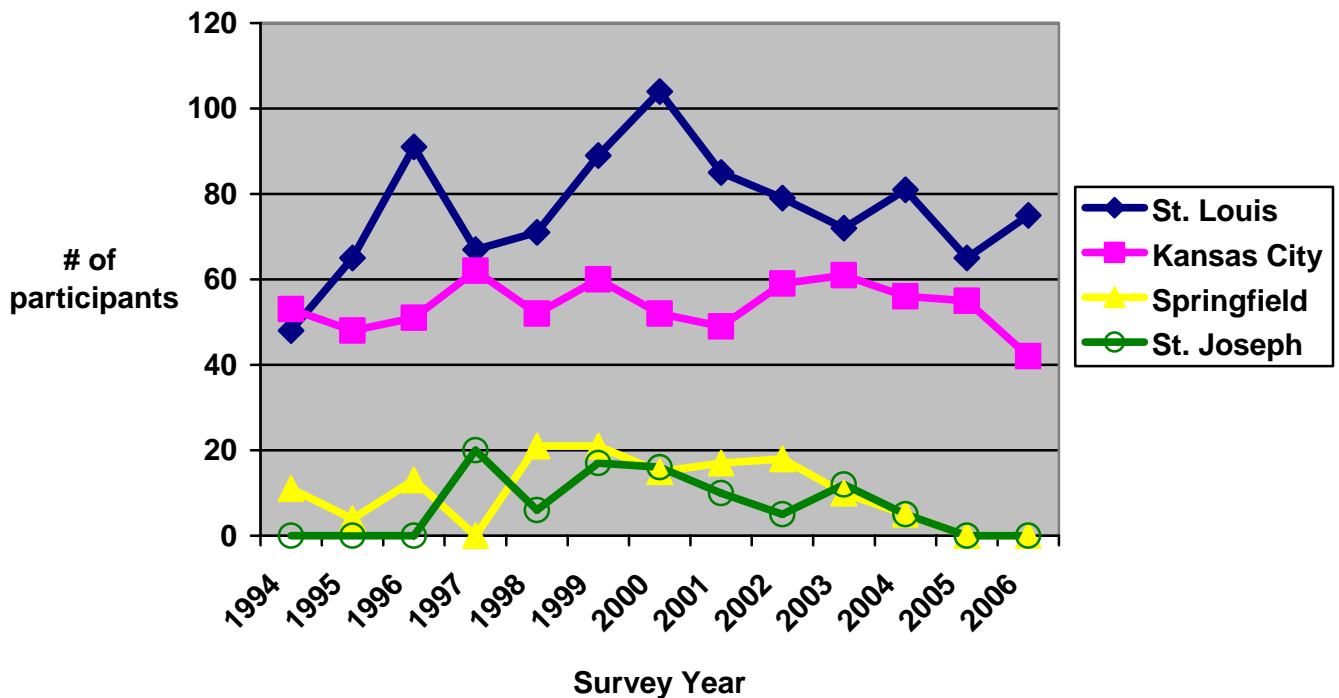
Total participants with renal disease that attended the class: 1918 (100%)  
 Total participants that answered at least one question in the survey: 1844 (96%)\*  
 \* For all analyses, all participants who answered individual questions are included.

### A. Participants at each Location

#### A1. Participation by Location and Year

	St. Louis (#)	Kansas City (#)	Springfield (#)	St. Joseph (#)	Total (#)
2006	75	42	0	0	117
2005	65	55	0	0	120
2004	81	56	5	5	147
2003	72	61	10	12	155
2002	79	59	18	5	161
2001	85	49	17	10	161
2000	104	52	15	16	187
1999	89	60	21	17	187
1998	71	52	21	6	150
1997	67	62	0	20	149
1996	91	51	13	0	155
1995	65	48	4	0	117
1994	48	53	11	0	112
<b>Total</b>	<b>992 (52%)</b>	<b>700 (36%)</b>	<b>135(7%)</b>	<b>91(5%)</b>	<b>1918</b>

#### A2. Participation by Location and Year



## ***B. Patient Attendance by Course Topic***

### B1. Patient Attendance by Topic by Year

	<b>Topic 1</b>	<b>Topic 2</b>	<b>Topic 3</b>	<b>Topic 4</b>	<b>Topic 5</b>	<b>Topic 6</b>
2006	86%	86%	81%	83%	83%	<b>77%</b>
2005	81%	83%	78%	78%	78%	<b>65%</b>
2004	74%	77%	73%	80%	78%	<b>71%</b>
2003	86%	87%	81%	77%	76%	<b>67%</b>
2002	82%	83%	81%	84%	83%	<b>78%</b>
2001	82%	84%	79%	80%	80%	<b>70%</b>
2000	83%	87%	81%	81%	82%	<b>77%</b>
1999	89%	89%	82%	83%	85%	<b>78%</b>
1998	91%	89%	87%	87%	83%	<b>71%</b>
1997	84%	87%	84%	80%	78%	<b>74%</b>
1996	80%	79%	78%	79%	77%	<b>74%</b>
1995	N/A	N/A	N/A	N/A	N/A	N/A
1994	N/A	N/A	N/A	N/A	N/A	N/A

Topic 1 = Introduction to Kidney Disease

Topic 2 = Diet and Kidney Disease

Topic 3 = Financing and Coping With Kidney Disease

Topic 4 = Hemodialysis

Topic 5 = Peritoneal Dialysis

Topic 6 = Kidney Transplant

***\*Data only available from 1996-2006***

### B2. Patient Attendance by Topic by Location

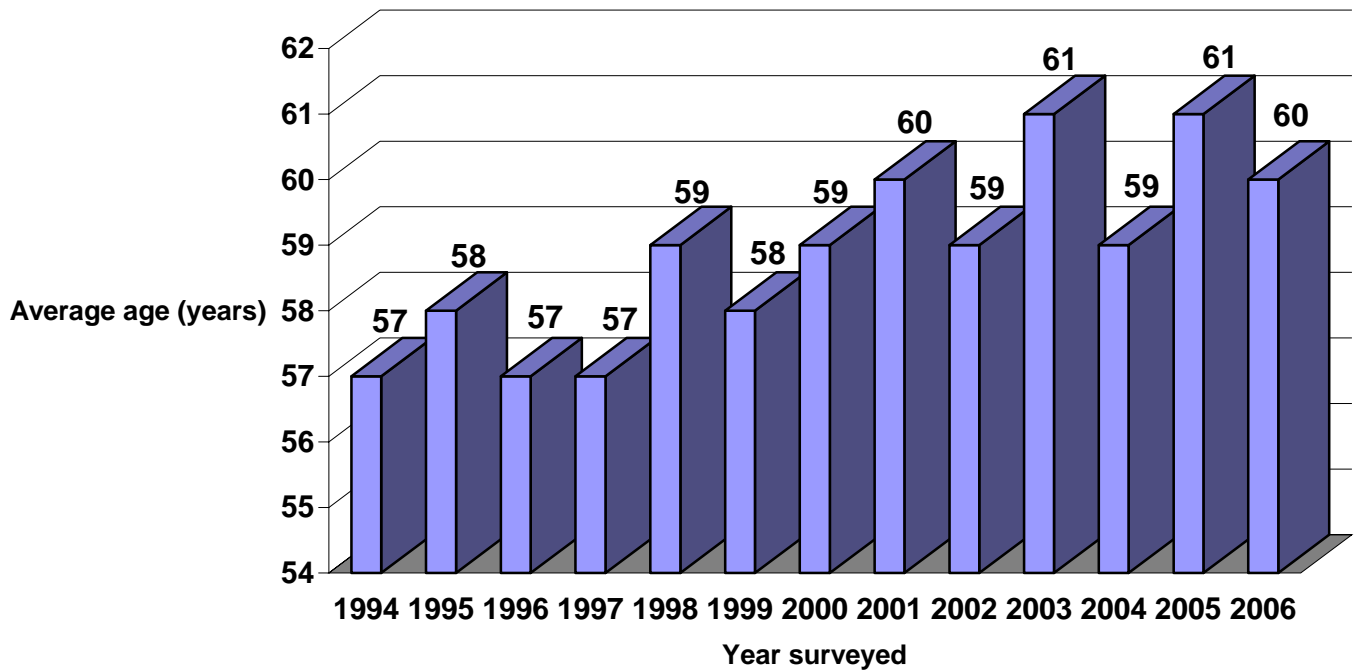
<b>Class Topics</b>	<b>St. Louis</b>	<b>Kansas City</b>	<b>Springfield</b>	<b>St. Joseph</b>	<b>Overall</b>
<b>Topic 1*</b>	750 (86%)	451 (82%)	97 (81%)	67 (77%)	1365 (84%)
<b>Topic 2*</b>	758 (87%)	461 (84%)	98 (82%)	66 (76%)	1383 (85%)
<b>Topic 3*</b>	742 (85%)	412 (75%)	95 (79%)	66 (76%)	1315 (81%)
<b>Topic 4*</b>	734 (84%)	428 (78%)	96 (80%)	66 (76%)	1324 (81%)
<b>Topic 5</b>	718 (82%)	430 (78%)	96 (80%)	69 (79%)	1313 (81%)
<b>Topic 6*</b>	676 (77%)	355 (64%)	93 (78%)	66 (76%)	1190 (73%)

**\*p<.05. Patients from St. Joseph were less likely to attend the course sessions “Introduction to Kidney Disease,” and “Diet and Kidney Disease” compared to patients in other regions. Patients in Kansas City were less likely to attend the “Kidney Transplant” course session than patients in other regions.**

***\*Data only available from 1996-2006***

## C. Patient Age

### C1. Patient Age by Year



### C2. Patient Age by Location

Age	St. Louis	Kansas City	Springfield	St. Joseph*	Overall
<b>Mean (SD)</b>	59 (14.2)	58 (14.5)	60 (12.9)	64 (13.3)	59 (14.2)
<b>Median</b>	61	59	61.5	66	61
<b>Mode</b>	57	62	60	67	62
<b>Range</b>	18-88	16-88	25-87	20-88	16-88

\* $p < 0.01$  – Participants at the St. Joseph classes were significantly older than participants at the St. Louis and Kansas City classes.

## ***D. Gender***

### D1. Gender by Year

	<b>Male</b>	<b>Female</b>
2006	51%	49%
2005	53%	47%
2004	54%	46%
2003	54%	46%
2002	30%	70%
2001	54%	46%
2000	48%	52%
1999	54%	46%
1998	60%	40%
1997	44%	56%
1996	49%	51%
1995	62%	38%
1994	55%	45%
<b><i>Total</i></b>	<b><i>925 (51%)</i></b>	<b><i>872 (49%)</i></b>

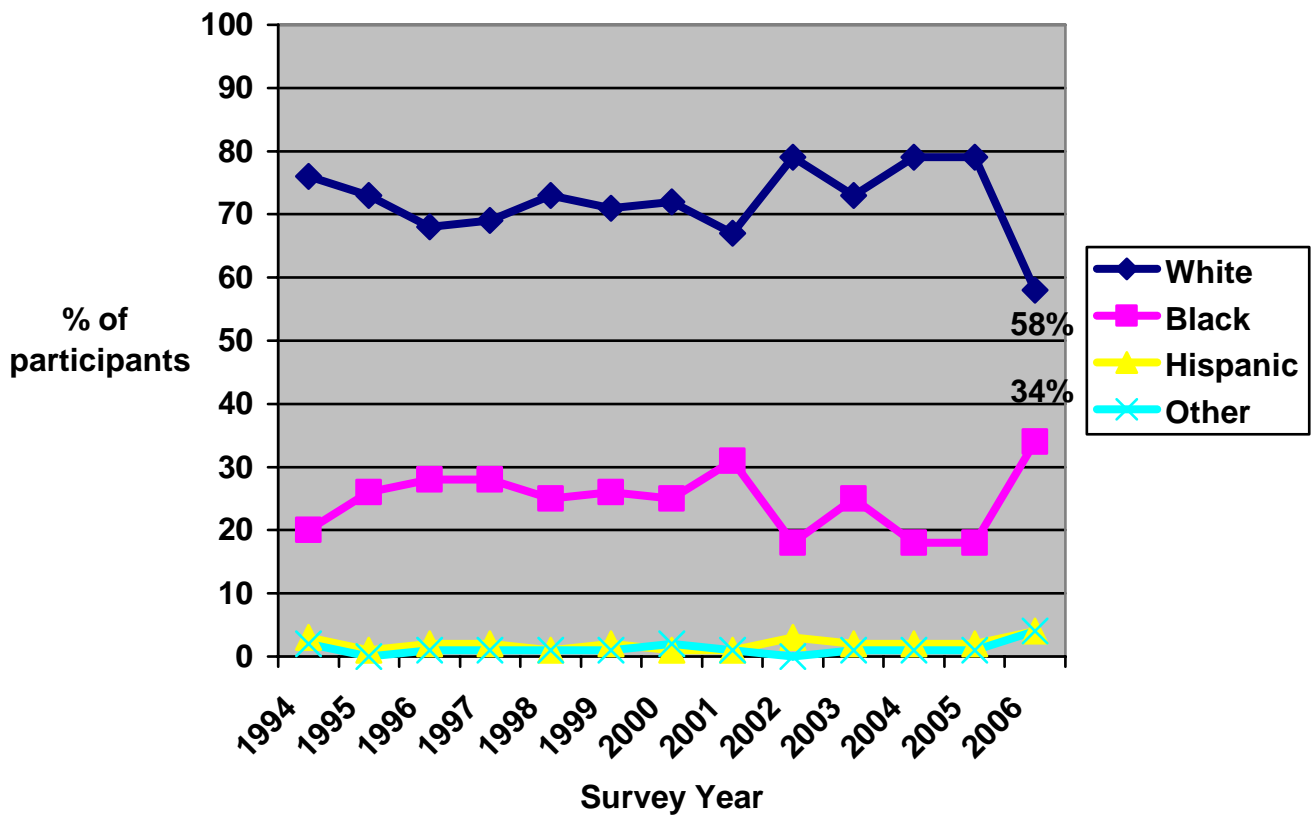
### D2. Gender by Location

<b>Gender</b>	<b>St. Louis</b>	<b>Kansas City</b>	<b>Springfield</b>	<b>St. Joseph</b>	<b>Overall</b>
<b>Male</b>	487 (51%)	374 (56%)	71 (53%)	42 (48%)	974 (53%)
<b>Female</b>	460 (49%)	294 (44%)	62 (47%)	46 (52%)	862 (47%)

**\*p=ns, No significant difference by city**

## E. Race

### E1. Race by Year



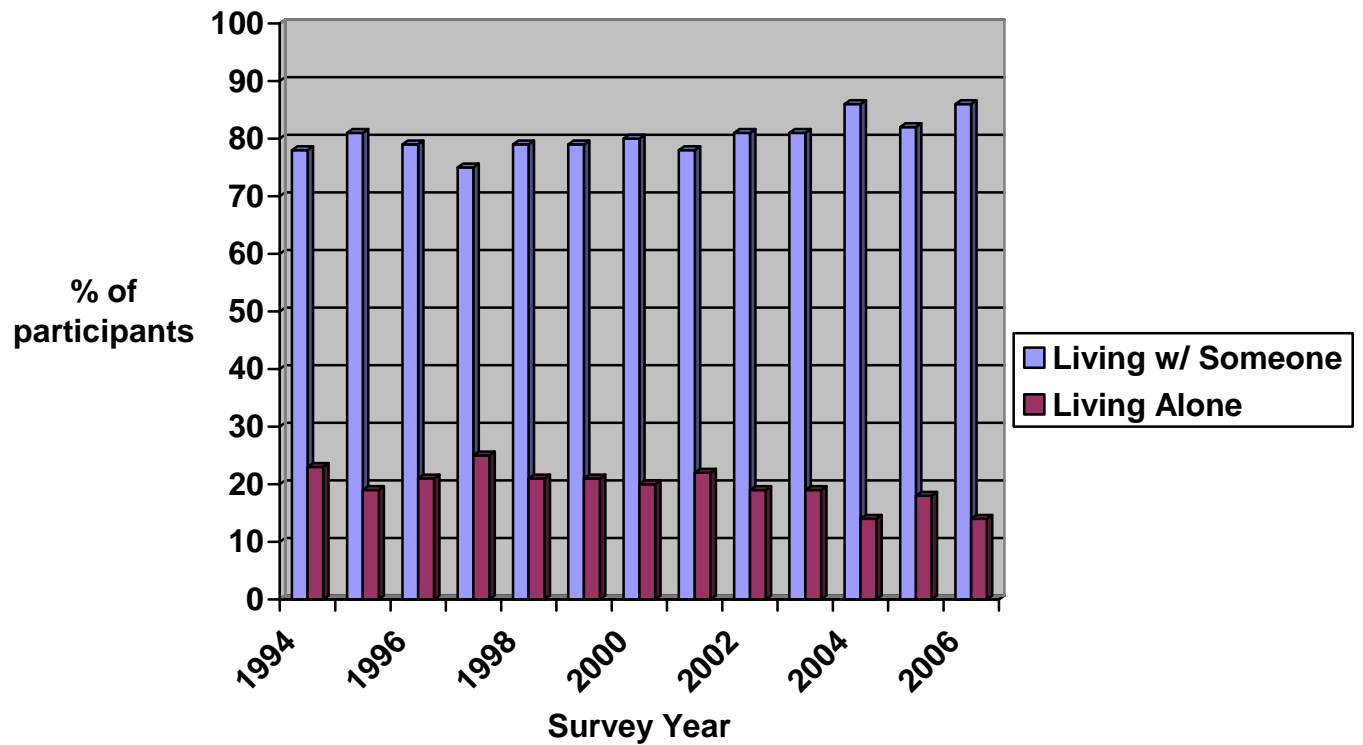
### E2. Race by Location

Race	St. Louis*	Kansas City	Springfield	St. Joseph	Overall
- White	584 (63%)	491 (75%)	124 (97%)	73 (88%)	1272 (71%)
- Black	324 (35%)	124 (19%)	0 (0%)	7 (8%)	455 (26%)
- Hispanic	4 (1%)	25 (4%)	4 (3%)	2 (3%)	35 (2%)
- Other	11 (1%)	12 (2%)	0 (0%)	1 (1%)	24 (1%)

\* $p < 0.05$  – St. Louis had significantly more Black participants attending PEP sessions than in any other city.

## F. Living Situation

F1. Living Situation by Year



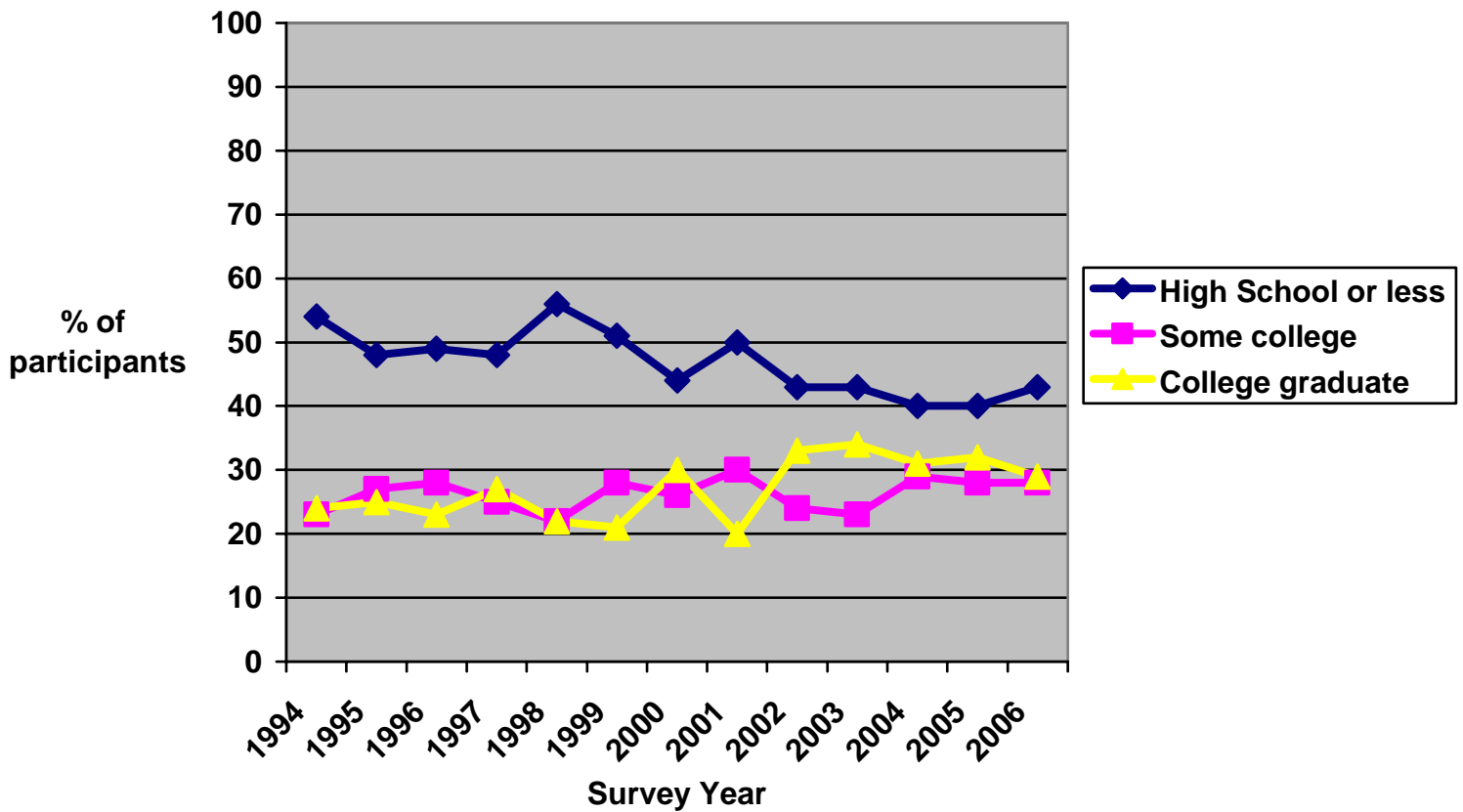
F2. Living Situation by Location

Living Status	St. Louis	Kansas City	Springfield	St. Joseph	Overall
- With Someone	727 (80%)	524 (81%)	108 (83%)	62 (76%)	1421 (80%)
- Alone	187 (20%)	122 (19%)	22 (17%)	20 (24%)	351 (20%)

\*p=ns, No significant differences by city.

## G. Education

### G1. Education by Year



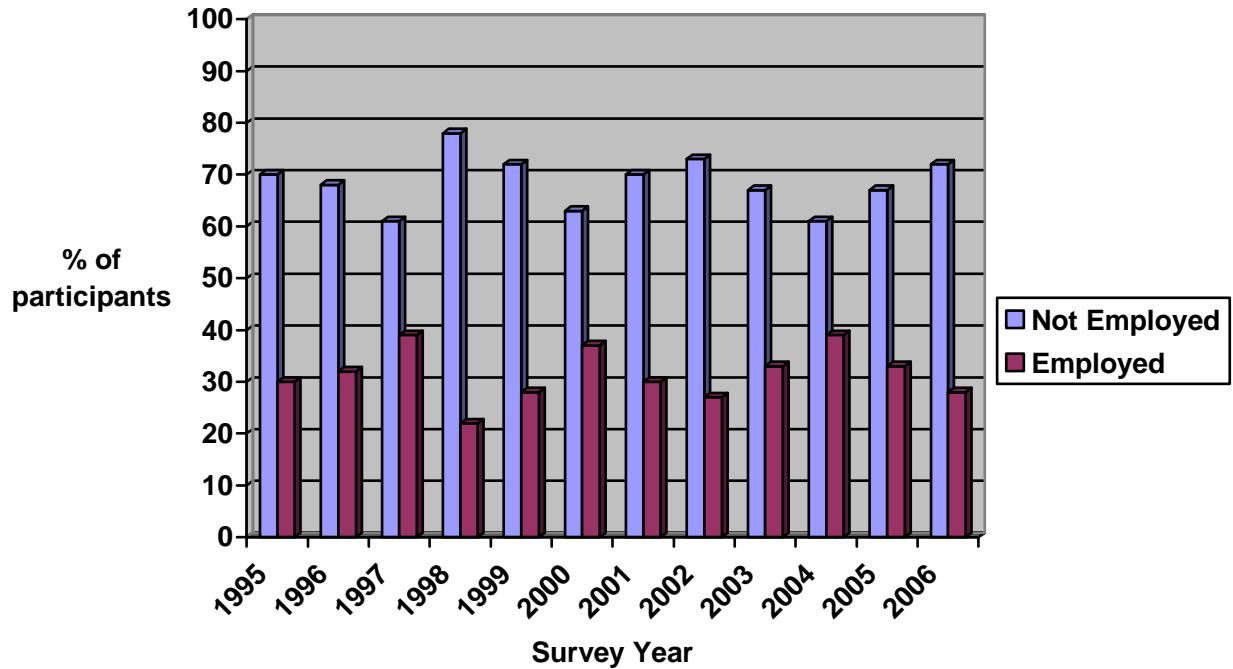
### G2. Education by Location

Education	St. Louis	Kansas City	Springfield*	St. Joseph*	Overall
High School or less	431 (47%)	278 (43%)	78 (59%)	47 (55%)	834 (47%)
Some College	233 (25%)	208 (32%)	31 (24%)	21 (24%)	493 (27%)
College Graduate	261 (28%)	166 (25%)	23 (17%)	18 (21%)	468 (26%)

\* $p < 0.05$ , Participants in Springfield and St. Joseph were more likely to have a high school education or less compared with participants in St. Louis and Kansas City.

## H. Employment Status

### H1. Employment Status by Year



\*Data only available from 1995-2006

### H2. Employment Status by Location

Employment Status	St. Louis*	Kansas City*	Springfield	St. Joseph	Overall
- Not Employed	575 (66%)	401 (67%)	99 (81%)	75 (87%)	1150 (69%)
- Employed	297 (34%)	198 (33%)	24 (19%)	11 (13%)	530 (31%)

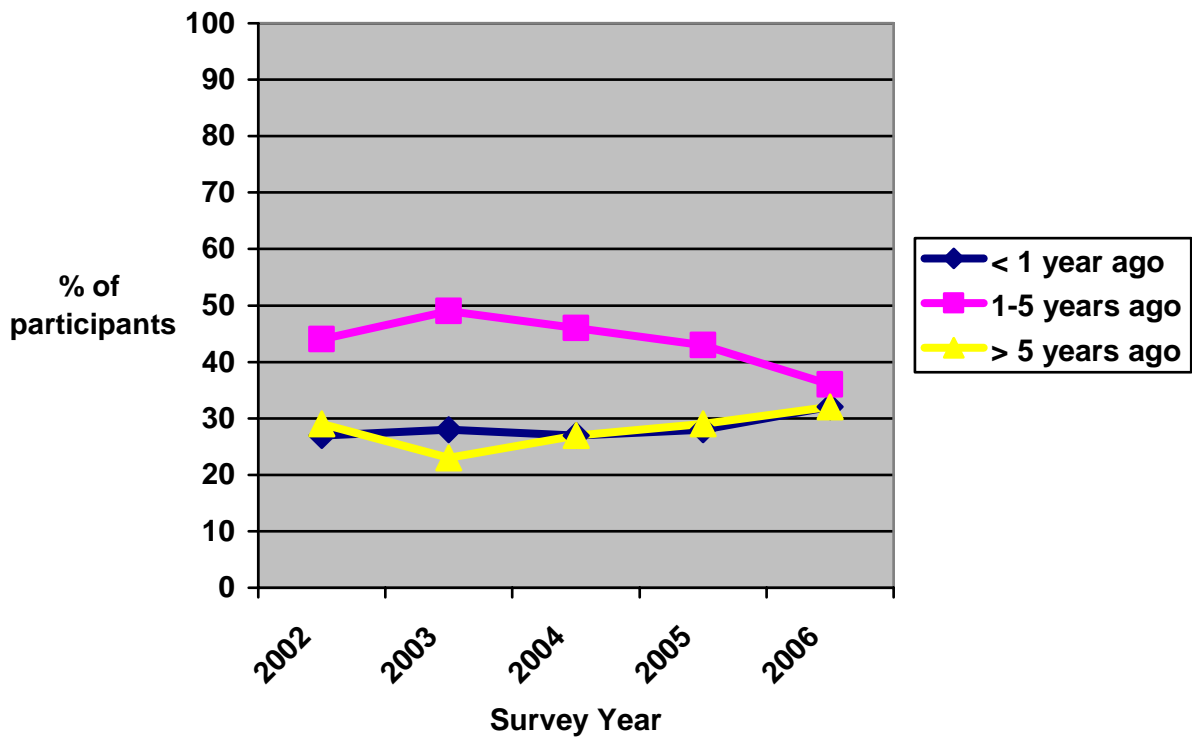
\* $p < 0.001$ , Participants in Springfield and St. Joseph were less likely to be employed compared with participants in St. Louis and Kansas City.

\*Data only available from 1995-2006

## II. Kidney Diagnosis and Dialysis Information

### A. Kidney Diagnosis

#### A1. Length of Time Since Diagnosed with Kidney Disease by Year



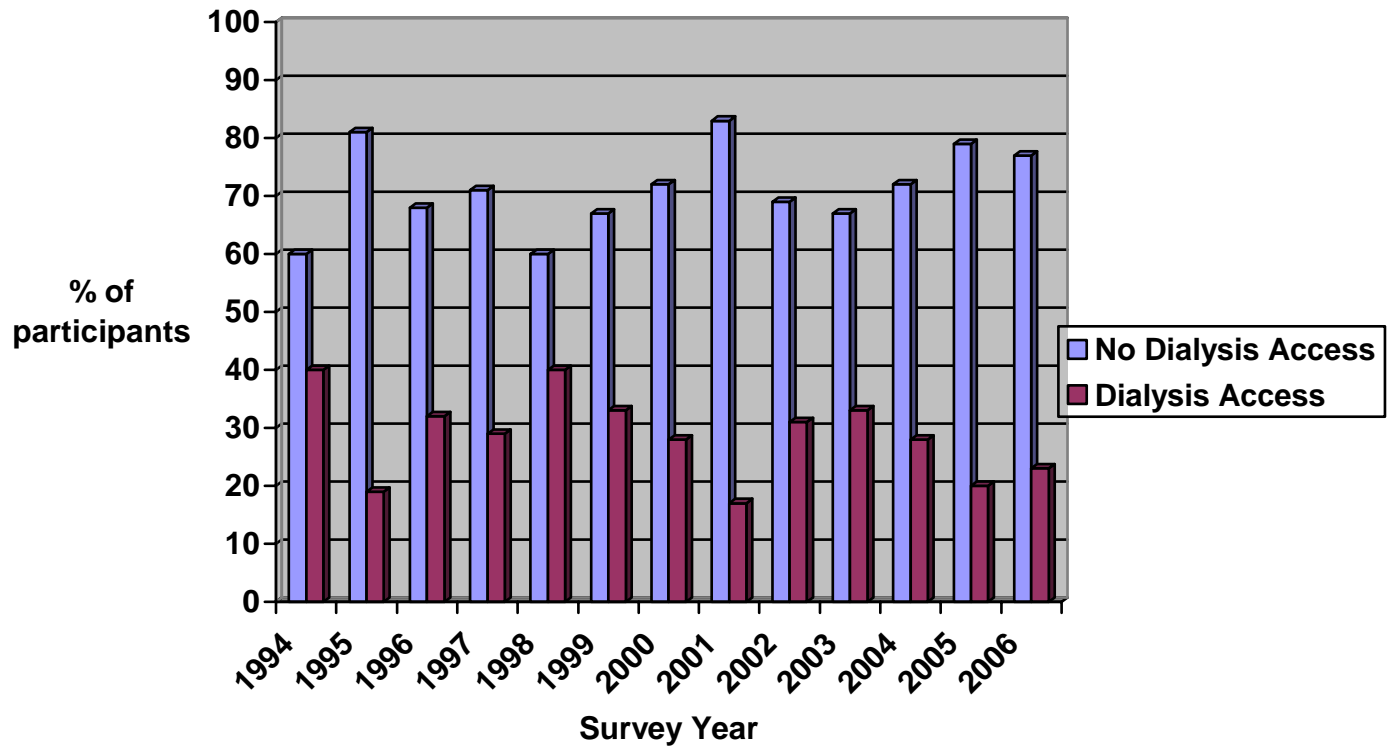
#### A2. Length of Time Since Diagnosed with Kidney Disease by Location

Diagnosed with kidney disease	St. Louis	Kansas City	Springfield	St. Joseph	Overall
< 1 year ago	94 (29%)	68 (29%)	7 (22%)	2 (10%)	171 (28%)
1-5 years ago	142 (43%)	101 (43%)	16 (50%)	10 (53%)	269 (44%)
> 5 years ago	91 (28%)	64 (28%)	9 (28%)	7 (37%)	171 (28%)

\*p=ns, No significant differences by city.

## B. Dialysis Access

### B1. Dialysis Access by Year



### B2. Dialysis Access by Location

Dialysis Access	St. Louis*	Kansas City	Springfield	St. Joseph	Overall
No Dialysis Access	701 (79%)	387 (62%)	76 (64%)	52 (67%)	1216 (71%)
Dialysis Access	190 (21%)	238 (38%)	43 (36%)	26 (33%)	497 (29%)

\*p<0.001, Participants in St. Louis were less likely to have a dialysis access than participants in any other city.

### ***C. Location of Dialysis Access***

#### **C1. Location of Dialysis Access by Year**

	<b>Arm</b>	<b>Chest/Neck</b>	<b>Stomach</b>	<b>Other</b>
2006	48%	48%	0%	4%
2005	44%	39%	13%	4%
2004	43%	37%	20%	0%
2003	64%	14%	19%	2%
2002	58%	15%	25%	2%
2001	60%	16%	24%	0%
2000	60%	31%	4%	4%
1999	61%	19%	12%	8%
1998	64%	13%	20%	4%
1997	39%	18%	32%	11%
1996	65%	9%	26%	0%
1995	45%	14%	41%	0%
1994	64%	11%	25%	0%
<b>Total</b>	<b>279 (57%)</b>	<b>100 (20%)</b>	<b>97 (20%)</b>	<b>16 (3%)</b>

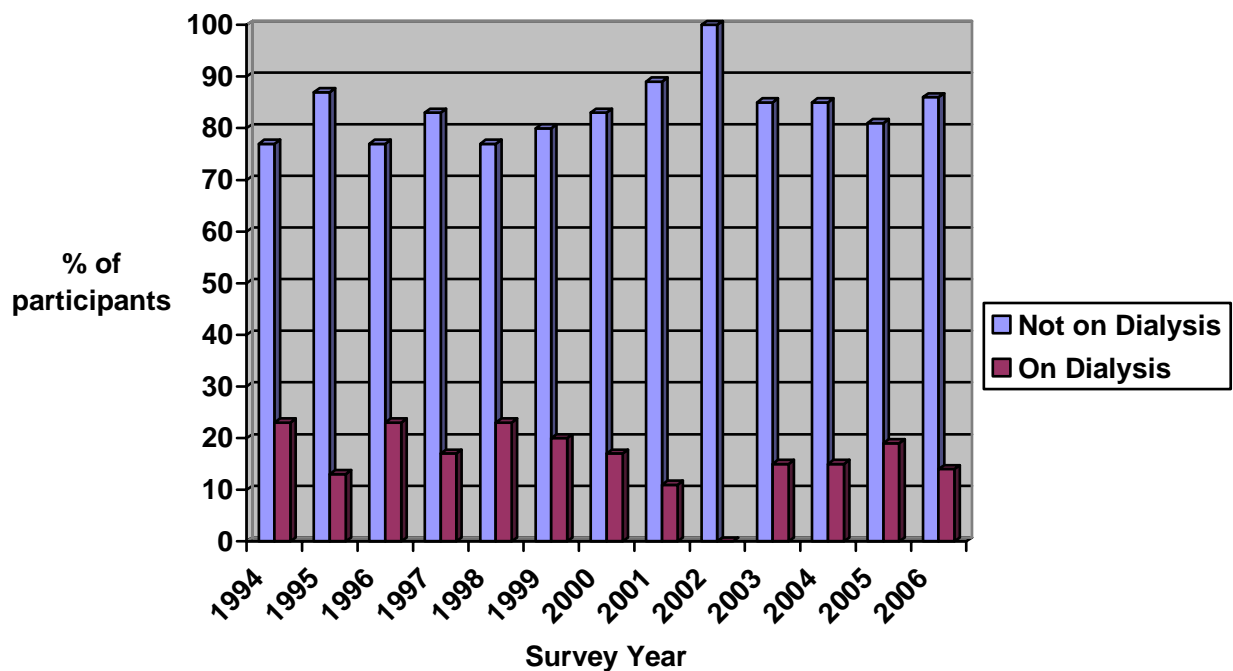
#### **C2. Location of Dialysis Access by Location**

<b>Dialysis Access</b>	<b>St. Louis*</b>	<b>Kansas City*</b>	<b>Springfield*</b>	<b>St. Joseph*</b>	<b>Overall</b>
<b>Arm</b>	109 (58%)	128 (55%)	25 (58%)	17 (65%)	279 (57%)
<b>Chest/Neck</b>	43 (23%)	53 (23%)	1 (2%)	3 (12%)	100 (20%)
<b>Stomach</b>	32 (17%)	43 (18%)	17 (40%)	5 (19%)	97 (20%)
<b>Other</b>	5 (2%)	10 (4%)	0 (0%)	1 (4%)	16 (3%)

**\*p<0.01 – Participants in St. Louis and Kansas City were more likely to have a dialysis access in the chest/neck area, while participants in Springfield were more likely to have access in their stomach and St. Joseph participants in their arm.**

## D. Dialysis Status

### D1. Dialysis Status by Year



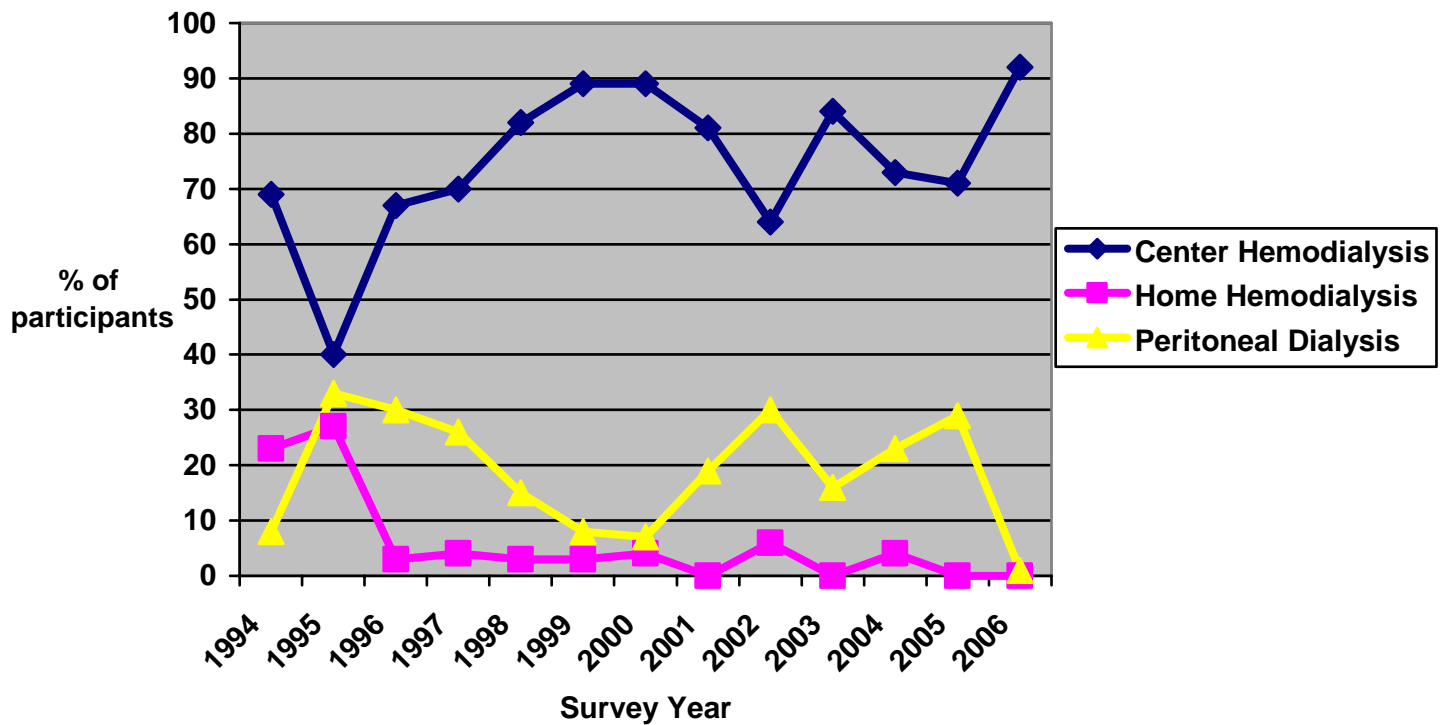
### D2. Dialysis Status by Location

Dialysis Status	St. Louis	Kansas City*	Springfield	St. Joseph	Overall
Not on Dialysis	775 (87%)	464 (73%)	105 (83%)	69 (82%)	1413 (82%)
On Dialysis	114 (13%)	167 (27%)	21 (17%)	15 (18%)	317 (18%)

\* $p < 0.001$  - Participants in Kansas City were significantly more likely to be on dialysis compared to participants in any other city.

## E. Current Type of Dialysis

### E1. Current Type of Dialysis by Year



### E2. Current Type of Dialysis by Location

Type of Dialysis	St. Louis	Kansas City	Springfield	St. Joseph	Overall
<b>Center Hemodialysis</b>	96 (81%)	135 (80%)	15 (68%)	11 (69%)	257 (79%)
<b>Home Hemodialysis</b>	0 (0%)	3 (2%)	0 (0%)	0 (0%)	3 (1%)
<b>Peritoneal Dialysis</b>	22 (19%)	31 (18%)	7 (32%)	5 (31%)	65 (20%)

\*p=ns, No significant differences by city.

### ***III. ATTENDANCE & DEMOGRAPHIC PROFILE SUMMARY***

#### ***Attendance***

- Since 1994, almost 2000 kidney patients have attended PEP classes.
- For each year between 1995-2006, more kidney patients attended the PEP classes in St. Louis compared with other regions in Missouri. Classes in St. Louis have averaged 80 participants per year, while Kansas City classes have averaged 50 participants per year. Springfield and St. Joseph classes had lower participation, with between 17-21 participants in any given year.
- Across the different years, attendance in different class sessions ranged from 65% to 91%. Although attendance varied by course topic, patients were least likely to attend the kidney transplant session. Possible explanations for poorer attendance in the transplant session could include a lack of patient interest in or motivation towards learning about transplant, patients may not be eligible for a transplant, or patient fatigue after multiple course sessions.

#### ***Demographic Profile***

- Patients attending the PEP classes ranged in age from 16-88, with a median age of 61 years. Equal proportions of men and women attended the courses. Patients from St. Joseph were significantly older than patients from other regions.
- Patients were primarily Caucasian (71%) or African-American (26%). In 2006, there was a noticeable increase in the proportion of African-Americans attending PEP courses compared with previous years (34% vs. 18%-30%). To maintain this trend, recruitment of PEP patients should continue to target communities and primary care providers with large numbers of renal patients of varying races and ethnicities. Although significantly more African-Americans attended PEP courses in St. Louis compared to other regions, this difference may be due to the fact that there are more African-Americans in the general population in St. Louis than in other areas.
- Most patients had been diagnosed with kidney disease 1-5 years ago (44%) but that trend appears to be decreasing. In 2006, more patients newly diagnosed with kidney disease or diagnosed >5 years ago attended the programs than in previous years. There were no significant differences in recency of diagnosis of kidney disease by city. This variation in recency of kidney disease diagnosis could affect the relevancy of the educational content presented in PEP courses. For example, it might become necessary to tailor sessions for patients already experienced in dealing with their kidney disease and for those newly diagnosed.
- Most patients attending PEP courses were not yet on dialysis (82%). Patients in Kansas City were more likely to already be on dialysis compared with patients in other cities. Patients on dialysis were most likely having center hemodialysis (79%), although there was a trend where more patients in Springfield and St. Joseph were on peritoneal dialysis (31-32%) than in other cities.
- Although most patients did not yet have a dialysis access (71%), patients in St. Louis were significantly less likely to have a dialysis access compared to other regions. Patients with an access generally had it in their arm (57%). St. Louis and Kansas City had significantly more participants with chest/neck area dialysis accesses, while Springfield had more with stomach accesses and St. Joseph with more arm accesses ( $p=0.01$ ).
- Most patients attending PEP courses were not college graduates (74%). Participants in Springfield and St. Joseph had significantly less education than patients in other regions.
- Overall, the majority of participants were not employed (69%) and that trend has remained relatively constant over the years. Participants in Springfield and St. Joseph were significantly less likely to be employed than patients in other regions.

**IMPACT OF EDUCATION  
ON PATIENT  
KNOWLEDGE,  
ATTITUDES, AND  
EMOTIONS  
(1994-2006)**

## I. Impact of Education:

### A. Differences in Dialysis Preferences

#### A1. Differences in Dialysis Preference

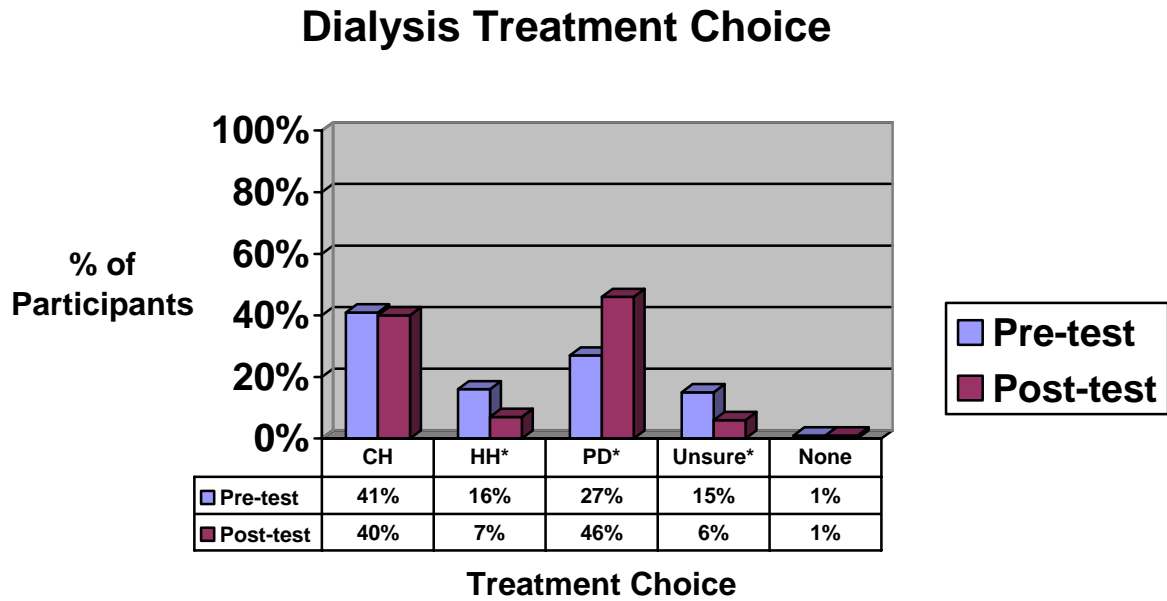
	Center hemodialysis (CH)		No Treatment	
	Pre-test	Post-test	Pre-test	Post-test
2006	25%	28%	1%	0%
2005	20%	33%	0%	1%
2004	23%	28%	3%	2%
2003	44%	N/A	2%	N/A
2002	48%	N/A	0%	N/A
2001	44%	41%	0%	0%
2000	52%	50%	0%	0%
1999	51%	52%	0%	0%
1998	47%	45%	0%	0%
1997	46%	46%	0%	0%
1996	45%	41%	0%	0%
1995	33%	31%	0%	0%
1994	48%	36%	0%	0%
<b>Total</b>	<b>552 (41%)</b>	<b>506 (40%)</b>	<b>6 (1%)</b>	<b>3 (1%)</b>

#### A1. Differences in Dialysis Preference (continued)

	Home hemodialysis (HH)		Undecided		Peritoneal dialysis (PD)	
	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test
2006	12%	9%	46%	19%	16%	44%
2005	10%	6%	51%	18%	19%	42%
2004	15%	8%	33%	9%	26%	52%
2003	24%	N/A	0%	N/A	30%	N/A
2002	48%	N/A	0%	N/A	4%	N/A
2001	19%	5%	0%	0%	37%	53%
2000	12%	7%	10%	5%	26%	38%
1999	12%	6%	4%	3%	33%	39%
1998	10%	9%	11%	3%	32%	43%
1997	14%	6%	7%	3%	34%	44%
1996	7%	5%	17%	5%	31%	49%
1995	15%	8%	17%	3%	35%	58%
1994	11%	7%	7%	2%	34%	55%
<b>Total</b>	<b>215 (16%)</b>	<b>87 (7%)</b>	<b>206 (15%)</b>	<b>73 (6%)</b>	<b>374 (27%)</b>	<b>582 (46%)</b>

*\*Data unavailable for 2002 and 2003 post-tests*

## A2. Overall Dialysis Treatment Choice



\* $p < 0.001$ . There was a significant increase in interest in peritoneal dialysis at post-test.

## A3. Overall Dialysis Treatment Choice

Overall	Pre-test	Post-test	Change Score
Center Hemodialysis	552 (41%)	506 (40%)	-1%
Home Hemodialysis	215 (16%)	87 (7%)	-9%
Peritoneal Dialysis	374 (27%)	582 (46%)	+19%
No Treatment	6 (1%)	3 (1%)	0
Undecided	206 (15%)	73 (6%)	-9%

A4. Dialysis Preference: St. Louis

<b>St. Louis</b>	<b>Pre-test</b>	<b>Post-test</b>	<b>Change Score</b>
<b>Center Hemodialysis</b>	264 (38%)	256 (38%)	0
<b>Home Hemodialysis</b>	111 (16%)	42 (6%)	-10%
<b>Peritoneal Dialysis</b>	191 (28%)	335 (50%)	+22%
<b>No Treatment</b>	4 (1%)	2 (1%)	0
<b>Undecided</b>	117 (17%)	41 (6%)	-11%

\*p=ns, No significant difference by city.

A5. Dialysis Preference: Kansas City

<b>Kansas City</b>	<b>Pre-test</b>	<b>Post-test</b>	<b>Change Score</b>
<b>Center Hemodialysis</b>	221 (43%)	186 (42%)	-1%
<b>Home Hemodialysis</b>	73 (14%)	36 (8%)	-6%
<b>Peritoneal Dialysis</b>	136 (27%)	187 (43%)	+16%
<b>No Treatment</b>	2 (1%)	1 (1%)	0
<b>Undecided</b>	80 (15%)	29 (6%)	-9%

\*p=ns, No significant difference by city.

A6. Dialysis Preference: Springfield

<b>Springfield</b>	<b>Pre-test</b>	<b>Post-test</b>	<b>Change Score</b>
<b>Center Hemodialysis</b>	40 (41%)	36 (44%)	+3%
<b>Home Hemodialysis</b>	22 (22%)	4 (5%)	-17%
<b>Peritoneal Dialysis</b>	31 (32%)	39 (48%)	+16%
<b>No Treatment</b>	0 (0%)	0 (0%)	0
<b>Undecided</b>	5 (5%)	2 (3%)	-2%

\*p=ns, No significant difference by city.

#### A7. Dialysis Treatment Choice in St. Joseph

St. Joseph	Pre-test	Post-test	Change Score
Center Hemodialysis	27 (48%)	28 (51%)	+3%
Home Hemodialysis	9 (16%)	5 (9%)	-7%
Peritoneal Dialysis	16 (29%)	21 (38%)	+9%
No Treatment	0 (0%)	0 (0%)	0
Undecided	4 (7%)	1 (2%)	-5%

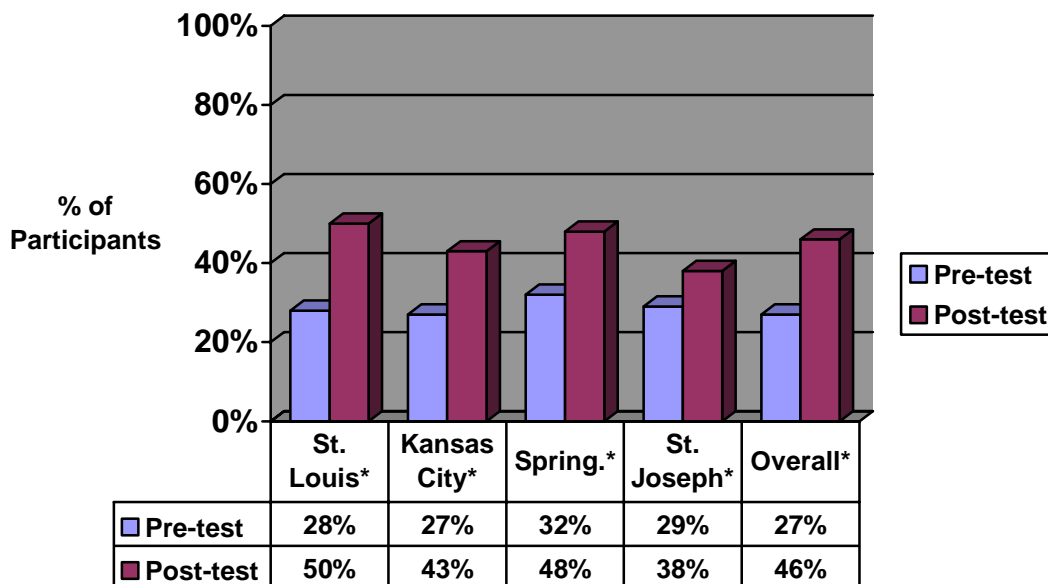
\*p=ns, No significant difference by city.

#### A8. Logistic Regression for Post-Class Dialysis Preference

*Did the type of dialysis they would choose at post-test vary as a function of age, sex, race, education level, or whether they lived with someone? (N=1178)*

In multivariate logistic regression analyses, participants who were older (57 vs. 60 years,  $p<0.001$ ), African-American (54% vs. 36%,  $p<0.001$ ), or had a high school education or less (52% vs. 48%,  $p=0.002$ ) were more likely to choose center hemodialysis compared to other participants. Younger (56 vs. 59 years,  $p=0.002$ ), non African-American (52% vs. 32%,  $p<0.001$ ) participants with greater than a high school education (59% vs. 41%,  $p=0.007$ ) were more likely to choose peritoneal dialysis compared to other participants.

#### A9. Increase in Interest in Peritoneal Dialysis at Post-Test by Location



\* $p<0.01$ , Patients in all cities were significantly more interested in peritoneal dialysis at post-test than at pre-test.

## ***B. Differences in Kidney Transplant Attitudes:***

### B1. Interest in Kidney Transplant by Year

	<b>Interest in Future Kidney Transplantation</b>	
	<b>Pre-test (%Yes)</b>	<b>Post-test (%Yes)</b>
2006	46%	45%
2005	50%	54%
2004	79%	77%
2003	57%	N/A
2002	63%	N/A
2001	53%	67%
2000	61%	57%
1999	61%	65%
1998	56%	55%
1997	51%	52%
1996	49%	56%
1995	49%	43%
1994	57%	49%
<b>Total</b>	<b>897 (56%)</b>	<b>718(57%)</b>

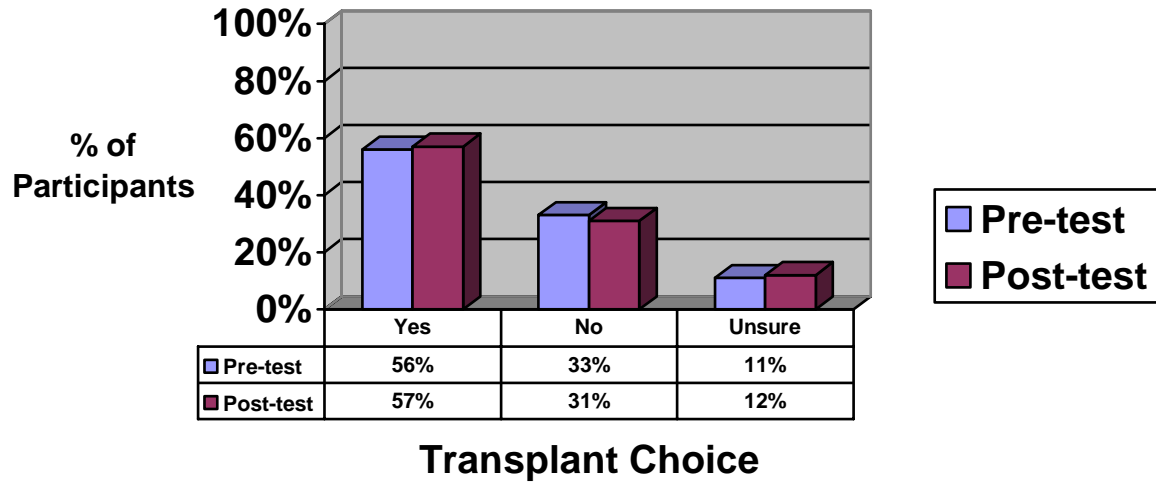
***\*Data unavailable for 2002 and 2003 post-tests***

### B1. Interest in Transplant by Year (continued)

	<b>No</b>		<b>Undecided</b>	
	<b>Pre-test</b>	<b>Post-test</b>	<b>Pre-test</b>	<b>Post-test</b>
2006	14%	18%	40%	37%
2005	13%	11%	37%	35%
2004	21%	23%	(0%	0%
2003	43%	N/A	0%	N/A
2002	37%	N/A	0%	N/A
2001	47%	33%	0%	0%
2000	37%	37%	2%	6%
1999	35%	33%	4%	2%
1998	29%	32%	15%	12%
1997	40%	41%	9%	7%
1996	40%	33%	11%	11%
1995	36%	44%	15%	13%
1994	27%	28%	16%	23%
<b>Total</b>	<b>522 (33%)</b>	<b>394 (31%)</b>	<b>168 (11%)</b>	<b>156 (12%)</b>

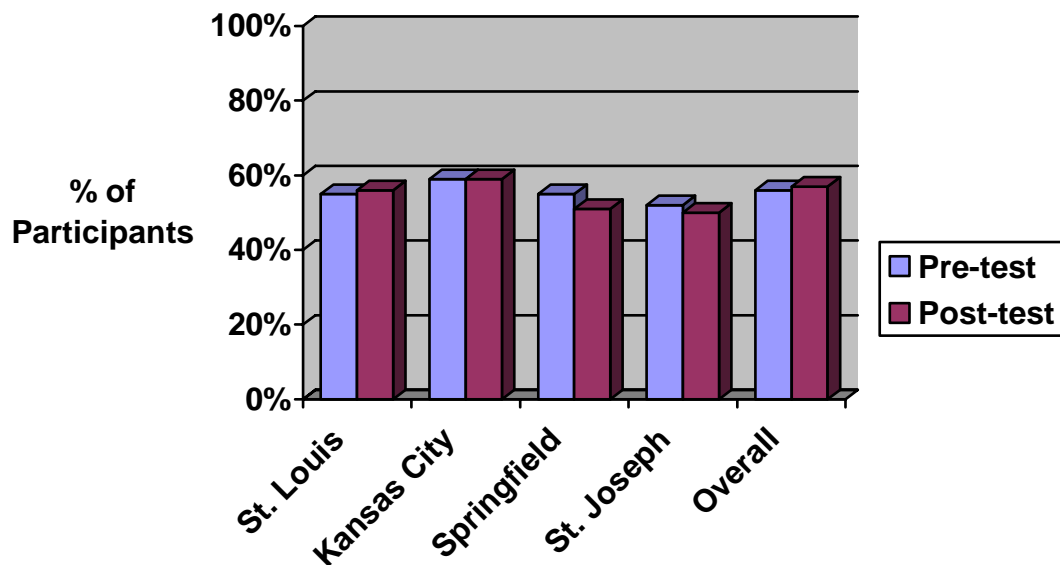
## B2. Change in Overall Transplant Interest

### Change in Overall Interest in Transplant



\*p=ns, no significant changes from pre-test to post-test for interest in transplant.

## B3. Change in Transplant Interest by Location



\*p=ns, No significant difference by city.

## B4. % Change in Transplant Interest by Location

Change Score	St. Louis	Kansas City	Springfield	St. Joseph	Overall
<b>Transplant</b>					
- Yes	+1%	0	-4%	-2%	+1%
- No	-3%	-1%	+2%	+5%	-2%
- Undecided	+2%	+1%	+2%	-3%	+1%

\*p=ns, No significant differences by city.

### B5. Logistic Regression for Pre-Class Kidney Transplant Interest

*Did willingness to receive a transplant at vary as a function of age, sex, race, education level, whether they were currently on dialysis? (N=1162)*

**In multivariate logistic regression analyses, patients who were younger (52 vs. 66 mean years,  $p<.001$ ) and male (59% vs. 54%,  $p=.02$ ) were more interested in having a transplant compared to other patients.**

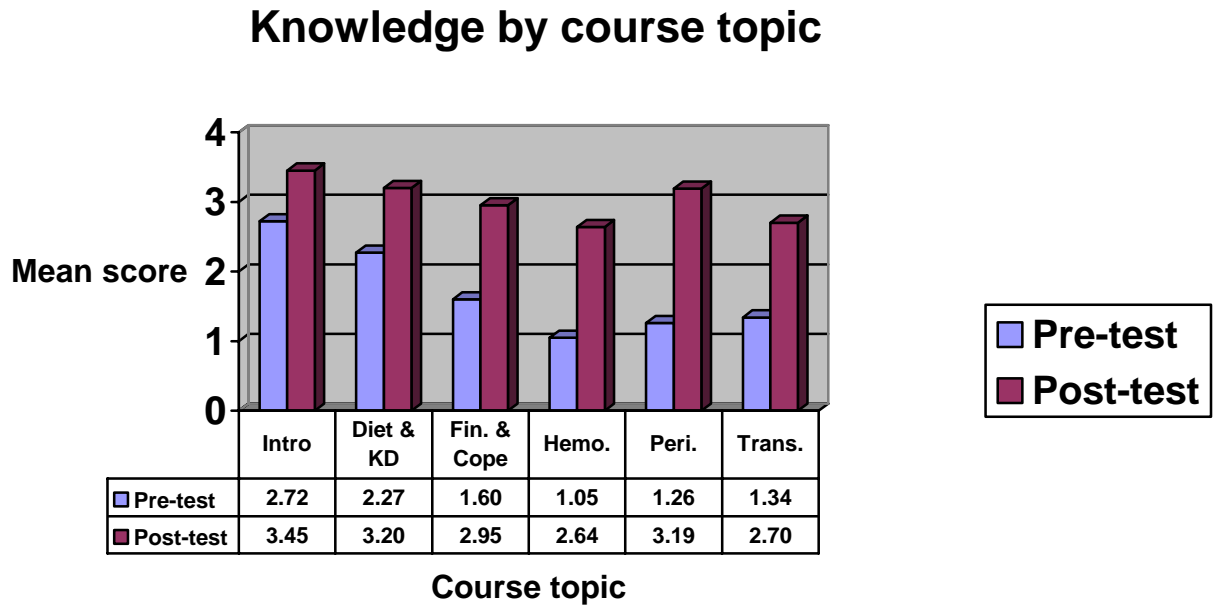
## ***C. Differences in Knowledge about Kidney Disease***

### C1. Pre- and Post-Class Knowledge Survey

Question	Pre-Test % Correct	Post-Test % Correct	% Change
<b>Introduction to Kidney Disease</b>			
Kidneys control blood pressure and anemia. (T)	76.5	91.5	+ 15.0
Poor appetite and headache can be symptoms of uremia. (T)	64.8	92.8	+ 28.0
Nothing can slow down how fast kidneys fail. (F)	60.8	77.6	+ 16.8
People with kidney failure can choose not to treat it. (T)	77.0	87.7	+ 10.7
<b>Diet and Kidney Disease</b>			
Transplant patients can eat anything they want. (F)	65.2	82.5	+ 17.3
People on peritoneal dialysis must eat more protein than those on hemodialysis. (T)	23.1	61.3	+ 38.2
Fluid gains don't matter because dialysis takes it off. (F)	74.5	91.5	+ 17.0
Over-the-counter medicines and herbs are safe to use. (F)	69.8	92.1	+ 22.3
<b>Financing and Coping with Kidney Disease</b>			
Medicare covers a live donor's surgery. (T)	35.1	71.5	+ 36.4
People on dialysis can't work full-time. (F)	66.8	83.4	+ 16.6
Symptoms of uremia can look like depression. (T)	39.6	88.5	+ 48.9
Medicare covers transplant drugs forever. (F)	28.4	56.9	+ 28.5
<b>Hemodialysis</b>			
A catheter is the best kind of hemodialysis access. (F)	38.5	48.9	+ 10.4
Good dialysis does 15% of what healthy kidneys do. (T)	36.2	87.1	+ 50.9
You must do center hemodialysis the same days, times. (T)	65.7	84.3	+ 18.6
You must do home hemodialysis the same days, times. (F)	16.3	49.3	+ 33.0
<b>Peritoneal</b>			
Peritoneal dialysis requires a helper. (F)	46.9	63.4	+ 16.5
People who are blind cannot do peritoneal dialysis. (F)	37.2	52.2	+ 15.0
Hernias can be a problem on peritoneal dialysis. (T)	38.5	87.4	+ 48.9
It's harder to travel on peritoneal than hemodialysis. (F)	37.8	88.6	+ 50.8
<b>Kidney Transplant</b>			
Patients over 70 may get transplants. (T)	27.9	73.3	+ 45.4
Getting a kidney transplant cures kidney disease. (F)	50.1	78.6	+ 28.5
Anti-rejection medicines can damage the kidney. (T)	19.3	52.4	+ 33.1
Kidneys from those who have died work longer than from living donors. (F)	47.3	80.1	+ 32.8
<b>TOTAL PERCENT OF QUESTIONS CORRECT</b>	<b>47.6%</b>	<b>76.0%</b>	<b>+ 28.4</b>

\*Only participants who answered True or False were included in the percentages. No missing values were included because participants could have failed to complete the post-test portion entirely or skipped a question. Participants who answered "Don't Know" were classified as answering the question incorrectly.

## C2. Knowledge by Course Topic\*



\*  $p < 0.001$ , Knowledge significantly increased in all 6 course topics.

## C3. Mean Knowledge Questions Correct

N=358 (2003-2006)	St. Louis	Kansas City	Springfield	St. Joseph	Overall
<b>Questions answered correctly (of 24 possible)</b>					
- <b>Pre-test Mean</b>	10.8 (5.1)	9.6 (4.9)	6.0 (3.2)	6.8 (5.4)	10.2 (5.1)
- <b>Post-test Mean</b>	16.4 (5.6)	16.0 (5.2)	11.4 (5.3)	16.4 (5.3)	16.1 (5.5)

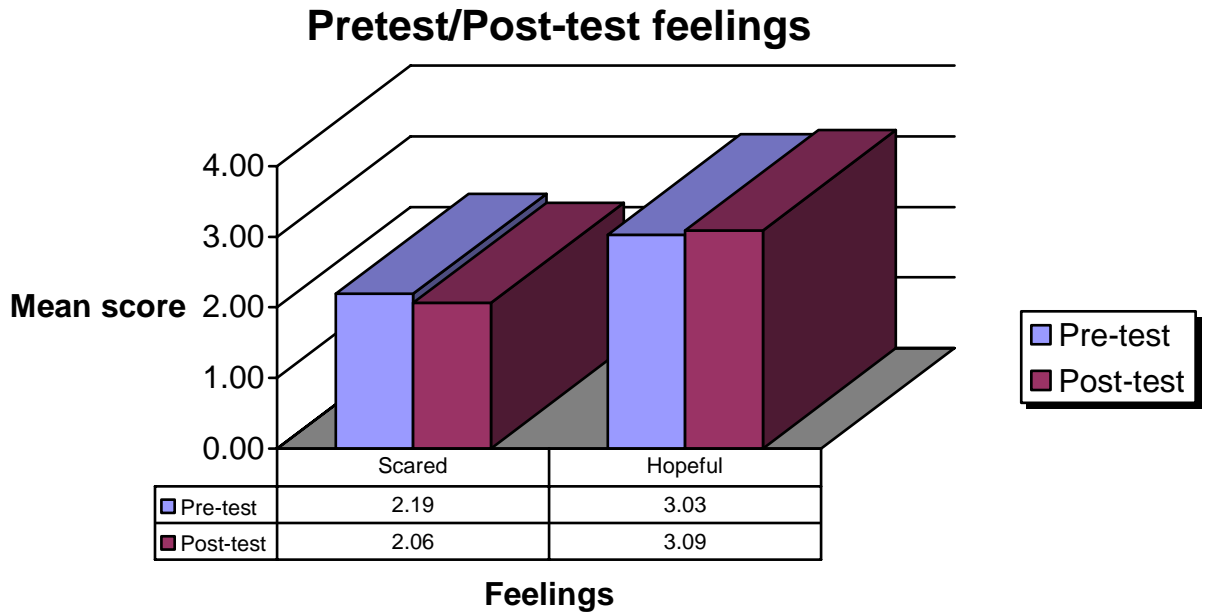
\* $p < 0.05$ , All cities had a significant increase in knowledge from pre to post-test.

\*Data available from 2003-2006

## ***D. Differences in Hopefulness and Fear Levels about Illness***

### **D1. Differences in Emotional State**

How do you feel right now? (1 less – 4 more)



After we conducted the paired t-test, the results indicated that there were no significant emotional changes from pre-test to post-test. Participants reported feeling slightly less scared and slightly more hopeful at post-test, but this change was not significant.

### **D2. Differences in Emotional State by Location**

	St. Louis	Kansas City	Springfield	St. Joseph
Pre-test scared	2.24	2.20	1.69	2.00
Post-test scared	2.07	2.11	1.88	1.58
Pre-test hopeful	3.12	2.88	3.03	3.28
Post-test hopeful	3.13	3.04	3.15	3.08

\*p=ns, There were no significant differences by city.

### **D3. Logistic Regression for Pre-Class Fear about Kidney Disease**

*Compared to their pre-class fear about their kidney disease, did post-class fear vary as a function of age, sex, race, education level, whether they were currently on dialysis, whether they were living alone or with someone, or how many classes they attended?*

In multivariate logistic regression analyses, female participants were significantly less afraid at post-test compared to male participants (p=0.01).

## ***II. IMPACT OF EDUCATION SUMMARY***

### ***Interest in Dialysis Options***

- At pre-test patients generally preferred center hemodialysis (41%), although there have been decreases in its popularity throughout the years. The proportion of patients who enter the PEP program undecided about their dialysis preference have also increased over the years.
- After the discussion about dialysis in the PEP course, patients' interest in center hemodialysis generally stayed the same, their interest in home dialysis decreased, and their interest in peritoneal dialysis significantly increased (27% to 46%). Many patients who were undecided about their dialysis treatment preference were able to indicate a preference at post-test.
- Interest in peritoneal dialysis significantly increased in all four cities from pre- to post-test ( $p < 0.01$ ).

### ***Interest in Kidney Transplant***

- 56%-57% of all patients were interested in transplant. Over time, more patients are entering the PEP program undecided about their transplant preference.
- After discussion of transplant in the PEP course, patient's interest in transplant did not significantly increase. There were no differences in transplant interest by city. One possible explanation for the lack of change in transplant attitudes might be explained by some patients not attending the transplant educational session.
- Patients who were younger (52 vs. 67 mean years,  $p < .001$ ) and male (59% vs. 54%,  $p = .02$ ) were more interested in having a transplant compared to other patients.

### ***Knowledge about Kidney Disease***

- After the PEP class content, patients were able to answer 76% of questions correctly, an increase of 28% from their pre-test scores. Knowledge significantly increased for all 6 course topics.
- The questions with the greatest increase in being answered correctly at post-test (>30% increase) were:
  - People on peritoneal dialysis must eat more protein than those on hemodialysis.
  - Medicare covers a live donor's surgery.
  - Symptoms of uremia can look like depression.
  - Good dialysis does what 15% of healthy kidneys do.
  - You must do home hemodialysis the same days, times.
  - Hernias can be a problem on peritoneal dialysis.
  - It's harder to travel on peritoneal dialysis than hemodialysis.
  - Patients over 70 may get transplants.
  - Anti-rejection medications can damage the kidney.
  - Kidneys from those who have died work longer than from live donors.
- All cities had a significant increase in knowledge from pre to post-test ( $p < 0.05$ ).

### ***Hopefulness about Kidney Disease***

- Although there was a trend where patients felt more hopeful and less scared about kidney disease at post-test, these changes were not significant.
- There were no differences in emotional state at post-test by city.

### **III. ANSWERS TO KEY RESEARCH QUESTIONS:**

1. Did the knowledge of PEP class participants significantly improve from pre- to post-class? **Yes.** *PEP participants' knowledge significantly increased from pre- to post-class.*
2. Did their interest in receiving a transplant increase from pre- to post-class? **No.** *The percentage of PEP class participants who were planning on receiving a kidney transplant remained relatively constant from pre-test (56%) to post-test (57%).*
3. Did their interest in types of dialysis differ from pre- to post-class? **Yes.** *When comparing dialysis preferences from pre- to post-test, PEP participants' preference for peritoneal (27% vs. 46%) significantly increased, while their preference for home hemodialysis (16% vs. 7%) and center hemodialysis (41% vs. 40%) decreased. There was also a decrease in the number of PEP patients who were unsure about which type of dialysis they would have (15% vs. 6%).*
4. Did willingness to receive a transplant vary as a function of age, sex, race, education level, or whether they were currently on dialysis? **Yes.** *Participants who were younger and male were significantly more likely to plan on receiving a future kidney transplant than older, female participants. Race, education level, and dialysis status did not significantly predict participants' plans to receive a future kidney transplant.*
5. Did the type of dialysis they would choose at post-test vary as a function of age, sex, race, education level, or whether they lived with someone? **Yes.** *Participants who were older, African-American, or had a high school education or less were more likely to choose center hemodialysis compared to participants who were younger, more educated, or of another race. Younger, non African-American, participants with greater than a high school education were more likely to choose peritoneal dialysis compared to older, African-American, less educated participants. Type of dialysis patients would choose did not vary by sex or whether they were living alone or with someone.*
6. Compared to their pre-class fear about their kidney disease, did post-class fear vary as a function of age, sex, race, education level, whether they were currently on dialysis, whether they were living alone or with someone, or how many classes they attended? **Yes.** *Using a variable measuring change in fear from pre- to post-class, female participants were significantly less afraid at post-test compared to male participants. Fear did not vary by race, education level, whether they were currently on dialysis, whether they were living alone or with someone, or how many classes they attended.*

**OVERALL PROGRAM  
EVALUATION BY  
LOCATION  
(2002-2006)**

# ***I. Overall Program Evaluation***

## ***A. St. Louis PEP Program Evaluation***

### A1. St. Louis Class Content

	<b>Introduction to Kidney Disease</b>	<b>Diet and Kidney Disease</b>	<b>Financing and Coping</b>	<b>Hemodialysis</b>	<b>Peritoneal Dialysis</b>	<b>Transplantation</b>	<b>Handout materials</b>
Excellent	191 (68%)	170 (61%)	163 (60%)	200 (69%)	212 (74%)	186 (71%)	124 (74%)
Good	86 (30%)	95 (34%)	100 (37%)	88 (30%)	72 (25%)	70 (27%)	43 (26%)
Fair	5 (2%)	12 (4%)	8 (3%)	2 (1%)	3 (1%)	4 (1%)	1 (1%)
Poor	0 (0%)	1 (1%)	1 (1%)	1 (1%)	1 (1%)	3 (1%)	0 (0%)

### A2. St. Louis Moderator/Speaker Quality

	<b>Moderator</b>	<b>Professional speakers</b>	<b>Patient speakers</b>
Excellent	134 (74%)	131 (73%)	124 (70%)
Good	45 (25%)	48 (27%)	51 (29%)
Fair	2 (1%)	1 (1%)	1 (1%)
Poor	0 (0%)	0 (0.0%)	0 (0.0%)

### A3. St. Louis Quality of PEP Format

	<b>Length of the program</b>	<b>Length of each class topic</b>	<b>Number of topics per day</b>	<b>Time for asking questions</b>	<b>Time to talk with people with kidney disease and their families</b>
Excellent	75 (41%)	79 (44%)	82 (46%)	98 (54%)	92 (53%)
Good	98 (54%)	95 (52%)	94 (52%)	82 (45%)	74 (42%)
Fair	9 (5%)	6 (3%)	4 (2%)	2 (1%)	7 (4%)
Poor	1 (1%)	1 (1%)	0 (0%)	0 (0%)	2 (1%)

### A4. St. Louis Overall Quality of PEP Program

	<b>Overall quality of the class in helping me make a decision about my treatment</b>	<b>Overall quality of the class in helping me cope with my kidney disease</b>	<b>Overall quality of the education offered</b>
Excellent	99 (54%)	71 (50%)	112 (62%)
Good	78 (43%)	59 (42%)	67 (37%)
Fair	5 (3%)	11 (8%)	1 (1%)
Poor	0 (0%)	0 (0%)	0 (0%)

A5. St. Louis Willingness to Refer Others to PEP Program

<b>Willingness to Refer</b>	<b>Frequency</b>	<b>Percent</b>
Yes	143	100%
No	0	0 %
<b><i>Total</i></b>	<b><i>143</i></b>	<b><i>100.0%</i></b>

***B. Kansas City***

B1. Kansas City Class Content

	<b>Introduction to Kidney Disease</b>	<b>Diet and Kidney Disease</b>	<b>Financing and Coping</b>	<b>Hemodialysis</b>	<b>Peritoneal Dialysis</b>	<b>Transplantation</b>	<b>Handout materials</b>
Excellent	125 (67%)	121 (64%)	97 (54%)	126 (69%)	126 (69%)	104 (68%)	73 (69%)
Good	59 (32%)	52 (27%)	61 (34%)	51 (28%)	51 (28%)	45 (29%)	28 (27%)
Fair	2 (1%)	13 (7%)	19 (11%)	6 (3%)	5 (3%)	2 (1%)	3 (3%)
Poor	0 (0%)	3 (2%)	2 (1%)	0 (0%)	0 (0%)	2 (1%)	1 (1%)

B2. Kansas City Moderator/Speaker Quality

	<b>Moderator</b>	<b>Professional speakers</b>	<b>Patient speakers</b>
Excellent	78 (63%)	84 (68%)	73 (65%)
Good	42 (34%)	39 (31%)	39 (34%)
Fair	3 (3%)	1 (1%)	1 (1%)
Poor	0 (0%)	0 (0%)	0 (0%)

B3. Kansas City Quality of PEP Format

	<b>Length of the program</b>	<b>Length of each class topic</b>	<b>Number of topics per day</b>	<b>Time for asking questions</b>	<b>Time to talk with people with kidney disease and their families</b>
Excellent	55 (46%)	54 (45%)	55 (47%)	71 (58%)	62 (53%)
Good	58 (48%)	61 (51%)	59 (50%)	50 (41%)	46 (39%)
Fair	4 (3%)	5 (4%)	3 (3%)	1 (1%)	6 (5%)
Poor	3 (3%)	0 (0%)	0 (0%)	1 (1%)	4 (3%)

#### B4. Kansas City Overall Quality of PEP Program

	<b>Overall quality of the class in helping me make a decision about my treatment</b>	<b>Overall quality of the class in helping me cope with my kidney disease</b>	<b>Overall quality of the education offered</b>
Excellent	76 (64%)	63 (58%)	83 (68%)
Good	40 (34%)	40 (37%)	38 (31%)
Fair	3 (2%)	6 (5%)	1 (1%)
Poor	0 (0%)	0 (0%)	0 (0%)

#### B5. Kansas City Willingness to Refer Others to PEP Program

<b>Willingness to Refer Others</b>	<b>Frequency</b>	<b>Percent</b>
Yes	108	99%
No	1	1 %
<b>Total</b>	<b>109</b>	<b>100.0%</b>

### ***C. Springfield***

#### C1. Springfield Class Content

	<b>Introduction to Kidney Disease</b>	<b>Diet and Kidney Disease</b>	<b>Financing and Coping</b>	<b>Hemodialysis</b>	<b>Peritoneal Dialysis</b>	<b>Transplantation</b>	<b>Handout materials</b>
Excellent	29 (97%)	23 (77%)	24 (80%)	21 (91%)	21 (91%)	21 (100%)	3 (75%)
Good	1 (3%)	3 (10%)	3 (10%)	2 (9%)	2 (9%)	0 (0%)	1 (25%)
Fair	0 (0%)	3 (10%)	2 (7%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Poor	0 (0%)	1 (3%)	1 (3%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

#### C2. Springfield Moderator/Speaker Quality

	<b>Moderator</b>	<b>Professional speakers</b>	<b>Patient speakers</b>
Excellent	4 (80%)	3 (75%)	2 (100%)
Good	1 (20%)	1 (25%)	0 (0%)
Fair	0 (0%)	0 (0%)	0 (0%)
Poor	0 (0%)	0 (0.0%)	0 (0.0%)

### C3. Springfield Quality of PEP Format

	<b>Length of the program</b>	<b>Length of each class topic</b>	<b>Number of topics per day</b>	<b>Time for asking questions</b>	<b>Time to talk with people with kidney disease and their families</b>
Excellent	2 (40%)	2 (40%)	2 (40%)	3 (60%)	3 (60%)
Good	3 (60%)	3 (60%)	3 (60%)	2 (40%)	2 (40%)
Fair	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Poor	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

### C4. Springfield Overall Quality of PEP Program

	<b>Overall quality of the class in helping me make a decision about my treatment</b>	<b>Overall quality of the class in helping me cope with my kidney disease</b>	<b>Overall quality of the education offered</b>
Excellent	3 (60%)	2 (40%)	3 (60%)
Good	2 (40%)	3 (60%)	2 (40%)
Fair	0 (0%)	0 (0%)	0 (0%)
Poor	0 (0%)	0 (0%)	0 (0%)

### C5. Springfield Willingness to Refer Others to PEP Program

<b>Willingness to Refer Others</b>	<b>Frequency</b>	<b>Percent</b>
Yes	5	100%
No	0	0 %
<b>Total</b>	<b>5</b>	<b>100.0%</b>

## ***D. St. Joseph***

### D1. St. Joseph Class Content

	<b>Introduction to Kidney Disease</b>	<b>Diet and Kidney Disease</b>	<b>Financing and Coping</b>	<b>Hemodialysis</b>	<b>Peritoneal Dialysis</b>	<b>Transplantation</b>	<b>Handout materials</b>
Excellent	10 (77%)	12 (92%)	10 (77%)	12 (80%)	12 (80%)	13 (87%)	3 (75%)
Good	3 (23%)	1 (8%)	0 (0%)	3 (20%)	3 (20%)	2 (13%)	1 (25%)
Fair	0 (0%)	0 (0%)	2 (15%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Poor	0 (0%)	0 (0%)	1 (8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

D2. St. Joseph Moderator/Speaker Quality

	<b>Moderator</b>	<b>Professional speakers</b>	<b>Patient speakers</b>
Excellent	2 (50%)	2 (50%)	3 (75%)
Good	2 (50%)	2 (50%)	1 (25%)
Fair	0 (0%)	0 (0%)	0 (0%)
Poor	0 (0%)	0 (0%)	0 (0%)

D3. St. Joseph Quality of PEP Format

	<b>Length of the program</b>	<b>Length of each class topic</b>	<b>Number of topics per day</b>	<b>Time for asking questions</b>	<b>Time to talk with people with kidney disease and their families</b>
Excellent	2 (50%)	2 (50%)	2 (50%)	2 (50%)	2 (50%)
Good	2 (50%)	2 (50%)	2 (50%)	2 (50%)	2 (50%)
Fair	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Poor	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

D4. St. Joseph Overall Quality of PEP Program

	<b>Overall quality of the class in helping me make a decision about my treatment</b>	<b>Overall quality of the class in helping me cope with my kidney disease</b>	<b>Overall quality of the education offered</b>
Excellent	3 (75%)	3 (75%)	3 (75%)
Good	1 (25%)	1 (25%)	1 (25%)
Fair	0 (0%)	0 (0%)	0 (0%)
Poor	0 (0%)	0 (0%)	0 (0%)

D5. St. Joseph Willingness to Refer Others to PEP Program

<b>Willingness to Refer Others</b>	<b>Frequency</b>	<b>Percent</b>
Yes	5	100%
No	0	0%
<b>Total</b>	<b>5</b>	<b>100.0%</b>

## ***II. PEP PROGRAM EVALUATION SUMMARY***

- 99% of the patients in every city would recommend the PEP program to other patients with kidney disease.
- At least 90% of the patients in every city rated these characteristics of the PEP program to be good or excellent:
  - The length of the program
  - The length of the class topic
  - The number of topics per day
  - The availability of time for asking questions
  - Time to talk with people with kidney disease and their families
  - The speaker quality
  - The ability of the class to help them make their decision about treatments
  - The ability of the class to help them cope with kidney disease
  - The handout materials
  - The education's overall quality
- In St. Louis, 95% of patients also rated the presentation of all six class topics to be excellent or good. In Kansas City, Springfield, and St. Joseph, although 95% patients rated the sessions, "Introduction to kidney disease," "Hemodialysis," "Peritoneal dialysis," "Transplantation," as excellent or good, two topics were less positively rated. In these regions, the "Financing and Coping" session was rated as fair or poor by 10%-23% of attendees and the "Diet and Kidney Disease" session was rated as fair or poor by 8-13% of patients.