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# Barriers to Preemptive Kidney Transplantation

A SURVEY OF PEOPLE WITH CHRONIC KIDNEY DISEASE FINDS THAT MANY SEE TRANSPLANTATION AS AN OPTION OF LAST RESORT.

## ABSTRACT

**Background:** Patients who receive kidney transplants before beginning dialysis (known as *preemptive transplantation*) have lower rates of morbidity and mortality and a longer work life than do those who receive them after beginning dialysis. But in the United States fewer than 2.5% of patients with end-stage kidney disease undergo transplantation as their initial therapy.

**Objective:** To understand barriers to early transplantation, the National Kidney Foundation (NKF) surveyed patients randomly selected from its database.

**Methods:** A 28-question survey on socioeconomic factors; perceptions, fears, and concerns about living-donor transplantation; and education regarding transplantation as a treatment option was distributed to a total of 3,586 people randomly chosen from the NKF's database. The database is not limited to kidney patients, and 19.3% of the responses were disqualified because the respondents didn't have chronic kidney disease (CKD) or hadn't undergone kidney transplantation. The 417 responses acceptable for analysis represented at least 12% of qualified survey recipients. Of these, 316 (76%) were kidney transplant recipients from either living or deceased donors and 101 (24%) were patients with CKD who had never undergone transplantation. The surveys sent to the latter group contained slight modifications from those sent to the transplant recipients. We compared responses from people who had undergone kidney transplantation with responses from those who hadn't undergone the procedure.

**Results:** Renal transplant recipients had higher incomes and more education, were more often white, and were more likely to have learned about treatment options from a physician than were those who hadn't undergone transplantation. Half of the respondents who hadn't undergone the procedure believed that dialysis must precede transplantation, and 60% viewed transplantation as a last resort. Out-of-pocket expenses were greater for transplant recipients, even though worries about future medical costs were common in both groups. Most respondents were willing to accept a kidney from a living donor, although they were uncomfortable with asking someone to donate.

**Conclusions:** Substantial barriers to preemptive kidney transplantation remain for patients with CKD; a lack of financial resources and educational deficits were the most common barriers found in the survey.

**K**idney transplantation before or within the first year of dialysis increases five-year survival rates by more than 10% over transplantation occurring a year or more after dialysis, according to one U.S. center's living-donor kidney transplantation data from 1963 to 1998.<sup>1</sup> Early transplantation from a living donor also reduces rates of dialysis-related illness, loss of employment, and costs. Because early transplantation often makes use of living donors, it may have the added benefit of removing a candidate from the deceased-donor waiting list. Even so, in the United States most patients begin kidney replacement therapy with dialysis. In 2005 fewer than 2.5% of patients with end-stage renal disease (ESRD) underwent transplantation instead of beginning chronic dialysis.<sup>2</sup> That this percentage has remained so low over the past decade was the subject of a recent interdisciplinary conference convened by the National Kidney Foundation (NKF). Attendees expressed hope that this situation could change, concluding that "with implementation of early education, referral to a transplant center coincident with creation of vascular access, timely transplant evaluation, and identification of potential living donors, early transplantation can be an option for substantially more patients with chronic kidney disease."<sup>3</sup>

Few data exist regarding the perspective on early or preemptive transplantation in patients with chronic kidney disease (CKD). Even as the advantages for most patients of early transplantation over dialysis have become evident,<sup>4</sup> the process culminating in preemptive transplantation remains rigorous and challenging.

There are many barriers to early transplantation for patients with progressive kidney disease, beginning with the infrequency of timely referral by a health care professional. In addition, patients are not always

**Table 1. Demographic Characteristics of Eligible Respondents<sup>a</sup>**

	Previous transplantation (n = 316)	No previous transplantation (n = 101)	Total (N = 417)	P value
<b>Currently on dialysis — no. (%)</b>	30 (9.5)	55 (54.5)	85 (20.4)	0.001
Age <sup>b</sup> (± SD)	52 ± 14	55 ± 14	53 ± 14	0.018
Sex (M/F)	140/173	43/55	183/228	0.882
<b>Race or ethnicity — no. (%)</b>				0.004
White	264 (83.5)	66 (65.3)	330 (79.1)	
African American	23 (7.3)	15 (14.9)	38 (9.1)	
Hispanic	34 (10.8)	14 (13.9)	48 (11.5)	
Other, or no answer	14 (4.4)	14 (13.9)	28 (6.7)	
<b>Highest education attained — no. (%)</b>				0.001
High school or less	44 (13.9)	18 (17.8)	62 (14.9)	
Some college or technical school	81 (25.6)	44 (43.6)	125 (30.0)	
College graduate	92 (29.1)	19 (18.8)	111 (26.6)	
Postgraduate	96 (30.4)	17 (16.8)	113 (27.1)	
<b>Residence — no. (%)</b>				0.869
Urban	110 (34.8)	37 (36.6)	147 (35.3)	
Suburban	143 (45.3)	42 (41.6)	185 (44.4)	
Rural	59 (18.7)	18 (17.8)	77 (18.5)	
<b>Year beginning kidney replacement therapy — no. (%)</b>				0.001
Before 2000	196 (62.0)	12 (11.9)	208 (49.9)	
2000–2003	55 (17.4)	10 (9.9)	65 (15.6)	
2004–2007	44 (13.9)	29 (28.7)	73 (17.5)	
Not yet started		46 (45.5)		
<b>Possible medical barriers — no. (%)</b>				
Placed on dialysis at diagnosis	80 (25.3)	18 (17.8)	98 (23.5)	0.083
Not a candidate	59 (18.7)	20 (19.8)	79 (18.9)	0.745

<sup>a</sup> Totals do not necessarily sum to the n if not all respondents answered each question or, as in the case of the question on race or ethnicity, they checked more than one. <sup>b</sup> Age was continuous.

informed that transplantation is associated with better outcomes when pursued early, and many may assume that it is a last resort. There are also possible psychosocial barriers, such as anxiety and misconceptions about the process, along with reservations about finding and approaching a potential living donor. Financial barriers can emerge at any stage; if they don't arise during the initial evaluation or preoperatively, patients may face financial challenges during the lifelong follow-up. Since 1973 Medicare has covered much of the cost of dialysis and kidney transplantation for Americans with ESRD, but the intricacies of the Medicare ESRD program can be daunting, even to the point of discouraging transplantation. In an effort to more fully understand patient

perceptions that influence access to early kidney transplantation, we constructed a self-administered survey to explore educational, psychosocial, and financial issues surrounding early transplantation.

#### METHODS

The 28-question survey was sent by either mail or e-mail. The questions created specifically for the survey were loosely based on a national survey of nephrologists' views on preemptive transplantation.<sup>5</sup> The survey was pilot tested by a small group of patients and health care professionals before being sent to the broader sample.

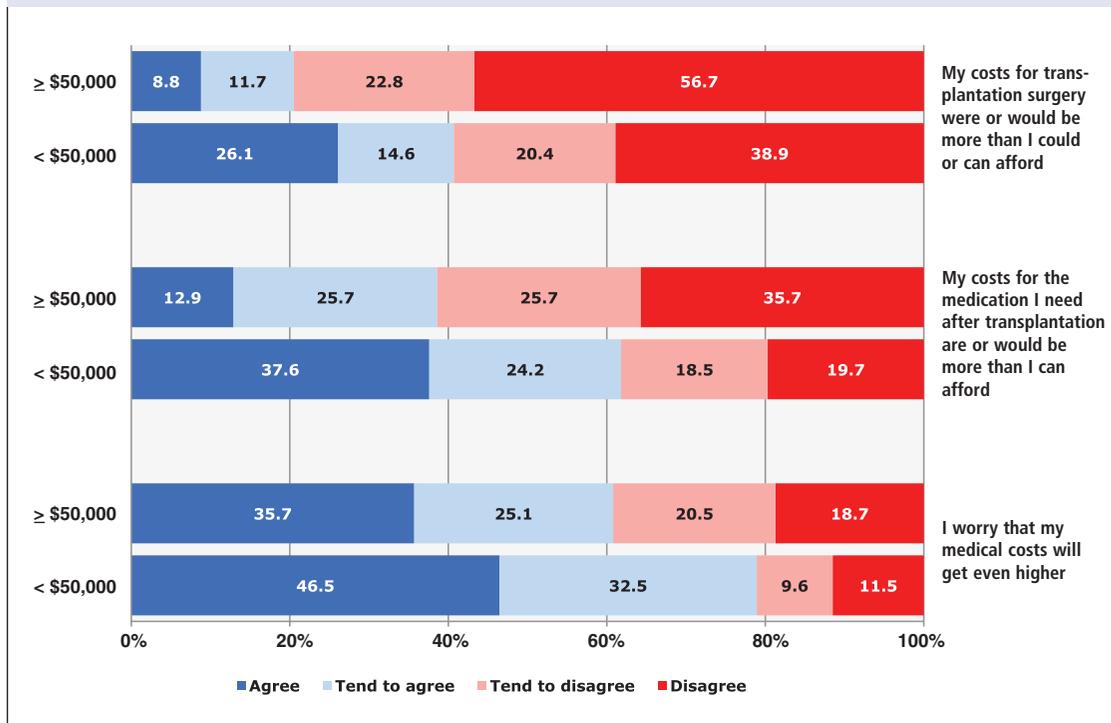
There were two versions of the survey, one for transplant recipients (76% of respondents; n = 316

**Table 2. Transplantation-Related Education Reported by Respondents**

	Previous transplantation no. (%)	No previous transplantation no. (%)	Total no. (%)	Number responding	P value
<b>Learned "a lot"<sup>a</sup> about these issues in transplantation (before transplantation)<sup>b</sup></b>					
The risks involved	161 (52.1)	26 (28.3)	187 (46.6)	401	0.001
How to live a healthy life after transplantation	172 (55.1)	17 (17.9)	189 (46.4)	407	0.001
The expected length of recovery	164 (52.2)	21 (21.9)	185 (45.1)	410	0.001
How to evaluate medical treatment options	104 (33.1)	17 (17.9)	121 (29.6)	409	0.001
Related finances	84 (26.8)	11 (11.7)	95 (23.2)	407	0.001
How long the government helps pay for medications after transplantation	117 (37.5)	22 (23.2)	139 (34.2)	407	0.001
<b>When respondent first discussed kidney transplantation with a health care professional</b>				417	0.001
After dialysis had started	96 (30.4)	16 (15.8)	112 (26.9)		
Never (wasn't discussed)		41 (40.6)	41 (9.8)		
<b>When respondent first learned living-donor transplantation was an option</b>				417	0.001
After dialysis had started	120 (38.0)	29 (28.7)	149 (35.7)		
Never (wasn't discussed)	9 (2.8)	12 (11.9)	21 (5.0)		
In enough time to plan for a live donor	97 (30.7)	10 (9.9)	107 (25.7)		
<b>Who first brought up living-donor transplantation</b>				417	0.114
A physician	161 (50.9)	35 (34.7)	196 (47.0)		
Other medical professional	28 (8.9)	10 (9.9)	38 (9.1)		
Patient or someone in patient's social network	85 (26.9)	21 (20.8)	106 (25.4)		
<b>Preferred ways to learn about treatment options and issues (respondents circled all that applied; top seven shown)</b>				417	0.166
One-on-one with a physician	237 (75.0)	61 (60.4)	298 (71.5)		
Booklet	145 (45.9)	50 (49.5)	195 (46.8)		
One-on-one with another patient	142 (44.9)	44 (43.6)	186 (44.6)		
The Internet	135 (42.7)	40 (39.6)	175 (42.0)		
One-on-one with a nurse	131 (41.5)	33 (32.7)	164 (39.3)		
A class or seminar	116 (36.7)	47 (46.5)	163 (39.1)		
One-on-one with a social worker	128 (40.5)	29 (28.7)	157 (37.6)		
<b>Most preferred way to learn about treatment options and issues (respondents circled one; top four shown)</b>				417	0.099
One-on-one with a physician	149 (47.2)	33 (32.7)	182 (43.6)		
A class or seminar	21 (6.6)	8 (7.9)	29 (7.0)		
A support group	20 (6.3)	8 (7.9)	28 (6.7)		
The Internet	15 (4.7)	11 (10.9)	26 (6.2)		
<b>Treatment options physician mentioned at initial diagnosis of kidney disease</b>				417	0.018
Hemodialysis at a dialysis center	196 (62.0)	49 (48.5)	245 (58.8)		
Hemodialysis at home	59 (18.7)	11 (10.9)	70 (16.8)		
Peritoneal dialysis	127 (40.2)	23 (22.8)	150 (36.0)		
Kidney transplantation <i>after</i> starting dialysis	171 (54.1)	32 (31.7)	203 (48.7)		
Kidney transplantation <i>before</i> starting dialysis	109 (34.5)	18 (17.8)	127 (30.5)		

<sup>a</sup> A single option is shown for ease of comparison with other measures. <sup>b</sup> Not everyone responded to this question, and of those who did, not everyone chose "a lot."

**Figure 1. Comparison of Higher and Lower Household Income Groups' Attitudes Toward Costs of Transplantation<sup>a</sup>**



<sup>a</sup> Numbers responding: < \$50,000, n = 157; ≥ \$50,000, n = 171. P = 0.000.

[of 417 responses appropriate for analysis]) and one for those with CKD who had never undergone transplantation (24%; n = 101). The surveys were identical except for a single question unique to each group and differing verb tenses in two other questions. Answer choices and options were rotated in the online version of the survey to minimize any possible impact of the order of the choices on respondents' answers. Such reordering wasn't possible for the surveys sent by mail. A comparison of the results of online and print versions of the survey revealed few differences in responses, except that those completing the survey over the Internet gave more extensive answers to open-ended questions.

In order to effectively reach a broad cross-section of patients with CKD, we used the NKF's national database of 33,780 constituents, randomly selecting every 10th person. We sought to include both those who wished to communicate by e-mail and those who preferred postal mail; all of them had previously indicated which method of communication they preferred.

While our *a priori* power calculations had indicated a small sample would be sufficient, we sought the narrower confidence intervals and greater insight that would come from receiving at least 300 completed surveys from CKD patients with and without functioning allografts. A larger sample would allow

us to keep the margin of error under 10% (95% confidence level), even as we identified the perceptions of and barriers to preemptive transplantation among the various key subgroups and began to explore how widespread those barriers might be.

This resulted in distribution of surveys to 3,586 people in July 2007, using e-mail (n = 2,986) or the U.S. Postal Service (n = 600). E-mail servers informed us that at least 32 surveys were undeliverable. More than 10% of the people on the list were recipients of organs other than a kidney and had never had kidney disease, which disqualified them from the study. The list also included an unknown number of others (such as caregivers, family members, and living donors) who may never have had kidney disease. A total of 19.3% (101 of the 524 who responded) fell into one of these categories and were disqualified. Another six responses were sent in too late to be included. Removing these 107 disqualified returns left us with 417 surveys available for analysis (322 received by e-mail and 95 by mail). The 417 eligible surveys represented at least 12.4% of all qualified people who received the survey. We estimate that no more than 3,369 surveys (93.9% of those initially mailed) were received by qualified people—those who had CKD or had undergone kidney transplantation. The number that reached qualified people could be considerably lower, which would mean the response rate

was actually higher. Those who received the survey by postal mail were slightly more likely to complete the survey (16.8% of print surveys mailed, compared with 11.5% of those sent by e-mail [and for which the e-mail invitation was not returned as undeliverable]).

The 417 respondents who qualified for inclusion represented a broad spectrum of those in the United States with CKD (see Table 1). Of these, 316 had previously undergone transplantation (286 had functioning allografts at the time of the survey) and 101 had not (55 were on dialysis at the time of the survey).

**Statistical methods.** Because this was an exploratory study, much time was spent on descriptive analysis (determining frequencies for nominal variables and measures of central tendency and dispersion for interval and ordinal variables). Although we analyzed the differences in responses according to several characteristics (such as race and income) that we thought would have a bearing on perceptions and barriers, our primary focus was the comparison of responses between those who had undergone transplantation and those who had not. For all comparisons of proportions  $\chi^2$  tests were used to derive *P* values. Means were compared using the *t* test for independent groups. The level of statistical significance was set at 0.05. For results based on the total sample, one can say with 95% confidence that the error attributable to sampling and other random effects is plus or minus 4.8 percentage points. For results based on transplant recipients (*n* = 316), the margin of sampling error is plus or minus 5.5 percentage points; for those who had not undergone transplantation (*n* = 101), it is plus or minus 9.8 percentage points.

In addition to sampling error, some error or bias may be introduced into the findings of opinion polls by the wording of questions and by practical difficulties in conducting mail and e-mail surveys.

## RESULTS

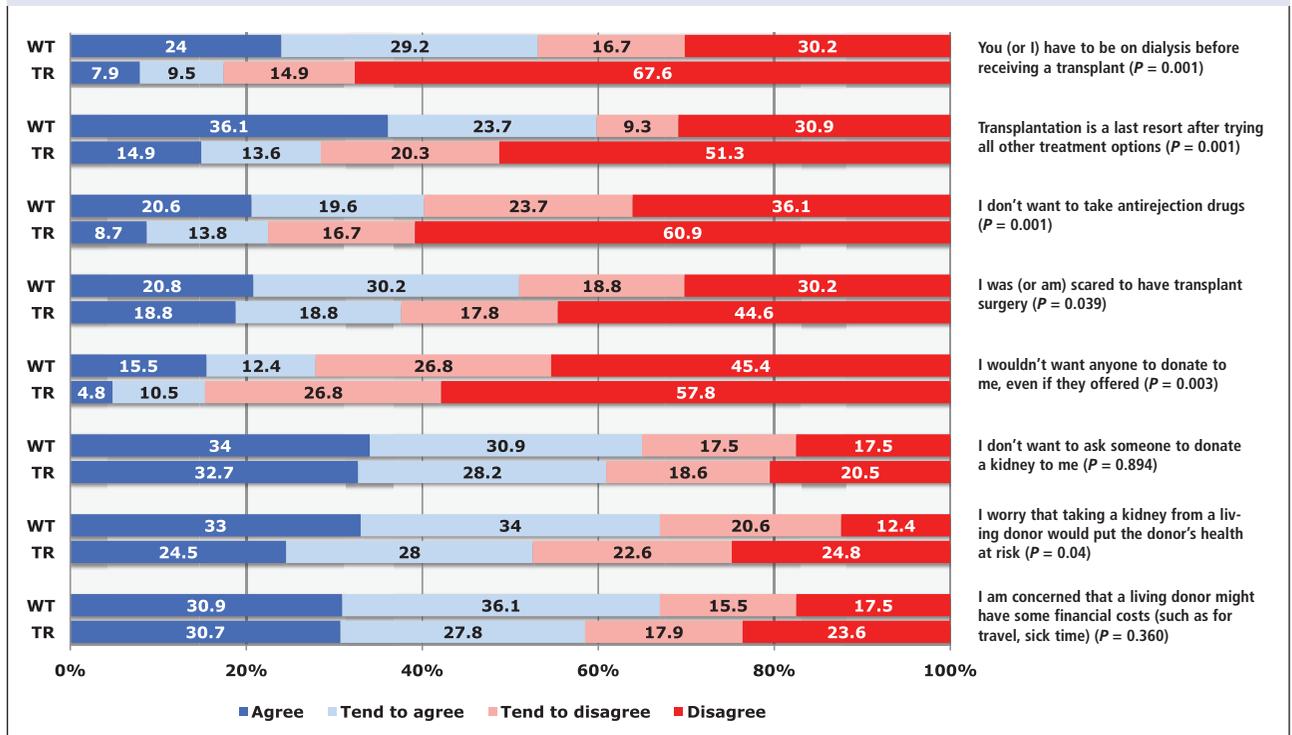
**Demographics.** As shown in Table 1 there was no significant difference in sex and little in age between patients who had undergone kidney transplantation and those who had not. Relative to the composition of the overall ESRD population in the United States, African American patients are underrepresented in both groups; nonetheless, the percentage of African American patients in our study who had not undergone transplantation (15%) was more than twice that among those who had (7%) (*P* = 0.004). Sixty percent of those surveyed who had undergone transplantation had attained at least a college degree, versus only 36% of those who hadn't undergone transplantation (*P* = 0.001). The regional distribution of this sample is similar to that of both the U.S. adult population and the ESRD population. The sole exception is that transplantation patients are slightly more likely to live in the Northeast and not the West. In general, the transplant recipients had dealt with dialysis and other ESRD care for a much longer time than those who hadn't received transplants.

**Educational issues.** Table 2 shows that about half of all patients said they had learned "a lot" before transplantation about risks (47%), the expected length of recovery (45%), and "how to live a healthy life after transplantation" (46%). Fewer had learned about the financial impact (23%), how to evaluate medical treatment options (30%), and how long the government

**Table 3. When Respondents First Learned that Living-Donor Transplantation Was an Option**

	All who responded (N = 417)	Received living-donor kidney transplant (n = 133)	Received only deceased-donor kidney transplant (n = 183)	Had not undergone kidney transplantation (n = 101)	Minorities (combined; n = 73)
<b>When learned of living-donor option (one answer) — no. (%)</b>					
In enough time to plan for living-donor transplantation, avoiding dialysis	107 (25.7)	62 (46.6)	35 (19.1)	10 (9.9)	14 (19.2)
After I started dialysis	149 (35.7)	52 (39.1)	68 (37.2)	29 (28.7)	39 (53.4)
Never	21 (5.0)	0 (0.0)	9 (4.9)	12 (11.9)	1 (1.4)
It wasn't an option for me	64 (15.3)	0 (0.0)	45 (24.6)	19 (18.8)	6 (8.2)
Not sure	69 (16.5)	18 (13.5)	26 (14.2)	25 (24.8)	11 (15.1)
No answer	7 (1.7)	1 (0.8)	0 (0.0)	6 (5.9)	2 (2.7)
<i>P</i> value		< 0.001	0.004	< 0.001	0.003

Figure 2. Patients' Attitudes Toward Living-Donor Transplantation and Other Issues<sup>a</sup>



<sup>a</sup> Not all respondents answered every question. Among transplant recipients (TR), the number of respondents ranged from 312 to 316. Among those without transplants (WT), the range was 96 to 97.

helps pay for medications after transplantation (34%). With all these measures, patients who had not undergone transplantation reported learning less. When queried about their *first* discussion about transplantation with a health care professional, 27% of all respondents reported that it didn't occur until after they had started dialysis, and nearly 10% reported never discussing transplantation with any health care professional. More than a third of all respondents reported that the option of a living donor had been first mentioned only after dialysis was begun, although more often (53%) in minority patients (see Table 3). Furthermore, 25% said a living donor was mentioned first by someone other than a health care professional (Table 2). Among patients who had not undergone transplantation, 12% said they had never heard of this option; another 31% were unable or unwilling to say when they learned of the option (Table 3).

Patients were open to receiving education from many sources, including discussions with nurses or social workers, booklets, online, classes, or from other patients. The most frequently preferred option among respondents was a one-on-one discussion with a physician (44%). But many respondents remembered physicians only discussing selected treatment options for ESRD. For example, fewer recalled their physician mentioning the option of transplantation that takes place *before* starting dialysis than recalled the physician

mentioning transplantation that takes place *after* starting dialysis (31% versus 49%, respectively). Even those who later underwent transplantation didn't always hear of preemptive transplantation when first diagnosed (35%, compared with 54% who heard only about transplantation occurring after dialysis). Only 26% of all patients found out about living-donor options in time to consider preemptive transplantation (Table 3). Early awareness of living-donor transplantation seemed to be associated with an overall likelihood of undergoing the procedure. For example, 47% of respondents who received a kidney from a living donor learned about it in time to avoid dialysis.

**Medical issues.** While this opinion survey did not specifically address clinical issues, it addressed two possible medical barriers to transplantation. First, as shown in Table 1, approximately one in five respondents needed immediate dialysis at the time of diagnosis of kidney failure—a factor thought to preclude early transplantation. Similarly, one in five respondents recalled being told they were not good candidates for transplantation. In neither case (needing immediate dialysis or being deemed a poor candidate) did it matter significantly whether the respondent had undergone transplantation.

**Financial issues.** As shown in Table 4, responses to questions about finances revealed significant differences between patients who had undergone

transplantation and those who had not. The annual income of the transplant recipients was substantially higher than that of those who hadn't received a transplant. Within the group that hadn't undergone transplantation, however, the cohort on long-term dialysis had roughly half the income of those not on dialysis (median of \$19,000 versus \$48,900, respectively). Indeed, the difference between those not on dialysis and those who had undergone transplantation was relatively small (median of \$48,900 versus \$59,600, respectively). In terms of out-of-pocket expenses, median annual costs associated with transplantation were significantly higher than for patients on dialysis (\$2,748 versus \$1,764, respectively). Fears that financial cost would worsen were similar across both groups; however, the perception that one was or would be unable to afford transplantation was much more common in the patients who hadn't undergone transplantation.

Concerns regarding the escalating costs of medical care in general as well as the cost of surgery and immunosuppressant medications varied according to income, regardless of the treatment group. Patients with a household income under \$50,000 were more likely to "worry that my medical costs will get even higher" in addition to worrying about the cost of surgery and the cost of medications (see Figure 1).

**Living-donor issues.** Figure 2 shows that concerns regarding medical and financial risks assumed by living donors were widespread, and generally more common among patients who hadn't undergone transplantation. For example, two-thirds expressed concern about health risks to living donors, compared with more than 52% of patients who had already undergone transplantation. Some respondents in both groups expressed concerns in written comments about the impact on the living donor if the kidney failed in the recipient. Both groups expressed reluctance to ask someone to donate. The overwhelming majority in both groups were willing to take a kidney from a living donor. Because 42% of the transplantation patients had received kidneys from living donors, it's clear that many had successfully overcome their reluctance.

**Other emotional considerations.** As shown in Figure 2, 51% of those who hadn't yet undergone transplantation expressed some fear of surgery. With only 38% of recipients reporting having experienced similar fear before transplantation, it's possible that such fears may prevent some CKD patients from moving toward transplantation. Likewise, responses of patients who hadn't undergone transplantation indicate much greater fear of immunosuppressive therapy.

Eighty-five percent of respondents included additional free-text comments, often lengthy and filled with emotion. Of these, 56% described an emotional barrier that prevented pursuing timely transplantation,

such as the worry that the operation would be unsuccessful or that, even if successful, it would not enhance the quality of their lives or those of their family. Many recipients indicated that if they had better understood the positive effect transplantation would have on their quality of life, they would have pursued it sooner.

A total of 60% of respondents without a transplant viewed the procedure as "a last resort after trying all other treatment options." Somewhat surprisingly, although 51% of kidney recipients fully disagreed that transplantation was a last resort, 29% still felt that way. Whether because of emotional barriers or gaps in education, more than half of the those who hadn't undergone transplantation believed that dialysis must precede transplantation (a total of 53%).

## DISCUSSION

Living-donor transplantation benefits patients and favorably affects the deceased donor waiting list. It also has cost benefits. A recent NKF conference recommended a proximate goal of converting the 26% of living-donor transplantations performed within a year of beginning dialysis into transplantations performed before the onset of dialysis.<sup>3</sup> Avoiding even a year of dialysis has the potential to decrease Medicare's ESRD expenditures by \$58,000 (34%) per patient over the first two years of kidney replacement therapy.<sup>3</sup>

The present survey indicates, however, that both real and perceived barriers to early transplantation persist. Financial circumstances vary widely in the CKD population, and financial well-being exerts a strong influence over beliefs about transplantation. Perhaps most noteworthy of the survey results are the income and educational disparities between those with and without transplants. Annual income was almost twice as high among those who had undergone transplantation (nearly 60% of whom had attained at least a college degree), compared with those on dialysis. Is a higher income partly responsible for access to transplantation, a consequence of undergoing successful transplantation—or perhaps a bit of both?

It's well documented that educational background and private insurance coverage promote early access to transplantation.<sup>6</sup> It's also well documented that transplant recipients are more likely to stay employed than are patients on dialysis, whose likelihood of returning to the workforce diminishes the longer they remain on dialysis.<sup>1,7</sup> These data suggest that transplantation may help preserve financial stability in recipients despite their greater out-of-pocket expenses.

A U.S. Government Accountability Office report estimated the cost of posttransplantation medications to be between \$5,000 and \$13,000 *annually*.<sup>8</sup> Another report puts the cost of medications for the *first* year after transplantation at \$26,000.<sup>9</sup> Some recipients return to dialysis because they cannot afford

these costs. In the United States, a charitable program will pay the insurance premiums for qualifying dialysis patients.<sup>10</sup> Once a patient has undergone transplantation, that patient is no longer eligible for those payments and the out-of-pocket expenses go

up. Dialysis patients receive Medicare coverage of their treatment for as long as they are on dialysis therapy; for transplant recipients, Medicare coverage of treatment, including the cost of immunosuppressant medications, is limited to 36 months. For many, the

**Table 4. Financial Data and Concerns Reported by Respondents**

	Previous transplantation	No previous transplantation	All respondents	P value
<b>Annual household income — no. (%)</b>				0.001
< \$25,000	37 (14.6)	33 (41.8)	70 (21.1)	
25,000–49,999	70 (27.7)	20 (25.3)	90 (27.1)	
50,000–74,999	51 (20.1)	14 (17.7)	65 (19.6)	
≥ \$75,000	95 (37.5)	12 (15.2)	107 (32.2)	
Total number responding	253	79	332	
<b>Median household annual income<sup>a</sup></b>	\$59,600	\$33,100	\$52,300	0.001
No dialysis	\$61,200	\$48,900	\$59,000	0.001
Dialysis	\$45,500	\$19,000	\$30,000	
<b>Median out-of-pocket expenses<sup>a</sup> (annual)</b>				0.002
No dialysis	\$2,748	\$1,848	\$2,436	0.001
Dialysis	\$2,904	\$1,848	\$2,700	
Total number responding	\$1,848	\$1,764	\$1,824	
	281	86	367	
<b>I worry that my medical costs will get even higher — no. (%)</b>				0.377
Agree	124 (39.6)	40 (40.8)	164 (39.9)	
Tend to agree	88 (28.1)	34 (34.7)	122 (29.7)	
Tend to disagree	46 (14.7)	13 (13.3)	59 (14.4)	
Disagree	55 (17.6)	11 (11.2)	66 (16.1)	
Total number responding	313	98	411	
<b>My costs for the medication I need after transplantation are or would be more than I can afford — no. (%)</b>				0.004
Agree	62 (19.8)	30 (30.9)	92 (22.4)	
Tend to agree	82 (26.2)	23 (23.7)	105 (25.6)	
Tend to disagree	69 (22)	29 (29.9)	98 (23.9)	
Disagree	100 (31.9)	15 (15.5)	115 (28)	
Total number responding	313	97	410	
<b>My costs for transplantation surgery were or would be more than I could or can afford — no. (%)</b>				0.001
Agree	41 (13.1)	27 (28.1)	68 (16.6)	
Tend to agree	43 (13.7)	19 (19.8)	62 (15.1)	
Tend to disagree	67 (21.3)	22 (22.9)	89 (21.7)	
Disagree	163 (51.9)	28 (29.2)	191 (46.6)	
Total number responding	314	96	410	

<sup>a</sup> Median estimates are based on ranges.

perception that transplantation-related expenses are unaffordable may be well-founded. A public policy priority of the NKF is to extend coverage of immunosuppressive drugs under Medicare for the duration of the transplant. That would be one incremental step toward improving access to transplantation. Health care professionals can both participate in and encourage patients to join the NKF's efforts to change policy in order to overcome this financial barrier.

The present survey also documents the impact of early education on transplantation as an option on the likelihood of undergoing kidney transplantation. Respondents who had undergone transplantation were substantially more likely (by a two-to-one ratio on some parameters) to have been given information regarding issues related to surgery and posttransplantation finances and health care. Likewise, more than two-thirds of transplantation patients reported that their physicians had initiated conversations regarding transplantation (even more among recipients who had received a kidney from a living donor); in contrast, only 36% of those who had not undergone the procedure remembered similar conversations.

**A role for nurses.** An interdisciplinary approach may help close the education gap between these two groups and increase early transplantation rates. Although patients welcome education from a wide variety of sources, a preponderance of patients in both groups expressing a preference for their physicians to be the ones who informed them about transplantation underscores how pivotal a timely conversation initiated by a physician can be. Nursing staff can both facilitate and supplement patient-physician communication. The ideal outcome is that the patient will understand the risks and benefits of transplantation, make an informed decision about becoming a transplantation candidate, and complete the evaluation process. The survey responses revealed, however, that education, problem solving, and advocacy by the nurse are essential if early transplantation—and especially living-donor transplantation—is to become a reality for more patients.

The responses regarding fears about surgery and immunosuppressive drug therapy point to another important focus of patient education for the nurse. Survey respondents were willing to receive a kidney from a living donor but were uncomfortable about asking someone to donate one. An example of an effective way nurses can help overcome this barrier is to use role playing to teach patients ways to initiate such a conversation. Patients are concerned about the living donor, and their fears could be reduced by a nurse who anticipates and answers their questions about health risks to living donors. Nurses might also help set up a chance for the patient to talk with a transplant recipient, provide printed information in the patient's preferred reading language, and use their nursing expertise to increase the likelihood of obtaining

informed consent and of successful transplantation by fostering greater understanding.

Nurses also are skilled at taking a case-coordinating role in bringing patients into contact with other professionals who have the specific knowledge the patients need to help them overcome identified barriers. Patients who have not yet undergone transplantation worry more about surgical and medication costs—including the costs to the potential living donor—than do those who already have transplants. A nurse who is sensitive to the enormity of the financial issues involved can suggest referral to a social worker, who can help the patient navigate the complexities of insurance, which, for some, are a barrier to transplantation.

Nurses are advocates. If evaluation for transplantation is pursued, the nurse can work in conjunction with the patient's referring physician to facilitate communication with the transplantation center, connect patients with appropriate resources within or outside of the immediate care team, and facilitate informed choices about treatment options.

Some aspects of this survey require caution in interpretation. First, the population surveyed was selected from those with enough interest in kidney disease to join an NKF-sponsored advocacy council and may not be representative of the CKD population in the United States. In addition, the response rate of 12% is lower than we would have desired. However, the respondents are a diverse group in terms of geography, age, ethnicity, and financial situation. Second, although our sample does include a small group who are less educated and with low income, the educational-background and annual-income data suggest that survey respondents were better educated and possibly more financially stable than the overall ESRD population. The strength of this survey is its insights into what patients hear and recall, sometimes years later. Whether or not they accurately represent what transpired, their answers reflect their perceptions of their experience and the kinds of things they might be saying to other patients.

Fears and emotions are subjective; they are not easy to quantify or alleviate. In the absence of appropriate education, patients learn myths instead of facts and will fail to grasp the consequences of inaction as their CKD progresses. The process of dealing with objective issues (such as ensuring adequate financial support to cover the costs of transplantation as completely as are those for dialysis) can diminish the impact of subjective feelings in some patients. Notice how some respondents who underwent transplantation overcame misinformation regarding candidacy, the timing of transplantation, and use of a living donor.

The barriers to wider adoption of preemptive transplantation can be diminished through timely information and referral, informed treatment choice,

public policy efforts, and efforts to raise awareness of living-donor transplantation. Nurses involved in care planning for people with progressive kidney disease who are approaching kidney replacement therapy can be integral to the success of cross-specialty efforts to accomplish this. ▼

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