

The Financial Burden of Transplantation: A Single-Center Survey of Liver and Kidney Transplant Recipients

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Little is known about the financial impact of transplantation on patients and families. We interviewed 333 liver transplant (LT) and 318 kidney transplant (KT) recipients who were at least 1 year posttransplant. Patients were asked whether transplantation caused financial problems, whether income had changed since transplantation, what resources they used to pay for transplant-related expenses, and what their out-of-pocket monthly expenses were. Descriptive and comparative statistics, measures of association, and logistic regression analyses were calculated. Many patients reported financial problems secondary to transplantation (40.6%) and less monthly income now than in the year preceding transplantation (46.5%). Average monthly out-of-pocket expense was \$476.60. LT recipients had higher out-of-pocket expenses than KT recipients ($t=2.46$, $P=0.015$). Patients used personal savings (53.9%) and credit cards (25.0%) to help offset these expenses, among other strategies. For both LT and KT recipients, older age, nonworking status before transplantation, and current nonworking status predicted greater financial impact, whereas younger age and current nonworking status predicted higher monthly out-of-pocket expenses. These findings highlight the potential financial impact of transplantation on patients and families, and they have implications for assisting patients in managing out-of-pocket expenses after transplantation.

Keywords: Financial burden, Liver transplantation, Kidney transplantation, Economic.

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Transplantation offers patients with progressive liver or kidney disease an opportunity for longer life and improved quality of life (1–3). In addition to its life-sustaining benefit, transplantation may be a cost-effective alternative to long-term disease management (4, 5). Consequently, insurance companies and government healthcare programs provide coverage for most transplant-related clinical services and medications.

Despite adequate health insurance, transplant recipients may still have expenses not otherwise covered under their plan. The nature and scope of these out-of-pocket expenses are largely unknown, but likely include required insurance copayments or deductibles, transportation to and from the transplant center for follow-up surgical and medical

care, temporary lodging and meals for patients and their caregivers, parking fees childcare expenses, and medications. Also, there are indirect costs in the form of lost wages due to ongoing medical disability in the patient and caregiving activities of the spouse or partner.

To date, there has not been any attempt to examine the financial burden of liver (LT) or kidney transplantation (KT) from the patient's perspective nor how this burden is managed by patients. Such information might provide important insights into their financial health and well-being, supplement the anecdotal experiences of transplant professionals suggesting that some patients experience significant financial hardships after transplantation, and offer guidance for best informing and assisting patients in managing these costs. The purpose of this study, therefore, was to survey LT and KT recipients about the financial impact of transplantation and to ascertain the strategies they used to manage non-reimbursed expenses related to transplantation.

MATERIALS AND METHODS

Participants and Recruitment Procedures

All patients who received LT or KT at the University of Florida between January 1995 and December 2004 and who were at least 1-year posttransplant were considered eligible for the study. A passive recruitment strategy was used. Patients were contacted by letter and informed of the

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opportunity to take part in a study examining the impact of transplantation on their lives. Patients desiring to take part in the study were instructed to mail back (in a prestamped envelope) a participation form on which they indicated the best time to call and a reliable telephone number. Once a form was received, the patient was called by a research assistant, who provided more information about the study, answered questions, requested study participation, and obtained verbal consent to proceed with the interview.

Data Collection Procedures

All interviews were conducted by telephone. Mean interview duration was 36.7 ± 6.4 min, with a range of 25 to 52 min. Interviewers were five research assistants who received 8 hours of training and behavioral rehearsal, as well as specialized education and training about organ transplantation, telephone crisis management, and the protection of human research participants. Participants were not offered any monetary compensation.

The structured interview (147 questions) was designed to gather information about the patient's transplant experience across several different parameters, including physical health status, pre- and posttransplant behavioral health (smoking, alcohol use, drug use, sleep, exercise), medication compliance, preventive health behaviors, psychological functioning, and financial impact. Regarding financial impact, patients were asked whether transplantation caused financial problems for them or their family; whether they had more, less, or comparable monthly income now relative to the year preceding transplantation; what resources they used to pay for out-of-pocket expenses related to transplantation; whether they felt adequately informed about the out-of-pocket expenses they would have after transplantation; and whether they would make the same decision to undergo transplantation now that its financial impact was known. The interview protocol was revised slightly during the study and one additional financial impact question was added in which patients were asked to estimate (in U.S. dollars) their average monthly out-of-pocket expenses for transplant-related costs during the past year. At the end of each interview, participants were provided with a referral to a mental health professional, if they so desired (9.7%). The University of Florida Institutional Review Board approved all study procedures.

Data Management and Statistical Analysis

Interview responses were recorded on the data collection tool developed for this study and coded based on the response options for each question. The research assistant conducting the interview entered the data into a comprehensive database and a research assistant not involved in the interviews served as a data checker. Discrepancies were identified and resolved prior to final statistical analysis. Univariate relationships between the responses to the financial questions and transplant type (LT vs. KT) were examined using *t*-tests for continuous variables, the Fisher exact test for variables with two categories, or a two-tailed χ^2 test for variables with three or more categories. A 2 (transplant type: LT, KT) \times 5 (time since transplant: Year 2, Year 3, Year 4, Year 5, Year 6+) analysis of variance was conducted to examine main and interaction effects for average monthly out-of-pocket expenses for transplant-

related costs. Significant effects were followed by post-hoc comparisons. Logistic regression analyses were then conducted, separately for liver and kidney transplant recipients, to examine whether certain factors were predictive of (1) overall financial impact of transplantation and (2) estimated monthly out-of-pocket expenses.

Overall financial impact was determined by the yes-no response to the question: Have health problems related to transplantation caused financial problems for you or your family? Estimated monthly out-of-pocket expenses was categorized as low or high based on median split (median = \$441). Variables considered for inclusion in these analyses were age, sex, race, ethnicity, marital status, educational background, employment status in the year preceding transplantation, time on the waiting list, body mass index at time of transplant, current working status, current medical disability status, number of hospitalizations in the past year, alcohol use in past year, current smoking status, and current insurance status. LT analyses also included whether liver disease was alcohol related. KT analyses also included pretransplant dialysis status, whether transplant was from deceased or living donor, and whether transplanted graft was still functioning. Variables that were significantly associated with financial impact or monthly expenses were included in the multivariate logistic regression analysis. All data were analyzed using the Statistical Package for the Social Sciences database (SPSS, Version 13, Chicago, IL).

RESULTS

Sample Characteristics

A total of 1,517 patients were mailed a study participation letter. This represented 79% of the 1,917 KTs and LTs performed during the study period. Seventy-eight letters (5%) were returned as undeliverable with no forwarding address ($n=61$) or were returned by a family member who informed us that the patient had died ($n=17$). Of the 1,439 who presumably received a letter, 763 patients (53%) returned the study participation form and 702 (333 liver, 318 kidney, 51 kidney-pancreas) completed the study interview. The 61 patients who mailed in the participation form but did not complete an interview could not be contacted by telephone (maximum four attempts), did not keep a scheduled interview appointment on more than one occasion, or decided not to take part after hearing more about the study. The 51 participants who received a kidney-pancreas transplant were excluded from the current study analysis and are the subject of a separate paper due to unique characteristics of this smaller cohort. Therefore, the total sample size for this study is 651 LT and KT recipients.

Participant sociodemographic and health characteristics are summarized in Table 1. Compared to KT patients, LT recipients were more likely to be older, male, and white ($P < 0.05$). Overall, these sociodemographic characteristics are comparable to the entire LT (age: 51.1 years; sex: 32.0% female; race: 77.3% white) and KT (age: 53.7 years; sex: 40.2% female; race: 62.1% white) recipient population at this transplant center during the study period. The vast majority (96.3%) of patients had current health insurance. We did not ask patients about the type of healthcare coverage. However, the primary payor mix at this transplant center is as follows: 63% managed care, 23% Medi-

TABLE 1. Sample characteristics for total sample and by transplant type

| | Total | Liver transplant | Kidney transplant | Test statistic |
|--|-------------|------------------|-------------------|---|
| N | 651 | 333 | 318 | |
| Age, years (mean ± SD) | 56.2 ± 10.9 | 57.2 ± 10.6 | 55.2 ± 11.2 | <i>t</i> (649) = 2.32, <i>P</i> = 0.021 |
| Female | 233 (35.8) | 104 (31.2) | 129 (40.6) | Fisher exact test, <i>P</i> = 0.01 |
| White | 515 (79.1) | 271 (81.4) | 244 (76.7) | Fisher exact test, <i>P</i> = 0.001 |
| Married | 459 (70.5) | 225 (67.6) | 234 (73.6) | χ^2 (5) = 7.96, <i>P</i> = 0.16 |
| Education, ≥ 12 years | 516 (79.3) | 279 (83.9) | 237 (74.5) | χ^2 (4) = 7.00, <i>P</i> = 0.14 |
| Employed | 206 (31.6) | 97 (29.1) | 109 (34.3) | Fisher exact test, <i>P</i> = 0.09 |
| Healthcare coverage | 627 (96.3) | 311 (93.4) | 316 (99.4) | Fisher exact test, <i>P</i> = 0.25 |
| Time since transplant, months (mean ± SD) | 42.9 ± 25.3 | 43.1 ± 28.3 | 42.3 ± 24.6 | <i>t</i> (649) = 0.56, <i>P</i> = 0.58 |
| General health now compared to before transplant | | | | |
| Much better | 469 (72.0) | 259 (77.8) | 210 (66.0) | |
| Somewhat better | 91 (14.0) | 48 (14.4) | 43 (13.5) | χ^2 (4) = 22.97, <i>P</i> = 0.0001 |
| About the same | 47 (7.2) | 16 (4.8) | 31 (9.7) | |
| Somewhat worse | 32 (4.9) | 7 (2.1) | 25 (7.9) | |
| Much worse | 12 (1.8) | 3 (0.9) | 9 (2.8) | |

Values are n (%) unless noted. Test statistic represents liver vs. kidney transplant comparison. Where only a *P* value is reported, Fisher exact test did not yield formal test statistic or critical value.

TABLE 2. Responses to financial impact questions for total sample and by transplant type

| | Total | Liver transplant | Kidney transplant | Test statistic |
|---|-------------|------------------|-------------------|---|
| N | 651 | 333 | 318 | |
| Have health problems related to transplantation caused financial problems? (% Yes) | 264 (40.6) | 142 (42.6) | 122 (38.4) | Fisher exact test, <i>P</i> = 0.26 |
| Which of the following statements is most true for you? More monthly income now than before transplant | 139 (21.4) | 51 (15.4) | 88 (27.7) | χ^2 (2) = 15.20, <i>P</i> = 0.001 |
| Less monthly income now than before transplant | 303 (46.5) | 170 (51.2) | 133 (41.8) | |
| Monthly income now is about the same as before transplant | 208 (32.0) | 111 (33.4) | 97 (30.5) | |
| Estimated monthly out-of-pocket expenses for transplant-related medical costs? (US dollars, mean ± SD) ^a | 476.6 ± 249 | 539.5 ± 289 | 467.5 ± 203 | <i>t</i> (278) = 2.46, <i>P</i> = 0.015 |
| Felt adequately informed of out-of-pocket expenses before transplant? (% Yes) | 505 (77.6) | 249 (75.2) | 256 (80.5) | Fisher exact test, <i>P</i> = 0.11 |
| If you had known about financial impact of transplant on you and family, would still have gone ahead with transplant? (% Yes) | 596 (91.6) | 304 (91.3) | 292 (91.8) | Fisher exact test, <i>P</i> = 0.89 |

Values are n (%) unless noted. Test statistic represents liver vs. kidney transplant comparison. Where only a *P* value is reported, Fisher exact test did not yield formal test statistic or critical value.

^a This question was subsequently added to the protocol; therefore, total n = 280; LT n = 122, and KT n = 158.

care, 8% Medicaid, and 6% self-pay for liver recipients; 74% Medicare, 21% managed care, 4% self-pay, and 1% Medicaid for kidney recipients. In addition to the foregoing, 39 (11%) KT recipients did not have functioning grafts at the time of study participation.

As noted in Table 1, the majority (86.0%) of patients reported that their general health had improved as a result of transplantation. There was a significant difference in general health perceptions by transplant type, with more LT recipients reporting better health now relative to pretransplant functioning (LT

92.2% vs. KT 79.5%). KT recipients were more likely to report that their general health was worse now than in the months prior to transplantation (KT 10.7% vs. LT 3.0%).

Financial Impact

As noted in Table 2, approximately 40% of all patients (42.6% and 38.4% for LT and KT recipients, respectively, $P>0.05$) reported that health problems related to transplantation have caused financial problems for themselves personally and/or for their families. Nearly half (46.5%) had less monthly income now than in the year preceding transplant surgery. LT recipients (51.2%) were more likely to have less monthly income since transplant, and KT recipients (27.7%) were more likely to report an increase in monthly income since transplantation ($P=0.001$). About one-third of LT (33.4%) and KT (30.5%) recipients reported no significant change in monthly income from pre- to posttransplantation.

Estimated monthly transplant-related expenses differed significantly by transplant type ($t=2.46$, $P=0.015$), with higher out-of-pocket for LT (\$540 USD) versus KT (\$467 USD) recipients. Estimated monthly expenses was not significantly correlated with time since transplantation ($r=-0.06$, $P=0.34$). Table 3 depicts the relationship between estimated monthly expenses, time since transplant, and transplant type. A significant time since transplant \times transplant type interaction was observed ($F=2.6$, $P=0.04$). For KT recipients, monthly expenses were significantly higher in Years 4 and 5 than in Year 3 ($P<0.05$). In contrast, monthly expenses were significantly lower in Year 4 than in Year 3 for LT recipients ($P<0.05$). Monthly expenses also were significantly higher for LT versus KT recipients in Year 2 ($P=0.04$) and Year 3 ($P=0.01$).

Although the majority (78.2%) felt fully informed about these likely out-of-pocket expenses prior to transplantation, approximately 8% would not have undergone transplantation had they known its true financial impact on them personally or on their family (Table 2). This was equally true for both LT (8.7%) and KT (7.6%) recipients.

Resources Used by Transplant Patients

Use of personal or family savings accounts (53.9%) and credit cards (25.0%) were by far the most common strategy to help offset the out-of-pocket expenses incurred as a result of transplantation (Table 4). LT recipients were significantly more likely than KT recipients to use personal savings, personal loans from a friend or family member, retirement funds, other investment accounts, funds from local charitable organizations, funds from community-based fundraising

campaigns, income from a family member's second job, and to declare bankruptcy (all $P<0.05$). Two-thirds of patients (69.1%) used at least one of these strategies to help pay for out-of-pocket expenses, and 44.8% of them used two or more of these strategies. LT and KT recipients used an average of 1.8 (± 1.8) and 1.5 (± 1.5) of these strategies, respectively ($t=2.99$, $P=0.003$).

Multivariate Predictors of Financial Impact and Monthly Expenses

The following variables predicted greater financial impact for LT recipients: older age (odds ratio [OR]: 1.92; confidence interval [CI]: 1.31, 3.76), unmarried (OR: 0.37; CI: 0.16, 0.82), nonworking status in the year preceding transplantation (OR: 0.26; CI: 0.16, 0.52), current nonworking status (OR, 0.63; CI: 0.48, 0.84), and longer time on the transplant waiting list (OR: 1.89; CI: 1.45, 4.69). For KT recipients, higher financial impact was predicted by: older age (OR: 1.22; CI: 1.04, 1.93), male gender (OR: 1.86; CI: 1.36, 3.54), nonworking status in the year preceding transplantation (OR: 0.58; CI: 0.11, 0.79), and current nonworking status (OR: 0.67; CI: 0.45, 0.94).

LT recipients with higher out-of-pocket monthly expenses were more likely to be younger (OR: 0.64; CI: 0.31, 0.87) and not currently working (OR: 0.54; CI: 0.28, 0.87). Similarly, among KT recipients, higher monthly expenses was predicted by younger age (OR: 0.86; CI: 0.69, 0.93), not currently working (OR: 0.43; CI: 0.20, 0.94), and not having a functioning graft at time of interview (OR: 0.39; CI: 0.17, 0.58).

DISCUSSION

This is the first known study to examine patients' perceptions of the financial impact of transplantation. We were unable to find any published literature describing transplant recipients' out-of-pocket expenses, beyond medication costs (6). Findings from our study highlight that: a) the financial impact of transplantation can be substantial, despite otherwise positive health outcomes from transplantation; b) patients use a variety of different strategies to manage the financial burden of transplantation; and c) certain sociodemographic characteristics may place some patients at higher risk of financial problems in the years after transplantation.

Patients at the study center reported spending approximately several hundred dollars per month on expenses related to transplantation. Commonly reported out-of-pocket expenses include physician visits and medication copay-

TABLE 3. Average monthly out-of-pocket expenses, by time since transplant and transplant type

| Time since transplant | Total | Liver transplant | Kidney transplant |
|---------------------------------------|-----------------------|-----------------------|-----------------------|
| Year 2 (12–23 months) | 521.2 \pm 279 (78) | 577.4 \pm 324 (44) | 448.5 \pm 187 (34) |
| Year 3 (24–35 months) | 492.9 \pm 280 (40) | 648.9 \pm 370 (13) | 417.8 \pm 190 (27) |
| Year 4 (36–47 months) | 495.6 \pm 207 (34) | 432.0 \pm 216 (11) | 526.0 \pm 201 (23) |
| Year 5 (48–59 months) | 539.2 \pm 252 (28) | 455.0 \pm 316 (9) | 531.7 \pm 226 (19) |
| Year 6 and beyond (\geq 60 months) | 473.7 \pm 212 (100) | 494.1 \pm 226 (45) | 457.0 \pm 201 (55) |
| Total | 499.9 \pm 245 (280) | 539.5 \pm 289 (122) | 467.5 \pm 203 (158) |

Values are means \pm SD (n).

TABLE 4. Resources used by patients to pay for uncovered medical expenses

| | Total | Liver transplant | Kidney transplant | P value |
|--|------------|------------------|-------------------|---------|
| N | 651 | 333 | 318 | |
| Personal or family savings | 351 (53.9) | 191 (57.4) | 160 (50.3) | 0.05 |
| Credit cards | 163 (25.0) | 78 (23.5) | 85 (26.7) | 0.32 |
| Personal loan from friend or family member | 87 (13.4) | 54 (16.2) | 33 (10.4) | 0.04 |
| Retirement funds | 83 (12.7) | 52 (15.6) | 31 (9.7) | 0.03 |
| Investment account (other than retirement) | 81 (12.4) | 51 (15.3) | 30 (9.4) | 0.03 |
| Second mortgage or equity line of credit | 60 (9.2) | 35 (10.5) | 25 (7.9) | 0.28 |
| Local charity funds | 46 (7.1) | 31 (9.3) | 15 (4.7) | 0.03 |
| Personal bank loan | 45 (6.9) | 21 (6.3) | 24 (7.5) | 0.54 |
| Community campaign funds | 42 (6.5) | 31 (9.3) | 11 (3.5) | 0.002 |
| Transplant organization funds | 38 (5.8) | 15 (4.5) | 23 (7.2) | 0.18 |
| Family member got second job | 38 (5.8) | 26 (7.8) | 12 (3.8) | 0.03 |
| Declared bankruptcy | 33 (5.1) | 26 (7.8) | 7 (2.2) | 0.001 |
| Children's savings account | 16 (2.5) | 8 (2.4) | 8 (2.5) | 1.00 |

Values are n (%). Test statistic represents liver vs. kidney transplant comparison by Fisher exact test.

ments, insurance deductibles, and travel to the transplant center. Since we asked patients to exclude any lost wages from their expense estimate, the true financial burden for many patients is likely much higher than our data suggest. KT recipients reported a 50% increase in out-of-pocket expenses from the third to fourth posttransplant year, which may reflect an increase in medication costs and deductibles for patients. For instance, KT recipients with a functioning graft who are not on dialysis retain Medicare benefits for immunosuppression medications for only 36 months, thus increasing their out-of-pocket medication costs in subsequent years. Overall, however, these data must be interpreted cautiously because there is so much variability across patients (range: \$25–2,400 per month) and there are numerous variables that can impact patient expenses (e.g., types of healthcare coverage, changes in government healthcare programs, travel distance to the transplant center).

Patients reported using personal or family savings, credit cards, personal loans from family members or friends, and retirement/investment accounts to pay for uncovered medical expenses. A surprising 5% of patients declared bankruptcy to reduce (or at least reorganize) debt to be able to afford continued healthcare after transplantation. Another 9% of patients acquired a second mortgage or obtained an equity line of credit, and a dozen patients spontaneously told interviewers that they were forced to sell their homes to meet transplant-related expenses. Still more patients informed us about being several months behind in mortgage payments, utility bills, and other essential services. Unfortunately, relatively few patients appeared to take advantage of funding resources from local and national organizations (e.g., National Transplant Assistance Fund, National Foundation for Transplants) or from pharmaceutical corporations that provide reduced-price or free medication programs for needy patients.

Not currently working was a significant predictor of financial impact and higher monthly out-of-pocket expenses for both LT and KT recipients. Many transplant recipients have not worked for quite some time due to medical disability

and they may benefit from a more coordinated vocational rehabilitation program in the months after transplantation (7). Transplant programs should consider forming partnerships with state-funded vocational rehabilitation programs to help transplant recipients acquire new job skills that may help to reduce financial pressures. Older patients may be less likely to return to work after transplant and, therefore, some may have fewer resources immediately available to them and may feel more of an impact financially. Alternatively, some elderly patients may have more resources to lose (a home, retirement accounts, investment accounts, etc.) than younger patients. They also may be less likely to have wage-earners in the family who can assist in offsetting the costs of posttransplant healthcare.

Interestingly, financial impact and monthly expenses do not appear to be influenced by alcohol/drug abuse history in LT recipients, nor by dialysis status or type of transplant (living vs. deceased) in KT recipients. However, LT recipients who waited longer for transplantation reported more financial burden. Longer waiting time for these patients may be associated with longer unemployment and more advanced disability status prior to transplant surgery, which exhausts available financial resources by the time patients reach transplantation. Thus, the downward financial trajectory may begin long before transplantation for some patients. The financial impact felt by the patient likely includes health problems that began long before the transplant event itself.

Also, KT recipients who did not have a functioning graft at the time of study participation reported more out-of-pocket healthcare expenses than those with a functioning kidney. In addition to the physical and psychological toll of graft loss, it is important to recognize that these patients also experience secondary financial loss as well.

Although these findings shed light on an important, yet often overlooked, transplant outcome that has particular importance to patients and their families, they should be interpreted within the context of a few methodological limitations. First, this study was conducted at a single transplant center with self-selected patients, which limits the generalizability of

the findings. While the response rate was excellent for this type of survey study, participants and nonparticipants may differ on important characteristics (e.g., socioeconomic status) that could skew the observed findings. Transplant programs vary considerably in their payer mix, contractual arrangements, patient selection, and charges, and the financial impact of transplantation is likely affected by these variables. Second, we relied exclusively on self-report and did not gather information about actual medical fees and charges, nor did we acquire receipts of patient expenditures to validate their estimates of monthly out-of-pocket expenses. Third, the cross-sectional nature of the study does not permit us to make any causal statements between transplantation and financial outcomes. It should be acknowledged that patients' perceptions of their financial circumstances likely fluctuate over time and perceptions about transplantation may become more favorable as financial exigencies improve or resolve. Finally, the overall financial impact of transplantation is likely underestimated in the current study. For instance, spouses or partners may have to discontinue working for some period of time to care for patients and this necessarily reduces available financial resources (8). Moreover, the use of personal savings and retirement accounts, credit cards, and bank loans incurs additional future financial losses by exchanging interest income for interest payments.

In conclusion, planning for the financial aspects of LT or KT is an overwhelming and complex task for most patients. Transplant financial coordinators and social workers can provide valuable assistance to individual patients and their families. However, in addition to these individualized services, transplant organizations (e.g., National Kidney Foundation, American Liver Foundation, American Society of Transplantation, Transplant Financial Coordinators Association, Society for Transplant Social Workers, Transplant Recipients International Organization, etc.) should consider a partnership to create a central repository of financial assistance information and grants programs to more efficiently assist patients in navigating this intricate maze of transplant financing. For instance, bone marrow transplant patients have the benefit of a financial guide (*Mapping the Maze: A Personal Financial Guide to Blood Stem Cell Transplant*) pre-

pared collaboratively by the National Endowment for Financial Education, The Marrow Foundation, and the National Marrow Donor Program (9). Also, it seems imperative that the pretransplant informed consent process include an element pertinent to likely out-of-pocket expenses. Finally, a recent article provided an excellent analysis of financial outcomes in transplantation, involving the complex interactions between payers, providers, and institutions (10). However, it begs the question: Where is the transplant recipient in this analysis? Certainly, the financial outcomes of transplantation from the patient's perceptive warrant further consideration and study. To ignore this perspective is to potentially jeopardize otherwise favorable health outcomes (11).

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