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Financial Preparedness for Kidney and Pancreas Transplant Patients

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ABSTRACT

Increasing demand from consumers and regulators for healthcare organizations to proactively address the financial implications of medical treatment options before care commences is well documented (Bailey, 2024; Centers for Medicare & Medicaid Services (CMS), 2023). This demand has generated considerable debate regarding the implementation of financial planning goals within transplant centers. To provide insight into patient perspectives, this study sought to elicit feedback from kidney and/or pancreas transplant recipients. The Mayo Clinic Florida kidney/pancreas transplant social work team conducted a prospective, descriptive study using a survey administered to post-transplant patients. The survey response rate was 47% among patients completing post-transplant social work appointments during the study period. Results revealed that 93% of respondents reported feeling financially prepared for their transplant. Furthermore, a comprehensive financial assessment and plan were overwhelmingly viewed as essential for patient preparation and post-transplant stress reduction. These findings underscore the importance of integrating proactive financial planning into transplant care.

INTRODUCTION

There is growing demand from consumers and regulators for healthcare organizations to address the financial impact of medical treatment options before care begins (Bailey, 2024; Centers for Medicare and Medicaid Services (CMS), 2023). Setting financial planning goals for patients has been controversial in transplant centers, with different perspectives and ethical concerns expressed among the multidisciplinary teams. Media coverage of fundraising requirements has highlighted limitations but has not led to any meaningful change in available resources (Aleccia, 2018).

Patients' views on financial planning are often overlooked. A study by Richards et al. (2022) found that, when costs were not discussed prior to treatment, patients struggled to find information and resources. A 2024 Gallup poll found that only 17% of adults understood healthcare costs before receiving services (Inc, 2024). Additionally, 95% believed healthcare organizations should inform them about cost before providing care. These findings were consistent across all key demographic categories. "Financial toxicity" refers to providing care that patients cannot afford. The National Cancer Institute (2024) noted that the effects of financial toxicity can include noncompliance with medication regimens due to cost, reduced quality of life, and negative financial consequences, such as debt and sometimes bankruptcy. Schulman and Richman in the *American Medical Association Journal of Ethics* (2022) stated:

We now need physicians to assume their ethical obligations in matters of finance. Government regulations will not substitute for physician self-policing and ethical leadership. It's time to address the harms associated with financial toxicity of health care by revising the AMA *Code of Medical Ethics* to address informed financial consent.

This research study was specifically designed to give patients a voice in the ongoing debate.

METHOD

The kidney/pancreas transplant social work team at Mayo Clinic in Florida designed a prospective, descriptive study to obtain feedback from post-transplant patients. The patient population is adults only with no defined age maximum. A brief 10-question survey was offered to patients during their four-month post-transplant social work appointment **(Figure 1)**. Items reviewed at this appointment are patient and caregiver coping, compliance, and any other concerns identified. Seven of the questions requested "yes" or "no" responses and three solicited written replies. The survey

began in June 2017 and ended in June 2023.

The project was approved by the Institutional Review Board of the facility (IRB # 19-003160) and appropriate patient consents were obtained.

During the study period, 1,321 kidney and/or pancreas patients received transplants in the program. Of these, 1,092 patients completed their post-transplant social work appointments. The survey response rate among these patients was 47% (n = 510).

The team also created an assessment tool focused on each patient's expected financial expenses **(Figure 2)**. This tool factored in specific insurance coverage, relocation requirements, and loss of income during the first year of transplant. It compares those projected costs to the patient's specific economic situation, i.e., insurance and patient-reported available resources. This tool was updated each year of the study, as cost, insurance, and external resources fluctuated.

This tool and educational materials were given to all patients during their initial and follow-up pre-transplant social work appointments. A social worker met with each patient, and usually their caregiver, in person or through a video visit. This tool was incorporated into our psychosocial assessment. Insurance information was verified, and income, discretionary income, and savings were reviewed. The tool in **Figure 2** was then used to summarize estimated cost information and provide a fundraising goal if needed. A copy of the tool was updated and provided to the patient during each social work visit. The tool helped ensure that the same standards were applied to each patient, regardless of race, gender, or other socioeconomic factors.

Data were analyzed using descriptive statistics, including means and standard deviations; frequencies and percentages were used to describe the sample. Responses to open-ended items were organized into categories by two members of the research team and confirmed by two other team members.

RESULTS

Between June 2017 and June 2023, 510 patients, aged 20 to 86 completed surveys. Results of the responses to Questions 1 through 7 are summarized in **Table 1** and demographics are in **Table 2.**

Question 1 asked patients if they felt prepared for the costs related to their transplant. A total of 93% of respondents felt the social worker adequately prepared them for their transplant expenses. Of those who reported they did not feel adequately prepared (35; 7%), 19 (54%) identified as White, 12 (34%) identified as Black/African American, and four identified as other races. A total of 24 men (69%) and 11 (31%) women responded that they did not feel the program prepared them. Regarding age, the largest number of "no" responses were in the 60–69 age range (37%).

Question 2 asked, "Are you prepared to pay for your insurance premiums for the rest of the year?" Of the 510 participants, 464 people (91%) identified that they were prepared to pay for their insurance for the rest of the year, while 43 individuals (8%) reported they were not. Only 20 of these 43 respondents were assigned a financial goal using the program's financial assessment tool **(Figure 2)**. A total of 16 of the 20 received transplants in the first two years of the study. A total of 25 (58%) of those who were not prepared identified as male and 72% of the 43 respondents identified as Black/African American.

Question 3 asked if patients were able to afford all their transplant medications. Ninety-three percent of study participants identified that they were able to afford these medications. Thirty-four patients (7%) reported they were not. Of these patients, a majority identified as male (68%), Black/African American (65%), and age 60–69 (29%). The majority of the "no" respondents had traditional Medicare as primary insurance, both pre- and post-transplant, 77% and 62%, respectively. Only 35% of the "no" respondents had a fundraising goal. A total of 24% of these patients indicated the loss of American Kidney Foundation (AKF) funding and another 9% listed valganciclovir (brand name Valcyte ®) cost as a financial stressor. There was a 10% increase in unemployment for all respondents from the time of evaluation to the four-month post-transplant visit, compared to a 23% increase for those who indicated "no" on this question.

Responses stating patients were not prepared for the costs related to transplantation occurred more in those receiving their transplants earlier in the study (54% from 6/2017–12/2018).

Question 4 asked if the patient had a fundraising goal prior to transplant. Of the respondents, 126 had been assigned a fundraising goal (25%). The mean total fundraising goal was $4,188. The median was $3,300. The mode was $3,000. The range was $300–$26,764. Of the 126 respondents with a fundraising goal, 89 were Medicare recipients (71%). Of those Medicare recipients, 78 (88%) had traditional Medicare and 11 (12%) had Medicare Advantage Plans. The gender breakdown of the respondents assigned a goal was as follows: 70 (56%) male and 55 (44%) female.

Question 5 asked if the patient felt prepared for their transplant-related expenses for the rest of the year. The majority of respondents (454; 89%) indicated "yes," while 10% (51) indicated "no" and 1% (5) did not respond. Of those who responded "no," the majority identified as male (59%), Black/African American (67%), and in the 50–59 age group (25%).

Additionally, 65% of those responding that they did not feel prepared for their post-transplant expenses were not assigned a fundraising goal prior to transplant.

Question 6 asked patients pre-transplant if they were working or planned to return to work in the future. Forty-one percent (210) of respondents reported that they were employed and 59% (300) reported that they were not employed at the time of the initial evaluation for transplant. At the four-month post-transplant appointment, 35% (177) reported that they were employed and 64% (328) reported that they were unemployed. Five patients did not respond to the question. This data show there was a 10% decrease in actively employed patients at four months post-transplant. Of those who responded they were unemployed post-transplant, 22% were retirement age (65+), and only 17% were employed prior to transplant.

Question 7 asked if patients were aware that they would vitally need to continue insurance coverage for the rest of their lives. Five hundred and three (503) individuals (99%) said they understood that it was vital to maintain insurance coverage through the rest of their lives, while seven (1%) reported they did not understand. Of the seven articipants who did not understand the importance, six (86%) identified as male and one (14%) as female. Five individuals (72%) identified as Black/African American, one (14%) identified as Asian/Vietnamese, and one (14%) identified as American Indian/Alaskan Native.

Question 8 asked if a financial goal was identified, what it was for. **Figure 3** summarizes the categories the goals were assigned for. Forty-two percent (42%) of the goals were for medication costs, which included copays and the Part D medication coverage gap or "donut hole." During the coverage gap period, Medicare Part D recipients were required to pay the full cost of their medications until they reached a specific spending threshold.

The mean medication costs were $3,656 for participants greater than or equal to age 65 and $2,324 for those under age 65. For participants with medication fundraising goals, 62% (78) had traditional Medicare, 9% (11) had Medicare Advantage Plans, and 29% (36) had commercial plans. Twenty-five percent of the respondents had goals for relocation expenses, with mean expenses of $2,019. Twenty-four percent had fundraising goals for insurance premiums with a mean cost of $4,322. Nine percent of patients had fundraising goals for loss of income, with the mean amount of $1,628. Less than 1% was for other expenses. For the one person with a fundraising goal of over $26,000, the goal was primarily due to the loss of American Kidney Foundation (AKF) funding of $22,464 for insurance premiums.

During the time of this study, AKF subsidized insurance premiums for financially eligible patients on dialysis. Dialysis centers facilitated the application and payment processing for various insurance types including Medicare, employer-sponsored insurance, COBRA, and Medicare supplements. Over time, AKF changed how they funded insurance premiums for transplant patients. Previously AKF terminated funding at the end of the insurance quarter after transplants, then extended funding to the end of the insurance plan calendar year (Healio.com, 2018) and now will sometimes extend an additional plan year if transplantation occurred in the last quarter of the insurance plan year (American Kidney Fund (AKF), 2022).

Question 9 asked how respondents reached their goals. One hundred sixty-nine (of 510) participants responded. The primary methods of reaching goals were fundraising campaigns and activities, support from family, friends, and faith-based and local communities. Sixty-two (37%) of the respondents indicated more than one method was used to achieve their goals.

The most frequently used fundraising platform was GoFundMe™ (21 times), followed by the Georgia Transplant Foundation (13 times), Help Hope Live (five times), while others held private fundraisers. Assistance from private donors was cited five times. Responses also included: savings, selling property, and insurance payouts, and one person indicated that they had closed out an IRA.

Question 10 asked, "Was there anything we could have done better to educate you about the costs related to transplant?" Only 34 patients responded from the 510 study participants.

The question most often raised by the medical team has been "Does this process delay patients getting to transplant?" Patients assigned a fundraising goal had a slightly higher average wait time to transplant of 721.6 days compared to 649.8 days for all study participants and 582.4 for all patients undergoing transplants during the study period. **Table 3** provides additional details about time to transplant.

DISCUSSION

Overall, 93% of patients felt financially prepared for kidney and/or pancreas transplantation, indicating they understood and utilized the information provided by social workers. Financial preparedness was defined in our study by the responses to Question 1, "Do you feel that we adequately prepared you for the costs related to your transplant?" **(Figure 1)**. Major factors in helping patients feel financially prepared for transplantation during the study period included social workers continuously providing patients with the financial assessment tool and updating it for the patients' current circumstances during each visit, explaining resources

available to help patients meet their financial needs, and providing education on alternatives to their current situations. Reduction in medication costs, changes in AKF funding of insurance premiums, and continuous improvement in the financial assessment tool also helped patients feel better prepared.

Patients who felt unprepared for transplant costs (35; 7%) were more likely to have received transplants earlier in the study (54% from 2017–2018) and during the height of the pandemic (37% from 2021–2022). During these periods, patients and caregivers faced more financial challenges, possibly due to inability or unwillingness to work, or depletion of resources reserved for their transplants.

Those who did not feel financially prepared for insurance premiums, medications, and other transplant expenses for the rest of the year, were disproportionately male and Black/African American. This may reflect a systemic inequity in healthcare communication and access to information, disproportionately impacting marginalized populations who may be perceived to have lower healthcare literacy (Muvuka et al, 2020), indicating a need for improved educational materials. The higher number of males experiencing issues may indicate that the methods used to provide education need to be reviewed. The current education method for the study population is predominantly visual and auditory, which research has shown is preferred by women, while men tend to prefer more multimodal formats, i.e., a combination of visual, auditory, kinesthetic, or tactile. (Wehrwein, Lujan, & DiCarlo, 2007).

Of the 43 participants who reported not feeling prepared to pay for their insurance premiums, only 20 had been assigned a financial goal by the financial assessment tool. This may indicate there was missing coverage or cost updates, or that the patient's financial circumstances changed between the last social work evaluation and their transplant. Many kidney and/or pancreas transplant patients are not seen every year by social workers, due to the substantial waitlist time for transplant. End-stage kidney disease (ESKD) patients often change insurance year-to-year, with the insurance verification system not identifying changes in a timely manner so that social workers could update the financial assessment tool for patients who had changed coverage.

Regarding the affordability of medications after transplantation, initial budgets did not consider valganciclovir because the social work team was not aware that an estimated 70% of the patients would potentially need it post-transplant. This medication became widely available in generic form in 2019, substantially reducing the cost (46brooklyn Research, 2014). According to the National Average Drug Acquisition Cost (NADAC) database, the annual cost of tacrolimus, mycophenolate, prednisone, and valganciclovir (at the doses normally prescribed at transplant) decreased by approximately $20,000 from 2017 to 2024 (46brooklyn Research, 2014). This 86% reduction in the cost of these medications and changes to eliminate the Medicare Part D coverage gap, significantly reduced patient out-of-pocket medication cost. Beginning in 2023, the Inflation Reduction Act capped insulin cost-sharing at $35 a month for Medicare Part D enrollees (Sayed et al., 2023).

The expansion and streamlining of the Medicare Savings Program in mid-2022 resulted in a higher number of patients qualifying for Medicare Part D Extra Help or Low-Income Subsidy (LIS) program (Oliver et al., 2023). This increased access to LIS helped cover the 20% of immunosuppressant medication costs not covered by Medicare Part B, secondary, or supplemental insurance. This was a significant cost reduction for patients who did not have other coverage and could not qualify for full or "medically needy" Medicaid (Oliver et al., 2023)

The "Immuno Bill," passed in December of 2020, extended Medicare Part B coverage of immunosuppressant medications past the original 36-month period of ESKD Medicare coverage (American Society of Transplantation (AST), 2020). This has had minimal impact on patients due to the significantly lower cost of the medications. The cash cost of basic immunosuppressant medications are approximately $125 a month at discount pharmacies like Mark Cuban's Cost-Plus Drug Company (2021) and Part B will pay 80% of that cost or about $100. The monthly cost to extend Part B coverage for immunosuppressant medications is $103 in 2024 and patients would also be responsible for the Part B deductible of $240 (Centers for Medicare & Medicaid Services (CMS), 2023).

Thirty of the 510 respondents had their transplants on or after July 1, 2022. Of those, only three (10%) indicated they were unable to afford their medications. This supports the premise that the medication costs were decreasing and the financial preparedness process was improving.

Reasons for fundraising goals included: medications, relocation, loss of income for the patient and/or the caregiver, and insurance premiums. Most transplant centers require patients who live a certain distance or travel time from the transplant center to relocate closer to the center's service area for a specific period at the time of transplant. For kidney and/or pancreas transplant patients that relocation period is typically two to six weeks. Closer to the end of the study period, more Medicare Advantage Plans began covering travel and lodging expenses for patients. Lower- income patients often do not have a credit card available to initiate the lodging

payment, making reimbursement plans impossible to use. It would be more helpful if lower-income patients received a lodging debit card to cover the lodging expense. Some insurance plans already offer this option.

Addressing patient and caregiver loss of income was more challenging. During the study, some states expanded Medicaid-funded "consumer directed" caregiver assistance during COVID-19, but the rules and qualifications differ significantly between states. This expanded funding was set to expire March 2025 and, prior to that date, many states already discontinued or rolled back these programs to only those patients who would otherwise qualify for nursing home care (Chidambaram, Burns, & Rudowitz, 2023).

The growing popularity of critical illness insurance policies (e.g., Aflac®) in employee benefit plans has helped some patients. These plans are low cost, often do not have pre-existing condition clauses, and sometimes pay out at the time of ESKD diagnosis and at transplant. The benefits are usually funded by the employee and normally cost a few dollars per pay period and may be maintained by the employee even if they leave their employer.

Many of the patients (37%) used multiple methods to raise funds for their transplants. Forty-four of the study participants sought assistance to meet their transplant expenses, even when told they had sufficient resources. The Mayo Clinic Florida patient education program discourages using GoFundMe, due to Medicaid eligibility concerns, but it was still the most popular fundraising platform.

Of the limited responses (34) received to the question "What could have been done better to educate you about the costs related to transplant?", 13 (34%) left "no comment," and eight (24%) stated hospital or billing issues were a concern. A review of the charts for the 13 patients with "no comment," did not reveal any specific financial issues identified during the four-month post-transplant social work appointment. The billing issues were outside the scope of the social work team and fell to the transplant financial coordinator role within the organization.

There were concerns raised by our transplant medical team about delaying transplants due to financial goal setting and the potential risk that patients may become too sick for kidney and/or pancreas transplantation. Advocates of this perspective maintain that prompt transplant can restore patients' health more rapidly, helping them rejoin the workforce and payoff any accrued debt. However, Mayo Clinic Florida social workers have witnessed patients and their caregivers who are not able to financially recover. The program has seen patients who have lost their homes, gone through divorces, and have ruined credit due to medical treatments they could not afford. Study data also shows that patients who were assigned a fundraising goal did not wait significantly longer for transplant.

The "Diagnosis: Debt" series of *Kaiser Family Foundation Health News articles* (2022) reported that more than 100 million adults in the U.S. (41% of adults) have medical debt they cannot pay. One of the articles in the series describes the current healthcare system as "systematically pushing patients into debt on a mass scale" (Levey, 2022). Families are forgoing essential spending, using up savings or retirement funds, and declaring bankruptcy to manage this debt. In the same poll, one in seven adults with healthcare debt reported being denied care by a medical provider due to their debt. About two-thirds reported skipping or delaying care or medications due to cost. Rakshit et al. (2024), in another KFF article, reported middle-aged adults, Black/African American people, and those living in rural areas and in the South as more likely to have medical debt.

A simple ten-question survey **(Figure 1)** was used to focus on specific areas of concern. Unfortunately, the questions requesting additional written comments did not always elicit usable data, resulting in a lack of clarity regarding issues experienced by patients. Question six regarding returning to work did not yield specific information due to a lack of data about why patients had not returned to work. This study also did not include a way to capture patients who walked away from transplant due to financial concerns. The Mayo Florida social work team makes every effort, from the initial evaluation, to help patients identify alternatives or resources that can assist them in strengthening their financial preparedness plans.

CONCLUSIONS

This study aimed to give transplant patients and candidates a voice in the financial planning debate. Results showed that 93% of patients felt financially prepared for their transplant, indicating they valued and understood the information provided by a social work team.

There is an increasing demand to find ways to avoid financial strain on patients, and social workers play a crucial role in navigating medical care, insurance, and safety net programs. Well-trained, financially literate social workers are essential for helping patients with these life- changing events (Wolfsohn, R., & Schwartz, M. L., 2021).

Without pre-transplant financial planning, patients, caregivers, social workers, and post-transplant coordinators are left to manage the fallout. Many transplant social workers view financial planning as important as caregiver plans, medical adherence, and mental health. It is sometimes difficult for team members to understand how restrictive limited

resources can be for low- or middle-income patients. Social work regularly observes the stress that the lack of preparation puts on patients and their caregivers at a time when they are already overwhelmed from the demands of transplant recovery. The system contributes to that stress when ignoring the importance of financial preparedness for post-transplant-related expenses, thus, disregarding a critical element of informed consent at a time when patients are most vulnerable.

Kidney and/or pancreas patients and advocacy groups have improved financial impacts, but challenges remain. Loss of income during transplantation remains a huge hurdle. The Family and Medical Leave Act (FMLA) is an option, but it is often unpaid and limited to specific family relationships (U.S. Department of Labor, n.d.). Nineteen states have implemented paid leave programs to expand FMLA and help fill this gap (Bipartisan Policy Center, 2024). Most centers require full-time caregivers for two to six weeks post-transplant. Critical illness, short-term, and long-term disability insurance policies can help alleviate some of the lost income. Efforts are needed to help patients retain their employment and return to work quickly after transplant while maintaining their benefits. AKF could expand insurance coverage for the post-transplant patients to one year to align with ESKD disability return-to-work requirements.

Study results showed that a comprehensive financial assessment and plan are welcomed and essential for preparing patients and reducing post-transplant stress. The push for more transparency in healthcare costs benefits patients so that they can plan.

Transplant programs can successfully educate patients early in the pre-transplant evaluation phase about expected costs and necessary resources. Lack of financial resources can lead to poor outcomes, including medication non-compliance, graft loss, patient emotional stress, caregiver stress, and longer hospital stays. Standardized financial educational materials should be used to improve patient education and address their unmet needs.

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REFERENCES

46brooklyn Research. (2014). What does it cost? Start with NADAC [drug pricing dashboard]. https://www.46brooklyn.com/nadac

Aleccia J. (2018, December 5). *Organ transplants, but only for those who can afford them.* ABC News. https://abcnews.go.com/Health/organ-transplants-afford/story?id=59631506

American Kidney Fund (AKF). (2022). *Health insurance premium program guidelines.* Kidneyfund.org. https://www.kidneyfund.org/assets/pdf/financial-assistance/akf-hipp-guidelines.pdf

American Society of Transplantation (AST). (2020, December 27). *Immuno Bill passes after 20 years.* MyAST.org. https://www.myast.org/about-ast/presidents-blog/immuno-bill-passes-after-20-years

Bailey, V. (2024). *Healthcare consumers want hospital price transparency, survey finds.* Rev Cycle Management; TechTarget. https://revcycleintelligence.com/news/healthcare-consumers-want-hospital-price-transparency-survey-finds

Bipartisan Policy Center. (2024, January 16). *State paid family leave laws across the U.S.* Bipartisanpolicy.org. https://bipartisanpolicy.org/explainer/state-paid-family-leave-laws-across-the-u-s/

Centers for Medicare and Medicaid Services (CMS). (2023, April 26). *Hospital price transparency enforcement updates.* CMS.gov. https://www.cms.gov/newsroom/fact-sheets/hospital-price-transparency-enforcement-updates

Centers for Medicare and Medicaid Services (CMS). (2023, October 12). *2024 Medicare Parts A & B premiums and deductibles.* CMS.gov. https://www.cms.gov/newsroom/fact-sheets/2024-medicare-parts-b-premiums-and-deductibles

Chidambaram, P., Burns, A., & Rudowitz, R. (2023, December 14). *Who uses Medicaid long-term services and supports?* KFF.org. https://www.kff.org/medicaid/issue-brief/who-uses-medicaid-long-term-services-and-supports/

Healio.com. (2018, February 15). *AKF extends premium coverage for patients who receive a transplant.* Healio.com. https://www.healio.com/news/nephrology/20180227/akf-extends-premium-coverage-for-patients-who-rece

Inc, G. (2024, January 31). *Few Americans know how much their healthcare costs.* Gallup.com. https://news.gallup.com/poll/609434/few-americans-know-healthcare-costs.aspx

KFF Health News. (2022). *Diagnosis: Debt.* KFF Health News. https://kffhealthnews.org/diagnosis-debt/

Levey, N. N. (2022, June 16). *100 million people in America are saddled with health care debt.* KFF Health News. https://kffhealthnews.org/news/article/diagnosis-debt-investigation-100-million-americans-hidden-medical-debt/

Mark Cuban Cost Plus Drugs Company. (2025). COST PLUS DRUGS™ [home page]. https://costplusdrugs.com

Muvuka, B., Combs, R. M., Ayangeakaa, S. D., Ali, N. M., Wendel, M. L., & Jackson, T. (2020). Health literacy in African American communities: Barriers and strategies. *HLRP: Health Literacy Research and Practice, 4*(3), e138–e143. https://doi.org/10.3928/24748307-20200617-01

National Cancer Institute (NCI). (2024, June 6). *Financial toxicity (financial distress) and cancer treatment.* Cancer.gov. https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq#_247

Oliver, T., Zhu, W., Lakhmani, E. W., & Wysocki, A. (2023, November 30). *Medicare Savings Program enrollment increases when states expand financial eligibility criteria.* AARP. https://www.aarp.org/pri/topics/health/coverage-access/medicare-savings-program-enrollment-increases-when-states-expand/

Rakshit, S., Rae, M., Claxton, G., Amin, K., & Cox, C. (2024, February 12). *The burden of medical debt in the United States.* Peterson-KFF Health System Tracker. https://www.healthsystemtracker.org/brief/the-burden-of-medical-debt-in-the-united- states/#Share%20of%20adults%20who%20have%20medical%20debt

Richards, O. K., Iott, B. E., Toscos, T. R., Pater, J. A., Wagner, S. R., & Veinot, T. C. (2022, February 19). "It's a mess sometimes": Patient perspectives on provider responses to healthcare costs, and how informatics interventions can help support cost-sensitive care decisions. *Journal of the American Medical Informatics Association, 29*(6), 1029–1039. https://doi.org/10.1093/jamia/ocac010

Sayed, B. A,, Finegold, K., Olsen, T. A., De Lew, N., Sheingold, S., Ashok, K., & Sommers, B. D. (2023, January). Insulin affordability and the Inflation Reduction Act: Medicare beneficiary savings by state and demographics [Issue Brief No. HP-2023-02]. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services (HHS). https://aspe.hhs.gov/sites/default/files/documents/bd5568fa0e8a59c2225b2e0b93d5ae5b/aspe-insulin-affordibility-datapoint.pdf

Schulman, K., & Richman, B. (2022). Informed consent as a means of acknowledging and avoiding financial toxicity as iatrogenic harm. *AMA Journal of Ethics, 24*(11), E1063–1068. https://doi.org/10.1001/amajethics.2022.1063

U.S. Department of Labor. (n.d.). Family and Medical Leave (FMLA). https://www.dol.gov/general/topic/benefits-leave/fmla

Wehrwein, E. A., Lujan, H. L., & DiCarlo, S. E. (2007). Gender differences in learning style preferences among undergraduate physiology students. *Advances in Physiology Education, 31*(2), 153–157. https://doi.org/10.1152/advan.00060.2006

Wolfsohn, R., & Schwartz, M. L. (2021, Fall). Social work and money: We need to talk about it. Social *Work Today, 21*(4), 18. https://www.socialworktoday.com/archive/Fall21p18.shtml

https://secure.viewer.zmags.com/publication/6f4bb3ac#/6f4bb3ac/1

TABLE 1. RESPONSE SUMMARY QUESTIONS 1–7 (*N* = 510) # RESPONSES (% RESPONSES)

	Yes	No	NR
Question 1	474 (93%)	35 (7%)	1 (0%)
Question 2	464 (91%)	43 (8%)	3 (0%)
Question 3	473 (93%)	34 (7%)	3 (0%)
Question 4	126 (25%)	384 (75%)	-
Question 5	454 (89%)	51 (10%)	5 (1%)
Question 6	177 (35%)	328 (64%)	5 (1%)
Question 7	503 (99%)	7 (1%)	-

TABLE 2: DEMOGRAPHIC SUMMARY OF STUDY PARTICIPANTS VS. ALL TRANSPLANTS

	Study, N = 510	All Transplants, N=1321
Mean Age	54.6 *(SD=14.1)*	57.5 *(SD=13.5)*
Gender		
Female	198 *(38.8%)*	543 *(41.1%)*
Male	311 *(61.0%)*	778 *(58.9%)*
NR	1 *(0.2%)*	-
Race		
African American/Black	185 *(36.3%)*	466 *(35.3%)*
Asian	26 *(5.1%)*	58 *(4.4%)*
Caucasian/White	283 *(55.5%)*	751 *(56.9%)*
Choose Not to Disclose	4 *(0.8%)*	19 *(1.4%)*
Other	12 *(2.4%)*	27 *(2.0%)*

TABLE 3. AVERAGE TIME TO TRANSPLANT - WAITLIST DAYS

	Facility Waitlist Days[a]
Study Participants w/FRG, *n*=125	721.6 *(SD=676.6)*
All Study Participants, *n*=510	649.8 *(SD=671.8)*
All Transplants, *n*=1321[b]	581.0 *(SD=657.9)*

a. days calculated using date patient listed at Mayo Clinic Florida and date of transplant
b. 12 patients were re-transplanted during study period (June 2017-June 2023), unique patient count is 1309

FIGURE 1. SURVEY SAMPLE

Kidney Pancreas Post Transplant Financial Questions

1. Do you feel that we adequately prepared you for the costs related to your transplant?	YES	NO
2. Are you prepared to pay for your insurance premiums for the rest of the year? ·	YES	NO
3. Are you able to afford all of your transplant medications?	YES	NO
4. Did you have a fundraising goal prior to transplant?	YES	NO
5. Do you feel prepared for your transplant expenses for the rest of the year?	YES	NO
6. Are you working now, or do you plan to go back to work in the future?	YES	NO
7. Are you aware that for the rest of your life, it is vital that you have insurance coverage?	YES	NO

8. If you had a fundraising goal, what was it and what was it for?

_____

9. How did you reach your goal?

_____

10. Was there anything we could have done better to educate you about the costs related to transplant?

_____

_____

_____

FIGURE 2. FIRST YEAR PROJECTED TRANSPLANT EXPENSES AND RESOURCES

MAYO CLINIC

TO BE SCANNED

First Year Projected Transplant Expenses and Resources

Form content retained in medical record.
Route to HIMS Scanning.

(complete fields or place patient label here)

Patient Name (First Middle Last)	
Birth Date (mm-dd-yyyy)	Room Number (if applicable)
Mayo Clinic Number	

Projected First Year Expenses		Reported Resources	
Immunosuppressant Copays (20% – $1,500/year – $125/month) ☐ If commercial insurance – TBD with speciality pharmacy registration ☐ If Medicare A and B, or MAP without extra help – 80% covered ☐ If Medicare B or MAP + Primary or Secondary or Supplement – 100% covered ☐ If Medicare B or MAP + Medicaid QMB/SSI/SLMB/LIS/SOC: ≤ $2,500 – 100% covered ☐ If Medicare B or MAP + Medicaid SOC: > $2,500 – 80% covered	$	Discretionary Income Immunosuppression Medications Preventative Medications Insurance Total	$
Preventative Medication Copays ☐ If commercial insurance – TBD with specialty pharmacy registration ☐ If Medicare Part D or MAP – with extra help – $100 per month ($600/year) ☐ If Medicare Part D or MAP – without extra help – $1,200 *Note: If you are on insulin prior to transplant, your insulin cost will likely continue.*	$	Savings	$
Insurance Premiums – Patients receiving American Kidney Fund (AKF) premium assistance • You must plan to cover 6 months of insurance premiums • Multiply your monthly premium × 6 or quarterly premium × 2 • If you do not know your premium, contact your dialysis social worker for amount	$	Investments	$
Relocation Lodging/Food/Travel – All patients more than 1 hour away, estimated ☐ $3,000 ($100 per day for 30 days) ☐ Georgia residents only – If you plan to utilize Georgia Transplant Foundation (GTF) for lodging assistance, estimated food/gas expense is $500 ☐ Relocation benefits (must be confirmed by Transplant Financial Coordinator [TFCs])	$	IRAs and 401(k)s – You must check your specific plan to see if you can access the funds and that you can afford any penalties and taxes	$
Loss of Income Patient	$	Letters of Support	$
Loss of Income Caregiver	$	Critical Illness Policy	$
Other Expenses (list, for example, Uber, Lyft, car rental)	$	Fundraising Help, Hope, Live	$
		GTF	$
Total First Year Projected Expenses (You must have available funds of this amount.)	$	GoFundMe	$
		Other	
		Available Resources	$

ACKNWL

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FIGURE 3. DOLLAR AMOUNT OF FUNDRAISING GOALS BY CATEGORY