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Concerns regarding the financial aspects of kidney transplantation: perspectives of pre-transplant patients and their family members

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Abstract

Background—African American and non-African American pre-transplant patients' and their families' concerns about the financial costs of kidney transplantation have not been well studied.

Methods—We conducted structured group interviews among pre-transplant patients (seven African American, five non-African American) and their family members (six African American, five non-African American) to identify their concerns about transplant health insurance coverage, out-of-pocket expenses, and living donor expenses. We reviewed transcribed group audio recordings and identified common discussion themes.

Results—African American and non-African American patients and family members expressed uncertainty about which transplant-related costs were covered by health insurance and wanted information about how to choose insurance policies accordingly. Patients were particularly concerned about the impact of pre-existing illness on securing optimal health insurance, while family members wanted information about non-insurance-based financial resources. Both patients and family members expressed concern about paying for immunosuppressant medications and about gradual loss of insurance benefits after transplantation. Both patients and family members also expressed concern about potential financial hardships for living donors.

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Focus group results identifying concerns regarding the financial costs of kidney transplantation.

Conflict of interest: None.

Conclusion—African American and non-African American pre-transplant patients and families expressed a broad range of concerns about transplant health insurance policies, out-of-pocket expenses, non-insurance-based financial resources, and resources to address donors' financial burden. Efforts to improve education and develop more comprehensive transplant insurance policies are needed to facilitate informed decision-making for potential transplant recipients and donors.

Keywords

end-stage renal disease; kidney transplantation; patient perspective; qualitative research; shared decision-making

Kidney transplantation is the optimal therapy for patients with end-stage renal disease (ESRD). However, the cost of kidney transplantation can be a significant financial burden. Ethnic/race minorities and those of low socioeconomic status may be particularly sensitive to the influence of finances on access to kidney transplantation. Studies suggest that these groups, particularly those with limited financial means, are less likely to receive live donor transplants and/or preemptive transplants, which are each associated with improved patient and graft survival (1). Transplantation is withheld from patients with limited finances or insurance due to fear of certain organ rejection as a result of inability to pay for transplant-related costs integral to transplant survival (2). Research shows that patients who receive transplants tend to have a higher income and fewer concerns about transplant-related costs, including medication co-payments compared with non-recipients (3).

Among insured individuals, insurance type (government sponsored vs. private insurance) has also been found to influence rate and duration of transplant wait-listing (4–6). Patients with private insurance have higher transplant survival rates compared to those with Medicare or Medicaid (7). Medicare recipients are still responsible for 20% of costs related to transplant. Those who lose coverage after 36 months are at a considerable disadvantage, particularly due to immunosuppressant medication costs. The estimated annual average cost of medications alone is greater than \$12 000 (8), potentially enhancing the risk of recipients' medication non-compliance and graft failure (9, 10). In addition, low income, unemployment, and low education have all been linked to poor health outcomes among transplanted patients (11).

Programs to assist patients with low incomes with transplant-related costs, such as the National Living Donor Assistance Program (12) and pharmaceutical manufacturer-based medication assistance programs, may be underutilized (13). The extent to which patients and their families receive information to make them aware of these programs or transplant health insurance policies is unclear. It is also unclear whether information needs among African Americans, who are less likely to undergo transplantation, differ from the information needs of non-African Americans. Studies identifying African American and non-African American patients' and their families' perceived needs for information regarding the financial costs of transplantation during the transplant evaluation process could help transplant programs better serve potential transplant recipients and donors.

Methods

Study design

We conducted an ancillary study to an NIH-funded trial for which we developed an intervention to meet educational needs relevant to patients' renal replacement therapy treatment decisions. During the intervention development phase of the parent study, we conducted 20 structured group interviews of patients receiving various forms of renal replacement therapy or patients with progressive chronic kidney disease (CKD) and their respective family members (14–16). For this ancillary study, we recruited four additional groups of patients with progressive CKD or ESRD who had recently undergone a kidney transplant recipient evaluation (two groups: one with African American patients and one with non-African American patients) and their family members (two groups: one with African American patients' family members and one with non-African American patients' family members). African American patient groups consisted of patients who self-identified themselves as African American prior to participation in groups during the study consent process, while non-African Americans did not identify themselves as African American, but were not otherwise restricted in terms of their race or ethnicity. Patients identified their family members for participation in family member focus groups, but family members were not selected for participation based on their self-identified race. We performed four structured group interviews of these pre-transplant patients and their family members to identify their perceived knowledge and concerns about key financial aspects of kidney transplantation, including transplant health insurance coverage, out-of-pocket expenses, and living donor expenses.

We recruited patients from the Johns Hopkins Comprehensive Transplant Center. Patients were identified by transplant coordinators as having recently completed a transplant evaluation. We invited patients to participate if they spoke English, were 18–70 yr of age, and had not yet received a kidney transplant. We asked recruited patients to identify a family member or friend (referred to as “family member”) who was involved in their treatment decisions. We obtained written informed consent from each participant. The Johns Hopkins School of Medicine Institutional Review Board approved all protocols and consent procedures.

Structured interview group and data analysis

We developed our questions in consultation with transplant professionals (including transplant surgeons, nephrologists, and coordinators). We posed slightly different questions to patients and their family members as patients selected their own family members to participate, and family members had varying levels of exposure to the transplant evaluation process. Prior to sessions, participants completed written questionnaires assessing their demographic characteristics and their agreement with the statement, “The rules for receiving government health insurance are the same regardless of whether a person is receiving dialysis or a kidney transplant” (answers included true [indicating agreement] or false [indicating disagreement]). Trained moderators performed structured interviews in the group setting using a scripted guide of six open-ended questions. Interviews lasted approximately 90 min. Participants were asked about how well informed they felt about what health

insurance typically covers pre- and post-transplantation, their out-of-pocket expenses during the evaluation process, their specific concerns and questions regarding individual expenses vs. costs covered by health insurance, and their concerns for living donor expenses (Table 1).

We audio-recorded and transcribed all group discussions verbatim for data analysis. We employed an inductive approach to analyzing findings (17). Four reviewers independently reviewed the transcripts and grouped participants' responses into themes and subthemes, using Microsoft Excel to manually catalog themes and subthemes. After the initial review, reviewers met to discuss their findings and establish consensus on themes. These findings were then discussed with other research team members, who helped to ensure clarity, consistency, and completeness of the identified themes. We then selected representative participant quotes to illustrate the core themes.

Results

Study population

Among 23 group participants (seven African American pre-transplant patients; five non-African American pre-transplant patients; six African American family members; and five non-African American family members), most were more than 60 yr of age. African American pre-transplant patients had the most number of participants between the ages of 30–60 yr of age. Overall, there were more men compared with women in the pre-transplant patient groups, and more women compared with men in the family member groups. Among the African American participants, a majority attended at least two yr of college, and among the non-African American participants, a majority had a graduate/professional degree. Most participants were married. Most participants were insured, however half of the African Americans participants had *only* government-sponsored insurance (Medicare, Medicaid, or Medical Assistance), while more non-African American participants had either private insurance or a combination of private insurance and Medicare. More African American pre-transplant patients were already on dialysis compared with non-African American pre-transplant patients. The majority of family members were spouses. Nearly half or more of each group responded incorrectly to the statement that rules for receiving government health insurance after dialysis or transplant are the same (Table 2).

Initial reports regarding participants' perceived information about transplant

In response to opening group discussion questions posed regarding how well informed group participants felt about health insurance coverage or medical costs related to transplant surgery (participants encouraged to respond with brief answers consisting of “well informed” or “not well informed”), most participants stated that they felt “well informed.” Despite this, upon further questioning during structured interviews, patients and family members identified multiple areas of concern regarding financial aspects of kidney transplantation (Table 3).

Subsequent areas of concern expressed among patients and families

We categorized these concerns into three major themes: (i) recipient expense of transplant and donor evaluation, (ii) recipient expenses post-transplantation, and (iii) living donor expenses. African American patients and families raised a greater range of concerns (e.g., paying for procedures/labs/outpatient visit co-pays, securing an optimal insurance policy with a pre-existing illness, and having access to non-insurance-based financial resources) during discussions compared with the non-African American groups. However, when similar concerns were raised by both African American and non-African American patients and their families (e.g., distinguishing which costs were covered by insurance, paying for recipient and donor out-of-pocket expenses, losing insurance coverage after transplant, and paying for medications), the content of discussions was similar.

Recipient expense of transplant and donor evaluation—Participants expressed concerns about health insurance coverage during the evaluation process. They reported a lack of understanding about which expenses were covered by health insurance vs. which expenses were the responsibility of the patient. They were concerned about not being able to pay for expenses not covered by insurance. One patient said:

In the beginning we were under the impression, somehow, of having the idea that we had to have \$10 000 up front in order to almost, like, maybe to get on the list, maybe if a kidney was available we had to have it right then. Somehow or another that, we got that impression and, you know, we were thinking, well, we have got to dig this up. How can we have this? It was a big concern and I think because we're not on Medicare...and every time he had something done they'd mess up our insurance because somebody out there thinks he's on Medicare so then they turn this down, turn that down, he makes phone calls all day. (Non-African American)

Similarly, one family member reported:

[I want to know] the percentages that our insurance would pick up...and some of the complications just because of having [Medicare]...they keep kicking in with Medicare and [then] turning[us] down, turning it back. (Non-African American)

Both patients and their family members reported a lack of knowledge about how to compare health insurance plans and select the most beneficial one.

One patient said:

I'm not really sure. I have private health insurance and they say they'll cover 90% of whatever the physician charges. I don't know what the actual surgery costs and I don't know what the physician is charging and I've been asking for several months now and I haven't gotten a clear answer. I don't know how much it would be for me to go into the hospital for the surgery...Would Medicare cover my medications better or would my private health insurance and it looks like my private health insurance would, so it's really a maze. It's just not clear. It's just not laid out. The cost changes...go up and the formularies change on the health plans. There's no way you can really figure out how much debt you're going to get in... (African American)

Another patient reported:

...Show people if you're not on Medicare and you are still working...how insurance takes care of thing(s) and how much does, how much doesn't, the balances of maybe a couple of the major insurances. (Non-African American)

One family member also said:

For instance, if... you have coverage with an insurance company...they don't tell you the pros and cons...if you accept Medicare A, they are going to knock this out, and if you accept Medicare B, you are going to have to pay another 200 dollars for this, they don't also tell you that you can go to, let's just say, the Renal Association of America, and they will give you a check for a month of this or they will make sure that you have all the pills you are going to need for the next six months, you have no idea what you are getting into until you are in it and once you are in it you might have made the wrong decision, as far as if you accept Medicare A or B, they might penalize you, and you have to pay that back, because you have this other insurance. (African American)

Patients were particularly concerned about having limited access to a variety of plans and supplementary aid programs due to a pre-existing illness. One patient said:

I just wanted to say, I'm not on dialysis yet...but even one of my medications costs \$400 for 30 pills and then I could get it for \$35, but now they're raising that to \$65, so it's once you're sort of locked into a plan then it's hard to get other types of insurance when you go in with an illness and they know they're going to have to pay for surgery and things. (African American)

Family members inquired about other financial resources (non-insurance based) available to cover medical and non-medical costs. One family member said:

We are telling you right now that the money is what the issue is. To be informed of the cost... of a kidney transplant and all the other things, the medication, this is what these people are facing, their whole life changed. It is a total life change... money. They don't have the resources that they need as far as money. There is no grant that you can give them that will help them toward a transplant. If there is some kind of program they could be in to help them... (African American)

Recipient expenses post-transplantation—Participants also expressed concerns about paying for immuno-suppressant medications. One patient said:

Before I found out I had kidney disease I wouldn't even take an aspirin. Now I'm paying for prescriptions and I'm concerned that I'm going to have to pay for more after the surgery. I'm pretty much on medications for the rest of my life. (African American)

Participants were particularly uncertain about how long their insurance plans paid for medications.

One family member said:

That is a question that I don't think has been totally answered...They have said our insurance will cover it. My question is does it cover it [medication] forever, you know, like we haven't really worked through our insurance...the details. In other words, at some point we will [have] to pay for part of it. (Non-African American)

Patients and their family members were also concerned that insurance coverage benefits would decrease after transplantation. One family member said:

Similar, just that, you know, that the coverage would change with the provider that we have and that it might not be as generous as it is now. (Non-African American)

One patient reported:

My concern is the government going broke and being able to fund these programs for these transplants. Your - - insurance company is going to do what they can do, but if the government - - Medicaid programs they're going to take funds away from you. You know they always like to take funds away, so - - what they're going to take. (African American)

Family members were particularly concerned about patients losing healthcare coverage one to three yr post-transplantation. One family member said:

Yes, because as [another group participant] stated, after a year you come off all benefits or anything that you are receiving so after a year you have a man that is almost 60 and what makes you think someone is going to give him a job after a transplant, and you are 60 or so, that is another hit. That is almost as bad as the surgery. (African American)

Finally, patients were worried about the impact of transplant status on securing future health insurance coverage. One patient said:

My concern is if I wanted to look for a better health plan would they deny me coverage because I've had the transplant... (African American)

Living donor expenses—Participants also expressed concerns about living donor expenses. Patients were most concerned about how lost work days and thus lost income would affect the donor's ability to manage expenses. They also mentioned concern about the donor covering any incidental expenses post-transplantation, such as pain medications. One patient said:

What I'm concerned [about is] if my donor doesn't have any type of insurance after they...go through the transplant and they give me the kidney. The pain medicine. Will they have to pay for that? After, how long are they going to be out from... when they give me the transplant and what medical things do they need to have done when they donate the kidney to me. (African American)

Family members were less vocal about this issue, but some did express concern regarding financial burdens on the donor. One family member said:

We are really concerned about the donor and more education for the donor and for us for the donor [in reference to missed time from work, sick time, and vacation].

We just don't know about any of these things you bring up. You feel kind of bad because you want to. (Non-African American)

Discussion

In this qualitative study, African American and non-African American pre-transplant patients and their family members expressed numerous concerns about the costs of transplant and donor evaluations (out-of-pocket expenses and how to choose the right insurance plan), costs post-transplantation (paying for immunosuppressant medications and losing health insurance coverage), and living donor expenses (donors' lost work days and incidental medical and non-medical expenses not covered by health insurance). African American patients and families raised a greater range of concerns during discussions compared with non-African Americans; however, the content of discussions was similar when common themes were discussed. Our findings highlight the financial complexity of transplantation when viewed from the vantage points of patients and families and emphasize the need for efforts to better assist them with financial considerations throughout the transplant evaluation, wait-listing, and living donor transplant process.

Prior studies have highlighted the importance of financial considerations as important stressors in the post-transplantation period (18) and have also demonstrated a strong correlation between patients' limited financial means (including inadequate health insurance coverage) and poor transplant outcomes (7, 11). Studies to identify patients' educational needs regarding renal replacement decisions have also shown that patients and family members desire information on the financial impact of their renal replacement therapy decisions (16, 19, 20). Our findings expand on those of prior studies by providing detailed insight into patients' and families' uncertainties regarding financial coverage policies for transplant and living donation as well as their specific concerns regarding the potential financial impact transplant evaluation, surgery, and recovery processes may have on both recipients' and donors' lives.

Concerns expressed by patients and their families may reflect potential shortcomings in financial education programs during the evaluation and transplant process. The complexities of insurance changes that occur when patients develop ESRD (e.g., including shifts from private insurance or no insurance to Medicare or dual insurance as well as termination of benefits after transplant for some) may pose substantial challenges to ensuring patients and their families are adequately well informed about the financial implications of transplantation. Patients and potential live donors are required to receive financial education as part of the transplant process (21, 22), but standardized content and methods for financial education programs have not yet been clearly established. Thus, the content of financial education may vary widely among transplant programs. Furthermore, the effectiveness of education has not been established. While patients may receive financial education, the extent to which education programs accommodate patients' varied comfort levels with financial information or result in patients' and families' full comprehension of information provided is unknown. Notably, while the majority of participants in our study groups reported that they felt well informed about the finances of transplantation at the beginning of group interviews, participants discussed numerous uncertainties about insurance coverage

plans and the potential financial impact of transplant on recipients and donors during subsequent group discussions. This suggests that patients and families may have some general understanding of financial aspects of transplantation, but they may still need information on numerous very specific concerns they also need addressed. Thus, programs focused on educating patients and their families about transplant finances should seek to cover a broad range of very specific concerns during the financial education process. Programs might also consider how families should receive education. We conducted our group interviews separately with patients and families, but we did not assess whether they had received financial counseling about transplantation jointly. It is possible that some family members may grasp financial information differently or that certain family members have more responsibility for handling family finances. The extent to which shared decision-making is incorporated into transplant financial counseling programs, and the role of individual or joint counseling on transplant finances warrants further examination.

Patients' and family members' distress about losing health insurance coverage (or certain benefits) during the post-transplantation period underscores the importance of enacting policies to ensure patients have adequate coverage for this life-saving therapy. Extended insurance coverage for transplant recipients is widely advocated among patient and healthcare provider advocacy groups as a critical solution to improving access to transplant as well as ensuring the success of transplants long-term (23–25). While expansion of health insurance coverage through the Patient Protection and Affordable Care Act will improve healthcare coverage for many seeking transplants, gaps in coverage leading to potential financial hardship will remain for many (26). In the absence of universal health insurance coverage for all post-transplant care, it remains important to ensure patients and families have adequate access to supplemental programs (e.g., for medication costs) that may help address current policy shortcomings.

Patients and family members also voiced concern about the financial impact of transplantation on living donors, especially concerns about lost work days and not being able to afford incidental medical and non-medical expenses not covered by health insurance. These findings highlight the importance of making patients and families aware of federal and state legislation that can protect time missed from work for live donors (27) as well as financial assistance programs such as the National Living Donor Assistance Program (12). These resources may facilitate pre-transplant patients' consideration of live kidney transplantation and identify potential donors who might not otherwise step forward due to financial barriers. Findings from previous studies also citing financial concerns expressed among potential and former living kidney donors have suggested that donors' concerns about finances can be mitigated through comprehensive education delivered by social workers or transplant coordinators to help them better understand the financial implications of donation and clarify donor health insurance coverage rules (20, 28).

The broad range of financial concerns expressed among African American participants may have significance, as perceived financial barriers to transplant could contribute to African Americans' poorer utilization of live donor transplantation compared with white people (29). Prior work has demonstrated African Americans may view financial support for potential donors more favorably than persons from other racial and ethnic groups, even

when accounting for income (30). Efforts to address a full range of financial barriers (e.g., greater family financial insecurity or caregiver stress) to transplantation that may be more frequently faced by underserved groups (e.g., by providing help to utilize financial assistance programs for potential donors or by providing professional social work assistance) may be needed to thwart African Americans' financial concerns and maximize their utilization of transplantation.

It is worth noting several limitations in this study. First, ours was a small ancillary study with limited resources to recruit several groups of pre-transplant patients and their family members. Recruitment of additional groups could have revealed further insights that we did not capture in this study. Second, we did not formally assess inter-rater reliability in our transcripts review. However, four reviewers independently reviewed group transcripts and derived discussion themes, strengthening confidence in our findings. Third, while our findings may reflect common concerns among all pre-transplant patients and their families, our sample was drawn from a single kidney transplant center, and our participants may not reflect characteristics of patients from other centers. For example, many of our participants had graduate or professional school education, which may vary substantially from patients commonly seen in other centers. Fourth, while all patient participants received transplant coordinator assistance as part of their transplant recipient evaluations, we did not ask participants specifically what education they received or the content of their individual discussions with counselors. It is therefore possible that participants' views may not be reflective of the viewpoints of other pre-transplant patients with kidney disease and their family members across the United States. Fifth, our pre-transplant patients differed in severity of kidney disease (some were on dialysis while others were not), which may have influenced their healthcare experiences, accumulation of financial knowledge, and urgency for transplantation. We also did not inquire about employment status or patients' co-morbid health conditions, and some participants did not complete information on their age. The role of education level, insurance type, and employment status in facilitating access to financial information (including navigating the health insurance and hospital billing system) and shaping discussions about finances cannot be underestimated. Furthermore, patients and their family members already faced with medical expenses from other illnesses may be particularly sensitive to limitations in health insurance coverage. Age also influences potential recipients' health insurance (e.g., Medicare) eligibility post-transplant and could therefore influence their health insurance-related concerns. Finally, our non-African American participants all identified themselves as being of white race. Therefore, we cannot generalize our findings to people of other ethnicity or race (e.g., Hispanics or Native Americans). The definitive nature of our findings should be viewed with caution, as they are based on a limited number of study participants. Nonetheless, our study draws attention to the need to advance efforts to better address the financial concerns of patients and families regarding the transplant and donation process.

In conclusion, patients and their family members identified a broad range of financial concerns related to kidney transplantation and donation. Efforts to address these concerns through enhanced education and comprehensive transplant health insurance policies are needed.

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Table 1

Questions posed during structured group interviews

Pre-transplant patient questions		Family member questions	
1	Do you feel well informed about what health insurance typically covers for transplant?	1	How well informed do you feel about what your family member or friend's health insurance will cover for a kidney transplant and other medical costs related to the surgery? (short answer: well informed or not well informed)
2	Have you had to pay any out-of-pocket costs that were related to the evaluation process? (child care, lodging, time off work)	2	For those of you who do not feel well informed, what kinds of questions do you have?
3	What other things were you were worried about spending money on that you did not have to pay for?	3	For those of you who are well informed, where did you find information about the financial details of transplantation?
4	Do you have any concerns about your health insurance coverage after the transplant surgery?	4	Have you or your family member or friend had to pay any out-of-pocket costs that were related to the evaluation process? – child care expenses – time off work – travel or lodging?
5	For those of you considering a living kidney transplant, do you have concerns about whether your donor will have to pay any money out of pocket before, during, or after the surgery?	5	Were there other things that you were worried about spending money on that you did not have to pay for?
6	What sorts of things related to donor expenses are you concerned about?	6	What do you know about your family member or friend's health insurance coverage after the transplant surgery?

Table 2

Pre-transplant patient and family member characteristics

Participant characteristics n (%)	Pre-transplant patients		Family members	
	African American (n = 7)	Non-African American ^a (n = 5)	African American (n = 6)	Non-African American ^a (n = 5)
Age				
30–60 yr of age	4 (57)	1 (20)	1 (17)	1 (20)
>60 yr of age	2 (29)	3 (60)	2 (33)	4 (80)
Unknown	1 (14) ^M	1 (20) ^R	3 (50) ^M	0 (0)
Gender				
Female	3 (43)	1 (20)	5 (83)	4 (80)
Male	4 (57)	4 (80)	1 (17)	1 (20)
Education				
HS or less	2 (29)	0 (0)	2 (33)	0 (0)
At least two yr of college	2 (29)	1 (20)	4 (67)	0 (0)
Graduate/Professional school	3 (42)	3 (60)	0 (0)	5 (100)
Unknown	0 (0)	1 (20)	0 (0)	0 (0)
Marital status				
Married	5 (72)	4 (80)	3 (50)	5 (100)
Divorced	1 (14)	0 (0)	1 (17)	0 (0)
Never married	1 (14)	0 (0)	1 (17)	0 (0)
Unknown	0 (0)	1 (20)	1 (17)	0 (0)
Health insurance				
Insured				
Private	2 (29)	2 (40)	2 (33)	2 (40)
Government sponsored ^b	3 (43)	0 (0)	3 (50)	0 (0)
Private + Medicare	2 (29)	2 (40)	0 (0)	3 (60)
Not insured	0 (0)	0 (0)	1 (17)	0 (0)
Unknown	0 (0)	1 (20)	0 (0)	0 (0)
Dialysis				
Yes	5 (72)	2 (40)	— ^c	—
No	1 (14)	3 (60)	—	—
Unknown	1 (14)	0 (0)	—	—
Family member relationship to patient				
Spouse	—	—	3 (50)	5 (100)
Parent	—	—	1 (17)	0 (0)
Child	—	—	2 (33)	0 (0)
Factual knowledge about insurance for kidney transplants				
Correct	4 (57)	2 (40)	1 (17)	1 (20)
Incorrect	3 (43)	3 (50)	5 (83)	4 (60)

R, refused; M, missing.

^a All participants self-designated as white people, non-Hispanic.

^b Medicare, Medicaid, Medical Assistance.

^c Item not applicable to that group.

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Table 3

Common themes on patient and family members' concerns regarding financial aspects of kidney transplantation

African American patients and family members	Non-African American patients and family members
Comfort with health insurance information Several reported feeling well informed about health insurance coverage for transplantation during early discussion (patients)	Comfort with health insurance information Several reported feeling well informed about health insurance coverage for transplantation during early discussion (patients and family members)
Concerns about recipient transplant expenses Which expenses are "out of pocket" and which expenses are covered by health insurance (patients, family members) Paying for procedures, imaging studies, labs, and physician visit co-pays (patients) How to choose the best health insurance plan (patients, family members) Having equal access to a variety of health insurance plans with a pre-existing illness (patients) Desired information on other financial resources to help pay for expenses not covered by health insurance (family members)	Concerns about recipient transplant expenses Which expenses are "out of pocket" and which expenses are covered by health insurance (patients, family members) How to choose the best health insurance plan (patients) Having equal access to a variety of health insurance plans with a pre-existing illness (patients)
Concerns about recipient post-transplant expenses Paying for medications (patients, family members) Health insurance coverage decrease after transplant (patients) Losing health insurance coverage after a fixed-period post-transplant (patient, family member) Pre-existing illness impacting access to new health insurance (patients)	Concerns about recipient post-transplant expenses Paying for medications (patients, family members) Health insurance coverage decrease after transplant (family members) Losing health insurance coverage after a fixed-period post-transplant (family members)
Concerns about living donor expenses Health insurance covering donor expenses (patients, family members) Out-of-pocket expenses (patients, family members) Financial burden on donor (patients)	Concerns about living donor expenses Out-of-pocket expenses (patients) Financial burden on donor (family members)