



Perceptions of Palliative Care Among Patients With Kidney Allograft Dysfunction: A Qualitative Study

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Rationale & Objective: Nearly half of kidney transplant recipients develop allograft failure within 10 years of transplantation and experience high mortality, significant symptom burden, and complex communication challenges. These patients may benefit from palliative care, but palliative care is infrequently provided in this population. This study explores palliative care perceptions and needs among patients with poorly functioning and declining kidney allografts.

Study Design: A qualitative study using semi-structured interviews.

Setting & Participants: Adult kidney transplant recipients with a glomerular filtration rate of <20 mL/min/1.73m² followed at a single transplant center were interviewed from April 2022 to November 2022.

Analytical Approach: An interdisciplinary team, including nephrology, palliative care, and surgery, conducted a thematic analysis.

Results: Twelve participants (3 women, 9 men; 9 White, 2 Black, and 1 Hispanic patient) were interviewed. The median age of participants was 59 (IQR 48-73). At 6 months postinterview, 7 participants had resumed dialysis, 1 participant

had been retransplanted, and 1 participant was deceased. Most participants had not heard of palliative care and those who had equated it with end-of-life care. Participants reported that emotional distress, particularly pervasive concern about the worsening of their kidney disease, was their most significant priority related to unmet palliative care needs. They also desired more discussion with their care team about future quality of life and lifespan. Participants described high trust in their transplant teams, suggesting that palliative care integration with these teams would be well-received.

Limitations: Limitations include recruitment from a single institution, lack of subject familiarity with palliative care, and limited racial and ethnic diversity among participants.

Conclusions: Patients with declining kidney allografts have heterogeneous, unmet palliative care needs, including emotional symptoms and a desire for better prognostic awareness. Our results suggest that patients are largely unaware of palliative care and may benefit from practice models in which transplant teams integrate palliative care education and timely palliative care engagement.

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Patients with kidney failure experience significant morbidity and mortality, diminished quality of life, and symptom severity comparable to that of advanced cancer.¹ Kidney transplantation improves survival and quality of life for patients with kidney failure. However, nearly half of kidney transplant recipients experience allograft failure within 10 years of transplantation.² Only about 48% of these patients are relisted for another transplant, whereas the rest remain dialysis-dependent.³ Patients with poorly functioning and declining kidney allografts face the symptom burden associated with kidney failure and unique challenges such as complex medical decision-making, uncertain prognosis, and an unpredictable clinical course.^{4,5}

Kidney palliative care aims to employ specialty-trained interprofessional teams to optimize quality of life for patients with kidney failure through symptom management, psychosocial and spiritual support, expert communication, and shared decision-making around the treatment of kidney failure.^{6,7} Palliative care interventions for adults with chronic kidney disease and pretransplant kidney failure have been associated with improved symptom management, quality of life, and increased completion of advance care

planning documentation.^{6,8} Similarly, an inpatient kidney palliative care intervention for patients with failing kidney allografts demonstrated increased rates of hospice use and more frequent selection of a time-limited trial of dialysis.⁹⁻¹¹ Nevertheless, studies evaluating palliative care provision in patients with poorly functioning and declining kidney allografts and the palliative care needs of these patients remain limited.¹²

Furthermore, patients with kidney failure receive palliative care less frequently than other seriously ill patients, especially following transplantation.^{13,14} Our previous work identified kidney transplant clinician-perceived barriers to palliative care referral in patients with poorly functioning and declining kidney allografts.¹⁵ These included equating palliative care with end-of-life care, difficulty determining optimal timing for palliative care referral, and concern that patients would be reluctant to engage in advance care planning conversations. However, it remains unclear whether patient perceptions match those of transplant clinicians. As such, this qualitative study aims to explore the needs, preferences, and perceptions of palliative care for patients with poorly functioning and declining kidney allografts through semistructured interviews.

PLAIN-LANGUAGE SUMMARY

Nearly half of patients with kidney transplants experience failure of their transplant within a decade, leading to high mortality, significant symptoms, and communication challenges. Palliative care can help address these issues but is not frequently provided to these patients. We interviewed 12 patients whose kidney transplants were no longer working well to understand their perspectives on palliative care and palliative care needs. Most were unaware of palliative care but expressed openness to additional support. Their greatest, unmet palliative care needs were emotional distress and worry about the worsening of their kidney disease, and a desire to better understand their prognosis and future quality of life. Integrating palliative care into transplant care is crucial for addressing these patients' needs.

METHODS**Study Design and Recruitment**

The study team included a transplant nephrologist (NM), palliative care physician (JRL), health services researcher (AJR), surgical resident (KH), surgeon (JW), and medical student (CC). We qualitatively evaluated the needs, preferences, and perceptions of palliative care among patients with poorly functioning and declining kidney allografts

using semistructured interviews. We purposively sampled adult kidney transplant recipients (≥ 18 years old) being followed at a single transplant center with an estimated glomerular filtration rate (eGFR) of <20 mL/min/ 1.73m^2 .¹⁶ Participants were identified through a transplant nephrologist's (NM) review of the electronic health record of those actively followed at the study site's kidney transplant clinic. Eligible participants were contacted by telephone to invite them to participate in an interview. We identified 41 patients and excluded 17 patients because of clinical reasons (eg, retransplantation, death, recovered acute kidney injury, etc.). Fourteen patients agreed to be interviewed, and 12 participated (Fig 1). The institutional review board of Mass General Brigham approved this study, and we adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines.¹⁷ We obtained verbal consent before interviews from all participants and remunerated participants with \$50 gift cards.

Interviews

We developed a semistructured interview guide that was pilot-tested and revised based on feedback from 2 kidney transplant recipients who were not included in the final analysis and field notes from initial participant interviews (Item S1). Participants completed audio or video interviews from April 2022 to November 2022 with 1 primary and 1 secondary interviewer (AJR, NM, KH, and JRL), and recorded interviews were transcribed verbatim.

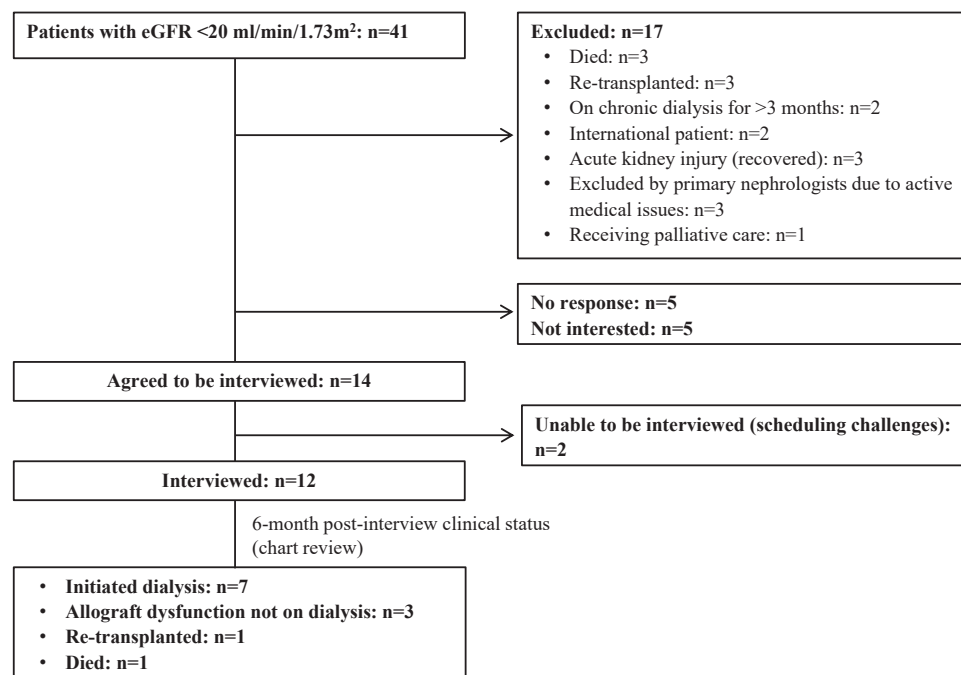


Figure 1. Study population. Forty-one patients with an eGFR of <20 mL/min/ 1.73m^2 were identified for the study, and 12 patients were ultimately interviewed. Seventeen patients were excluded, 5 could not be contacted, 5 indicated that they were not interested in the study, and 2 patients were not interviewed due to scheduling challenges. Six months after the interview, 7 patients had reinitiated dialysis, 1 patient had been retransplanted, and 1 patient was deceased. eGFR, estimated glomerular filtration rate.

Interviewers also documented notes, impressions, and key takeaways for each interview.

Data Analysis

We conducted qualitative thematic analysis of interview data using ATLAS.ti version 22.¹⁸ The authors developed a codebook including deductive codes from domains queried in the interviews and inductive codes that emerged in the data (AJR, JRL, KH, NM, JW, and CC). Three transcripts were coded concurrently by 3 independent researchers (KH, JW, and CC) and compared line-by-line for agreement. We iteratively revised the codebook based on weekly research meetings with regular discussion to address ambiguities until a consensus was reached. The researchers independently coded all interviews with the final codebook.

RESULTS

Twelve interviews were performed, with a median interview length of 40 minutes (IQR 26.5-47.5). Participants were mostly male and White. The median age of

participants was 59 (IQR 48-73), and the median time posttransplant was 11 years (IQR 4.7-16.2). Six months after the interview date, 7 patients were receiving dialysis, 3 patients had advanced allograft dysfunction but were not treated with dialysis, 1 patient was retransplanted, and 1 patient was deceased (Table S1). We identified 3 main themes illustrating palliative care perceptions, needs, and preferences among patients with poorly functioning and declining kidney allografts (Table 1). Our study also yielded specific recommendations for improved provision of palliative care for this patient population (Box 1).

Theme 1: Most Participants Were Not Aware of Palliative Care

Most participants had not heard of palliative care and had not received palliative care services. The participants who knew about palliative care equated it with end-of-life or hospice care. For example, one participant noted, “It sort of signals to me that I should be preparing for the end.” (participant 8) Another described palliative care as “late-stage care for people that are sort of at the tail-end of their

Table 1. Themes and Notable Quotations

Theme	Subthemes and Relevant Quotations
Perceptions of palliative care	<p>“Yes, I have [heard of palliative care]. I’ve been a hospice volunteer. I spent two years doing that just before the COVID problem became what it was.” (participant 8)</p> <p>“The only thing [related to palliative care] ... when we had taken care of my parents... I know [the hospital] helped us with them when they were near death. We had hospice come in.” (participant 2)</p>
High burden of emotional symptoms	<p>Emotional symptoms</p> <p>“Well, it’s stressful. It’s kind of depressing. It’s sad. I guess that’s really it. Overwhelming. I don’t know if I said stressful.” (participant 10)</p> <p>“It’s unlike perhaps just having an operation and you’re healed, and you’re living with someone else’s organ or you’re in dialysis, and it’s always with you.” (participant 11)</p> <p>“Well, when I first had the antibody-mediated rejection, just dealing with that, it was really stressful... I had a harder time with that than I did being diagnosed with cancer believe it or not... so I talked to someone, a psychiatrist.” (participant 1)</p> <p>Stress associated with physical symptoms</p> <p>“I was at my wit’s end with dialysis. I actually came home one day and said, “I can’t do this anymore.” You don’t know where it’s going to go...” (participant 6)</p> <p>“I’ve landed in the hospital on several occasions since my transplant for breathing problems, for rapid heartbeats, for a whole host of situations... I keep asking myself very quietly and in the back of my mind, ‘What’s next after this?’” (participant 8)</p> <p>Prognostic uncertainty and anxiety about future health</p> <p>“I’m thinking about going back on [dialysis], sitting in that chair. That brought a lot of anxiety.” (participant 3)</p> <p>“I’m just thinking about [my kidney failing]. You have to get it out of your head. You can have thoughts of if it’s not working. This time around, if I’m facing a kidney transplant in the future, I don’t have a donor like I had my mother...” (participant 1)</p>
Relationships	<p>Peer and family support</p> <p>“It was nice talking to somebody else who’s had a transplant and just knew what it was like to go through...even if you don’t talk to somebody who’s had a transplant, but they’ve had a chronic illness like me...” (participant 1)</p> <p>“No, my wife is very spiritual. I’m not, but I’m a believer. But she is just incredible. I mean, I’m still alive today because of her.” (participant 4)</p> <p>“And I have wonderful, wonderful sons. My husband’s always here to help me. They’re really my support system...” (participant 2)</p> <p>High trust in the clinical team</p> <p>“You’ve got to have that absolute faith in your medical team that they’re doing the right things for you.” (participant 8)</p> <p>“I think [my doctor] who I love dearly by the way—he’s something else—handled my situation very well...And he was very patient. He listened to me and did all that he could to encourage me to hang in there, to do what I can to.” (participant 11)</p>

Box 1. Recommendations for Palliative Care Delivery for Patients with Poorly Functioning and Declining Kidney Allografts**Like other populations dealing with chronic and serious illnesses, patients with poorly functioning and declining kidney allografts have limited knowledge of palliative care but are open to receiving it.**

1. Information about the many facets of palliative care, beyond end-of-life care, should be provided to patients as part of education about graft dysfunction by transplant teams and the palliative care teams working along with them.
2. Transplant and palliative care clinicians should lean into patients' openness to palliative care and collaborate earlier in graft dysfunction for seriously ill patients to break a self-fulfilling cycle where late palliative care referrals associate palliative care with hospice and end-of-life for patients, families, and clinicians.

Palliative care needs vary in degree and timing among patients with poorly functioning and declining kidney allografts.

1. Because of the variability of patient needs and the unique care structure and relationships of transplant teams, palliative care delivery can be improved through integrated models of transplant and palliative care teams.
2. Evaluation for palliative care needs should be repeated regularly with transplant teams, as their needs are dynamic and vary in relation to their allograft function and other clinical factors.

The most significant palliative care needs identified in this study were prognostic uncertainty and psychological suffering related to uncertainty about graft function and the threat of returning to dialysis.

1. Aligning palliative care with transplant teams may be particularly useful to help navigate the complex suffering and information needs created from declining allograft function, the possibility of returning to dialytic management, and the promise of retransplantation.
2. Patients are often reluctant to share emotional symptoms with their transplant providers and therefore may benefit from formal, validated psychosocial evaluation during clinical visits and opportunities to meet with allied professionals such as palliative care teams.

lifespan.” (participant 4) A few participants had experiences as hospice volunteers: “When you say palliative care, the only thing I’ve been involved with regard to palliative care is I was a volunteer for hospice when I was with the [organization name].” (participant 11) Some participants shared that their parents or other loved ones had received hospice care and described the experience as positive overall. One noted, “During the late stages, very late stages, they kept my mother very comfortable, and she was aware that both my brother and I were there. So, they did a great job.” (participant 4)

Theme 2: Emotional Symptoms Were Participants' Most Significant Priority Related to Palliative Care Needs

When asked about the experience of living with kidney disease and graft dysfunction, almost all participants described emotional symptoms, including stress, depression, and anxiety, as their primary challenge (Fig 2). Reflecting on his journey, 1 participant stated, “finding out that I’m going to have to go back on the transplant list has probably been emotionally the hardest week through the whole thing.” (participant 5) Several participants spoke about feelings of isolation, which can compound the distress associated with this experience: “Right now, I feel like I’m the only person going through (kidney disease), even though it affects the whole country.” (participant 6)

Many participants explained that living with a kidney transplant, which has the potential to fail, was a substantial source of their emotional distress: “The one thing that we all have in common was just a sensitivity and ongoing fear. It’s not like you break your leg, you get it fixed and you forget about it. You are constantly living with this organ.

You don’t know how long it’s going to last.” (participant 11) Others similarly described this phenomenon of illness anxiety: “But it lingers, lingering in your mind, eventually your body’s going to start breaking down mentally and physically....” (participant 3) This constant preoccupation with their transplant and its inevitable decline in function was a clear source of worry and psychological distress. Relatedly, uncertainty about their prognosis and the future

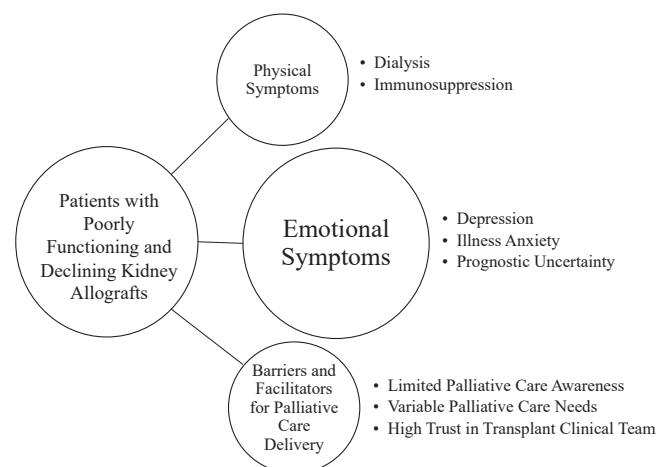


Figure 2. Palliative care needs among patients with poorly functioning and declining kidney allografts. Palliative care needs identified in this study included physical symptoms and emotional symptoms such as depression and illness anxiety. The most prominent unmet palliative care needs for most patients were emotional symptoms, which are indicated in the largest circle. Barriers and facilitators to palliative care delivery such as variable palliative care needs among participants were also described.

of their health contributed to these emotional symptoms. Many specifically expressed frustration that their physicians could not give them a timeline for this deterioration. One participant stated, “The thing that causes me the most stress is being uninformed or not knowing the unknown.” (participant 7). Several participants mentioned that staying as informed as possible about their health and the transplantation process helped ease their anxiety.

Other palliative care needs were less prominent across interviews. Although participants discussed their experiences of physical symptoms, it was often in the context of the anxiety or stress associated with dealing with them. One participant noted, “My biggest fear is I don’t want to go back on dialysis again... what happens is because of my dialysis, actually, I end up getting charley horses every day...that does a job on you emotionally when you can’t get out of the chair because some guy is stabbing you.” (participant 6) Several also discussed the physical toll of recurrent hospitalizations for complications of kidney failure and graft rejection.

Theme 3: Participants’ Relationships With Their Peers, Family, and Clinicians Were a Significant Mediator of Anxiety

One participant aptly summarized the critical role that relationships play in helping him and others live with kidney transplants. When asked what helped him get through difficult times, he stated, “My hope, my faith. My faith in my fellow person, and my faith in my medical team, and my faith in my God, and my wife, and all the people who know me and understand what I’m going through.” (participant 8) Several participants described important connections they formed with other patients with kidney disease. They described sharing anxieties, supporting each other through setbacks, and deriving hope from others’ victories. Some gained fulfillment from sharing their story with other patients with kidney disease and offering advice and help. Similarly, participants

reported relying heavily on family for emotional support and caregiving needs. However, 2 participants reported little to no family support, and 1 reported a difficult relationship with her primary care physician. For these patients, the absence of a strong support network seemed to compound their emotional symptoms and the challenges of living with a kidney transplant.

Nearly all participants also reported a high degree of trust in their medical team, particularly their nephrologists. For many, the relationship they built with their transplant nephrologist was a key component of their support system: “He was very patient. He listened to me and did all he could to encourage me to hang in there, to do what I can do.” (participant 11) Another said, “I have absolute trust in [my medical team]... In making the right calls, in making the right judgments, and trying the right balance of medications.” (participant 8)

Theme 4: Palliative Care Needs are Heterogeneous and Often Hidden

Although all participants had advanced allograft dysfunction with an eGFR of <20 mL/min/1.73m², they had variable symptom burdens and palliative care needs (Table 2). In addition, several participants mentioned that although they trust their clinical team, they are not always open with clinicians about the emotional distress they are experiencing. One participant wrestled with sharing his emotional symptoms during the interview: “Yeah, I mean, I’m doing fine. I’m doing fine... And I’m very private. I’m kind of surprised I’m doing this [interview]. I’d be like, ‘I’m good, I’m good.’” (participant 3) Participants encouraged providers to normalize how emotionally challenging living with poorly functioning and declining allografts can be and to specifically ask about how patients are feeling mentally at each visit: “Our first line of communication is our nephrologist. And I think our nephrologist is the one probe and say, ‘Tell me the truth. Are you okay with what’s going on? Is there anything we

Table 2. Lessons Learned

Lessons Learned	Quote
Patients with poorly functioning and declining kidney allografts have highly variable palliative care needs despite similarly poor kidney function.	“Individual side effects [are] so different for everybody. I may have a couple of side effects that you may never, never experience. And we both have the same kidney failure. I may not be able to sleep, and you may not be able to eat.” (participant 5)
Patients with poorly functioning and declining kidney allografts have significant emotional symptoms but are often reluctant to share them with their providers.	“If one thing that I think could be of help is that the nephrologist digs a little deeper [and] probe into the psychological effects that a person goes through... we tend to, ‘Oh no, everything’s okay.’ But really probe because you kind of treat the whole person, you know.” (participant 11)
Patients with poorly functioning and declining kidney allografts desired more discussion with their care team about their prognosis and future quality of life.	“I would just like to know— really, I know [my doctor] can’t tell me exactly, but I would just like to have a little better idea of maybe what the next three or four years may look like for me. I would like to know when [my doctor] thinks that the kidney would start to go the other way.” (participant 5)
Patients with poorly functioning and declining kidney allografts have limited knowledge of palliative care but are open to receiving palliative care services.	“I don’t know what [palliative care] is like, but I think I would get something out of having those talks.” (participant 9) “Of course [I am interested in palliative care]. Why not, right? Any support is good support.” (participant 6)

can do?” (participant 11). Beyond this, many participants desired more discussion with their medical team about their prognosis and future health: “Information is power, in my situation, any info I can get-I accept and need it.” (participant 12) Another participant who self-identified as “not a planner,” still wanted a better understanding of his disease trajectory: “I know they can’t tell me exactly, but I would just like to have a little better idea of maybe what the next three or four years may look like for me.” (participant 5). Finally, nearly all participants stated that they would be interested in receiving extra support from their medical care team and would be open to palliative care services.

DISCUSSION

Our qualitative, single-center study identified notable but heterogeneous, unmet palliative care needs among participants with poorly functioning and declining kidney allografts, which is consistent with previous studies in patients with kidney failure.^{6,19,20} The most prominent unmet palliative care needs for most patients were emotional symptoms, particularly anxiety regarding the future of their health and help envisioning an uncertain future. We also identified several recommendations to inform models of palliative care delivery in this population. Although many participants were open to receiving additional support, few had heard of or received palliative care. Participants strongly endorsed a desire for providers to ask them about their emotional symptoms and to have more in-depth conversations with their medical team about prognostication and future care planning. Finally, although all participants had an eGFR of <20 mL/min/ 1.73m^2 , the heterogeneity of palliative care needs in our sample suggests that palliative care needs in this population are heterogeneous and dynamic.

Like other populations with chronic and serious illnesses, patients with poorly functioning and declining kidney allografts had limited knowledge of palliative care and equated it with end-of-life and hospice care.¹¹ However, when the definition of palliative care was shared with them, they were all open to receiving this additional layer of support and specifically desired goal-oriented discussions with their clinical team about the overall trajectory of their illness and its effect on their quality of life and the feasibility of retransplantation. This is particularly notable because, in previous studies, clinicians who care for these patients believed that goals of care discussions or palliative care referrals would take away patients’ and families’ hope or suggest that they had given up on life-extending therapies.^{15,20,21} This hesitation has been reported among many providers caring for transplant patients.²¹⁻²³ Patients, families, and clinicians understandably associate palliative care with end-of-life due to the cycle of late referrals. Earlier referral may serve to leverage patient openness to palliative care and reframe this perception.

Furthermore, our study highlights that there is significant variability in the degree and timing of palliative care needs among patients who meet glomerular filtration rate (GFR) criteria for poorly functioning and declining kidney allografts. This reflects the complex and unpredictable disease course of kidney allograft dysfunction.^{6,20} Some of the participants in the study reported relatively few palliative care needs at this point in their illness but described other periods in which they would have benefited significantly from palliative care intervention. These variations argue for an integrated model of palliative care delivery in which patients can be screened and connected to palliative care during routine clinic visits, ideally with transplant teams. In studies investigating the provision of palliative care in advanced cancer and heart failure, palliative care embedded within these clinics has been shown to increase access to palliative care and improve physical, psychosocial, and spiritual symptoms.²⁴⁻²⁶

Most participants endorsed high trust in the health care system, particularly their transplant surgeons and nephrologists, which suggests that palliative care integration with transplant teams or primary palliative care delivery from their transplant team would be well-received. However, several studies in the chronic kidney disease population have identified lower trust in physicians and the health care system as a whole among non-White patients when compared with their White counterparts.^{27,28} Furthermore, Black patients with kidney failure are less likely to have discussed advance care planning with their providers and more likely than White patients to receive goal-discordant treatment near death.^{29,30} Although trust was high overall in our sample, we did find that the Black patients in the study described more self-advocacy throughout their transplant journey. We did not identify specific evidence that this eroded their trust in the transplant team. Nevertheless, differences in patient-provider trust among these patients should be further studied to ensure that disparities are not reinforced through palliative care referral patterns.

Finally, the most significant palliative care needs identified in this study were prognostic uncertainty and psychological suffering related to uncertainty about graft function and the threat of return to dialysis. In particular, participants strongly endorsed that the threat of a possible decline in overall and allograft health was “always on their mind.” These findings are consistent with literature, which demonstrates that high illness anxiety and emotional burden is a consistent finding among patients with chronic illnesses such as malignancy, heart failure, and kidney disease and is particularly amenable to palliative care interventions.³¹⁻³⁵ Untreated anxiety and depression among patients with kidney disease have been shown to lead to further setbacks including medication nonadherence, hospitalization, and death.³⁶⁻³⁸ Participants also noted specific, unique distress related to graft failure, including anticipatory dread about reinitiating dialysis and uncertainty about their ability to tolerate future interventions,

including a return to dialysis or retransplantation. In addition, many participants in this study reported not discussing these emotional symptoms with clinicians with some denying or downplaying this distress as a coping mechanism. These data signal that patients with poorly functioning and declining kidney allografts may benefit from deliberate screening for informational, coping, and emotional support needs and integration of specialist palliative care to address them alongside transplant teams.

This study is not without limitations. It is a single-center study, and the findings are intended to provide pilot data for further exploration of palliative care needs and preferences in this population. Relatedly, the sample was predominantly White, making it challenging to assess racial differences in palliative care-related preferences. In addition, our results are affected by participants' unfamiliarity and lack of experience with palliative care at the time of interview. Nevertheless, our work provides key information to inform future palliative care delivery for patients with poorly functioning and declining kidney allografts.

In conclusion, patients with poorly functioning and declining kidney allografts have variable but distinct palliative care needs, including significant emotional symptoms, fear related to an uncertain future, and a desire to better understand their prognosis in all its facets. Our results suggest patients are largely unaware of palliative care and may benefit from a practice model in which transplant clinical teams integrate palliative care education and timely palliative care engagement for patients with poorly functioning and declining kidney allografts, ideally with close collaboration and even integration of palliative care and transplant teams. Given the limited experience with palliative care and the diverse and complex palliative care needs among participants, further research is needed to fully characterize palliative care priorities in this population.

SUPPLEMENTARY MATERIALS

Supplementary File (PDF)

Item S1: Interview Guide.

Table S1: Demographic and Clinical Characteristics of Study Participants with Kidney Allograft Dysfunction.

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