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Title: Navigating the Emotional Landscape of Kidney Allograft Failure
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Introduction

Kidney transplantation is the preferred treatment for end-stage kidney disease (ESKD), improving survival and quality of life. Yet, allograft failure is common, a clinically and emotionally difficult journey for patients and care teams alike. Recognizing this shared burden, the Forum of ESRD Networks invited patients, and physicians from the Kidney Patient Advisory Council (KPAC) and Medical Advisory Council (MAC) to share written reflections on graft failure, edited for length and clarity with authors' approval. Through these narratives, we hope to encourage continued clinical and research attention to the emotional aspects of kidney allograft failure.

Patient Experience

Patient voice #1: Guilt, Hopelessness, Building resilience

"Living with kidney disease since childhood, I've received the "gift of life" through four transplants, but the journey has been a rollercoaster. I'll never forget my doctor entering the room, eyes downcast, to deliver the news: "The kidney is rejecting." It felt like the air left the room. After eleven years with my third transplant, I was shattered: "Would I return to dialysis?" "What did I do wrong?"

I moved from asking "why me" to "what now," embracing resilience over despair. This determination carried me through the loss until I received a fourth chance at life.

Yet, I live with the constant, uncertainty of "what if this kidney fails too?" Supported by family and friends, taking it one day at a time is my only path forward, balancing gratitude with fear of the unknown. Repeated loss does not build immunity to the pain; each failure makes the emotional burden harder to endure."

Patient voice #2: Emotional exhaustion, Disappointment, Making peace

"As a patient living with kidney disease for 35 years, I thought I was prepared for anything. Having experienced multiple treatment modalities, I headed into my second transplant feeling confident. When the call came, I was excited to wake up and finally urinate again. Instead, when the surgeon told me the transplant could not happen because my vessels were too calcified, hope turned into a deep, dark hole that took nearly a year to climb out of. I returned to dialysis immediately, facing multiple complications and emotional exhaustion. While my family and care team supported me, experiences like this reveal a critical gap in kidney care. Patients need stronger physical, psychological, and emotional support to truly recover. I was offered reconstructive surgery to make a third transplant possible but chose not to pursue it. Instead, I found peace continuing home hemodialysis and feel grateful for the quality of life I have today."

Patient voice #3: Uncertainty, Anticipatory fear, Feelings of loss

"My kidney-pancreas (K-P) transplant rejection was defined by loss and persistent uncertainty with return to hemodialysis for eight years, restructuring daily life around survival. A second

transplant, a solitary kidney since I was no longer eligible for K-P transplantation, offered renewed stability; yet, this too was temporary, resulting in another return to dialysis. These setbacks were compounded by the devastating loss of my child, just days before the second transplant rejection, intensifying grief and distress. Living now with my third transplant, each routine lab assessment carries constant fear and anticipation. Although my previous experience with dialysis helped me know what to expect, it did not make the adjustment easier; returning to dialysis after transplant failure felt like a greater loss because I was losing the health, independence, and hope that transplantation had restored. Repeated graft failure reshapes not only physical health, but psychological well-being."

Provider Reflections:

Providers 1, 2*: *Moral Distress, Burnout, Risk Aversion

"After nearly 20 years caring for people with kidney disease, I still feel the weight of a failing allograft in a way that is hard to explain. I want to protect hope, but I also know my patients deserve honesty about uncertainty, graft loss, dialysis, and even death; conversations that leave me feeling torn, as every option carries emotional consequences. When a patient has trusted me and the transplant team for years, I sometimes feel responsible for outcomes I cannot fully control."

"The pressure to satisfy regulatory metrics can unknowingly push us towards 'safer' patients and away from marginal donors, increasing donor kidney discards. Balancing honesty, guilt, and regulatory pressure while preserving patients' trust becomes morally exhausting. "

Provider 3: Navigating Difficult Conversations

"When I sit with a patient facing allograft failure, I know the conversation has to hold both hope and heartbreak. I begin by focusing on what may be reversible, but also feel the urgency of preparing the patient for what may come next. That means speaking honestly about dialysis, changes to immunosuppression, possible allograft nephrectomy, and the hope of another transplant. These discussions are never just clinical; they are emotional, personal, and often frightening. I try to lead with empathy, listen carefully to what matters, and coordinate care so the patient does not feel abandoned in the hardest part of the journey."

Provider 4: Care Transitions

"One of the hardest parts of caring for a patient with a failing allograft is helping them transition back to dialysis before the situation becomes urgent. I have seen patients come to me when kidney function is already very low, and it can be overwhelming for them to make major decisions with someone they are just beginning to trust. They may be grieving the loss of the transplant while also being asked to choose a dialysis plan quickly, creating stress for everyone involved. Earlier involvement of a general nephrologist can give patients more time, more support, and a steadier path through an already painful transition."

Similar themes of grief, guilt, uncertainty and loss of control run through both patient and clinician reflections. While patients experience the loss physically and emotionally in daily lives, clinicians carry it as professional responsibility for an outcome they cannot fully control.

Emotional and mental health support - Gaps in Care

Allograft failure can feel like a personal loss, upending patients' identities, roles, and expectations. Much like fear of cancer recurrence, it is shaped by loss of control, chronic anticipation, disenfranchised grief (grief unacknowledged by social and medical community), and gaps in the healthcare ecosystem[1-5]. Therefore, care for allograft failure should look less like a handoff between medical teams and more like a survivorship model, with repeated distress screening, and caregiver-inclusive planning beginning before transplantation, continuing across the life of the graft rather than just starting once graft failure occurs. Yet, emotional support received during hospitalization is rarely sustained after discharge, and transition to dialysis is a vulnerable time, with patients losing trusting relationships with their transplant team. Mental health access remains limited, even where screenings exist, leaving a critical window of distress unaddressed.

Potential Interventions

Evidence specific to allograft failure is limited, but models studied in the broader ESKD population may be extrapolated. A trial of cognitive behavioral therapy in transplant recipients showed greater improvement in depression scores while the control group worsened over a year suggesting the progressive nature of untreated depression [6]. A stepped telehealth collaborative-care model led to clinically significant improvements in fatigue and pain compared with controls[7]. Peer support shows promise for improved psychological well-being, self-efficacy, and engagement, although results are heterogeneous[8].

From the provider perspective, resilience training and system-level quality improvement rather than individual blame, and employee assistance programs offering psychological support after adverse outcomes can help mitigate moral injury[9].

Recommendations and Future Directions

Addressing the burden of allograft failure requires coordinated clinical, educational and health-system effort. Research should focus on psychosocial outcomes of graft failure, validation of distress-screening tools adapted to transplant patients, and effect of interventions on improving resilience and reducing provider burnout and moral distress. Policy must prioritize mental health access for transplant, and ESKD patients broadly. Meaningful progress can only be made with an interdisciplinary effort structurally supported by the health system and led jointly by patients and clinicians.

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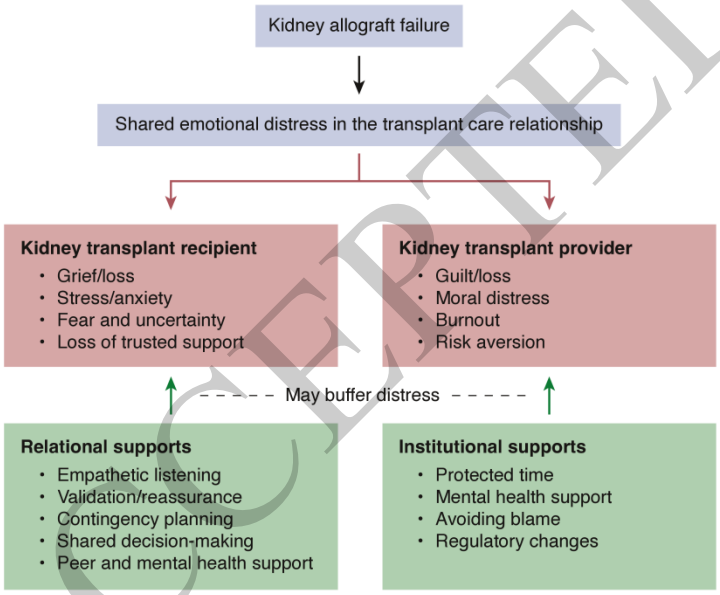
Figure Legend:

Figure 1: Shared emotional distress in the transplant care relationship following kidney allograft failure: Kidney allograft failure can lead to overlapping, but distinct distress patterns in patients[2-5] and providers[9]. Relational supports for patients and institutional supports for providers can potentially buffer this shared distress.



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M. Baliker reports the following:
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D. Edwards reports the following:
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A. Howard reports the following:
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P. McCowan has nothing to disclose.

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