

Wait expectations: The impact of delisting as an outcome from the kidney transplant waitlist

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Abstract

Background: While kidney transplantation is optimal for the treatment of end-stage kidney disease, available organs do not meet demand. Little is known about the outcomes of patients who are delisted (removed from the waitlist) and unable to benefit from transplant. We describe patients who are delisted and their life expectancy after delisting.

Methods: Patients ≥ 18 years listed for deceased donor kidney transplant between 01/2003 and 12/2013 were identified in the Scientific Registry of Transplant Recipients and followed through 12/2018. A competing risk model was used to measure the association of demographic and clinical factors with waitlist outcomes of delisting, transplant, and death. Multivariate Cox modeling was used to evaluate factors associated with death after delisting.

Results: Of 324,582 patients listed, 18.0% were delisted, most common reasons were "too sick" or "other." After delisting, half (49.7%) had died by end of follow-up; time to death after removal was 5 years. Increasing age and public insurance were associated with increased risk of death.

Conclusions: Nearly one in five patients will be delisted from the kidney transplant waitlist. These patients live a surprisingly long time after removal. Much remains unknown about these patients, which could be improved through data collection. Delisting is an important patient outcome that warrants further exploration.

KEYWORDS

delisting, kidney disease, patient-centered outcome, waitlist management

1 | INTRODUCTION

Care of patients with end-stage kidney disease (ESKD) is costly and complex.¹⁻³ Compared with dialysis as a method of renal replacement therapy, kidney transplantation has improved survival and quality of life.⁴ Eligibility for and access to the kidney transplant waitlist is an enigma for many patients with ESKD, causing stress, anxiety, and the feeling of "living in limbo."⁵ For patients successfully

listed for transplant, entry onto the waiting list is a source of hope, and patients often believe that achieving entry to the waitlist makes transplant inevitable.⁵

Recent policy initiatives, such as the 2019 Advancing American Kidney Health (AAKH), prioritize equitable and improved access to the transplant waitlist.^{6,7} While this is a laudable goal, it will increase registrants to the waitlist and subsequently increase number of eligible candidates without a significant change in supply,

TABLE 1 Demographic information for patients on waitlist by outcome, N = 324,582

| | Transplanted 61.7% (200,149) | Died 16.0% (52,024) | Delisted 18.0% (58,346) |
|---------------------------------------|---|--------------------------------|------------------------------------|
| Age at removal (median, IQR) | 52.0 (41.3–61.1) | 58.6 (49.8–65.5) | 59.3 (49.2–67.6) |
| 18–29 years | 7.7% | 2.3% | 3.1% |
| 30–39 years | 14.6% | 6.8% | 7.8% |
| 40–49 years | 22.3% | 16.0% | 15.4% |
| 50–59 years | 27.3% | 29.6% | 25.4% |
| 60–69 years | 22.4% | 34.2% | 30.8% |
| ≥70 years | 5.8% | 11.1% | 17.4% |
| Race | | | |
| White | 66.9% | 61.4% | 59.3% |
| African American | 25.6% | 30.9% | 33.3% |
| Asian | 6.0% | 5.8% | 5.3% |
| American Indian/Alaskan Native | 0.9% | 1.1% | 1.3% |
| Native Hawaiian/Pacific Islander | 0.4% | 0.5% | 0.5% |
| Multiracial | 0.3% | 0.3% | 0.3% |
| Gender | | | |
| Male | 60.8% | 60.7% | 59.2% |
| Female | 39.2% | 39.3% | 40.8% |
| Primary ESKD | | | |
| Diabetes | 29.2% | 48.0% | 42.4% |
| HTN | 21.3% | 21.2% | 24.2% |
| Glomerulonephritis | 22.6% | 11.8% | 12.8% |
| Cystic kidney | 9.1% | 3.6% | 4.1% |
| Congenital anomalies | 1.4% | 0.6% | 0.8% |
| Tubular/interstitial | 4.1% | 3.3% | 3.4% |
| Vascular | 0.2% | 0.2% | 0.2% |
| Neoplasm | 0.3% | 0.3% | 0.4% |
| Other cause | 11.9% | 11.0% | 11.7% |
| Dialysis type | | | |
| Hemodialysis (HD) | 50.3% | 60.2% | 59.5% |
| Peritoneal dialysis (PD) | 9.8% | 10.0% | 7.9% |
| No dialysis | 29.1% | 16.7% | 20.2% |
| Unknown | 10.7% | 13.1% | 12.4% |
| Primary payer | | | |
| Medicare | 37.3% | 47.3% | 51.8% |
| Medicaid | 6.1% | 8.1% | 8.4% |
| Other government | 5.8% | 7.8% | 5.9% |
| Private | 50.0% | 36.0% | 33.4% |
| Other | 0.7% | 0.7% | 0.5% |
| Median household income | \$51,227 | \$49,081 | \$47,473 |
| Geographic location | | | |
| Urban | 75.3% | 74.7% | 75.1% |
| Rural | 24.7% | 25.3% | 24.9% |
| Previous transplant | 12.5% | 15.7% | 14.3% |
| Calculated PRA (% , median, IQR) | 0 (0-0.18) | 0 (0-0.45) | 0 (0-0.1) |
| BMI (kg/m ² , median, IQR) | 27 (24-31) | 28 (24-32) | 28 (24-33) |

(Continues)

TABLE 1 (Continued)

| | Transplanted 61.7% (200,149) | Died 16.0% (52,024) | Delisted 18.0% (58,346) |
|---------------------------------------|---------------------------------|------------------------|----------------------------|
| Comorbidities at listing | | | |
| Hypertension | 73.7% | 71.9% | 72.5% |
| Diabetes | 37.2% | 60.2% | 53.9% |
| Previous malignancy | 5.4% | 6.0% | 6.4% |
| Chronic obstructive pulmonary disease | 1.1% | 2.0% | 2.0% |
| Peripheral vascular disease | 5.3% | 8.6% | 7.3% |
| Coronary artery disease | 5.3% | 9.0% | 8.1% |
| Cerebrovascular disease | 2.4% | 4.3% | 4.2% |
| Blood group | | | |
| A | 36.6% | 29.5% | 30.0% |
| O | 45.4% | 51.9% | 51.4% |
| B | 13.4% | 15.7% | 15.7% |
| AB | 4.7% | 3.0% | 2.9% |

creating the risk that more patients will be listed and ultimately not be transplanted.

Traditionally, the publicly reported outcomes on the transplant waitlist have been transplant or death; however, since 2015 one in five patients listed for transplant have been removed from the waitlist,^{8,9} the outcome of delisting also requires careful scrutiny. How delisting decisions are made is not well studied, and there are no standardized criteria for removal from the waitlist. Because those delisted are no longer clinically followed by transplant programs in the United States, very little is known about these patients no longer able to benefit from transplant. To better inform center practice and future transplant policy surrounding waitlist management, our objective was to (a) describe patients who are removed from the waitlist and (b) to understand their life expectancy after removal.

2 | MATERIALS and METHODS

2.1 | Study population

This study used data from the Scientific Registry of Transplant Recipients (SRTR). The SRTR data system includes data on all donors, wait-listed candidates, and transplant recipients in the United States, submitted by the members of the Organ Procurement and Transplantation Network (OPTN). The Health Resources and Services Administration (HRSA), US Department of Health and Human Services, provides oversight to the activities of the OPTN and SRTR contractors.

The study cohort included all adult candidates added to the kidney transplant waitlist between January 1, 2003, and December 31, 2013, and followed until December 31, 2018. SRTR codes candidate removal from the waitlist into one of the 21 categories, which can be found in Appendix 1. Death dates were obtained from the SRTR.

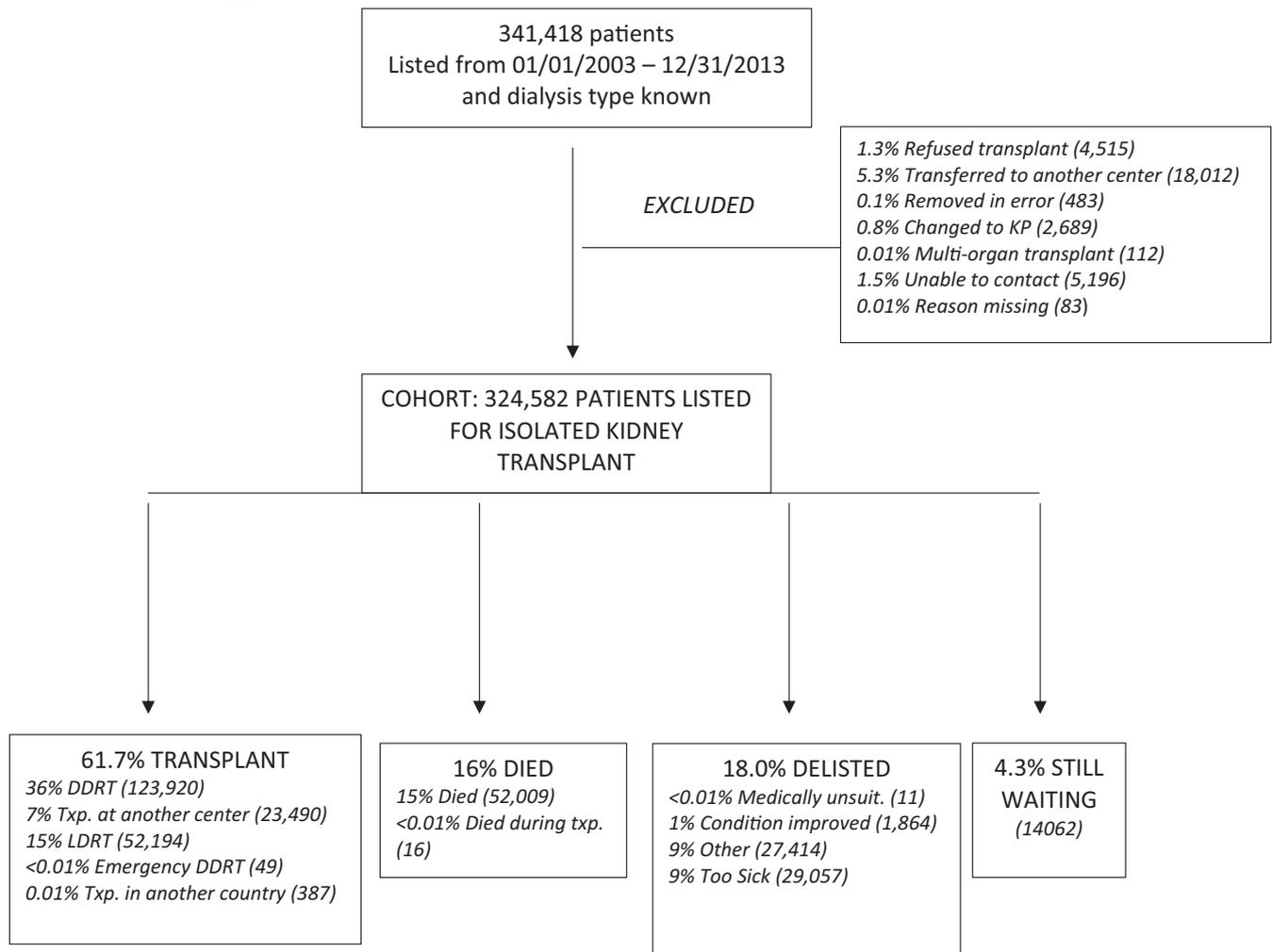
Median household income was obtained from US Census Data. Urban vs. rural residence was defined using zip codes and rural-urban commuting area (RUCA) codes.¹⁰

2.2 | Variables

Patient characteristics included age, gender, race, and body mass index (BMI). Primary insurance providers included private, Medicare, Medicaid, and "other." Patient comorbidities include hypertension, diabetes, coronary artery disease, peripheral vascular disease, previous malignancy, chronic obstructive pulmonary disease, and cerebrovascular disease. Additional clinical information included primary ESKD for transplant wait-listing, dialysis type (hemodialysis, peritoneal dialysis, no dialysis), blood group (A, O, B, AB), previous transplant, and calculated panel-reactive antibodies (PRAs). Median household income was calculated from US Census Data. Zipcodes at waitlist registration were linked to rural-urban commuting area codes and place of residence defined as either rural or urban.

2.3 | Analysis

Descriptive statistics were used for the basic cohort of patients who were delisted. As part of the competing risk analysis, we first plotted cumulative incidence functions for the outcomes of delisting, transplant, and death on the waitlist. We then utilized a competing risk model (R package *cmprsk*)¹¹ to measure associations of these factors with the risk of delisting, transplant, and death on the waitlist. Focusing next on the patients who were delisted, we used the Kaplan-Meier method to estimate unadjusted time to death after delisting. A multivariate Cox proportional hazard model was used to evaluate the impact of patient characteristics on time to death after delisting. For both time-to-event analyses, the covariates were



Italicized %/N total the original N of those listed from 01/01/2003 – 12/31/2013 with known dialysis type.

FIGURE 1 Flow diagram, establishment of cohort

chosen as clinically relevant or important in kidney policy. Additional analysis compared demographics and clinical data by most common reason for delisting, “other” and “too sick.” Statistical analyses were carried out using Stata SE v14.2 (StataCorp LLC, College Station, Texas) and R 4.0.2 (R Foundation for Statistical Computing, Vienna, Austria).¹²

2.4 | IRB approval

The Institutional Review Board of Partners Healthcare approved the study as the SRTR provides limited use data sets (2019P002763). The data that support the findings of this study are available from the corresponding author upon reasonable request, and the manuscript complies with STROBE guidelines for cohort studies.¹³

3 | RESULTS

3.1 | Demographics and reasons for delisting

From January 1, 2003, to December 31, 2013, 341,418 adult patients were listed for kidney transplant with a known dialysis type (no dialysis, HD, or PD). Patients were excluded from analysis if they were listed for transplant other than isolated kidney (0.8% changed to kidney-pancreas, 0.01% listed for multi-organ transplant), refused transplant (1.3%), transferred to another center (5.3%), or were removed for administrative reasons (0.1% removed in error, 1.5% unable to contact). Of the remaining 324,582, 61.7% (200,149) underwent transplant, 16.0% (52,024) died on the list, 18.0% (58,346) were removed from the waitlist, and 4.2% (14,063) were still on the list awaiting transplant at the end of follow-up.

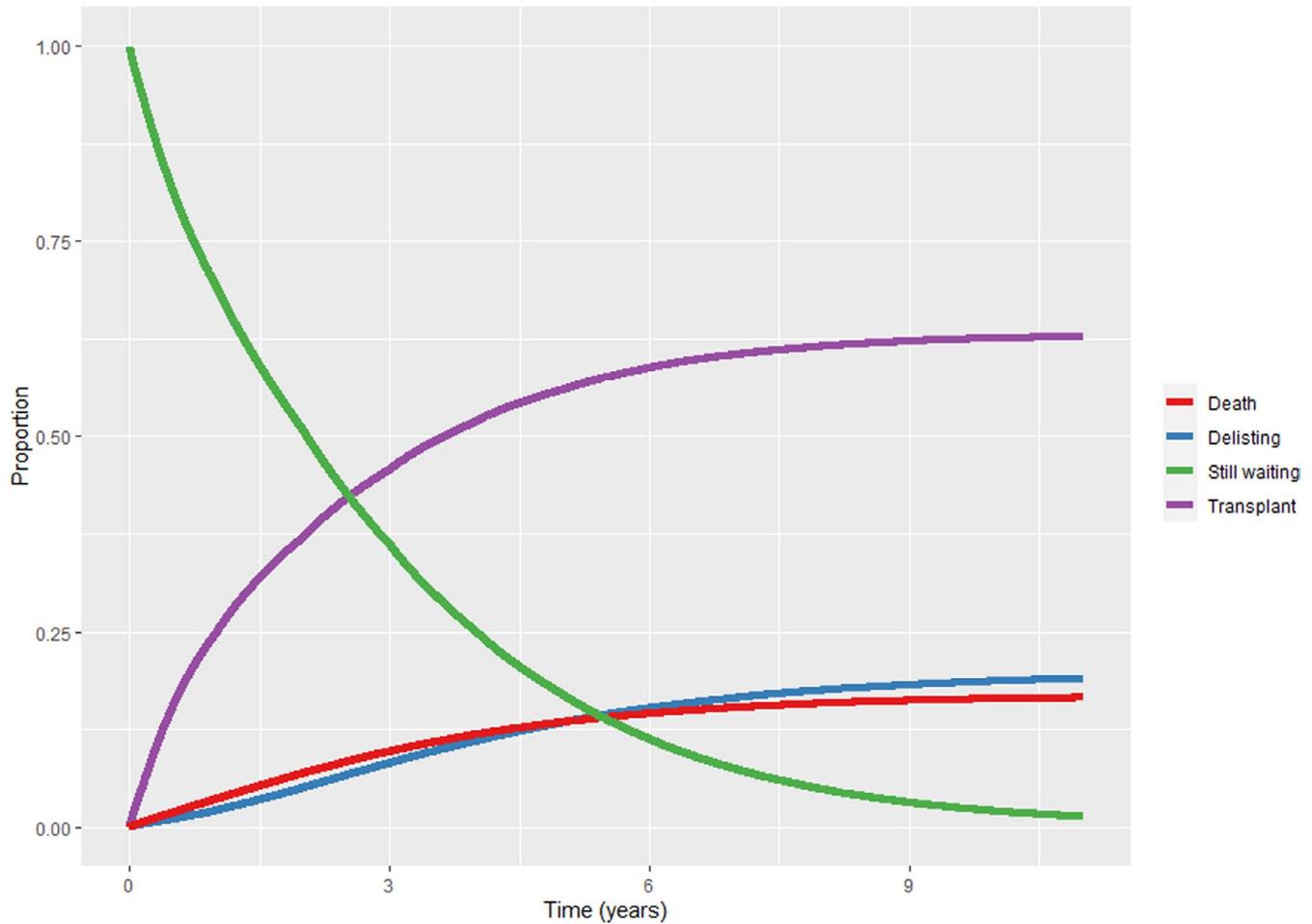


FIGURE 2 Competing risks, cumulative incidence plot of delisting, death, and transplant

Table 1 summarizes the demographic and clinical information for patients who were transplanted, died, or delisted. The most common reasons for removal were defined as being “too sick to transplant” (49.8%) and “other” (47%), with remaining patients being removed for “condition improved” (Figure 1). For delisted patients, median age at removal from the list was 59.3 years (IQR: 49.2–67.6); 17.4% were ≥ 70 years old. Over half (59.3%) of delisted patients were White, and 59.2% were male. The primary disease for which patients had been listed for transplant was diabetes (42.4%). Half of patients had Medicare as primary insurer; one-third reported private insurance. 14.3% had undergone previous transplant. Most patients resided in urban areas, and median household income of their respective ZIP codes was \$47,473.

3.2 | Factors associated with delisting, transplant, and death on waitlist

We estimated time to delisting as a primary outcome, with death and transplant as competing risks (Figure 2). Delisting was associated with increasing age (≥ 70 years, HR 3.80 relative to those 18–29 years, CI: 3.46–4.18, $p < 0.01$), non-White race (African American HR 1.12, CI: 1.01–1.20, $p < 0.01$; Asian HR 1.15, CI: 1.0–1.32,

$p = 0.04$), primary disease other than diabetes (HTN HR 0.80, CI: 0.77–0.83, $p < 0.01$), and public health insurance (Medicare HR 1.33, CI: 1.28–1.38; Medicaid 1.52, CI: 1.44–1.61, $p < 0.01$). The outcomes of transplant and death were consistent with known risk factors for adverse outcomes, including increase age, diabetes, and increasing PRA (Table 2).

3.3 | Mortality after delisting

The second survival analysis addressed time to death after removal from the transplant waitlist, censored at end of follow-up. Half (49.4%) of candidates were dead at the end of follow-up. Median time from removal delisting to death was 5 years. In multivariate analysis, delisting for reason of “too sick” (ref: “other,” HR 1.90, CI: 1.85–1.95, $p < 0.01$), increasing age (≥ 70 years, HR 3.11, CI: 2.80–3.45, $p < 0.01$), and rural residence (HR 1.06, CI: 1.03–1.08, $p < 0.01$) were associated with an increased likelihood of death, while non-White race (African American HR 0.87, CI: 0.84–0.89; Asian 0.88, CI: 0.79–0.97, $p < 0.01$) and primary disease diagnosis other than diabetes (HTN HR 0.84, CI: 0.81–0.87, $p < 0.01$) had improved life expectancy (Table 3). When stratified by reasons for delisting, patients delist for a reason of “other” lived significantly longer than patients

TABLE 2 Competing risk analysis for waitlist outcomes

| Variable | Delisting HR (95% CI) | p-value | Transplant HR (95% CI) | p-value | Death HR (95% CI) | p-Value |
|---|-----------------------|---------|------------------------|---------|-------------------|---------|
| Age group | | <0.01 | | <0.01 | | <0.01 |
| 18–29 years | [ref] | | [ref] | | [ref] | |
| 30–39 years | 1.17 (1.06–1.29) | | 0.82 (0.81–0.84) | | 1.30 (1.22–1.39) | |
| 40–49 years | 1.36 (1.24–1.49) | | 0.66 (0.66–0.68) | | 1.85 (1.74–1.97) | |
| 50–59 years | 1.67 (1.52–1.83) | | 0.52 (0.51–0.53) | | 2.53 (2.38–2.69) | |
| 60–69 years | 2.18 (1.99–2.39) | | 0.41 (0.40–0.42) | | 3.05 (2.87–3.24) | |
| >70 years | 3.80 (3.46–4.18) | | 0.27 (0.26–0.28) | | 2.88 (2.70–3.07) | |
| Sex | | | | | | 0.16 |
| Male | [ref] | | [ref] | | [ref] | |
| Female | 0.94 (0.91–0.97) | <0.001 | 1.04 (1.03–1.05) | <0.01 | 0.99 (0.97–1.01) | |
| Race | | | | <0.01 | | |
| White | [ref] | | [ref] | | [ref] | |
| African American | 1.12 (1.01–1.20) | <0.01 | 0.76 (0.75–0.77) | | 1.03 (1.01–1.05) | <0.01 |
| AI/AN ^a | 0.95 (0.89–1.01) | 0.13 | 0.80 (0.79–0.82) | | 0.94 (0.90–0.97) | <0.01 |
| Asian | 1.15 (1.0–1.32) | 0.04 | 0.83 (0.79–0.87) | | 0.89 (0.82–0.97) | <0.01 |
| NH/PI ^a | 1.08 (0.87–1.34) | 0.50 | 0.69 (0.64–0.74) | | 1.05 (0.94–1.19) | 0.40 |
| Multiracial | 1.18 (0.92–1.51) | 0.19 | 0.81(0.75–0.88) | | 1.02 (0.88–1.19) | 0.76 |
| ESKD group | | <0.01 | | <0.01 | | <0.01 |
| Diabetes | [ref] | | | | [ref] | |
| HTN | 0.80 (0.77–0.83) | | 1.26 (1.24–1.28) | | 0.65 (0.63–0.66) | |
| Glomerulonephritis | 0.61 (0.58–0.64) | | 1.42 (1.40–1.44) | | 0.49 (0.47–0.50) | |
| Cystic kidney | 0.53 (0.49–0.57) | | 1.65 (1.62–1.67) | | 0.37 (0.36–0.39) | |
| Congenital anomalies | 0.77 (0.66–0.90) | | 1.28 (1.23–1.33) | | 0.47 (0.43–0.53) | |
| Tubular/interstitial | 0.80 (0.76–0.83) | | 1.31 (1.27–1.34) | | 0.65 (0.62–0.68) | |
| Vascular | 0.52 (0.35–0.77) | | 1.38 (1.25–1.53) | | 0.69 (0.57–0.84) | |
| Neoplasm | 0.83 (0.66–1.06) | | 1.29 (1.18–1.39) | | 0.71 (0.61–0.82) | |
| Other | 0.85 (0.81–0.90) | | 1.23 (1.21–1.25) | | 0.71 (0.69–0.73) | |
| Median household income (per \$10,000) [#] | 1.0 (0.99–1.0) | <0.01 | 1.0 (1.0–1.0) | <0.01 | 1.0 (1.0–1.0) | 0.78 |
| Rural | 1.0 (0.97–1.04) | 0.81 | 1.00 (0.99–1.01) | 0.69 | 1.03 (1.01–1.05) | <0.01 |
| PRA category | | | | <0.01 | | <0.01 |
| 0–0.80 | [ref] | | | | [ref] | |
| >0.80–0.95 | 1.10 (1.01–1.20) | 0.09 | 0.90 (0.87–0.92) | | 1.21 (1.15–1.27) | |
| >0.95 | 1.38 (1.29–1.48) | <0.01 | 0.56 (0.54–0.57) | | 1.56 (1.50–1.62) | |
| Previous transplant | 1.26 (1.23–1.30) | <0.01 | 0.74 (0.73–0.75) | <0.01 | 1.43 (1.39–1.47) | <0.01 |
| Dialysis type | | <0.01 | | <0.01 | | <0.01 |
| HD | [ref] | | | | [ref] | |
| PD | 0.88 (0.83–0.93) | | 0.95 (0.94–0.97) | | 0.66 (0.64–0.68) | |
| No HD | 0.82 (0.79–0.86) | | 1.21 (1.20–1.23) | | 1.19 (1.07–1.13) | |
| Insurance | | | | <0.01 | | <0.01 |
| Private | [ref] | | | | [ref] | |
| Medicaid | 1.52 (1.44–1.61) | <0.01 | 0.62 (0.61–0.63) | | 1.45 (1.40–1.50) | |
| Medicare | 1.33 (1.28–1.38) | <0.01 | 0.83 (0.82–0.84) | | 1.18 (1.16–1.21) | |
| Other government | 1.05 (0.98–1.12) | 0.18 | 0.91 (0.90–0.93) | | 1.43 (1.38–1.48) | |
| Other | 1.03 (0.84–1.27) | 0.76 | 0.89 (0.84–0.93) | | 1.42 (1.29–1.57) | |

(Continues)

TABLE 2 (Continued)

| Variable | Delisting HR (95% CI) | p-value | Transplant HR (95% CI) | p-value | Death HR (95% CI) | p-Value |
|---------------------------|-----------------------|---------|------------------------|---------|-------------------|---------|
| Blood group | | <0.01 | | <0.01 | | <0.01 |
| A | [ref] | | [ref] | | [ref] | |
| O | 1.19 (1.15–1.23) | | 0.76 (0.75–0.77) | | 1.22 (1.19–1.24) | |
| B | 1.20 (1.14–1.26) | | 0.78 (0.77–0.79) | | 1.20 (1.17–1.24) | |
| AB | 0.78 (0.71–0.86) | | 1.30 (1.27–1.33) | | 0.84 (0.80–0.89) | |
| Time in years on dialysis | 1.01 (1.01–1.02) | <0.01 | 1.00 (1.00–1.00) | 0.48 | 1.02 (1.01–1.02) | <0.01 |

Abbreviations: CI, confidence interval; HR, hazard ratio.

^aAsian American/Pacific Islander, Alaskan Indian/Native America.

removed for being “too sick” (“other” median time to death 8.2 years; “too sick” time to death 3.0 years). Patients delisted for a reason of “too sick” were older and higher rates of all comorbidities at time of listing (Appendix 2). There was no appreciable era effect of reasons such as death or delisting other than transplant; only “too sick” and “other” increased over the course of the time period; a graph of removal by waitlist code by year can be found in Appendix 3.

4 | DISCUSSION

We sought to identify patients who are removed from the transplant waitlist and unable to benefit from transplant and describe their outcomes. In our cohort, 18% of patients were delisted for reasons of “too sick” or “other” and subsequent median time to death was 5 years. Given that expected remaining life years for the typical 65-year-old hemodialysis patients is less than 5 years, these patients lived a surprisingly long time. Factors known to be associated with adverse outcomes, including age, non-White race, and public insurance at time of listing, were associated with delisting and death. However, current analysis of possible waitlist outcomes is hampered by the lack of granularity in the data. With nearly one in five waitlist candidates being removed for reasons of “too sick to transplant” or “other,” with no additional detail, there is an urgent need to expand data capture to better understand this important patient-centered outcome.

The current system of evaluating and tracking transplant candidates does not require that a transplant program take responsibility for the clinical trajectories of delisted patients. This oversight functionally excludes a significant portion of patients from analysis of long-term outcomes.^{8,14} With waitlist mortality linked to center utilization patterns and performance, removal from the transplant list may be partially influenced by performance ratings or individual programs’ inability to manage their transplant waitlist.¹⁵ A 2016 study of waitlist removals showed that low-performance centers, as defined by the Centers for Medicare & Medicaid, had higher rates of waitlist removal but lower candidate mortality rates after removal, suggesting that threshold to remove patients from the waitlist is lower among centers that receive low-performance evaluations.¹⁶ Effectively, the lack of oversight indirectly incentivizes centers to

delist patients who are “unfit,” without being responsible for their ongoing, potentially increased, healthcare needs.¹⁶

The lack of transparency in criteria for delisting has facilitated “forgetting” this population, despite our findings and previous analyses showing that over the past 10 years, removal from the kidney transplant waitlist for reasons of “too sick” or “other” has outpaced death on the waitlist.¹⁶ Given the associated comorbid conditions that ultimately lead to ESKD, it is not surprising that some patients will deteriorate and no longer be operative candidates. However, there is no standardized scoring system for determining what makes kidney waitlist candidates “too sick” to transplant. Additionally, without granular data it is impossible to know the breadth of “other” reasons for delisting, but social support and compliance with care are two criteria for listing not otherwise captured in the delisting data, and it is worth investigating whether “other” reasons for delisting are subjective or modifiable. Transplant providers have estimated that almost 10% of candidates evaluated for transplant during the prior year were ruled out due to inadequate social support; it stands to reason that this is an unrecorded and overlooked indication for delisting.¹⁷

This missing information may be skewing patient expectations. When choosing a transplant center, patients prioritize ease of getting onto the waitlist and time on the waitlist over traditional post-operative outcomes when choosing a transplant center.^{18,19} Patients removed from the waitlist or made inactive reported confusion surrounding their disqualification, with emotions ranging from suspicion of an unjust system to guilt for their perceived fault leading to disqualification.⁵ Without adequate information on the characteristics of candidates who may achieve listing and be subsequently removed, we are inhibiting healthcare providers’ ability to appropriately counsel patients on all possible outcomes from the waitlist. Patient-provider discordance in expectations regarding prognosis and transplant candidacy has already been demonstrated, with patients being more optimistic about their 1- and 5-year survival and candidacy for transplant, and almost half reported these beliefs in the setting of preferring care focused on extending life, even if it meant discomfort.²⁰ However, no previous analyses of patient expectations have included the competing risk of delisting.

There are a few limitations to this study. First, this retrospective cohort includes data that span a 15-year period inclusive of major

TABLE 3 Cox model for death after delisting. Note : Death: 49.7% (N = 28 960); time to death: 5.0 years.

| Variable | Hazard ratio 95% confidence interval | p-value |
|--------------------------------------|---|---------|
| Reason for removal | | <0.01 |
| "Other" | [ref] | |
| "Too sick" | 1.90 (1.85–1.95) | |
| Age group | | <0.01 |
| 18–29 years | [ref] | |
| 30–39 years | 1.42 (1.27–1.59) | |
| 40–49 years | 1.89 (1.70–2.10) | |
| 50–59 years | 2.50 (2.25–2.76) | |
| 60–69 years | 3.04 (2.75–3.37) | |
| ≥70 years | 3.11 (2.80–3.45) | |
| Time on list | 0.97 (0.97–0.98) | <0.01 |
| Sex | | <0.01 |
| Male | [ref] | |
| Female | 1.08 (1.05–1.10) | |
| Race | | <0.01 |
| White | [ref] | |
| African American | 0.87 (0.84–0.89) | |
| AI/AN ⁱ | 0.69 (0.65–0.73) | |
| Asian | 0.88 (0.79–0.97) | |
| NH/PI ⁱ | 0.72 (0.60–0.87) | |
| Multiracial | 0.90 (0.73–1.10) | 0.31 |
| ESKD group | | |
| Diabetes | [ref] | |
| HTN | 0.84 (0.81–0.87) | <0.01 |
| Glomerulonephritis | 0.82 (0.79–0.85) | <0.01 |
| Cystic kidney | 0.75 (0.70–0.80) | <0.01 |
| Congenital anomalies | 0.89 (0.76–0.10) | 0.12 |
| Tubular/interstitial | 1.07 (1.00–1.14) | 0.05 |
| Vascular | 1.02 (0.78–1.34) | 0.86 |
| Neoplasm | 0.93 (0.77–1.11) | 0.40 |
| Other | 0.96 (0.92–0.99) | 0.04 |
| Median household income [#] | 1.00 (1.00–1.01) | 0.24 |
| Rural | 1.06 (1.03–1.09) | <0.01 |
| PRA category | 1.09 (1.06–1.11) | <0.01 |
| Previous transplant | 0.97 (0.93–1.00) | 0.07 |
| Dialysis type | | <0.01 |
| HD | [ref] | |
| PD | 1.15 (1.10–1.20) | |
| No HD | 0.89 (0.86–0.92) | |
| Insurance | | <0.01 |
| Private | [ref] | |
| Medicaid | 0.91 (0.86–0.95) | |
| Medicare | 1.08 (1.05–1.11) | |

(Continues)

TABLE 3 (Continued)

| Variable | Hazard ratio 95% confidence interval | p-value |
|------------------|---|---------|
| Other government | 1.21 (1.15–1.27) | |
| Other | 1.08 (0.92–1.28) | 0.34 |
| Blood type | | |
| A | [ref] | |
| O | 0.99 (0.96–1.02) | 0.69 |
| B | 1.00 (0.96–1.04) | 0.85 |
| AB | 1.03 (0.96–1.11) | 0.40 |

ⁱAsian American/Pacific Islander, Alaskan Indian/Native America
[#]per \$10,000

transplant policy change in the United States, notably the December 2014 implementation of the kidney allocation system; by utilizing 2013 as our final year of listing, we avoid any significant change in those listed due to KAS. However, the primary limitation remains the granularity of the data rather than any change in transplant policy. These databases provide patient information at time of inclusion; in our cohort, patients accrued significant time on and off the list; we cannot comment on their true burden of disease and other barriers to transplant at time of either removal or death. Additionally, there are no standard definitions of "too sick to transplant" and "other" reasons for delisting nor is additional information available on individual transplant center policies for delisting. These factors limit our ability to draw conclusions regarding prognosis or life expectancy, and thus benefit of transplant, and understanding transplant center policies for removal from the list represents an area of research that warrants further exploration.

4.1 | Conclusions

Kidney transplant candidates who are removed from the list for any reason accrue a significant amount of time prior to removal and live a surprisingly long time after removal. However, current data collection is inadequate to describe or understand delisting as a patient-centered outcome. Future research is needed to explicitly define reasons for delisting, including "too sick" and "other," to better understand the functional status, quality of life, and social costs of being delisted.

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AUTHOR CONTRIBUTIONS

Sokas, Rodrigue, and Adler contributed to study concept and design. Sokas and Adler analyzed and interpreted the data. Sokas and Adler

drafted the article. Sokas, Cooper, Salim, Rodrigue, and Adler *critically revised the article*. Sokas, Cooper, Salim, Rodrigue, and Adler approved the article.

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APPENDIX 1.

SRTR reason why candidate was removed

| | |
|----|--|
| 4 | Deceased Donor tx, removed by transplanting center |
| 5 | Medically unsuitable |
| 6 | Refused transplant |
| 7 | Transferred to another center |
| 8 | Died |
| 9 | Other |
| 10 | Candidate listed in error |
| 11 | Candidate listed for unacceptable antigens only |
| 12 | Candidate condition improved, tx not needed |
| 13 | Candidate condition deteriorated, too sick for tx |
| 14 | Transplant at another center (multilisted) |
| 15 | Living donor tx, removed by transplanting center |
| 16 | Candidate removed in error |
| 17 | Changed to KP (by system) |
| 18 | Deceased donor emergency Tx |
| 19 | Deceased donor multi-organ Tx |
| 20 | Program inactive for 2 + years |
| 21 | Patient died during TX procedure |
| 22 | Transplanted in another country |
| 23 | Patient died during living donor TX procedure |
| 24 | Unable to contact candidate |

APPENDIX 2.

Comorbid conditions for delisted patients

| | Other | Too sick |
|---------------------|-------|----------|
| Age (median), years | 54.6 | 63.1 |
| HTN | 72.2% | 73.7% |
| DM | 47.9% | 60.5% |
| Previous malignancy | 4.4% | 8.4% |
| COPD | 1.3% | 2.6% |
| PVD | 5.4% | 9.2% |
| CAD | 6.1% | 9.9% |
| CVD | 3.3% | 5.5% |

APPENDIX 3.

Removal by waitlist code by year, 2003-2018

