




# End-of-Life Care among US Adults with ESKD Who Were Waitlisted or Received a Kidney Transplant, 2005–2014

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## ABSTRACT

**Background** The care of patients in the United States who have ESKD is often shaped by their hopes and prognostic expectations related to kidney transplant. Little is known about how patients' engagement in the transplant process might relate to patterns of end-of-life care.

**Methods** We compared six measures of intensity of end-of-life care among adults in the United States with ESKD who died between 2005 and 2014 after experiencing differing exposure to the kidney transplant process.

**Results** Of 567,832 decedents with ESKD, 27,633 (5%) had a functioning kidney transplant at the time of death, 14,653 (3%) had a failed transplant, 16,490 (3%) had been removed from the deceased donor waitlist, 17,010 (3%) were inactive on the waitlist, 11,529 (2%) were active on the waitlist, and 480,517 (85%) had never been waitlisted for or received a transplant (reference group). In adjusted analyses, compared with the reference group, patients exposed to the transplant process were significantly more likely to have been admitted to an intensive care unit and to have received an intensive procedure in the last 30 days of life; they were also significantly more likely to have died in the hospital. Those who died on the transplant waitlist were also less likely than those in the reference group to have been enrolled in hospice and to have discontinued dialysis before death.

**Conclusions** Patients who had engaged in the kidney transplant process received more intensive patterns of end-of-life care than other patients with ESKD. These findings support the relevance of advance care planning, even for this relatively healthy segment of the ESKD population.

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Kidney transplant is the preferred form of RRT for many patients with ESKD because it offers the opportunity for longer survival and better quality of life compared with remaining on dialysis.<sup>1,2</sup> However, only a small and relatively healthy segment of the ESKD population will ultimately receive a kidney.<sup>3</sup> Available evidence suggests that for patients with advanced kidney disease, hopes and expectations around kidney transplant strongly shape their prognostic expectations<sup>4,5</sup> and may affect how they think about and plan for the future.

Little is currently known about how engagement in the kidney transplant process—whether this be in the form of evaluation, waitlisting, or receipt of a

kidney transplant—might shape the care that patients receive as they approach the end of life. Prior work among candidates for, and recipients of, other kinds of solid organ transplant (*i.e.*, heart, lung, or

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liver) describes their limited involvement in advance care planning (ACP)<sup>6–10</sup> and high burden of unmet palliative care needs.<sup>11–15</sup> Although results are mixed,<sup>10,16</sup> there is some evidence that patients preparing for these other types of solid organ transplant received more intensive patterns of end-of-life care than similar patients who had not been considered for transplant, even when their death was expected.<sup>8</sup> However, systematic differences in the selection process for kidney, as compared with other kinds of solid organ transplant,<sup>17</sup> and the availability of dialysis as an alternative form of organ replacement therapy for people with ESKD may contribute to distinctive patterns of end-of-life care for patients engaged in the kidney transplant process.

We are not aware of prior studies that have described patterns of end-of-life care for patients engaged in the kidney transplant process. We hypothesized that because of their younger age, lower burden of comorbidity, and engagement in a process intended to extend life, patients who had been waitlisted for, or received, a kidney would experience more intensive patterns of end-of-life care than other patients with ESKD. To test this hypothesis, we examined patterns of end-of-life care among a national cohort of decedents with ESKD with differing exposure to the kidney transplant process.

## METHODS

### Cohort Derivation

Using data from the United States Renal Data System (USRDS), a national registry of patients with ESKD, we identified all adults (ages 19–99 years) who had been treated with maintenance dialysis or received a kidney transplant; died between January 1, 2005 and December 31, 2014; and had Medicare Parts A and B coverage throughout their final year of life (Figure 1). We excluded patients who had been treated with maintenance dialysis but subsequently recovered kidney function and those who received a kidney transplant outside the United States. We also excluded patients for whom it was unclear from source data whether their allograft was functioning at the time of death (Supplemental Table 1).

### Exposure

Using USRDS Standard Analysis Files, we defined six mutually exclusive groups of patients with differing exposure to the transplant process at the time of death: (1) patients with a functioning kidney transplant; (2) patients who were active on the deceased donor waitlist; (3) patients who were inactive on the waitlist; (4) patients who had been removed from the waitlist without receiving a kidney; (5) patients with a failed kidney transplant; and (6) patients who had never been waitlisted for or received a kidney transplant.

We used the following stepwise hierarchical approach to assign each patient to one of these six exposure groups. First, we used the USRDS Treatment History and Death Files to identify patients with a functioning kidney transplant at the

### Significance Statement

For patients with ESKD, hoping for or receiving a kidney transplant can shape prognostic expectations and care processes. In this manuscript, the authors describe more intensive, inpatient-oriented patterns of end-of-life care for patients with ESKD who had been waitlisted for a kidney transplant or received a transplant, compared with other patients with ESKD. Patients who died while on the transplant waitlist were also less likely to have received hospice services and less likely to have discontinued dialysis before death. Because there are powerful defaults favoring use of aggressive interventions to prolong life in most health systems in the United States, these findings suggest that the broad relevance of advance care planning for patients with ESKD extends to the relatively healthy segment of this population that has engaged in the transplant process.

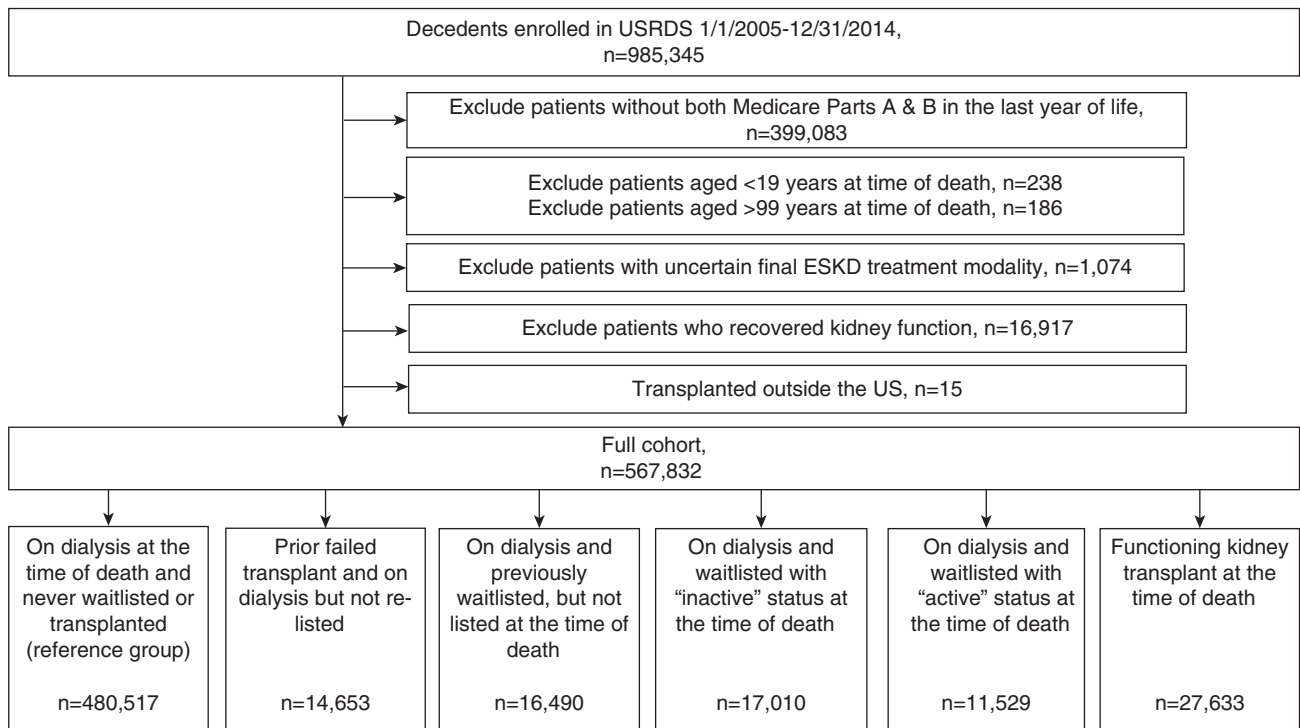
time of death. Second, among the remaining patients, we used waitlist removal codes in the USRDS Kidney and/or Kidney-Pancreas Transplant Files to identify patients who died while on the deceased donor waitlist. These patients were further classified as active or inactive on the waitlist at the time of death on the basis of their most recent United Network of Organ Sharing (UNOS) status codes. Patients were classified as being active on the waitlist at the time of death if they were listed as such by at least one transplant center. Third, patients were classified as having been removed from the waitlist at the time of death if they were not included in any of the preceding groups and their most recent UNOS removal code in the USRDS Kidney and/or Kidney-Pancreas Transplant Files indicated that they had been removed for reasons other than death (e.g., “condition deteriorated,” “medically unsuitable”). Fourth, patients were classified as having a failed transplant if they were not included in any of the preceding groups and had a record of at least one prior kidney transplant in the USRDS Patients File. The remaining cohort members, who were on maintenance dialysis but had never been waitlisted for or received a kidney transplant, were assigned to the reference group.

### Outcomes

We used Medicare fee-for-service institutional claims to define the following measures of intensity of end-of-life care during the last 30 days of life or at the time of death<sup>18</sup>: admission to a short- or long-stay hospital and admission to an intensive and/or coronary care unit in the last 30 days of life, receipt of one or more intensive procedures (cardiopulmonary resuscitation, mechanical ventilation, and/or artificial nutrition) in the last 30 days of life, and death in a hospital. We used the Centers for Medicare and Medicaid Services (CMS)-2746 form to ascertain whether patients were enrolled in hospice at the time of death and whether they had discontinued dialysis before death.

### Covariates

Using Medicare institutional claims, the Medicare Denominator File and the USRDS Patients and Medical Evidence Files



**Figure 1.** Cohort derivation.

(CMS-2728 form), we ascertained each cohort member's date of death, age at the time of death, sex, and race (Asian, American Indian or Alaska Native, Native Hawaiian or Pacific Islander, Black, White, or other or multiple races). We identified the following comorbid conditions on the basis of the International Classification of Diseases (ICD)-9 diagnostic codes for claims during the year before death: diabetes mellitus, coronary artery disease, congestive heart failure, stroke, emphysema, cirrhosis, and dementia. Because all of these characteristics could both differ across exposure groups and be associated with study outcomes, these were treated as potential confounding variables in the relationship between the exposure of interest (exposure to the transplant process) and study outcomes (measures of intensity of end-of-life care).

### Statistical Analyses

We described cohort member characteristics using percentages for categorical variables and mean (SD) or median (interquartile range [IQR]) values for continuous variables. We used logistic regression to measure the association between exposure to the transplant process and each study outcome. Results of logistic regression analyses were adjusted for the following measured patient characteristics: age, sex, race, individual comorbid conditions, and date of death. Results are presented as adjusted proportions and risk differences with 95% confidence intervals on the basis of the distribution of covariates in the overall cohort. We used a  $P$  value of  $<0.002$  as a threshold defining statistical significance for individual tests to achieve an overall false-positive error rate ( $\alpha$ -level) of 0.05

for all comparisons on the basis of the Bonferroni correction.<sup>19</sup>

### Supplementary Analyses

We examined time between the most recent transplant procedure and death among patients who died with a functioning kidney transplant ( $\leq 1$  year,  $>1$ –5 years,  $>5$ –10 years,  $>10$  years versus the reference group of patients who were not transplanted or waitlisted). We also examined time between graft failure and death among patients with a failed transplant who had not been waitlisted after their most recent graft had failed ( $\leq 1$  year,  $>1$ –5 years,  $>5$ –10 years,  $>10$  years versus the same reference group). These analyses were adjusted for the same covariates as the primary analyses.

### Sensitivity Analyses

The mortality follow-back approach is often used to describe patterns of end-of-life care among decedents. A limitation of this approach is that it cannot capture patterns of end-of-life care for patients who survive the ascertainment period. For this reason, for studies that aim to comprehensively describe patterns of end-of-life care among a prospective cohort, the mortality follow-back approach can produce biased results if there are systematic differences between cohort members who die and those who survive beyond the ascertainment period. To evaluate the extent to which our results might be sensitive to this type of bias, we repeated the primary analysis among the subset of cohort members who developed ESKD early on in the ascertainment period between January 1, 2005 and

December 31, 2008. As compared with patients who developed ESKD later in the ascertainment period, patterns of end-of-life care for these patients would be expected to more closely resemble those of a denominator population of otherwise eligible patients who developed ESKD over the same time period.

The analytic approach was guided by the Strengthening of Reporting of Observational Studies in Epidemiology (STROBE) criteria<sup>20</sup> and statistical tests were conducted using R studio (version 1.1.453, RStudio, Inc.)<sup>21</sup> and Stata SE, version 13.1 (Stata Corp, College Station, TX). The study was approved by the Institutional Review Board at the University of Washington in Seattle, WA.

## RESULTS

In this national cohort of 567,832 adults with ESKD who died between 2005 and 2014, 27,633 patients (5%) had a functioning kidney transplant at the time of death, 14,653 (3%) were on dialysis after a failed transplant and had not been relisted, 16,490 (3%) had been removed from the waitlist, 17,010 (3%) were inactive on the waitlist, 11,529 (2%) were active on the waitlist, and 480,517 (85%) had never been waitlisted for or received a kidney transplant (Table 1). For patients with a functioning transplant at the time of death, the median interval between their most recent transplant procedure and death was 6.7 (IQR 2.9–11.4) years. For those with a failed transplant, the median time since their most recent transplant failure was 2.5 (IQR 0.9–5.8) years. For those who had been removed from the waitlist, the median time since their most recent waitlist removal was 1.8 (IQR 0.7–3.6) years.

Patients exposed to the transplant process were much younger than the reference group of patients who had never been transplanted or waitlisted, with the mean age ranging from 56.9 (SD 12.1) years for patients who were active on the waitlist to 65.1 (SD 11.6) years for those with a functioning transplant at the time of death as compared with 72.5 (SD 12.3) years for the reference group (Table 1). The proportion of Black patients was higher for all except those with a functioning transplant (in whom the proportion of Black patients was lower) compared with the reference group. With the exceptions of cancer (which was more common in those with a functioning transplant) and cirrhosis (which was more common in those who had been waitlisted or had a failed transplant), the prevalence of comorbid conditions was highest among members of the reference group.

### Adjusted Association of Transplant Status with Study Outcomes

With the exception of patients who were active on the waitlist at the time of death, the adjusted proportion admitted to a hospital in the last 30 days of life was higher for those exposed to the transplant process than for the reference group (adjusted proportion 75% for those with a transplant, 77% for

those with a failed transplant, 75% for those removed from the waitlist, 76% for those who were inactive on the waitlist, and 72% for those who were active on the waitlist versus 73% for the reference group;  $P$  value for adjusted risk difference  $<0.002$  for all comparisons except for patients active on the waitlist) (Figure 2, Supplemental Table 2). Compared with the reference group, a higher adjusted proportion of all groups exposed to the transplant process was admitted to an intensive and/or coronary care unit (55%, 55%, 53%, 56%, and 54% versus 51%, respectively;  $P<0.002$  for all comparisons) and received an intensive procedure (35%, 31%, 30%, 33%, and 34% versus 28%, respectively;  $P<0.002$  for all comparisons) in the last 30 days of life and a higher adjusted proportion died in the hospital (49%, 45%, 44%, 46%, and 45% versus 40%, respectively;  $P<0.002$  for all comparisons). Compared with the reference group, a lower adjusted proportion of patients who were waitlisted at the time of death received hospice services (18% of patients inactive on the waitlist and 12% of those active on the waitlist versus 25% of those in the reference group;  $P<0.002$  for both comparisons) and discontinued dialysis before death (25% and 17% versus 28%, respectively;  $P<0.002$  for both comparisons).

### Supplementary Analyses

In adjusted analyses, intensity of care was higher than for the reference group for patients with a functioning transplant regardless of time since transplant and was especially high for those who had died within a year of transplant. These patients were also less likely than the reference group to have received hospice services (Figure 3, Supplemental Table 3).

Among patients with a failed transplant, adjusted measures of inpatient intensity of care were all higher than for the reference group regardless of time since transplant failure (Supplemental Table 4). Use of hospice and dialysis discontinuation followed a similar pattern to the reference group and did not vary as a function of time since transplant failure.

### Sensitivity Analyses

Results of a sensitivity analysis among cohort members who developed ESKD between 2005 and 2008 were similar to the primary analysis (Supplemental Table 5).

## DISCUSSION

Patients with ESKD who had been waitlisted for or received a kidney transplant received more intensive patterns of end-of-life care than other members of this population, even after adjusting for differences in measured patient characteristics. Those patients who died on the kidney transplant waitlist—regardless of whether they were active or inactive at the time of death—were also less likely to have received hospice services and to have discontinued dialysis. Patterns of end-of-life care were more intensive than for the reference group regardless of time since transplant or transplant failure.

Table 1. Cohort characteristics

| Characteristic                               | Transplant<br>(n=27,633) | Failed<br>Transplant,<br>Never Relisted <sup>a</sup><br>(n=14,653) | Removed<br>from Waitlist <sup>b</sup><br>(n=16,490) | Inactive on<br>the Waitlist<br>(n=17,010) | Active on the<br>Waitlist<br>(n=11,529) | On Dialysis, Never<br>Waitlisted or<br>Transplanted<br>(Reference Group)<br>(n=480,517) | Full Cohort<br>(n=567,832) |
|--|--------------------------|--|---|---|---|---|----------------------------|
| Age category (%)                             |                          |  |   |   |   |   |                            |
| 19–54  | 4710 (17.0)              | 4888 (33.4)  | 3479 (21.1)   | 5794 (34.1)                               | 4169 (36.2)                             | 40,476 (8.4)  | 63,516 (11.2)              |
| 55–64  | 6330 (22.9)              | 4014 (27.4)  | 4600 (27.9)   | 5556 (32.7)                               | 3789 (32.9)                             | 66,926 (13.9)   | 91,215 (16.1)              |
| 65–74  | 10,286 (37.2)            | 4017 (27.4)  | 5704 (34.6)   | 4727 (27.8)                               | 3004 (26.1)                             | 128,895 (26.8)  | 156,633 (27.6)             |
| 75–100                                       | 6307 (22.8)              | 1734 (11.8)  | 2707 (16.4)   | 933 (5.5)                                 | 567 (4.9)                               | 244,220 (50.8)  | 256,468 (45.2)             |
| Age, mean (SD)                               | 65.1 (11.6)              | 58.9 (13.2)  | 62.9 (11.6)   | 57.8 (11.6)                               | 56.9 (12.1)                             | 72.5 (12.3)   | 70.7 (12.9)                |
| Sex  |                          |  |   |   |   |   |                            |
| Women  | 10,152 (36.7)            | 5965 (40.7)  | 6718 (40.7)   | 6936 (40.8)                               | 4599 (39.9)                             | 221,858 (46.2)  | 256,228 (45.1)             |
| Men  | 17,479 (63.3)            | 8687 (59.3)  | 9771 (59.3)   | 10,074 (59.2)                             | 6929 (60.1)                             | 258,566 (53.8)  | 311,506 (54.9)             |
| Missing                                      | <11                      | <11  | <11   | <11                                       | <11                                     | 93 (0.0)  | 98 (0.0)                   |
| Race (%)                                     |                          |  |   |   |   |   |                            |
| Asian  | 771 (2.8)                | 324 (2.2)  | 599 (3.6)   | 528 (3.1)                                 | 570 (4.9)                               | 10,548 (2.2)  | 13,340 (2.3)               |
| American<br>Indian or<br>Alaska<br>Native    | 400 (1.4)                | 186 (1.3)  | 281 (1.7)   | 224 (1.3)                                 | 146 (1.3)                               | 5330 (1.1)  | 6567 (1.2)                 |
| Native<br>Hawaiian or<br>Pacific<br>Islander | 122 (0.4)                | 70 (0.5)   | 176 (1.1)   | 164 (1.0)                                 | 131 (1.1)                               | 3220 (0.7)  | 3883 (0.7)                 |
| Black  | 5299 (19.2)              | 4777 (32.6)  | 5737 (34.8)   | 5909 (34.7)                               | 3997 (34.7)                             | 129,437 (26.9)  | 155,156 (27.3)             |
| White  | 20,791 (75.2)            | 9189 (62.7)  | 9567 (58.0)   | 10,025 (58.9)                             | 6571 (57.0)                             | 329,187 (68.5)  | 385,330 (67.9)             |
| Other or<br>multiple<br>races                | 221 (0.8)                | 105 (0.7)  | 123 (0.7)   | 152 (0.9)                                 | 107 (0.9)                               | 2682 (0.6)  | 3390 (0.6)                 |
| Missing                                      | 29 (0.1)                 | <11  | <11   | <11                                       | <11                                     | 113 (0.0)   | 166 (0.0)                  |
| Year of death<br>category (%)                |                          |  |   |   |   |   |                            |
| 2005–2006                                    | 4921 (17.8)              | 2918 (19.9)  | 2070 (12.6)   | 2821 (16.6)                               | 2853 (24.7)                             | 102,202 (21.3)  | 117,785 (20.7)             |
| 2007–2008                                    | 4992 (18.1)              | 2804 (19.1)  | 2552 (15.5)   | 3302 (19.4)                               | 2501 (21.7)                             | 97,379 (20.3)   | 113,530 (20.0)             |
| 2009–2010                                    | 5470 (19.8)              | 2912 (19.9)  | 3311 (20.1)   | 3595 (21.1)                               | 2229 (19.3)                             | 95,026 (19.8)   | 112,543 (19.8)             |
| 2011–2012                                    | 5884 (21.3)              | 2947 (20.1)  | 4008 (24.3)   | 3748 (22.0)                               | 1940 (16.8)                             | 93,339 (19.4)   | 111,866 (19.7)             |
| 2013–2014                                    | 6366 (23.0)              | 3072 (21.0)  | 4549 (27.6)   | 3544 (20.8)                               | 2006 (17.4)                             | 92,571 (19.3)   | 112,108 (19.7)             |
| Comorbidities (%)                            |                          |  |   |   |   |   |                            |
| Diabetes<br>mellitus                         | 19,873 (71.9)            | 10,708 (73.1)  | 12,555 (76.1)                                       | 13,065 (76.8)                             | 8649 (75.0)                             | 378,342 (78.7)  | 443,192 (78.0)             |
| Coronary artery<br>disease                   | 16,855 (61.0)            | 10,367 (70.8)  | 12,677 (76.9)                                       | 12,605 (74.1)                             | 7877 (68.3)                             | 372,320 (77.5)  | 432,701 (76.2)             |
| Congestive<br>heart failure                  | 15,934 (57.7)            | 11,089 (75.7)  | 12,555 (76.1)                                       | 12,490 (73.4)                             | 7606 (66.0)                             | 390,614 (81.3)  | 450,288 (79.3)             |
| Stroke                                       | 7965 (28.8)              | 5023 (34.3)  | 5983 (36.3)   | 5933 (34.9)                               | 3556 (30.8)                             | 185,240 (38.6)  | 213,700 (37.6)             |
| Cancer                                       | 10,378 (37.6)            | 3475 (23.7)  | 3777 (22.9)   | 3534 (20.8)                               | 1761 (15.3)                             | 127,755 (26.6)  | 150,680 (26.5)             |
| Emphysema                                    | 9263 (33.5)              | 6112 (41.7)  | 7199 (43.7)   | 6475 (38.1)                               | 3524 (30.6)                             | 251,447 (52.3)  | 284,020 (50.0)             |
| Cirrhosis                                    | 1611 (5.8)               | 1249 (8.5)   | 1706 (10.3)   | 1594 (9.4)                                | 789 (6.8)                               | 31,054 (6.5)  | 38,003 (6.7)               |
| Dementia                                     | 2434 (8.8)               | 1290 (8.8)   | 1915 (11.6)   | 1191 (7.0)                                | 503 (4.4)                               | 89,084 (18.5)   | 96,417 (17.0)              |

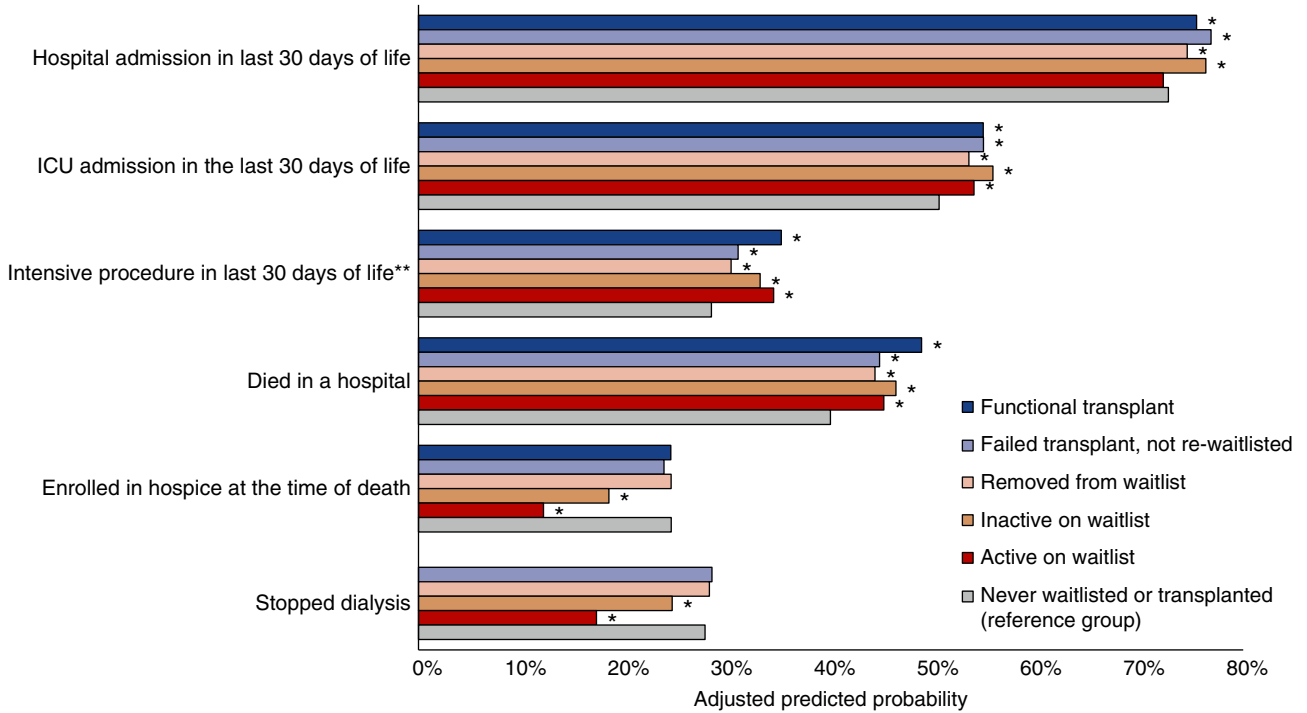
Chi-squared or ANOVA for difference between groups was <0.001 for all comparisons.

<sup>a</sup>This group includes patients with a prior transplant that failed and who were not subsequently relisted or retransplanted.

<sup>b</sup>This group includes patients on dialysis with a failed transplant who were subsequently waitlisted and then removed.

Prior studies in the wider population with ESKD have described intensive patterns of end-of-life care focused on life extension<sup>22,23</sup> that do not seem to reflect the kind of care many of these patients say they would want to receive if they were

seriously ill or dying.<sup>24,25</sup> Because there are strong defaults favoring use of aggressive interventions to prolong life in many US health systems,<sup>26,27</sup> our findings underline the importance of educating patients engaged in the transplant

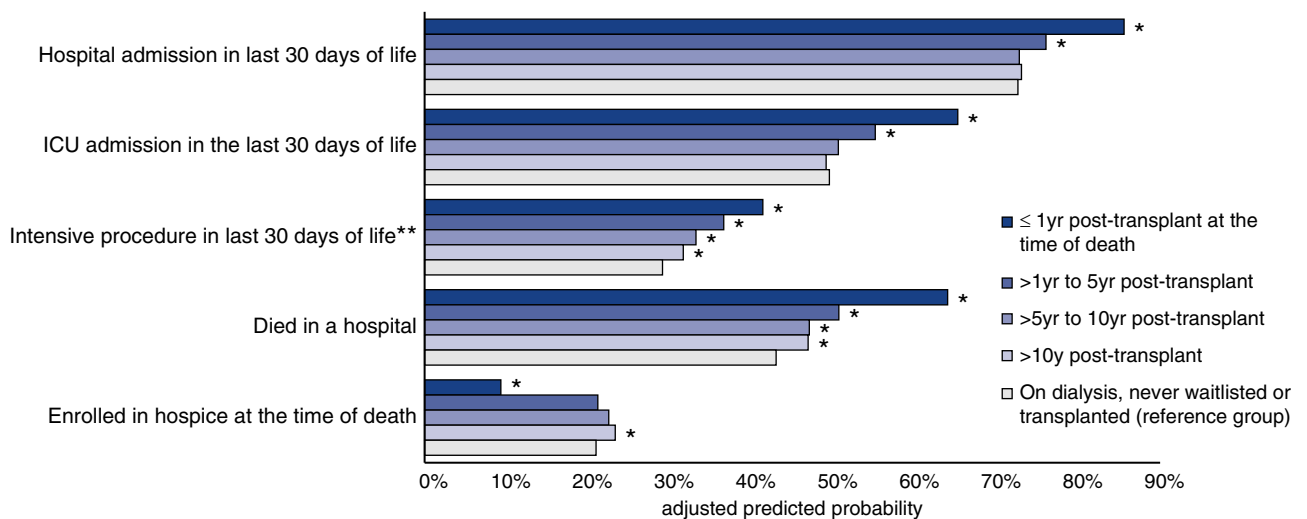


**Figure 2.** Measures of intensity of end-of-life care for adults with ESKD with exposure to the transplant process. Proportions adjusted for age, sex, race, date of death, and all measured individual comorbidities. \*P value for adjusted risk difference <0.002. \*\*Mechanical ventilation, cardiopulmonary resuscitation, and/or artificial nutrition. ICU, intensive or coronary care unit.

process about what to expect at the end of life and offering opportunities to engage in advance care planning (ACP).<sup>28,29</sup> High levels of end-of-life intensity of care among patients engaged in the kidney transplant process highlight the relevance of ACP even for this relatively healthy segment of the ESKD population. Our findings may also help to inform discussions

with patients and families about the kinds of situations and treatment decisions that might lie ahead were they to become seriously ill.

Existing models of ACP developed for patients undergoing other kinds of organ transplant<sup>30–33</sup> and for the overall ESKD population<sup>34–36</sup> may need to be adapted to accommodate the



**Figure 3.** Measures of intensity of end-of-life care among cohort members with a functioning kidney transplant at the time of death by time since transplant. Proportions adjusted for age, sex, race, date of death, and all measured individual comorbidities. \*P value for adjusted risk difference <0.002. \*\*Mechanical ventilation, cardiopulmonary resuscitation, and/or artificial nutrition. ICU, intensive or coronary care unit.

potentially dynamic and varied illness trajectories of patients engaged in the kidney transplant process. Unlike patients with other kinds of organ failure, where deteriorating health is anticipated (or even required) before they can receive a transplant, patients awaiting kidney transplant must remain relatively healthy in order to maintain their transplant candidacy.<sup>37–40</sup> Most patients are thus relatively young and healthy when they are first listed for kidney transplant. However, within 3 years of listing, approximately one in five patients die or are removed from the waitlist due to deteriorating health.<sup>41</sup> Although many of the deaths that occur among patients who are active on the waitlist or recently transplanted may be sudden and unexpected, even cohort members who had been inactivated or removed from the list received very intensive patterns of end-of-life care, as did those who had not been relisted after a failed kidney transplant.

Prior studies among candidates for other kinds of solid organ transplant suggest that patients generally welcome the opportunity to receive palliative care services and engage in ACP while planning for transplant.<sup>13,30–33,42</sup> However, there may be unique challenges to integrating ACP with care processes related to kidney transplant. Existing qualitative work suggests that an emphasis on preventative and curative interventions during the evaluation can sometimes undermine other care processes,<sup>43,44</sup> particularly if these seem inconsistent with the goal of receiving a transplant.<sup>45–49</sup> Further, hope for transplant—even for patients unlikely to receive a kidney—can foster overly optimistic expectations or uncertainty about the future that could limit the effectiveness of ACP.<sup>4,5</sup> Uncertainty about where patients stand in the transplant evaluation process and about whether they are likely to receive a kidney may also make it difficult for patients and families to formulate realistic plans for their future care.<sup>50,51</sup> This may perhaps explain why patterns of end-of-life care for patients who had been inactivated or removed from the transplant waitlist—events that may signal worsening health status<sup>52,53</sup>—largely mirrored those for patients who were actively listed at the time of death.

We suspect that conceptualizing of ACP as an ongoing and iterative “process”<sup>54</sup> rather than a one-time event may be particularly helpful in supporting patients engaged in the kidney transplant process. Early on, strategies to support patients and families in understanding prognostic uncertainty,<sup>55,56</sup> including “hoping for the best and preparing for the worst,”<sup>57</sup> may help to align ACP with the transplant evaluation process. Patients’ values, goals, and future expectations could then be revisited over time, particularly in the setting of deteriorating health and/or at critical junctures in the transplant process such as allograft failure or removal from the waitlist. More open communication and clear delineation of roles between the multiple clinicians who care for patients engaged in the transplant process may also help to support ACP in this population.

Our study has the following limitations. First, although the results of the sensitivity analysis provide some reassurance that patterns of end-of-life care would likely be similar for patients who did not die during the ascertainment period, it is possible

that our results may not be generalizable to patients who survive for long periods of time after ESKD onset. Second, our results do not speak to whether patterns of end-of-life care were aligned with the goals, preferences, and values of individual patients. Third, our cohort was restricted to fee-for-service Medicare beneficiaries, which may limit generalizability to patients with Medicare Advantage or other types of health insurance. Fourth, our analyses do not describe patterns of end-of-life care for the subgroup of patients who had been accepted for living donor transplant but had not yet received a kidney. Fifth, because selection for waitlisting and transplant relies on information ascertained during a detailed physical and psychosocial evaluation, there are almost certainly unmeasured differences between patients in the reference group and those exposed to the transplant process. Our analyses also do not account for other factors (*e.g.*, socioeconomic status) that can shape patterns of end-of-life care.<sup>58</sup> Finally, inaccurate or incomplete information on transplant status at the time of death in source data may have led to misclassification of the exposure, although this would likely have biased our results toward detecting no differences between groups.

In a national cohort of Medicare beneficiaries with ESKD who died between 2005 and 2014, those who had engaged in the transplant process—regardless of the nature of this engagement—received more intensive patterns of end-of-life care than other patients with ESKD. Because there are powerful defaults favoring aggressive intervention to prolong life in most US health systems, these findings highlight the broad relevance of ACP even for this relatively healthy segment of the ESKD population.

## DISCLOSURES

All authors have nothing to disclose.

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## DATA SHARING STATEMENT

The data reported here have been supplied by the United States Renal Data System and are available upon request. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as official policy or interpretation of the US government.

## SUPPLEMENTAL MATERIAL

This article contains the following supplemental material online at <http://jasn.asnjournals.org/lookup/suppl/doi:10.1681/ASN.2020030342/-/DCSupplemental>.

Supplemental Table 1. USRDS registry codes used to define exposure groups.  
Supplemental Table 2. Measures of intensity of end-of-life care by exposure to the transplant process.

Supplemental Table 3. Measures of intensity of end-of-life care among cohort members with a functioning kidney transplant at the time of death by time since transplant.

Supplemental Table 4. Measures of intensity of end-of-life care among cohort members with a failed transplant at the time of death by time since transplant failure.

Supplemental Table 5. Measures of intensity of end-of-life care by exposure to the transplant process for patients who developed ESKD from 2005 to 2008.

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## Online-Only Material

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**eTable1:** USRDS registry codes used to define exposure groups

|   | Category classification strategy   |
|---|--|
| Excluded                                  | <ol style="list-style-type: none"> <li>1. Patients with most recent REMCODE=12 (transplanted in a foreign country) (SAF: <i>WAITLIST_KI, WAITLIST_KP</i>)</li> <li>2. Patients with most recent treatment type “recovered kidney function” (RXCATGP=x) (SAF <i>RXHIST</i>)</li> <li>3. Patients with most recent treatment modality is “transplanted” (RXCATGP=T) but for whom there is also indication that the patient was on dialysis at the time of death (CMS form 2746 states modality at time of death was dialysis; Medicare claims indicate that the patient withdrew from dialysis; primary cause of death was withdrawal from dialysis or dialysis-related infection [PRICOD=104, 33, 34, 45, 46, 47, 49, 50, 51, or 74]). (SAF: <i>DEATH_NOTIFICATION, PATIENT</i>)</li> </ol> |
| Transplanted                              | <p>Most recent treatment type is “transplanted” (RXCATGP=T) (SAF <i>RXHIST</i>)</p> <p><u>Subgroup analysis:</u></p> <ol style="list-style-type: none"> <li>1. Most recent transplant date defined by most recent TDATE (SAF <i>WAITLIST_KI, WAITLIST_KP</i>)</li> <li>2. If no transplant date listed in waitlist files and number of transplants was 1 (SAF <i>PATIENT</i>), then date of first transplant defined as the most recent transplant date.</li> <li>3. Interval between most recent transplant date and date of death taken as the time since transplant at the time of death.</li> <li>4. Time since transplant groups categorized (<math>\leq 1</math> year, <math>&gt;1-5</math> years, <math>&gt;5-10</math> years, <math>&gt;10</math> years)</li> </ol>                |
| “Inactive” and “Active” Waitlisted groups | <ol style="list-style-type: none"> <li>1. Not included in “transplanted” group and presence of any waitlist removal code 8, 21, or 23 (SAF <i>WAITLIST_KI, WAITLIST_KP</i>)</li> <li>2. UNOSSTAT associated with most recent UNOSSDT identified (SAF: <i>WAITLIST_KI, WAITLIST_KP</i>).</li> <li>3. “Active” on waitlist defined by UNOSSTAT 4050, 4060, or 5010</li> <li>4. “Inactive” on waitlist defined by UNOSSTAT 4099, 4999, 5099, or 5999</li> <li>5. If simultaneous most recent UNOSSTAT indicating a member was listed (at different institutions) both “active” and “inactive”, they were included in the “active” group.</li> </ol>   |
| Removed from waitlist                     | <ol style="list-style-type: none"> <li>1. Exclude ambiguous removal codes: 7,9,11,14, or 17 (SAF: <i>WAITLIST_KI, WAITLIST_KP</i>)</li> <li>2. Identify most recent removal code by REMDATE</li> </ol>   |

|  |  |
|--|--|
|  | <p>3. Removed from waitlist defined by removal codes 5,6,12,13,20, or 24</p> <p>4. If most recent removal code indicates the member was transplanted but member was not included in transplant group (did not have a functioning transplant at the time of death), then member included in reference group (SAF WAITLIST_KI, WAITLIST_KP).</p> <p>4. If only ambiguous removal codes listed (7,9,11,14, or 17), member included in "removed from waitlist" group.</p>  |
| Prior failed transplant and not re-listed before death | <p>1. Not included in "transplanted", "active", "inactive", or "removed" groups</p> <p>2. Any modality code = "transplanted" (SAF: RXHIST)</p> <p><u>Subgroup analysis:</u></p> <p>1. Among members of this group, we identified the most recent (if any) episode of transplant (RXGROUP=T) and defined the date of transplant failure by the end-date of that episode (ENDDATE).</p> <p>2. The interval between transplant failure date and the date of death was defined as the time since transplant failure.</p> <p>3. Time since transplant failure groups categorized (<math>\leq 1</math> year, <math>&gt;1-5</math> years, <math>&gt;5-10</math> years, <math>&gt;10</math> years)</p> |
| Reference group  | Not categorized above  |

Abbreviations: United States Renal Data System Standard Analysis File, SAF

**eTable2:** Measures of intensity of end-of-life care associated with exposure to the transplant process

|   | Univariable      |                       |         | Multivariable    |                   |         |
|---|------------------|-----------------------|---------|------------------|-------------------|---------|
|   | aPP (95% CI)     | aRD (95% CI)          | p-value | aPP (95% CI)     | aRD (95% CI)      | p-value |
| hospital admission in last 30 days of life          |                  |                       |         |                  |                   |         |
| transplanted  | 0.69 (0.69-0.70) | -0.04 (-0.04-(-)0.03) | <0.001  | 0.75 (0.75-0.76) | 0.03 (0.02-0.03)  | <0.001  |
| failed transplant, not re-waitlisted                | 0.76 (0.75-0.76) | 0.02 (0.02-0.03)      | <0.001  | 0.77 (0.76-0.78) | 0.04 (0.03-0.05)  | <0.001  |
| removed from waitlist                               | 0.74 (0.73-0.75) | 0.01 (0.00-0.01)      | 0.037   | 0.75 (0.74-0.75) | 0.02 (0.01-0.02)  | <0.001  |
| inactive on waitlist                                | 0.75 (0.75-0.76) | 0.02 (0.01-0.03)      | <0.001  | 0.76 (0.76-0.77) | 0.04 (0.03-0.04)  | <0.001  |
| active on waitlist                                  | 0.68 (0.67-0.69) | -0.05 (-0.06-(-)0.04) | <0.001  | 0.72 (0.71-0.73) | 0.00 (-0.01-0.00) | 0.216   |
| on dialysis, never waitlisted or transplanted (ref) | 0.73 (0.73-0.73) | 0 (Ref)               |         | 0.73 (0.73-0.73) | 0 (Ref)           |         |
| ICU admission in the last 30 days of life           |                  |                       |         |                  |                   |         |
| transplanted  | 0.50 (0.49-0.51) | -0.01 (-0.01-0.00)    | 0.07    | 0.55 (0.54-0.55) | 0.04 (0.04-0.05)  | <0.001  |
| failed transplant, not re-waitlisted                | 0.56 (0.56-0.57) | 0.06 (0.05-0.07)      | <0.001  | 0.55 (0.54-0.56) | 0.04 (0.03-0.05)  | <0.001  |
| removed from waitlist                               | 0.56 (0.55-0.56) | 0.05 (0.04-0.06)      | <0.001  | 0.53 (0.53-0.54) | 0.03 (0.02-0.04)  | <0.001  |
| inactive on waitlist                                | 0.58 (0.57-0.59) | 0.07 (0.07-0.08)      | <0.001  | 0.56 (0.55-0.56) | 0.05 (0.04-0.06)  | <0.001  |
| active on waitlist                                  | 0.54 (0.53-0.55) | 0.03 (0.02-0.04)      | <0.001  | 0.54 (0.53-0.55) | 0.03 (0.02-0.04)  | <0.001  |
| on dialysis, never waitlisted or transplanted (ref) | 0.51 (0.50-0.51) | 0 (Ref)               |         | 0.51 (0.50-0.51) | 0 (Ref)           |         |
| intensive procedure in last 30 days of life         |                  |                       |         |                  |                   |         |

|   |                  |                       |        |                  |                       |        |
|---|------------------|-----------------------|--------|------------------|-----------------------|--------|
| transplanted  | 0.33 (0.33-0.34) | 0.05 (0.05-0.06)      | <0.001 | 0.35 (0.35-0.36) | 0.07 (0.06-0.07)      | <0.001 |
| failed transplant, not re-waitlisted                | 0.36 (0.35-0.37) | 0.08 (0.07-0.09)      | <0.001 | 0.31 (0.30-0.32) | 0.03 (0.02-0.03)      | <0.001 |
| removed from waitlist                               | 0.35 (0.34-0.36) | 0.07 (0.06-0.08)      | <0.001 | 0.30 (0.30-0.31) | 0.02 (0.01-0.03)      | <0.001 |
| inactive on waitlist                                | 0.40 (0.39-0.40) | 0.12 (0.11-0.13)      | <0.001 | 0.33 (0.32-0.34) | 0.05 (0.04-0.05)      | <0.001 |
| active on waitlist                                  | 0.40 (0.39-0.41) | 0.12 (0.11-0.13)      | <0.001 | 0.34 (0.34-0.35) | 0.06 (0.05-0.07)      | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.28 (0.28-0.28) | 0 (Ref)               |        | 0.28 (0.28-0.29) | 0 (Ref)               |        |
| died in a hospital                                  |                  |                       |        |                  |                       |        |
| transplanted  | 0.45 (0.45-0.46) | 0.06 (0.05-0.06)      | <0.001 | 0.49 (0.48-0.49) | 0.09 (0.08-0.09)      | <0.001 |
| failed transplant, not re-waitlisted                | 0.47 (0.46-0.48) | 0.07 (0.06-0.08)      | <0.001 | 0.45 (0.44-0.46) | 0.05 (0.04-0.06)      | <0.001 |
| removed from waitlist                               | 0.46 (0.45-0.47) | 0.06 (0.05-0.07)      | <0.001 | 0.44 (0.44-0.45) | 0.04 (0.04-0.05)      | <0.001 |
| inactive on waitlist                                | 0.49 (0.48-0.50) | 0.09 (0.09-0.10)      | <0.001 | 0.46 (0.46-0.47) | 0.06 (0.06-0.07)      | <0.001 |
| active on waitlist                                  | 0.47 (0.46-0.48) | 0.08 (0.07-0.08)      | <0.001 | 0.45 (0.44-0.46) | 0.05 (0.04-0.06)      | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.40 (0.40-0.40) | 0 (Ref)               |        | 0.40 (0.40-0.40) | 0 (Ref)               |        |
| enrolled in hospice at the time of death            |                  |                       |        |                  |                       |        |
| transplanted  | 0.24 (0.23-0.24) | -0.02 (-0.02-(-)0.01) | <0.001 | 0.24 (0.24-0.25) | 0.00 (-0.01-0.00)     | 0.86   |
| failed transplant, not re-waitlisted                | 0.18 (0.17-0.19) | -0.07 (-0.08-(-)0.07) | <0.001 | 0.24 (0.23-0.25) | -0.01 (-0.01-0.00)    | 0.068  |
| removed from waitlist                               | 0.20 (0.20-0.21) | -0.05 (-0.06-(-)0.05) | <0.001 | 0.25 (0.24-0.25) | 0.00 (-0.01-0.01)     | 0.978  |
| inactive on waitlist                                | 0.13 (0.12-0.13) | -0.13 (-0.13-(-)0.12) | <0.001 | 0.18 (0.18-0.19) | -0.06 (-0.07-(-)0.05) | <0.001 |
| active on waitlist                                  | 0.07 (0.07-0.08) | -0.18 (-0.19-(-)0.18) | <0.001 | 0.12 (0.11-0.13) | -0.12 (-0.13-(-)0.12) | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.25 (0.25-0.25) | 0 (Ref)               |        | 0.25 (0.24-0.25) | 0 (Ref)               |        |
| stopped dialysis prior to death                     |                  |                       |        |                  |                       |        |
| failed transplant, not re-waitlisted                | 0.21 (0.21-0.22) | -0.07 (-0.08-(-)0.07) | <0.001 | 0.28 (0.28-0.29) | 0.01 (0.00-0.01)      | 0.107  |
| removed from waitlist                               | 0.23 (0.22-0.23) | -0.06 (-0.07-(-)0.05) | <0.001 | 0.28 (0.27-0.29) | 0.00 (0.00-0.01)      | 0.271  |
| inactive on waitlist                                | 0.17 (0.17-0.18) | -0.12 (-0.12-(-)0.11) | <0.001 | 0.25 (0.24-0.25) | -0.03 (-0.04-(-)0.02) | <0.001 |
| active on waitlist                                  | 0.11 (0.10-0.12) | -0.18 (-0.18-(-)0.17) | <0.001 | 0.17 (0.16-0.18) | -0.11 (-0.11-(-)0.10) | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.29 (0.29-0.29) | 0 (Ref)               |        | 0.28 (0.28-0.28) | 0 (Ref)               |        |

Predicted probabilities and risk difference in the multivariable model are adjusted for sex, race, age, date of death, and all measured individual comorbidities.

\*p-value for adjusted risk difference <0.001

\*\*Mechanical ventilation, cardiopulmonary resuscitation, and/or artificial nutrition

Abbreviations: aPP, adjusted predicted probability; aRD, adjusted risk difference; ICU, intensive or coronary care unit

**eTable3:** Measures of intensity of end-of-life care among cohort members with a functioning kidney transplant at the time of death associated with time since transplant

|   | Univariable      |                       |         | Multivariable    |                       |         |
|---|------------------|-----------------------|---------|------------------|-----------------------|---------|
|   | aPP (95% CI)     | aRD (95% CI)          | p-value | aPP (95% CI)     | aRD (95% CI)          | p-value |
| <b>hospital admission in last 30 days of life</b>   |                  |                       |         |                  |                       |         |
| <=1yr post-transplant at the time of death          | 0.83 (0.81-0.84) | 0.09 (0.08-0.11)      | <0.001  | 0.86 (0.84-0.87) | 0.13 (0.11-0.15)      | <0.001  |
| >1yr to 5yr   | 0.70 (0.69-0.71) | -0.03 (-0.04-(-)0.02) | <0.001  | 0.76 (0.75-0.77) | 0.03 (0.02-0.05)      | <0.001  |
| >5yr to 10yr  | 0.68 (0.67-0.69) | -0.05 (-0.06-(-)0.04) | <0.001  | 0.73 (0.72-0.74) | 0.00 (-0.01-0.01)     | 0.734   |
| >10y  | 0.66 (0.65-0.67) | -0.07 (-0.08-(-)0.06) | <0.001  | 0.73 (0.72-0.74) | 0.00 (0.00-0.01)      | 0.338   |
| on dialysis, never waitlisted or transplanted (ref) | 0.73 (0.73-0.73) | 0 (Ref)               |         | 0.73 (0.72-0.73) | 0 (Ref)               |         |
| <b>ICU admission in the last 30 days of life</b>    |                  |                       |         |                  |                       |         |
| <=1yr post-transplant at the time of death          | 0.66 (0.64-0.68) | 0.16 (0.14-0.17)      | <0.001  | 0.65 (0.63-0.67) | 0.16 (0.13-0.18)      | <0.001  |
| >1yr to 5yr   | 0.51 (0.50-0.52) | 0.01 (-0.01-0.02)     | 0.321   | 0.55 (0.54-0.57) | 0.06 (0.04-0.07)      | <0.001  |
| >5yr to 10yr  | 0.49 (0.47-0.50) | -0.02 (-0.03-(-)0.01) | <0.001  | 0.51 (0.50-0.52) | 0.01 (0.00-0.02)      | 0.062   |
| >10y  | 0.46 (0.45-0.47) | -0.05 (-0.06-(-)0.04) | <0.001  | 0.49 (0.48-0.50) | 0.00 (-0.01-0.01)     | 0.476   |
| on dialysis, never waitlisted or transplanted (ref) | 0.51 (0.50-0.51) | 0 (Ref)               |         | 0.50 (0.49-0.50) | 0 (Ref)               |         |
| <b>intensive procedure in last 30 days of life</b>  |                  |                       |         |                  |                       |         |
| <=1yr post-transplant at the time of death          | 0.47 (0.45-0.49) | 0.19 (0.18-0.21)      | <0.001  | 0.41 (0.39-0.44) | 0.12 (0.10-0.15)      | <0.001  |
| >1yr to 5yr   | 0.36 (0.35-0.37) | 0.08 (0.07-0.09)      | <0.001  | 0.37 (0.35-0.38) | 0.07 (0.06-0.09)      | <0.001  |
| >5yr to 10yr  | 0.32 (0.31-0.33) | 0.04 (0.03-0.05)      | <0.001  | 0.33 (0.32-0.34) | 0.04 (0.03-0.05)      | <0.001  |
| >10y  | 0.28 (0.28-0.29) | 0.01 (0.00-0.01)      | 0.253   | 0.32 (0.31-0.33) | 0.03 (0.02-0.04)      | <0.001  |
| on dialysis, never waitlisted or transplanted (ref) | 0.28 (0.28-0.28) | 0 (Ref)               |         | 0.29 (0.29-0.29) | 0 (Ref)               |         |
| <b>died in a hospital</b>                           |                  |                       |         |                  |                       |         |
| <=1yr post-transplant at the time of death          | 0.64 (0.62-0.66) | 0.24 (0.22-0.26)      | <0.001  | 0.64 (0.62-0.66) | 0.21 (0.19-0.23)      | <0.001  |
| >1yr to 5yr   | 0.46 (0.45-0.47) | 0.06 (0.05-0.07)      | <0.001  | 0.51 (0.49-0.52) | 0.08 (0.06-0.09)      | <0.001  |
| >5yr to 10yr  | 0.43 (0.42-0.44) | 0.03 (0.02-0.04)      | <0.001  | 0.47 (0.46-0.48) | 0.04 (0.03-0.05)      | <0.001  |
| >10y  | 0.41 (0.40-0.42) | 0.02 (0.01-0.03)      | 0.003   | 0.47 (0.46-0.48) | 0.04 (0.03-0.05)      | <0.001  |
| on dialysis, never waitlisted or transplanted (ref) | 0.40 (0.40-0.40) | 0 (Ref)               |         | 0.43 (0.43-0.43) | 0 (Ref)               |         |
| <b>enrolled in hospice at the time of death</b>     |                  |                       |         |                  |                       |         |
| <=1yr post-transplant at the time of death          | 0.07 (0.06-0.08) | -0.18 (-0.19-(-)0.17) | <0.001  | 0.09 (0.08-0.11) | -0.12 (-0.13-(-)0.10) | <0.001  |
| >1yr to 5yr   | 0.22 (0.21-0.23) | -0.04 (-0.05-(-)0.03) | <0.001  | 0.21 (0.20-0.22) | 0.00 (-0.01-0.01)     | 0.73    |
| >5yr to 10yr  | 0.26 (0.25-0.26) | 0.00 (-0.01-0.01)     | 0.784   | 0.23 (0.22-0.23) | 0.02 (0.01-0.02)      | 0.001   |

|   |                  |                  |        |                  |                  |        |
|---|------------------|------------------|--------|------------------|------------------|--------|
| >10y  | 0.28 (0.27-0.29) | 0.03 (0.02-0.04) | <0.001 | 0.23 (0.23-0.24) | 0.02 (0.02-0.03) | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.25 (0.25-0.25) | 0 (Ref)          |        | 0.21 (0.21-0.21) | 0 (Ref)          |        |

Predicted probabilities and risk difference in the multivariable model are adjusted for sex, race, age, date of death, and all measured individual comorbidities.

\*p-value for adjusted risk difference <0.001

\*\*Mechanical ventilation, cardiopulmonary resuscitation, and/or artificial nutrition

Abbreviations: aPP, adjusted predicted probability; aRD, adjusted risk difference; ICU, intensive or coronary care unit

**eTable4:** Measures of intensity of end-of-life care among cohort members with a failed transplant at the time of death associated with time since transplant failure

|   | Univariable      |                   |         | Multivariable    |                  |         |
|---|------------------|-------------------|---------|------------------|------------------|---------|
|   | aPP (95% CI)     | aRD (95% CI)      | p-value | aPP (95% CI)     | aRD (95% CI)     | p-value |
| hospital admission in last 30 days of life          |                  |                   |         |                  |                  |         |
| <=1yr post-transplant failure                       | 0.81 (0.80-0.82) | 0.08 (0.06-0.09)  | <0.001  | 0.80 (0.79-0.81) | 0.07 (0.05-0.08) | <0.001  |
| >1yr to 5yr   | 0.74 (0.73-0.75) | 0.01 (0.00-0.02)  | 0.094   | 0.75 (0.74-0.76) | 0.02 (0.01-0.03) | 0.002   |
| >5yr to 10yr  | 0.73 (0.71-0.75) | 0.00 (-0.02-0.01) | 0.676   | 0.75 (0.74-0.77) | 0.02 (0.00-0.03) | 0.03    |
| >10y  | 0.74 (0.72-0.77) | 0.01 (-0.01-0.03) | 0.28    | 0.78 (0.76-0.80) | 0.05 (0.03-0.07) | <0.001  |
| on dialysis, never waitlisted or transplanted (ref) | 0.73 (0.73-0.73) | 0 (Ref)           |         | 0.73 (0.73-0.74) | 0 (Ref)          |         |
| ICU admission in the last 30 days of life           |                  |                   |         |                  |                  |         |
| <=1yr post-transplant failure                       | 0.58 (0.57-0.60) | 0.08 (0.06-0.09)  | <0.001  | 0.54 (0.52-0.55) | 0.04 (0.02-0.05) | <0.001  |
| >1yr to 5yr   | 0.56 (0.54-0.57) | 0.05 (0.04-0.06)  | <0.001  | 0.52 (0.51-0.53) | 0.02 (0.01-0.03) | 0.003   |
| >5yr to 10yr  | 0.56 (0.54-0.58) | 0.05 (0.03-0.07)  | <0.001  | 0.52 (0.51-0.54) | 0.02 (0.00-0.04) | 0.018   |
| >10y  | 0.56 (0.54-0.59) | 0.06 (0.03-0.08)  | <0.001  | 0.54 (0.52-0.57) | 0.04 (0.02-0.06) | 0.001   |
| on dialysis, never waitlisted or transplanted (ref) | 0.51 (0.50-0.51) | 0 (Ref)           |         | 0.50 (0.50-0.50) | 0 (Ref)          |         |
| intensive procedure in last 30 days of life         |                  |                   |         |                  |                  |         |
| <=1yr post-transplant failure                       | 0.36 (0.34-0.37) | 0.08 (0.06-0.09)  | <0.001  | 0.32 (0.30-0.33) | 0.02 (0.01-0.04) | 0.008   |
| >1yr to 5yr   | 0.36 (0.35-0.37) | 0.08 (0.07-0.09)  | <0.001  | 0.31 (0.30-0.32) | 0.01 (0.00-0.02) | 0.084   |
| >5yr to 10yr  | 0.37 (0.35-0.39) | 0.09 (0.07-0.11)  | <0.001  | 0.31 (0.29-0.33) | 0.01 (0.00-0.03) | 0.092   |
| >10y  | 0.37 (0.35-0.40) | 0.09 (0.07-0.12)  | <0.001  | 0.32 (0.29-0.34) | 0.02 (0.00-0.04) | 0.086   |
| on dialysis, never waitlisted or transplanted (ref) | 0.28 (0.28-0.28) | 0 (Ref)           |         | 0.30 (0.29-0.30) | 0 (Ref)          |         |
| died in a hospital                                  |                  |                   |         |                  |                  |         |
| <=1yr post-transplant failure                       | 0.47 (0.45-0.49) | 0.07 (0.06-0.09)  | <0.001  | 0.46 (0.44-0.47) | 0.02 (0.00-0.04) | 0.02    |

|   |                  |                       |        |                  |                    |        |
|---|------------------|-----------------------|--------|------------------|--------------------|--------|
| >1yr to 5yr   | 0.46 (0.45-0.47) | 0.06 (0.05-0.07)      | <0.001 | 0.45 (0.44-0.46) | 0.01 (0.00-0.03)   | 0.068  |
| >5yr to 10yr  | 0.48 (0.46-0.50) | 0.08 (0.06-0.10)      | <0.001 | 0.47 (0.45-0.49) | 0.03 (0.01-0.05)   | 0.001  |
| >10y  | 0.50 (0.48-0.53) | 0.11 (0.08-0.13)      | <0.001 | 0.50 (0.48-0.52) | 0.06 (0.04-0.09)   | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.40 (0.40-0.40) | 0 (Ref)               |        | 0.44 (0.43-0.44) | 0 (Ref)            |        |
| enrolled in hospice at the time of death            |                  |                       |        |                  |                    |        |
| <=1yr post-transplant failure                       | 0.20 (0.19-0.21) | -0.05 (-0.07-(-)0.04) | <0.001 | 0.21 (0.20-0.23) | 0.01 (-0.01-0.02)  | 0.243  |
| >1yr to 5yr   | 0.18 (0.17-0.19) | -0.07 (-0.08-(-)0.07) | <0.001 | 0.21 (0.20-0.22) | 0.00 (-0.01-0.01)  | 0.746  |
| >5yr to 10yr  | 0.15 (0.14-0.17) | -0.10 (-0.11-(-)0.09) | <0.001 | 0.19 (0.18-0.21) | -0.01 (-0.03-0.01) | 0.206  |
| >10y  | 0.17 (0.15-0.19) | -0.08 (-0.10-(-)0.06) | <0.001 | 0.23 (0.21-0.25) | 0.02 (0.00-0.04)   | 0.037  |
| on dialysis, never waitlisted or transplanted (ref) | 0.25 (0.25-0.25) | 0 (Ref)               |        | 0.21 (0.20-0.21) | 0 (Ref)            |        |
| stopped dialysis prior to death                     |                  |                       |        |                  |                    |        |
| <=1yr post-transplant failure                       | 0.24 (0.22-0.25) | -0.05 (-0.07-(-)0.04) | <0.001 | 0.26 (0.25-0.28) | 0.01 (0.00-0.03)   | 0.135  |
| >1yr to 5yr   | 0.22 (0.21-0.23) | -0.07 (-0.08-(-)0.06) | <0.001 | 0.27 (0.25-0.28) | 0.02 (0.00-0.03)   | 0.019  |
| >5yr to 10yr  | 0.19 (0.17-0.20) | -0.10 (-0.11-(-)0.08) | <0.001 | 0.24 (0.23-0.26) | -0.01 (-0.03-0.01) | 0.55   |
| >10y  | 0.19 (0.17-0.21) | -0.09 (-0.11-(-)0.08) | <0.001 | 0.26 (0.24-0.29) | 0.01 (-0.01-0.04)  | 0.292  |
| on dialysis, never waitlisted or transplanted (ref) | 0.29 (0.29-0.29) | 0 (Ref)               |        | 0.25 (0.25-0.25) | 0 (Ref)            |        |

Predicted probabilities and risk difference in the multivariable model are adjusted for sex, race, age, date of death, and all measured individual comorbidities.

Reference group comprised of participants without functioning transplant and not on the transplant waiting list at the time of death.

\*p-value for adjusted risk difference <0.001

\*\*Mechanical ventilation, cardiopulmonary resuscitation, and/or artificial nutrition

Abbreviations: aPP, adjusted predicted probability; aRD, adjusted risk difference; ICU, intensive or coronary care unit

**eTable5:** Measures of intensity of end-of-life care associated with exposure to the transplant process for patients who developed ESKD from 2005-2008

|  | Univariable      |                    |         | Multivariable    |                  |         |
|--|------------------|--------------------|---------|------------------|------------------|---------|
|  | aPP (95% CI)     | aRD                | p-value | aPP              | aRD              | p-value |
| hospital admission in last 30 days of life |                  |                    |         |                  |                  |         |
| transplanted                               | 0.72 (0.71-0.73) | -0.01 (-0.03-0.00) | 0.083   | 0.79 (0.78-0.81) | 0.06 (0.05-0.08) | <0.001  |
| failed transplant, not re-waitlisted       | 0.75 (0.72-0.78) | 0.02 (-0.01-0.05)  | 0.221   | 0.79 (0.76-0.81) | 0.06 (0.03-0.08) | <0.001  |
| removed from waitlist                      | 0.72 (0.71-0.73) | -0.01 (-0.03-0.00) | 0.093   | 0.74 (0.73-0.76) | 0.01 (0.00-0.03) | 0.037   |



|   |                  |                       |        |                  |                       |        |
|---|------------------|-----------------------|--------|------------------|-----------------------|--------|
| inactive on waitlist                                | 0.75 (0.73-0.76) | 0.01 (0.00-0.02)      | 0.05   | 0.77 (0.76-0.78) | 0.04 (0.03-0.05)      | <0.001 |
| active on waitlist                                  | 0.67 (0.65-0.69) | -0.06 (-0.08-(-)0.05) | <0.001 | 0.72 (0.71-0.74) | 0.00 (-0.02-0.01)     | 0.568  |
| on dialysis, never waitlisted or transplanted (ref) | 0.73 (0.73-0.74) |                       |        | 0.73 (0.73-0.73) |                       |        |
| ICU admission in the last 30 days of life           |                  |                       |        |                  |                       |        |
| transplanted  | 0.53 (0.52-0.55) | 0.03 (0.01-0.05)      | <0.001 | 0.57 (0.56-0.59) | 0.07 (0.06-0.09)      | <0.001 |
| failed transplant, not re-waitlisted                | 0.55 (0.51-0.58) | 0.05 (0.01-0.08)      | 0.005  | 0.53 (0.50-0.56) | 0.03 (-0.01-0.06)     | 0.102  |
| removed from waitlist                               | 0.54 (0.53-0.56) | 0.04 (0.03-0.06)      | <0.001 | 0.52 (0.50-0.53) | 0.02 (0.00-0.03)      | 0.016  |
| inactive on waitlist                                | 0.58 (0.57-0.60) | 0.08 (0.07-0.10)      | <0.001 | 0.56 (0.55-0.57) | 0.06 (0.04-0.07)      | <0.001 |
| active on waitlist                                  | 0.54 (0.52-0.56) | 0.04 (0.02-0.06)      | <0.001 | 0.54 (0.52-0.56) | 0.04 (0.02-0.06)      | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.50 (0.50-0.50) |                       |        | 0.50 (0.50-0.50) |                       |        |
| intensive procedure in last 30 days of life         |                  |                       |        |                  |                       |        |
| transplanted  | 0.36 (0.35-0.38) | 0.09 (0.07-0.11)      | <0.001 | 0.37 (0.35-0.38) | 0.09 (0.07-0.10)      | <0.001 |
| failed transplant, not re-waitlisted                | 0.35 (0.32-0.38) | 0.07 (0.04-0.10)      | <0.001 | 0.29 (0.26-0.31) | 0.01 (-0.02-0.04)     | 0.559  |
| removed from waitlist                               | 0.34 (0.33-0.35) | 0.07 (0.05-0.08)      | <0.001 | 0.29 (0.28-0.31) | 0.02 (0.00-0.03)      | 0.02   |
| inactive on waitlist                                | 0.41 (0.39-0.42) | 0.13 (0.12-0.15)      | <0.001 | 0.33 (0.32-0.35) | 0.06 (0.04-0.07)      | <0.001 |
| active on waitlist                                  | 0.41 (0.39-0.42) | 0.13 (0.11-0.15)      | <0.001 | 0.34 (0.33-0.36) | 0.06 (0.05-0.08)      | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.27 (0.27-0.28) |                       |        | 0.28 (0.28-0.28) |                       |        |
| died in a hospital                                  |                  |                       |        |                  |                       |        |
| transplanted  | 0.46 (0.45-0.48) | 0.07 (0.05-0.08)      | <0.001 | 0.50 (0.49-0.52) | 0.11 (0.09-0.12)      | <0.001 |
| failed transplant, not re-waitlisted                | 0.43 (0.40-0.47) | 0.04 (0.01-0.07)      | 0.018  | 0.43 (0.40-0.46) | 0.03 (0.00-0.07)      | 0.033  |
| removed from waitlist                               | 0.42 (0.41-0.44) | 0.03 (0.01-0.04)      | <0.001 | 0.42 (0.40-0.43) | 0.02 (0.01-0.04)      | 0.003  |
| inactive on waitlist                                | 0.47 (0.46-0.49) | 0.08 (0.06-0.09)      | <0.001 | 0.45 (0.44-0.47) | 0.06 (0.05-0.07)      | <0.001 |
| active on waitlist                                  | 0.45 (0.44-0.47) | 0.06 (0.04-0.07)      | <0.001 | 0.44 (0.43-0.46) | 0.05 (0.03-0.06)      | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.40 (0.39-0.40) |                       |        | 0.40 (0.39-0.40) |                       |        |
| enrolled in hospice at the time of death            |                  |                       |        |                  |                       |        |
| transplanted  | 0.25 (0.23-0.26) | -0.01 (-0.02-0.00)    | 0.19   | 0.25 (0.23-0.26) | 0.00 (-0.02-0.01)     | 0.74   |
| failed transplant, not re-waitlisted                | 0.21 (0.18-0.24) | -0.05 (-0.07-(-)0.02) | 0.001  | 0.25 (0.22-0.28) | 0.00 (-0.03-0.03)     | 0.904  |
| removed from waitlist                               | 0.24 (0.22-0.25) | -0.02 (-0.03-(-)0.01) | 0.005  | 0.26 (0.25-0.27) | 0.01 (-0.01-0.02)     | 0.287  |
| inactive on waitlist                                | 0.14 (0.13-0.15) | -0.12 (-0.13-(-)0.11) | <0.001 | 0.19 (0.18-0.20) | -0.06 (-0.08-(-)0.05) | <0.001 |
| active on waitlist                                  | 0.08 (0.07-0.09) | -0.18 (-0.19-(-)0.17) | <0.001 | 0.12 (0.11-0.14) | -0.13 (-0.14-(-)0.11) | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.26 (0.25-0.26) |                       |        | 0.25 (0.25-0.25) |                       |        |
| stopped dialysis prior to death                     |                  |                       |        |                  |                       |        |
| failed transplant, not re-waitlisted                | 0.23 (0.20-0.26) | -0.06 (-0.09-(-)0.04) | <0.001 | 0.30 (0.27-0.33) | 0.01 (-0.02-0.04)     | 0.579  |

|   |                  |                       |        |                  |                       |        |
|---|------------------|-----------------------|--------|------------------|-----------------------|--------|
| removed from waitlist                               | 0.26 (0.24-0.27) | -0.04 (-0.05-(-)0.02) | <0.001 | 0.31 (0.29-0.32) | 0.02 (0.00-0.03)      | 0.029  |
| inactive on waitlist                                | 0.17 (0.16-0.19) | -0.12 (-0.13-(-)0.11) | <0.001 | 0.25 (0.24-0.26) | -0.04 (-0.05-(-)0.03) | <0.001 |
| active on waitlist                                  | 0.12 (0.11-0.13) | -0.18 (-0.19-(-)0.17) | <0.001 | 0.19 (0.17-0.20) | -0.10 (-0.12-(-)0.09) | <0.001 |
| on dialysis, never waitlisted or transplanted (ref) | 0.30 (0.29-0.30) |                       |        | 0.29 (0.29-0.29) |                       |        |

Predicted probabilities and risk difference in the multivariable model are adjusted for sex, race, age, date of death, and all measured individual comorbidities. Reference group comprised of participants without functioning transplant and not on the transplant waiting list at the time of death.

\*p-value for adjusted risk difference <0.001

\*\*Mechanical ventilation, cardiopulmonary resuscitation, and/or artificial nutrition

Abbreviations: aPP, adjusted predicted probability; aRD, adjusted risk difference; ICU, intensive or coronary care unit