Implications for Changes in US Federal Death Record Databases for Estimation of Mortality After Delisting

Abstract #45

Maria Masotti[1], Daniel Y. Johnson[2], Jessica R. Golbus[3], Ryutaro Hirose[1,4], William F. Parker[2], Jon J. Snyder[1,5,6], Grace R. Lyden[1,5]

[1]Scientific Registry of Transplant Recipients, Minneapolis, MN, USA; [2]Dept. of Medicine, University of Chicago, USA; [3]Division of Cardiovascular Medicine, University of Michigan, Ann Arbor, USA; [4]Transplant Institute, School of Medicine, University of Washington, Seattle, USA; [5]Dept. of Medicine, University of MN, Minneapolis, USA; [6]Division of Epidemiology and Community Health, School of Public Health, University of MN, Minneapolis, USA

Introduction

- Per Organ Procurement and Transplantation Network (OPTN) policy, deaths after delisting are included in monitoring of program-specific pretransplant mortality.
- The OPTN supplements death records reported by transplant programs with additional death records from the Social Security Administration (SSA).
- In 2011, the SSA restricted access to its publicly available death master file (DMF).
- In response, the OPTN gained access to the SSA's full DMF but had to start independently verifying these records using external sources (Figure 1).
- Our aim was to determine the association of changes to SSA's DMF with survival among candidates removed from the waiting list focusing on removals for deteriorated condition.

Methods

- All adult (18+) first-time heart, kidney, liver, or lung single-organ candidates removed from waiting list for deteriorated condition Jan. 1, 2003–Dec. 31, 2024.
- Death sources categorized as Limited Access DMF (LADMF) deaths; LADMF + OPTN-verified deaths; and the SRTR internal database (includes LADMF deaths, OPTN-verified deaths, unverified deaths, and CMS deaths that SRTR cannot release to external researchers).
- Candidates followed from removal date until earliest recorded death date or Dec. 31, 2024. Those with no death date were assumed to be alive Dec. 31, 2024.
- Kaplan-Meier method to generate survival probabilities.
- Cox proportional hazards models to estimate association of date of removal with hazard of death (95% confidence intervals) within 1 year of removal, adjusted for candidate characteristics.

Results

- 1-year survival estimates using SRTR internal data increased from 38% to 62%, 23% to 54%, and 32% to 45% between 2015 and 2023 for heart, liver, and lung candidates removed for deteriorated condition, respectively (Figure 2).
- Relative to Jan. 1, 2010, hazard of death on Jan. 1, 2024, was 0.33 (0.28-0.39) for heart, 0.39 (0.36-0.41) for liver, and 0.44 (0.36-0.52) for lung (Figure 3).

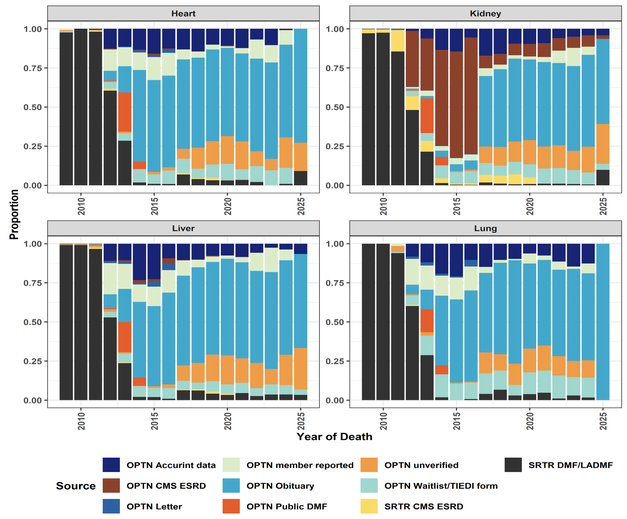

Figure 1: Proportion of deaths after removal for deteriorated condition by source in death verification process by year of removal and organ.

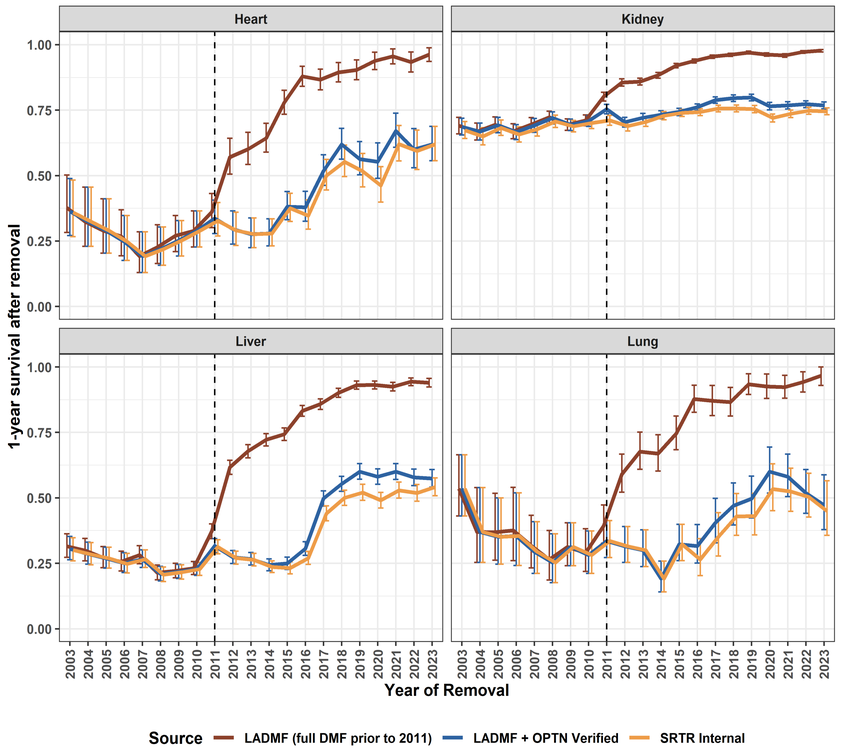

Figure 2: Observed (unadjusted) 1-year survival probabilities for candidates removed for deteriorated condition by removal year, organ, and data source (color). Dotted black line marks the restriction to the full DMF. Error bars show 95% confidence intervals.

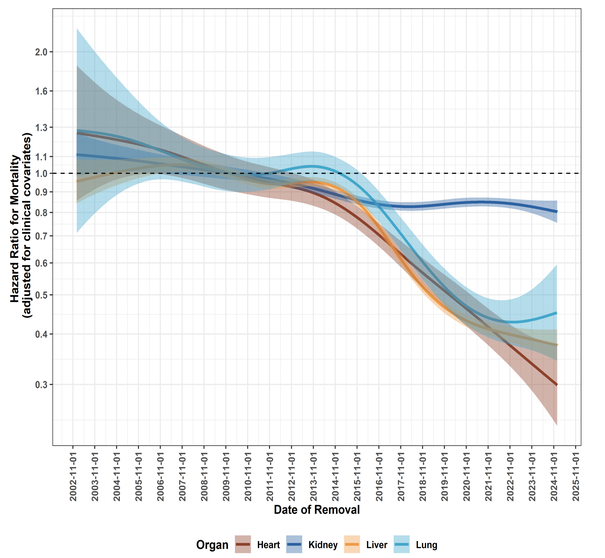

Figure 3: Adjusted hazard ratio of death within 1 year of removal for deterioration using all SRTR internal data by removal date and organ. Reference date is Jan. 1, 2010.

Conclusions

An implausible increase in survival estimates of candidates removed from the waiting list for deteriorated condition suggests a decline in accuracy of SSA's death records. This may have major implications for researchers and policymakers evaluating not only the organ transplant system, but also other programs that rely on these data.

This work was supported wholly or in part by HRSA contract 75R60220C00011. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of HHS, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.