

SDC, Materials and Methods

Additional Variable Information

Demographics

- Race: During the first interview, respondents could select as many of the following race categories as appropriate: “American Indian or Alaska Native”, “Asian”, “Black or African American”, “Native Hawaiian or Other Pacific Islander”, “White”, or “Other”. If the “Other” category was specified, respondents had the opportunity to provide a verbatim response that was used to re-categorize any “Other” responses into a known category, if possible. For the purposes of this article, “Non-Hispanic African American” refers to respondents who self-identified with only one race group (“Black or African American”) and were also non-Hispanic. “Non-Hispanic white” refers to respondents who self-identified with only one race group (“white”) and were also non-Hispanic. “Other Minorities” refers to respondents who were Hispanic (regardless of race), as well as other non-Hispanic respondents who could not be directly classified as either “Non-Hispanic African American” or “Non-Hispanic white”.
- Age: This variable was defined as the difference (in years) between the completion date of the first interview and the date of birth.
- Insurance: During the first interview, respondents could select as many of the following current healthcare coverage categories as appropriate: “VA”, “Medicare”, “Medicaid”, “Private Health Insurance”, “Self-pay”, “None”, and “Other”. If the “Other” category was specified, respondents had the opportunity to provide a verbatim response that was used to re-categorize any “Other” responses into a known category, if possible. For purposes of this article, “Public” coverage included any mention of “VA”, “Medicare”, or “Medicaid” without any mention of “Private Health Insurance”. “Private Only” coverage included the reporting of “Private Health Insurance” without the mention of any public coverage (“VA”, “Medicare”, “Medicaid”). “Private and Public” coverage included the mention of “Private Health Insurance” along with at least one mention of “VA”, “Medicare”, or “Medicaid”.

- Occupational Status: During the first interview, respondents were asked if they currently had paid employment. If the answer was “yes”, the respondent was asked to provide a verbatim response describing the kind of the work they currently perform. If the answer was “no”, the respondent was asked to provide a verbatim response describing the kind of work they performed when they last worked. These verbatim responses were used to classify the occupation verbatim responses into a categorization based on the Hollingshead Occupational Scale.(1)

Medical Information

- Charlson Comorbidity Index: For all study participants, VA inpatient and outpatient medical utilization records were examined for the purposes of calculating the Charlson Comorbidity Index.(2) Any applicable ICD-9-CM code occurring no more than 12 months prior to presentation for evaluation at the VA kidney transplant center was utilized.
- Living Donors: The network of potential living donors available for evaluation was determined by asking participants to indicate how many living relatives and friends they had aged 18-70 years, the age range of living kidney donors.(23) Actual living donors were individuals who were undergoing, had already undergone, or were planning to undergo evaluation for living donation to a specific patient. For our analyses, we summed across these three groups for an overall number of living donors.

Culturally-Related Factors

- Perceived Discrimination: Assessed with an adapted version of the perceived discrimination in health care measure.(3-5) For this 7-item measure, participants indicate the extent to which they have experienced a set of discriminatory practices (e.g., “When getting healthcare, I was treated with less respect than other people because of my race or color.”), with a range of 1 (never) to 5 (always). We summed across these items for an overall experience of discrimination score.

- Perceived Racism: Assessed with four items based on the work of LaViest et al.(6, 7) These items assess the extent to which patients believe that racism is common in healthcare, as opposed to having personal experience with racism in healthcare (e.g., “Doctors treat African American and white people the same.”). Item responses range from 1 (strongly disagree) to 5 (strongly agree). An overall mean score was calculated for this variable.
- Medical Mistrust: Assessed with 18 items adapted from LaVeist’s medical mistrust index.(6-8) This index assesses the degree to which participants believe their hospital to be trustworthy, competent, and acting in their best interests (e.g., “I trust hospitals.”; 1 = strongly disagree to 5 = strongly agree). An overall mean score was calculated for this variable.
- Trust in Physicians: Assessed using the 11 item Trust in Physician Scale.(9) It assesses the degree of patient trust in their physician (e.g., “I doubt that my doctor really cares about me as a person”; 1 (totally disagree) to 5 (totally agree)). An overall mean score was calculated for this variable.
- Family Influence: Assessed with the 16-item Bardis Familism scale.(10) The scale has been widely used in diverse cultural groups to assess feelings of loyalty and mutual support regarding the family (e.g., “The family should consult close relatives (uncles, aunts, first cousins) concerning its important decisions”; 1 (strongly disagree) to 5 (strongly agree)). An overall mean score was calculated for this variable.
- Religious Preference: This set of items assessed religious affiliation and level of importance/influence of religious beliefs (e.g., “Regardless of whether you attend religious services, please indicate on a scale from 1 (not at all) to 9 (extremely) how important your religious beliefs are to you.”). An overall mean score was calculated for this variable.
- Religious Objections to LDKT: Assessed with a revised subscale of the Organ Donation Attitude Survey.(11) The ODAS was created by experts in the psychological evaluation of religious beliefs as a measure of individuals’ attitudes towards organ donation. We revised this 8-item scale to assess religious beliefs as they relate to living donor kidney transplantation (e.g., “I believe that living

donor kidney transplantation is against my religion”; 1 (strongly disagree) to 5 (strongly agree)). An overall mean score was calculated for this variable.

Psychosocial Characteristics

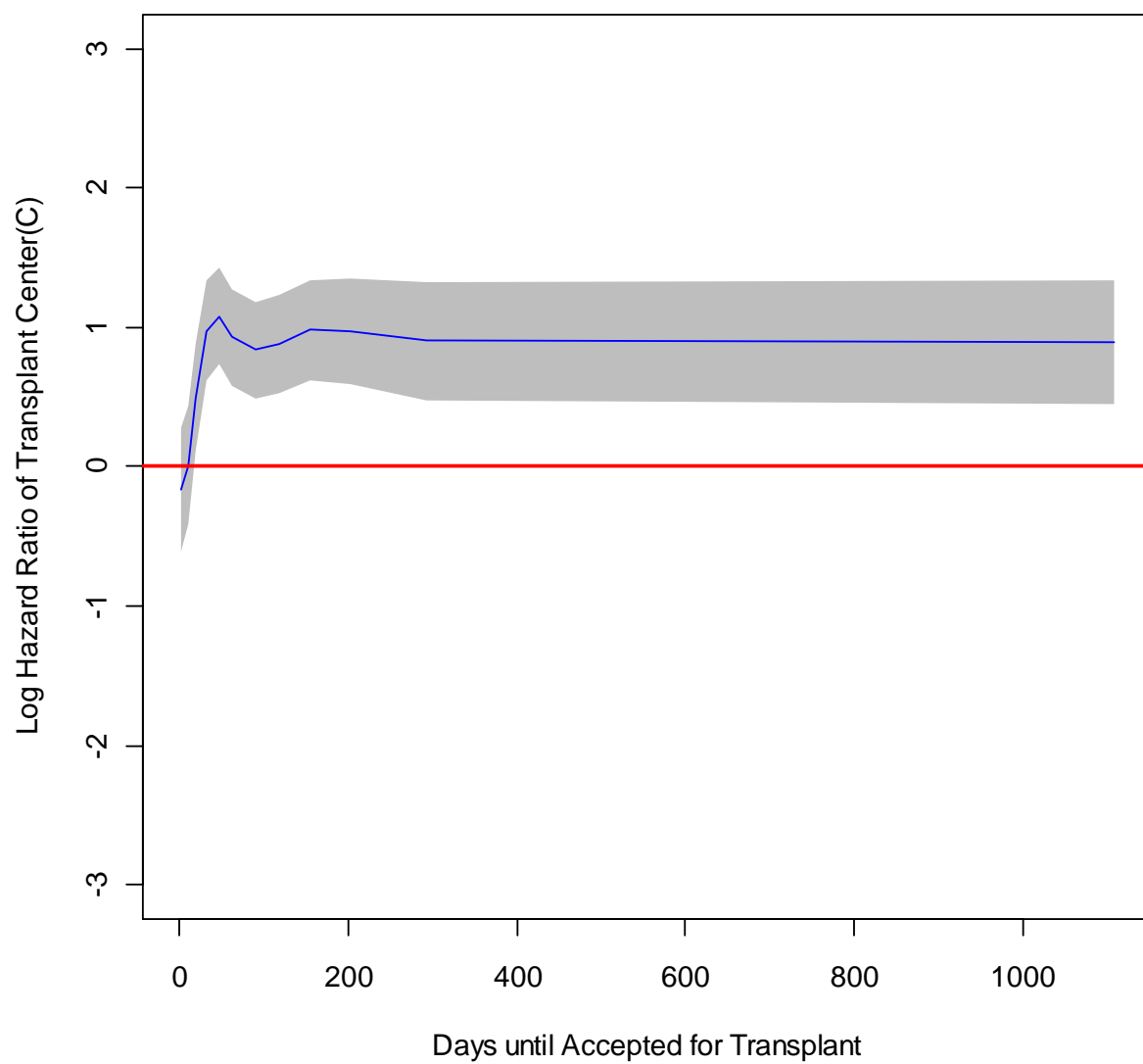
- **Emotional Distress**: Measured with the anxiety and depression subscales of the Brief Symptom Inventory (BSI).(12) Each subscale comprises 6 items related to either anxiety or depression (e.g., “Please indicate how bothered or distressed you have been by that feeling during the past two weeks: nervousness or shakiness inside”; 1 (not at all) to 5 (extremely)). An overall mean score was calculated for this variable.
- **Social Support**: Measured with a 12-item version of the Interpersonal Support Evaluation List (ISEL-12). The ISEL assesses patients’ perceived availability of 3 separate functions of social support. The "tangible" subscale is intended to measure perceived availability of material aid; the "appraisal" subscale, the perceived availability of someone to talk to about one's problems; and the "belonging" subscale, the perceived availability of people with whom one can do things (e.g., “I feel that there is no one I can share my most private worries and fears with;” 1(definitely false) to 4 (definitely true)). An overall mean score was calculated for this variable.
- **Self-esteem**: Measured using the Rosenberg Self-Esteem Scale.(13) The self-esteem scale assesses patients’ feelings of self-worth and self-respect (e.g., “I feel that I am a person of worth, at least on an equal plane with others”). Individual responses range from 1(strongly agree) to 4 (strongly disagree). An overall mean score was calculated for this variable.
- **Sense of Mastery**: Assessed using the Sense of Mastery Scale(14). The Sense of Mastery Scale assesses the degree to which participants feel they have personal control over the things that happen to them (e.g, “I have little control over the things that happen to me.”) Individual responses range from 1(strongly agree) to 4 (strongly disagree). An overall mean score was calculated for this variable.

- Locus of Control: Assessed with the 18-item Multidimensional Health Locus of Control (MHLC) scales, Form C.(15) The scale includes separate subscales to assess the extent to which recipients view their health condition is due to: (1) their own behavior; (2) the behavior of doctors; (3) the behavior of other people, not including doctors; and, (4) chance, luck, or fate (e.g., If my health related to my spinal cord injury worsens, it is my own behavior that determines how soon I feel better again). Responses to items range from 1 (strongly disagree) to 6 (strongly agree). An overall mean score was calculated for this variable.

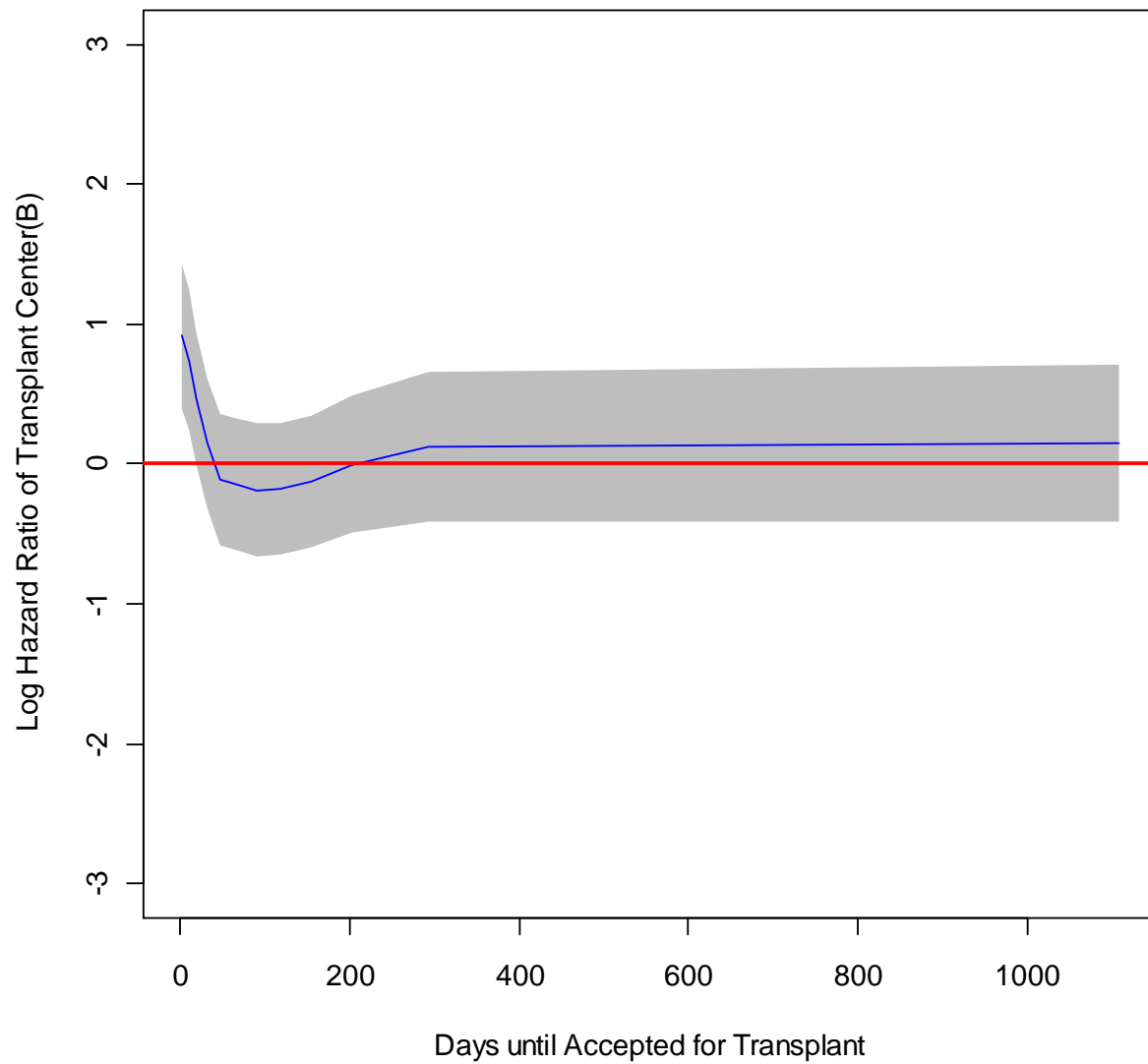
Transplant Knowledge, Concerns, and Preference

- Transplant Knowledge: Assessed with items adapted from the KT Knowledge Survey(16) and the KT Questionnaire.(17, 18) This measure includes 27 multiple choice and true-false items. A summative score is created for the total number of items that patients answered correctly.
- Transplant Learning Activities: The type, number, and time spent in each educational activity were assessed by self-report. Patients were asked to indicate whether they had engaged in any of a list of activities to learn or think about transplantation (e.g., “Read brochures about kidney transplant from living donors”). Then, patients were asked to indicate how much time was spent on each of the activities that they checked. A summative score was calculated for the total number of items checked and total time spent on all learning activities.
- Transplant Concerns: Assessed using 30 items adapted from the KT Questionnaire.(17, 18) This measure asks patients to indicate whether any of a list of concerns affected their decisions about getting a transplant, including concerns about transplant for themselves and concerns about the potential donors future health status. The items can be summed to indicate overall level of concern about transplantation, or examined individually in order to determine particular concern items that vary by race.
- Transplant Preference: Assessed via self-report by asking participants whether they preferred a living or deceased donor kidney transplant, and if they had someone being worked up as a potential LD.(19)

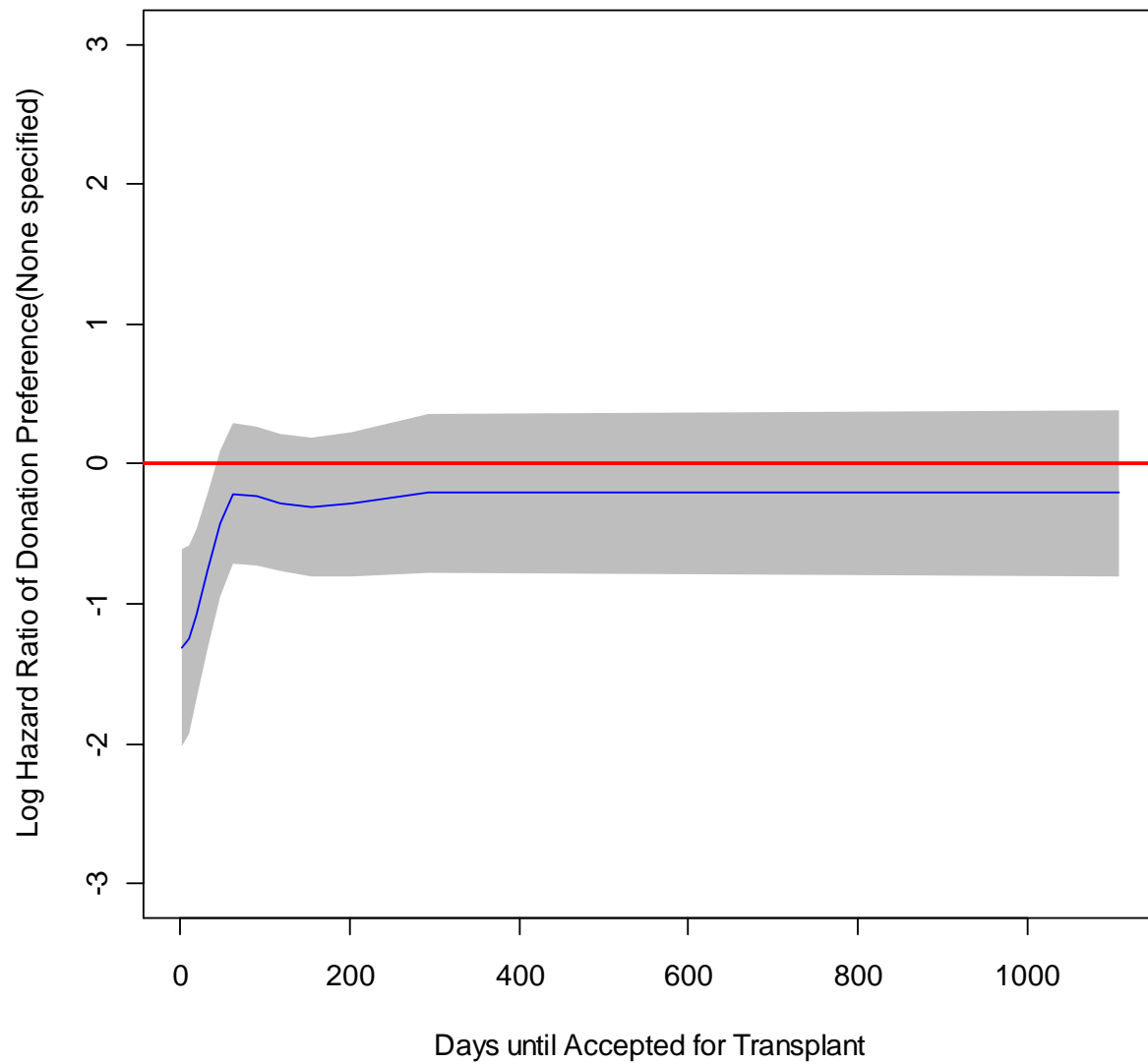
SDC, Figure 1. Log Hazard Ratio for Transplant Center (C) with 95% Confidence Bands



SDC, Figure 2. Log Hazard Ratio for Transplant Center (B) with 95% Confidence Bands



SDC, Figure 3. Log Hazard Ratio for Donation Preference (None Specified) with 95% Confidence Bands



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