# **Approval Sheet**

Effect of Neighborhood-Level English Proficiency on Initial Kidney Transplant Registration and Interaction by Rural / Urban Residence

By

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Epidemiology

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#### Abstract

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#### By Amandha Darius

Despite kidney transplantation being the preferred method of renal replacement therapy for end-stage renal disease patients, patients of minority background continue to experience disparities in waitlist registration. It is known that language barriers impede access to healthcare, but these barriers have not been extensively addressed at the neighborhood level, nor have the differential effects of rural vs urban status on these barriers. We assess the association between neighborhood-level English proficiency and likelihood of patients to register on the kidney transplant waitlist, and we examine potential effect modification by rural vs urban status. In this retrospective cohort study, we use data from the most recent American Community Survey to determine ZIP-code level English proficiency. A Cox procedure stratified by rural vs. non-rural status was used to measure time to waitlisting among adult ESRD patients in the United States Renal Data System (USRDS) from 2013 to 2017, controlling neighborhood socioeconomic status, and for individual factors such as race, Hispanic ethnicity, age, sex, and BMI. Among non-rural patients, patients in the second quintile of LEP (0.6 - 1.6%) were 9% more likely to be waitlisted than those in the lowest quintile of LEP (0 - 0.5%) (HR = 1.09, 95% CI 1.01 - 1.18). This association was not present among other quintiles of LEP considered to be non-rural, and was not present for rural patients at all. These results suggest that neighborhood English proficiency alone does not explain disparities in waitlisting, but rather that neighborhood socioeconomic status and individual demographic factors may explain this relationship.

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#### Introduction

Over 14% of the U.S. population lives with chronic kidney disease. The most severe form of this disease, end-stage renal disease (ESRD), affects over 726,000 people in the U.S., with over 124,000 new ESRD cases being reported in 2016 alone (1). Without the proper treatments, individuals with chronic kidney disease, especially those with end-stage renal disease, are at great risk of complications including cardiovascular disease, hypertension, anemia, and bone disorders (2). Racial and ethnic minorities, who already experience higher rates of risk factors associated with end-stage renal disease(3, 4), have tended to also experience higher incidence rates of ESRD than their white counterparts (5), While these disparities have improved over time, black and African-American patients still experience ESRD incidence at three times the rate of their white counterparts. American Indians / Alaska Natives experience incidence rates 20% higher than whites, and Hispanics experience incidence rates 30% higher than non-Hispanics (5).

Kidney transplantation remains the preferred treatment for ESRD (6, 7). It has been shown to increase longevity and quality of life, as well as being more cost-effective (7, 8). Despite the benefits of kidney transplantation over other renal replacement therapies such as hemodialysis and peritoneal dialysis, only one-third of ESRD patients received kidney transplants as of 2013 (1).

There are several steps that a patient must undergo in order to receive a kidney transplant. Patients are first educated about transplantation as an option for ESRD treatment, before being referred for evaluation at a transplant center to determine their fit for candidacy. After this evaluation, if a patient is found to be a good candidate for transplantation, then this patient will be added to the transplant waitlist (9-12).

However, barriers to transplantation exist at multiple steps in the above process. In addition to the organ shortage faced by ESRD patients across the U.S. (8), previous research has identified minority race and ethnicity as a risk factor for lower likelihood for waitlisting (13, 14). Neighborhood poverty has been shown to exacerbate racial / ethnic disparities in waitlisting and transplantation between Black and White patients (14). In addition, the effect of rural residence on likelihood of poor healthcare access (15-17), is differential along racial and ethnic lines, as Black and Indigenous patients are more likely to suffer worse outcomes than their white counterparts in rural counties (18). Health literacy is also lower in rural populations than it is in urban populations (19), and low health literacy is more likely to be experienced by minority patients, especially those for whom language is a significant barrier (20-25).

Despite these findings, few studies have considered the effects of neighborhoodlevel language barriers as a social determinant of health and healthcare access. Interestingly, a high percentage of limited English proficiency was found to be associated with lower odds of late-stage colorectal cancer diagnosis among Hispanics, although this association did not exist among other races or ethnicities (26). Even so, another study found that lower ZIPcode level English proficiency was associated with higher odds of inactive status on the kidney transplant waitlist (27).

While this study is informative of the relationship between neighborhood limited English proficiency (LEP) and waitlist status, there are several limitations to its approach. First, the above study uses U.S. Census data, which is collected decennially rather than annually. Neighborhood composition is dynamic and can change rapidly in the ten years between censuses, and therefore using annually-collected representative samples such as the American Community Survey would reflect this more accurately. Second, while this study compares outcome risk, it does not take time-to-event into account, as it would with a survival analysis. Third, as previously explained, this study fails to consider the differential effects that rural and non-rural status may have on neighborhood LEP and waitlist time. Finally, while it is important to consider waitlist status, as patients are unable to receive transplant offers while inactive, this would be irrelevant without initial waitlist registration.

Therefore, our study aims to (1) determine whether an association between neighborhood limited English proficiency and time to initial registration on the kidney transplant waitlist, and (2) to assess whether rural residence modifies the effect between neighborhood LEP and initial kidney transplant waitlist registration. Addressing these risk factors together will hopefully more completely inform potential methods of intervention at each of the steps between ESRD diagnosis and waitlisting.

#### Methods

### United States Renal Data System

The United States Renal Data System (USRDS) is a national database that collects demographic and medical information about all individuals treated for chronic kidney disease (CKD) or end-stage renal disease (ESRD) in the U.S., with information obtained from the Centers for Medicare and Medicaid Form 2728 (CMS 2728). Our study population includes ESRD patients between the ages of 18 and 99 years old, and whose first date of ESRD service was between January 1, 2013 and December 31, 2017. Patients who were missing ZIP code information (n = 5,449), or information on sex, age, race (n = 1,620), or Hispanic ethnicity (n = 4,203), or state of residence were excluded. In addition, patients whose ZIP codes and states of residence were listed as U.S. territories or P.O. boxes were also excluded (n = 8,746). Due to the very large sample size and limited computational power to run analyses, a random sample of 10% was used for analytical purposes. Our final sample size was N = 59,188 (Figure 1).

Patient demographics, such as race, ethnicity, sex, and residential information such as state and ZIP code of residence, as well as medical information such as date of first ESRD service (dialysis or transplant), date of waitlisting (for transplant), date of death, primary cause of ESRD, whether or not the patient received nephrology care prior to ESRD diagnosis, and whether or not the patient was informed of kidney transplantation as a treatment option, were all obtained from CMS Form 2728. This information is collected by law for each new ESRD patient at the time that ESRD treatment (e.g., dialysis or transplant) begins.

The American Community Survey is an annual survey conducted by the U.S. Census Bureau that collects demographic and residential information from a representative sample of U.S. residents at the ZIP code level. ZCTAs, or ZIP-Code Tabulation Areas, are estimations of postal ZIP codes used for census purposes.(28) However, unlike ZIP codes, ZCTAs are bound by state and county lines, and do not include P.O. boxes. For the purposes of this study, we have obtained data from the 2017 ACS 5-year estimates, which average data estimates between 2013 and 2017, at the level of 5-digit ZIP Code Tabulation Area (ZCTA).

The definition of a Limited English Proficiency (LEP) household according to the U.S. Census Bureau is a household in which "no one over the age of 14 speaks English alone or very well." (29, 30) Neighborhood-level LEP is defined as the percentage of households in each ZCTA that are considered to be LEP households according to the census definition. The total number of surveyed households in each ZCTA, as well as the number of households defined as Limited English households and the percentage of households that were Limited English, were provided by the 2017 ACS 5-year estimates. Our study population was divided into quintiles with the following categories of neighborhood-level LEP: less than 0.5%; 0.6 - 1.6%; 1.7 - 3.5%; 3.6 - 8.9%; 9.0% or more. In addition to Limited English Proficiency, median household income and educational attainment were additional indicators of socioeconomic status obtained from the 2017 ACS 5-year estimates. Educational attainment levels included in the dataset were as follows: No school; Nursery; Kindergarten; 1st - 12th (individually); Graduated high school; GED or equivalent; Less than a year of college; More than a year of college, no degree; Associates degree; Bachelor's degree; Masters; Other professional degree; Doctorate degree. For the purpose of this study, these levels were condensed into the following categories: Less than high school; High school / GED; College Degree (Associate's or Bachelor's); Graduate Degree (Master's or other professional degree).

#### Neighborhood Level Covariates

Rural status was defined by the Federal Office of Rural Health Policy (FORHP). Using ZIP codes, the federal office of rural health policy defined, defines Rural ZIP Codes as "any ZIP code where more than 50% of its population resides in either a non-metro county and/or a rural Census Tract," with a metro county being defined as "a core urban area of 50,000 residents or more." Any county that is not considered a metro county is considered to be a rural county.(31) This dataset was merged with ACS 2017 5-year estimates by ZIP code, and an indicator variable was created whereby ZIP codes in the FORHP dataset were considered rural, and ZIP codes not included in the FORHP were considered non-rural.

Neighborhood socioeconomic status was a variable created as a combination of both highest mean level of education and median household income. Neighborhoods where the highest level of education was high school or less, and median household income was less than the overall median, were considered "low SES." Neighborhoods where the highest level of education was college or more, and neighborhood median household income was above the overall median, were considered "high SES." Neighborhoods where highest level of education was high school or less and median income was above the overall median, and vice-versa, were all considered to be "middle SES."

#### Statistical Analyses

Summary and descriptive statistics were used to examine differences in individualand neighborhood-level demographic and clinical characteristics of the study population across strata of neighborhood LEP, and again by waitlisting status. We followed patients from ESRD diagnosis date until December 31st, 2017, waitlisting date, date of death, or date of transplant, whichever occurred first. Patients who were transplanted without having a date of waitlisting were considered pre-emptively transplanted and were censored at transplantation date. As these patients would have contributed 0 person-years of follow-up, and thus been excluded for models, we recoded their follow-up time as 0.001 person-years. We generated a Kaplan-Meier survival curve and conducted a Log-Rank Test with 95% confidence to examine the crude relationship between neighborhood LEP and likelihood of waitlist registration.

Cox proportional hazards regression was used to assess the effects of neighborhood LEP on waitlisting in unadjusted and adjusted models. An unadjusted model included only the effect of neighborhood LEP on waitlisting (Model 1). To assess the interaction of rural residence with neighborhood LEP, we first stratified our exposure and outcome on rural residence. We then assessed whether a difference in hazards existed between rural and nonrural residence with a Cox proportional hazards model. A Wald chi-squared test was used to determine the statistical significance of interaction by rural residence with neighborhood LEP in a fully adjusted model.

A second model was adjusted for rural residence status alone (Model 2). A third model was adjusted for neighborhood socioeconomic status alone (Model 3). A fourth model was adjusted for both rural residence and neighborhood socioeconomic status (Model 4). A fifth model was adjusted for rural residence, neighborhood SES, and Hispanic ethnicity (Model 5). A sixth model was additionally adjusted for patient race (Model 6). A seventh model was additionally adjusted for other individual level characteristics at baseline such as age, BMI category according to CDC obesity guidelines (32), and sex as reported on CMS Form 2728 (Model 7). Models were informed by DAGitty, an online program for creating causal diagrams, was used to generate a directed acyclical graph (Figure 2).

#### Results

We included a random 10% sample of ESRD patients that met our inclusion criteria (total study sample N=59,188). Of these patients, 10,360 (17.5%) were waitlisted, and 23,320 (39.4%) died before the end of follow-up. The mean age of the overall study population was 63 years (SD 14.6 years), and was a majority male (58.0%), white (67.1%), non-Hispanic (86.3%), and non-rural (81.5%). Diabetes was the leading primary cause of ESRD for this population (46.4%), followed by hypertension (29.3%). The mean BMI of the study population was 29.7 (SD 8.0). Most had been informed of kidney transplantation as a treatment option (82.7%), had received nephrology care (62.3%), and were insured through Medicare or Medicare Advantage (62.1%). The majority of patients lived in neighborhoods that were low (48.3%) or middle (34.8%) socioeconomic status (Table 1). Percentage Asian patients, percentage of Hispanic patients, percentage of uninsured patients, and percentage of patients in non-Rural areas increased with neighborhood LEP. Percentage of non-Hispanic patients, mean BMI of patients, and percentage of patients in the care of a nephrologist prior to ESRD diagnosis (Table 1.)

Patients who were waitlisted were more likely to be male (62.5%), have glomerulonephritis as a primary cause of ESRD (16.5%), have been in the care of a nephrologist (74.9%), have employer-based health insurance (34.7%), and live in a neighborhood of higher socioeconomic status than those who were not waitlisted (Table 2). Patients who were not waitlisted were more likely to have died (37.7%), were older at baseline (65.3 years), more likely to be female (43.0%), black (27.0%), non-Hispanic (86.9%), have diabetes (48.2%) or hypertension (30.3%) as a primary cause of ESRD, and were more likely to have not been informed of kidney transplantation as a treatment option (15.3%) (Table 2).

Nearly half of patients who resided in rural areas were in the first quintile of neighborhood LEP (Quintile 1: 48.5%) (Table3). After conducting joint Wald Chi-Squared tests, rural residence was found to interact with neighborhood LEP in both unadjusted (p =(0.02) and adjusted (p = (0.02) models. In an unadjusted Cox model, among patients who lived in rural ZIP codes, patients living in the highest quintile of neighborhood LEP (vs. the lowest quintile) were 25% more likely to be waitlisted during follow-up (HR = 1.25; 95% CI: 1.01 - 1.54). Among residents of non-rural areas, waitlisting was 8 - 10% more likely to occur for patients residing in higher quintiles of neighborhood LEP (vs. the lowest quintile) (HR = 1.08, 95% CI 1.00 - 1.16 in Quintile 5; HR = 1.10, 95% CI 1.02 - 1.18 in Quintile 4;HR = 1.12, 95% CI 1.04 – 1.21 in Quintile 3; HR = 1.13, 95% CI 1.04 – 1.22 in Quintile 2). However, after adjusting for neighborhood socioeconomic status, race, Hispanic ethnicity, age, and BMI, the association between neighborhood LEP and time to waitlisting was no longer present among rural residents (HR = 0.92, 95% CI 0.80 - 1.05 in Quintile 2; HR = 1.01, 95% CI 0.95 - 1.28 in Quintile 3; HR = 1.02, 95% CI 0.86 - 1.21 in Quintile 4, HR = 1.16, 95% CI 0.94 – 1.07 in Quintile 5). After adjusting for the same covariates, among patients who live in non-rural areas, patients living in the second quintile of neighborhood LEP were 9% more likely to be waitlisted than those in the lowest quintile (HR = 1.09, 95%CI 1.10 - 1.18 in Quintile 2). However, this association did not persist in higher quintiles (Quintile 3: HR = 1.03, 95% CI 0.95 – 1.11; Quintile 4: HR = 0.98, 95% CI 0.90 – 1.05; Quintile 5: HR = 0.98, 95% CI 0.91, 1.07) (Table 4).

#### Discussion

After adjusting for neighborhood SES and additional individual-level covariates, patients living in non-rural ZIP codes in the second quintile of neighborhood LEP were 9% more likely to be waitlisted compared to those in the lowest quintile of neighborhood LEP, although this association did not persist among other quintiles, nor among any patients in rural ZIP codes.

Objective CKD-12 of the HealthyPeople 2020 Initiative is to increase the proportion of adults with ESRD who are waitlisted within a year of starting dialysis from 16.9% to 18.6% (33). Disparities age, sex, race and ethnicity are known to exist in the kidney transplant waitlisting process (33). However, these disparities all exist at the level of the individual patient, and neighborhood-level variables have not been studied in depth. Previous research has considered the effect of geography on transplantation and transplant outcomes at various steps (14, 16, 26). Neighborhood-level LEP has been associated with lower likelihood of active status on the transplant waitlist (27), as well as with low transplantation rates (13, 34). However, our study found that there was little difference between neighborhood level LEP and likelihood of waitlisting after adjusting for similar individual covariates, as well as additional neighborhood level covariates. These results suggest a high level of complexity in the relationships between neighborhoods, their geography, and their residents.

The relationship between rurality and limited English proficiency in ZIP codes was such that rural ZIP codes were more likely to be lower in limited English proficiency. This is rather plausible, given that rural neighborhoods were more likely to have white, non-Hispanic patients as well (35). However, the socioeconomic status of these neighborhoods was lower in both the lowest and highest LEP ZIP codes, but neighborhood socioeconomic status was higher in ZIP codes in the middle quintiles. A possible explanation for this could be that the most urbanized and most rural areas are both areas with high rates of poverty, but urban areas tend to be more diverse than their rural counterparts (35). The likelihood of waitlisting being higher among higher LEP neighborhoods could be explained by the fact that higher LEP neighborhoods may already be providing services to mitigate language barriers and improve health literacy for its residents (36), while those who live in the lowest quintile are already more likely to be rural according to our study, and therefore more likely to be experiencing the previously mentioned disparities that exist for rural residents (15, 16, 19, 37, 38). Finally, some of this association could be explained by the Latino Paradox, in which immigration from Latin or Hispanic countries tends to have a protective effect against negative outcomes (39).

This study has several limitations. First, we were unable to measure individual levels of English proficiency and socioeconomic status. Therefore neighborhood socioeconomic status was used as a proxy for individual socioeconomic status, since neighborhood socioeconomic status is often dependent on the socioeconomic status of the individuals who reside in these neighborhoods (40). This may have led to ecological fallacy in drawing conclusions about individual outcomes based on neighborhood-level exposures. Because we do not have much information on immigration status, country of origin, or first language for the patients in this study population, we cannot be sure of individual patients' proficiency in English. However, it is likely that neighborhoods with higher levels of LEP are likely to have bilingual services, including health care services (36). It has been shown that bilingual tools are beneficial to aiding the transplant process for ESRD patients who speak Spanish (41). If that is the case, this may imply that bilingual patients may require bilingual services to improve health literacy, as mentioned above. Another limitation of this study is the use of 5-

year estimates from the ACS rather than 1-year estimates, despite one-year estimates potentially being more accurate representations of zip code demographics in each year a patient was diagnosed with ESRD. Five-year estimates contain average results from the five years prior to that year's survey data collection. However, one-year estimates were not available from the Census Bureau by zip code, and therefore, five-year estimates were used. Finally, there is the potential for ESRD patients to move out of their zip code of residence after their diagnosis. However, studies show that if they move, they are likely to move to a neighborhood with similar demographics (42-44).

Even so, this study has several strengths. First, we use data from the American Community Survey (ACS) to determine zip-code levels of linguistic isolation instead of the U.S. Census. While previous studies have used census data for their exposures, the census is only conducted once every ten years. Therefore, the information contained in the census might be outdated for outcomes measured later in the decade. The ACS is smaller, but also nationally representative and conducted annually. A second strength of this study is its use of the USRDS, a national registry for ESRD diagnosis. Although this study only used a sample of eligible patients, this sample was representative of all ESRD patients in the U.S., and still large enough to maintain statistical power. Another strength is that we were able to adjust for several confounding variables, although individual socioeconomic status and individual English proficiency remained unmeasured. Overall, we conclude that high neighborhood level limited English proficiency (LEP) may be associated with higher likelihood of waitlisting when compared to neighborhoods with nearly no LEP. This implies that differences in neighborhood level English proficiency and its effects on waitlisting might be explained by other factors at both the individual and neighborhood levels. Further research is needed to determine with certainty if these patients are experiencing individual-level language barriers.

#### References:

- National Institute of Diabetes and Digestive and Kidney Diseases. Kidney Disease Statistics for the United States. National Institutes of Health. (Accessed 2020).
- Centers for Disease Control and Prevention. Chronic Kidney Disease Surveillance System - United States. Centers for Disease Control and Prevention. (<u>https://nccd.cdc.gov/CKD/detail.aspx?Qnum=Q67</u>). (Accessed 2020).
- Kazancioğlu R. Risk factors for chronic kidney disease: an update. *Kidney Int Suppl* (2011) 2013;3(4):368-71.
- Luyckx VA, Tuttle KR, Garcia-Garcia G, et al. Reducing major risk factors for chronic kidney disease. *Kidney Int Suppl (2011)* 2017;7(2):71-87.
- United States Renal Data System. 2018 USRDS Annual Data Report: Epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases,; 2018. (https://www.usrds.org/2018/view/v2\_01.aspx). (Accessed March 22 2020).
- Patzer RE, Paul S, Plantinga L, et al. A Randomized Trial to Reduce Disparities in Referral for Transplant Evaluation. J Am Soc Nephrol 2017;28(3):935-42.
- Abecassis M, Bartlett ST, Collins AJ, et al. Kidney transplantation as primary therapy for end-stage renal disease: a National Kidney Foundation/Kidney Disease Outcomes Quality Initiative (NKF/KDOQITM) conference. *Clin J Am Soc Nephrol* 2008;3(2):471-80.
- 8. Bastani B. The worsening transplant organ shortage in USA; desperate times demand innovative solutions. *J Nephropathol* 2015;4(4):105-9.
- Kucirka LM, Purnell TS, Segev DL. Improving Access to Kidney Transplantation: Referral Is Not Enough. JAMA 2015;314(6):565-7.

- Frequently Asked Questions. United Network for Organ Sharing.
  (<u>https://unos.org/transplant/frequently-asked-questions/</u>). (Accessed 2020).
- Reese PP, Bloom RD. The Long and Winding Road to Kidney Transplantation.
  American Journal of Transplantation 2011;11(7):1357-8.
- Patzer RE, Pastan SO. Policies to promote timely referral for kidney transplantation. Semin Dial 2020;33(1):58-67.
- Hall YN, Choi AI, Xu P, et al. Racial ethnic differences in rates and determinants of deceased donor kidney transplantation. *Journal of the American Society of Nephrology : JASN* 2011;22(4):743-51.
- Patzer RE, Amaral S, Wasse H, et al. Neighborhood Poverty and Racial Disparities in Kidney Transplant Waitlisting. *Journal of the American Society of Nephrology* 2009;20(6):1333-40.
- Warshaw R. Health Disparities Affect Millions in Rural U.S. Communities. AAMCNews, 2017.
- Loftus J, Allen EM, Call KT, et al. Rural-Urban Differences in Access to Preventive Health Care Among Publicly Insured Minnesotans. J Rural Health 2018;34 Suppl 1(Suppl 1):s48-s55.
- Chan L, Hart LG, Goodman DC. Geographic Access to Health Care for Rural Medicare Beneficiaries. *The Journal of Rural Health* 2006;22(2):140-6.
- Henning-Smith CE, Hernandez AM, Hardeman RR, et al. Rural Counties With Majority Black Or Indigenous Populations Suffer The Highest Rates Of Premature Death In The US. *Health Aff (Millwood)* 2019;38(12):2019-26.
- Zahnd WEMS, Scaife SLMS, Francis MLMD. Health Literacy Skills in Rural and Urban Populations. *American Journal of Health Behavior* 2009;33(5):550-7.

- Lora CM, Gordon EJ, Sharp LK, et al. Progression of CKD in Hispanics: potential roles of health literacy, acculturation, and social support. *Am J Kidney Dis* 2011;58(2):282-90.
- 21. Warsame F, Haugen CE, Ying H, et al. Limited health literacy and adverse outcomes among kidney transplant candidates. *Am J Transplant* 2019;19(2):457-65.
- 22. Flores G. Language Barriers to Health Care in the United States. *New England Journal* of Medicine 2006;355(3):229-31.
- Singleton K, Krause EM. Understanding cultural and linguistic barriers to health literacy. *Ky Nurse* 2010;58(4):4, 6-9.
- Jang Y, Yoon H, Park NS, et al. Health Vulnerability of Immigrants with Limited English Proficiency: A Study of Older Korean Americans. J Am Geriatr Soc 2016;64(7):1498-502.
- 25. Calo WA, Cubillos L, Breen J, et al. Experiences of Latinos with limited English proficiency with patient registration systems and their interactions with clinic front office staff: an exploratory study to inform community-based translational research in North Carolina. *BMC Health Serv Res* 2015;15:570.
- 26. Mojica C, Glenn B, Chang L-J, et al. The Relationship between Neighborhood Immigrant Composition, Limited English Proficiency, and Late-Stage Colorectal Cancer Diagnosis in California. *BioMed Research International* 2015;2015.
- Talamantes E, Norris KC, Mangione CM, et al. Linguistic Isolation and Access to the Active Kidney Transplant Waiting List in the United States. *Clin J Am Soc Nephrol* 2017;12(3):483-92.

- ZIP Code Tabulation Areas (ZCTAs). U.S. Census Bureau: U.S. Census Bureau. (<u>https://www.census.gov/programs-surveys/geography/guidance/geo-areas/zctas.html</u>). (Accessed February 6 2020).
- U.S. Census Bureau. Census 2000 summary file technical documentation.
  Washington, D.C., 2004.
- Link MW, Mokdad AH, Stackhouse HF, et al. Race, ethnicity, and linguistic isolation as determinants of participation in public health surveillance surveys. *Prev Chronic Dis* 2006;3(1):A09.
- Defining Rural Population. Health Resources & Services Administration. (<u>https://www.hrsa.gov/rural-health/about-us/definition/index.html</u>). (Accessed 2020).
- Centers for Disease Control and Prevention. About Adult BMI. Centers for Disease Control and Prevention,.

(https://www.cdc.gov/healthyweight/assessing/bmi/adult\_bmi/index.html). (Accessed).

- Chronic Kidney Disease Objectives. HealthyPeople 2020; 2020.
  (<u>https://www.healthypeople.gov/2020/topics-objectives/topic/chronic-kidney-disease/objectives</u>). (Accessed April 23 2020).
- 34. Hall YN, O'Hare AM, Young BA, et al. Neighborhood poverty and kidney transplantation among US Asians and Pacific Islanders with end-stage renal disease. *Am J Transplant* 2008;8(11):2402-9.
- 35. Parker K HJ, Brown A, Fry R, Cohn D, Iglielnik R. Demographic and economic trends in urban, suburban and rural communities. Pew Research Center; 2018.

(https://www.pewsocialtrends.org/2018/05/22/demographic-and-economictrends-in-urban-suburban-and-rural-communities/). (Accessed 2020).

- 36. Schrauf RW. English Use Among Older Bilingual Immigrants in Linguistically Concentrated Neighborhoods: Social Proficiency and Internal Speech as Intracultural Variation. *Journal of Cross-Cultural Gerontology* 2009;24(2):157-79.
- Axelrod DA, Guidinger MK, Finlayson S, et al. Rates of solid-organ wait-listing, transplantation, and survival among residents of rural and urban areas. *Jama* 2008;299(2):202-7.
- O'Hare AM, Johansen KL, Rodriguez RA. Dialysis and kidney transplantation among patients living in rural areas of the United States. *Kidney Int* 2006;69(2):343-9.
- Franzini L, Ribble JC, Keddie AM. Understanding the Hispanic paradox. *Ethn Dis* 2001;11(3):496-518.
- 40. Robinette JW, Charles ST, Gruenewald TL. Neighborhood Socioeconomic Status and Health: A Longitudinal Analysis. *J Community Health* 2017;42(5):865-71.
- 41. Gordon EJ, Feinglass J, Carney P, et al. An interactive, bilingual, culturally targeted website about living kidney donation and transplantation for hispanics: development and formative evaluation. *JMIR Res Protoc* 2015;4(2):e42.
- Sanbonmatsu L, Kling JR, Duncan GJ, et al. Neighborhoods and Academic Achievement: Results from the Moving to Opportunity Experiment. *Journal of Human Resources* 2006;XLI(4):649-91.
- Jacob BA. Public Housing, Housing Vouchers, and Student Achievement: Evidence from Public Housing Demolitions in Chicago. *American Economic Review* 2004;94(1):233-58.

Martens PJ, Chateau DG, Burland EMJ, et al. The effect of neighborhood socioeconomic status on education and health outcomes for children living in social housing. *American journal of public health* 2014;104(11):2103-13.

	Total Pop. N = 59,188	Q1 N = 11,623	Q2 N = 12,301	Q3 N = 11,517	Q4 N = 11,809	Q5 N = 11,938
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Mean Age (SD)	63.1 (14.6)	64.0 (14.2)	63.3 (14.5)	63.2 (14.7)	62.9 (14.8)	62.0 (14.8)
Sex (%)						
Male	34,318 (58.0)	6,632 (57.1)	7,122 (57.9)	6,725 (58.4)	6,910 (58.5)	6,929 (58.0)
Female	24,870 (42.0)	4,991 (42.9)	5,179 (42.1)	4,792 (41.6)	4,899 (41.5)	5,009 (42.0)
Race (%)						
White	39,728 (67.1)	8,687 (74.7)	8,068 (65.7)	7,638 (66.3)	7,409 (62.7)	7,926 (66.4)
Black / African- American	15,756 (26.6)	2,691 (23.2)	3,884 (31.6)	3,293 (28.6)	3,340 (28.3)	2,548 (21.3)
American Indian / Alaska Native	501 (0.8)	136 (1.2)	115 (0.9)	75 (0.7)	96 (0.8)	79 (0.7)
Asian	2,398 (4.1)	69 (0.6)	148 (1.2)	353 (3.1)	715 (6.1)	1,113 (9.3)
Native Hawaiian / Pacific Islander	636 (1.1)	24 (0.2)	64 (0.5)	125 (1.1)	205 (1.7)	218 (1.8)
Other / Multiracial	169 (0.3)	16 (0.1)	22 (0.2)	33 (0.3)	44 (0.4)	54 (0.5)
Hispanic Ethnicity (%)	8,136 (13.7)	211 (1.8)	421 (3.4)	832 (7.2)	1,918 (16.2)	4,754 (39.8)
Mean BMI (SD)	29.7 (8.1)	30.3 (8.2)	30.1 (8.3)	29.8 (8.1)	29.5 (8.0)	28.8 (7.7)
Rural (%)	11,115 (18.8)	5,393 (46.4)	2,591 (21.1)	1,492 (13.0)	1,068 (9.0)	571 (4.8)
Neighborhood SES						
Low	28,595 (48.3)	6,687 (57.5)	5,775 (47.0)	4,362 (37.9)	4,758 (40.3)	7,013 (58.8)
Middle	20,612 (34.8)	4,003 (34.4)	4,344 (35.3)	4,445 (38.6)	4,270 (36.2)	3,550 (29.7)
High	9,834 (16.6)	813 (7.0)	2,180 (17.7)	2,710 (23.5)	2,777 (23.5)	1,354 (11.3)
Unknown	147 (0.3)	120 (1.0)	2 (0.0)	0 (0.0)	4 (0.0)	21 (0.2)

Table 1. Characteristics of Patients registered in U.S. Renal Data System by Quintile of Neighborhood Limited English Proficiency at Baseline, 2013 – 2017.

	Total Population N = 59,188	Waitlisted N = 10,360	Not Waitlisted N = 48,828
	N (%)	N (%)	N (%)
Waitlisted (%)	10,360 (17.5)	-	-
Mean Age (SD)	63.1 (14.6)	52.5 (13.2)	65.3 (13.9)
Sex (%)			
Male	34,318 (58.0)	6,475 (62.5) 3,885	27,843 (57.0)
Female	24,870 (42.0)	(37.5)	20,985 (43.0)
Race (%)			
White	39,728 (67.1)	6,863 (66.2) 2,582	32,865 (67.3)
Black / African-American	15,756 (26.6)	(24.9)	13,174 (27.0)
American Indian / Alaska Native	501 (0.8)	69 (0.7)	432 (0.9)
Asian	2,398 (4.1)	672 (6.5)	1,726 (3.4)
Native Hawaiian / Pacific Islander	636 (1.1)	142 (1.4)	494 (1.0)
Other / Multiracial	169 (0.3)	32 (0.3)	137 (0.3)
Hispanic Ethnicity (%)	8,136 (13.7)	1,727 (16.7)	6,409 (13.1)
Mean BMI (SD)	29.7 (8.1)	29.0 (6.5)	29.8 (8.3)
Rural Residence (%)	11,115 (18.8)	1,542 (14.9)	9,573 (19.6)
Neighborhood SES		1.0.10	
Low	28,595 (48.3)	4,048 (39.1) 3,974	24,547 (50.3)
Middle	20,612 (34.8)	(38.4) 2,309	16,638 (34.1)
High	9,834 (16.6)	(22.3)	7,525 (15.4)
Unknown	147 (0.3)	29 (0.3)	118 (0.2)

Table 2. Characteristics of Patients registered in U.S. Renal Data System by Waitlisting Status

on December 31, 2017.

Table 3. Association of Rural Residence with Neighborhood Limited English Proficiency and Waitlisting, 2013 – 2017.

	Total Population N = 59,188		Rural N = 11,115		Non-Rural N = 48,073	
	Ν	0⁄0	Ν	%	Ν	%
Q1: 0 - 0.5%	11,623	19.6	5,393	48.5	6,230	13.0
Q2: 0.6 - 1.6%	12,301	20.8	2,591	23.3	9,710	20.2
Q3: 1.7 - 3.5%	11,517	19.5	1,492	13.4	10,025	20.9
Q4: 3.6 - 8.9%	11,809	20.0	1,068	9.6	10,741	22.3
Q5: 9.0%	11,938	20.2	571	5.1	11,367	23.6
Waitlisted	10,360	17.5	1,542	13.9	8,818	18.3
Not Waitlisted	48,828	82.5	9,573	86.1	39,255	81.7

Neighborhood Limited English Proficiency (NLEP), Crude and Adjusted, USRDS 2013 -

## 2017.

	U	nadjusted		Adjusted*			
	Rural	Non-Rural	P-value	Rural	Non-Rural	P-value	
NLEP							
Q1	Ref	Ref	0.02	Ref	Ref	0.02	
Q2	0.93 (0.82, 1.06)	1.13 (1.04, 1.22)		0.92 (0.80, 1.05)	1.09 (1.01, 1.18)		
Q3	1.15 (0.99, 1.34)	1.12 (1.04, 1.21)		1.10 (0.95, 1.28)	1.03 (0.95, 1.11)		
Q4	1.08 (0.91, 1.29)	1.10 (1.02, 1.18)		1.02 (0.86, 1.21)	0.98 (0.90, 1.05)		
Q5	1.25 (1.01, 1.54)	1.08 (1.00, 1.16)		1.16 (0.94, 1.43)	0.98 (0.91, 1.07)		

\*Adjusted for Rural Residence, Neighborhood SES, and individual demographic characteristics at baseline

(race, ethnicity, sex, BMI, age).







Proficiency and Time to Initial Registration on Kidney Transplant Waitlist.

Figure 2. Directed Acyclical Graph of Association between Neighborhood Limited English



Figure 3. Kaplan-Meier Survival Curve of Initial Registration for Kidney Transplant Waitlisting by Neighborhood Limited English Proficiency, 2013 – 2017.

Product-Limit Survival Estimates by Quintile of Neighborhood Limited English Proficiency. Log-Rank Test:  $X^2 = 44.1$ , p-value < 0.0001.

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