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Taylor A. Melanson Date

The Impact of Recent Policy Changes on the Treatment of Patients with Kidney Disease in the U.S.

By

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Doctor of Philosophy

Health Services Research and Health Policy

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The Impact of Recent Policy Changes on the Treatment of Patients with Kidney Disease in the U.S.

By

Taylor Andrew Melanson

B.A., Washington & Lee University, 2013

Advisor: Jason M. Hockenberry, PhD

An abstract of

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Abstract

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By Taylor Andrew Melanson

In the United States, chronic kidney disease is a large, and growing public health concern that disproportionately affects minorities and individuals with low socioeconomic status. While Medicare covers patients who have progressed to end-stage renal disease, coverage prior to ESRD is critical to improving patient outcomes. Medicaid expansion has extended coverage to millions of Americans and presents a significant opportunity to improve the care of CKD patients. Guidelines for the care of these patients have changed over time and it is important to understand how insurance coverage interacts with such changes. Once patients progress to ESRD, the preferred treatment is a living donor kidney transplant. Both Medicaid expansion and the recently implemented Kidney Allocation System have potential to significantly alter access to living donor kidney transplantation. This dissertation seeks to illuminate the interactions between guidelines, changes in insurance coverage, and organ allocation policy, and how these factors impact care of patients with CKD. The three essays of my dissertation examine: the impact of Medicaid expansion and guideline changes on pre-ESRD nephrology care; the impact of Medicaid expansion on rates of living donor kidney transplantation; and the impact of Medicaid expansion and the new Kidney Allocation System on racial disparities in living donor kidney transplantation rates.

The findings of this dissertation provide evidence that, although improving coverage for low socioeconomic status individuals is an important step towards improved access to care, it is not sufficient to ensure that all patients are receiving equitable treatment. Given the large downstream costs associated with poorly treated CKD, it is important that efforts are made to improve preventive care and to encourage living donation. The findings also suggest that improving access to deceased donor kidney transplantation for minorities may have inadvertently worked to funnel minorities to suboptimal care. Policies targeting patients with CKD need to be carefully considered within the framework of existing health care policy to ensure that as we increase access for vulnerable populations we do not further disadvantage them by discouraging them from seeking optimal treatment.

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To my committee members:

Jason, you played a larger role in my graduate school experience than you probably know. When I first met you, I was convinced that I was going to take a job rather than go to grad school. I interviewed with a number of schools but none of them really felt right. You were the first person I spoke to who seemed legitimately interested in me as a student. I was nervous about making such a large commitment, to steering my life into uncharted territory but you convinced me it was the right choice. I still remember what you said: "You could go work for [a well-known electronic health records company] and I am sure you would be quite successful. I am sure you would make a lot of money too, but I think it would be a loss to the profession for you do that." Those words really struck me and I realized that Emory was a place where I could work with people who believed in me at least as much as I believed in myself. I am incredibly grateful for your hard sell and your continued belief that I have something to offer our discipline.

David, you have played an invaluable role in my progress as a researcher. You have always been straightforward, honest, and clear. Those are rare qualities and I appreciate the fact that I know you will not sign off on something that you don't believe in. You never let me make a claim without thoroughly defending it and I know that my work has become much better for it. You have taught me to anticipate criticism and think through the flaws in my assumptions and arguments before sharing them with others. Your approval was never easy to earn but that only increased the satisfaction of completing my dissertation.

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To my parents:

As a child you encouraged me to work hard in school and to stay curious. Without that foundation I would never have gotten to where I am today. You have supported me and my education for almost three decades now and I hope you are proud of how things have turned out.

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Victoria, you have been there for me through the entirety of my graduate school career and I don't think I could have done it without you. You are the light of my life and the one who keeps me going when things get tough. I love you and I hope I make you as proud to be my wife as I am proud to be your husband.

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Chapter 1: Introduction

1.1 CKD & its Treatment

1.1.1 CKD and ESRD

Chronic Kidney Disease represents a large and growing public health concern in the United States and will continue to play a large role in our health care system. End-stage renal disease (ESRD) is the final stage of chronic kidney disease (CKD), a chronic and progressive illness which affected over 700,000 patients in the US and cost $33.9 billion in 2015 (System 2018) . Medicare has covered ESRD patients for decades but it has become increasingly clear that earlier intervention is crucial both for the sake of patients and the federal budget. With 15% of adults in America currently suffering from CKD any major changes in our healthcare system need to consider the needs of this vulnerable population. This dissertation aims to illustrate how recent guidelines and policy changes have impacted care of patients in the period surrounding their transition to ESRD.

1.1.2 Living Donor Kidney Transplantation vs Deceased Donor Kidney Transplantation

Living donor kidney transplant (LDKTx) is the preferred treatment for patients with end-stage renal disease (ESRD) but continues to be significantly less common than deceased donor KTx (DDKTx). In 2015 there were 18,021 kidney transplants in the US, 5,672 of which were LDKTxs(System 2018). Patients who have developed ESRD require treatment in order to replace their renal function, either in the form of a transplant or through dialysis(Goodman WG 2005). Dialysis is quite common despite it being more expensive, riskier for the patient, and providing a lower quality of life compared to transplantation (Whiting, Kiberd et al. 2004, Goodman WG 2005, Tonelli, Wiebe et al. 2011).

1.1.3 Nephrologists and the Physician Shortage

The timing of access to specialized provider human capital and its role in the efficiency and effectiveness of care is an area of ongoing debate (Jungers, Massy et al. 2001, Avorn, Winkelmayer et al. 2002, Ansari, Alexander et al. 2003, Indridason, Coffman et al. 2003, Link and Saxena 2014, Samal, Wright et al. 2015, Johnston and Hockenberry 2016). In the case of patients with complex chronic diseases, the involvement of physician specialists in care may improve outcomes, but also could increase costs. Specialty societies try to balance benefits and costs when they develop guidelines for when in the course of a patient's illness they should be referred for specialty care. Appointment availability and insurance coverage also influence the timing of referral.

The factors associated with receiving a LDKTx differ from DDKTx in that a patient hoping to receive a LDKTx generally must find a willing donor, while DDKTx recipients wait for an available kidney once they have been waitlisted at a kidney transplant center. Previous work has found that individuals with lower SES and/or minorities tend to have both worse access to healthcare and less education about ESRD and their various treatment options, including LDKTx (Patzer, Amaral et al. 2009, Axelrod, Dzebisashvili et al. 2010, Saunders, Cagney et al. 2010, Waterman, Rodrigue et al. 2010, Patzer, Perryman et al. 2012, Mohan, Mutell et al. 2014, Hart, Smith et al. 2017) .

Many studies have raised the concern of a developing physician shortage in the US (Mehrotra, Shaffer et al. 2011, Grover and Niecko-Najjum 2013, Markit 2017). As the population grows older, the demand for services is increasing faster than our medical education system can keep up with (Professions 2008, Mehrotra, Shaffer et al. 2011, Grover and Niecko-

Najjum 2013, Markit 2017). This is problematic because giving more individuals coverage will only be beneficial if they are able to access the covered services. A shortage of physicians, in our case nephrologists, would reduce the potential positive impact of Medicaid expansion. Evidence of such a shortage would likely come in the form of crowding out of uninsured patients. If such a shortage occurred in response to Medicaid expansion, it would suggest that we may have reached the limits of availability of nephrology care. There is some disagreement in the literature about the extent to which predicted shortages have actually materialized, which suggests that additional evidence suggesting a shortage, or lack thereof, would be valuable.

1.2 Policy related to ESRD Care and ESRD Patients

1.2.1 The 2014 Kidney Allocation System

The United Network for Organ Sharing implemented a new kidney allocation system in December 2014 ((OPTN) 2014), in part to address long-standing racial/ethnic disparities in the allocation of deceased donor kidneys. Under the new system, the starting point for calculating waiting time was changed from the date the patient was put on the waiting list to the earliest of either that date or the date of the patient's first regular dialysis. This change was expected to benefit minorities because blacks and Hispanics spend more time on dialysis before being put on the waiting list, compared to white patients (Arce, Mitani et al. 2012, Israni, Salkowski et al. 2014).

While many papers have examined the impact of KAS on DDKTx(Colovai, Ajaimy et al. 2017, Hahn, Mackey et al. 2017, Hart, Gustafson et al. 2017, Hickey, Zheng et al. 2017, Melanson, Hockenberry et al. 2017), which was its intended target, the indirect impact it may

have had on LDKTx remains unknown. KAS had the intended effect of reducing disparities in access to deceased donor kidney transplant (DDKTx) nationwide (Melanson, Hockenberry et al. 2017). It led to white and non-white patients having similar likelihood of receiving a DDKTx once they had reached the kidney waitlist. However, LDKTx is the preferred treatment for ESRD but requires more resources and effort to acquire a willing donor. Patients who receive increased priority for a DDKTx may feel less inclined to search for a living donor and therefore KAS may indirectly impact LDKTx rates. A given patient will receive either a living or a deceased kidney for a given transplant and therefore LDKTx and DDKTx likely act as substitutes. For this reason, we expect that changes in the allocation of DDKTx will impact the demand for LDKTx via a substitution effect(NELSON 2003, Crost B 2012).

1.2.2 The 2012 Kidney Disease Improving Global Outcomes Guidelines

In 2002 the National Kidney Foundation–Kidney Disease Outcomes Quality Initiative (NKF-KDOQI) issued guidelines recommending that "consultation and/or co-management with a kidney disease care team is advisable during Stage 3, and referral to a nephrologist in Stage 4 is recommended"(National Kidney 2002). At that time late referral to a nephrologist was defined as a referral within 3 months of ESRD start. In 2003, the Nation Kidney Foundation founded an international organization, called Kidney Disease Improving Global Outcomes, for the purpose of synthesizing information regarding chronic kidney disease from around the world and producing and disseminating guidelines and best practices. In subsequent years, evidence accumulated that the 2002 recommendations needed revision, especially the definition of late referral. In 2009, KDIGO convened a working group to develop an update to the 2002 guidelines which would end up becoming the 2012 KDIGO Clinical Practice Guideline for the Evaluation

and Management of CKD. These new guidelines recommended that CKD patients should receive at least 12 months of pre-ESRD nephrology care (Inker, Astor et al. 2014). This recommendation is graded 1B (According to UpToDate: "A Grade 1B recommendation is a strong recommendation and applies to most patients. Clinicians should follow a strong recommendation unless a clear and compelling rationale for an alternative approach is present)" which is the strongest recommendation possible without a random control trial, which is likely impossible in this context due to ethical concerns. These guidelines were published in Kidney International Supplements on January 1, 2013 and have since been cited over 240 times.

1.2.3 Medicaid and Medicare

The Affordable Care Act (ACA) intended to expand Medicaid to cover a larger range of individuals than had been previously covered. The ACA was passed in 2010 and seven states (CA, CO, CT, DC, MN, NJ, WA) expanded Medicaid from 2010-2012, while 20 states (including DC) expanded in 2014 and 6 states have expanded since 2014 (KFF State Health Facts 2018).

Medicaid has historically reimbursed providers at a lower rate than Medicare(Zuckerman, McFeeters et al. 2004, Zuckerman, Williams et al. 2009, Decker 2012, Mabry, Gurien et al. 2016) or employer-based insurance plans (Decker 2009). This means that providers have less financial incentive to see a Medicaid patient than to see a patient with other forms of insurance. However, Medicaid reimbursement is better than no reimbursement, so physicians are more likely to accept patients after they gain Medicaid coverage than when they were uninsured.

The Medicaid population has historically had a significantly larger proportion of non-whites than the overall population. In 2016, the US was 76.9% white(Bureau 2016), while whites

made up only 43% of Medicaid beneficiaries(Foundation 2016). If Medicaid Expansion has increased coverage to a group that looks similar demographically to the pre-existing Medicaid beneficiaries, then expansion has a large potential to impact the care of minority patients.

Medicaid Expansion lead to an increase in enrollment of over 15 million individuals by 2016, with expansion-related enrollment making up ~20% of total Medicaid enrollment in 2016 (Foundation 2016). The question remains as to how much this increased population of insured individuals will impact patterns of care across the country.

While patients become eligible for Medicare after being diagnosed with ESRD, the care of these patients prior to reaching the end-stage of the disease is not covered by Medicare, leaving many individuals unable to afford preventive care.

Studies have shown that patients who see nephrologists prior to being diagnosed with ESRD (i.e. before their kidneys completely fail) tend to have better outcomes than patients who do not see a nephrologist until ESRD diagnosis (Jungers, Massy et al. 2001, McClellan, Wasse et al. 2009, Maripuri, Ikizler et al. 2013, Plantinga, Kim et al. 2014, Gillespie, Morgenstern et al. 2015, Hao, Lovasik et al. 2015, Norris, Williams et al. 2017). There is a large body of evidence supporting the benefits of referral to a nephrologist for CKD patients. However, pre-ESRD nephrology care is significantly lower than guidelines recommend; approximately 36% of incident ESRD cases in 2015 having received little or no pre-ESRD nephrology care (Arora, Obrador et al. 1999, Obrador, Ruthazer et al. 1999, Maripuri, Ikizler et al. 2013, Yan, Cheung et al. 2013, Gillespie, Morgenstern et al. 2015, System 2018).

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Chapter 2: The Impact of Medicaid Expansion on the Receipt of Pre-ESRD Nephrology Care

2.1 Introduction

The timing of access to specialized provider human capital and its role in the efficiency and effectiveness of care is an area of ongoing debate (Jungers, Massy et al. 2001, Avorn, Winkelmayer et al. 2002, Ansari, Alexander et al. 2003, Indridason, Coffman et al. 2003, Link and Saxena 2014, Samal, Wright et al. 2015, Johnston and Hockenberry 2016). In the case of patients with complex chronic diseases, the involvement of physician specialists in care may improve outcomes, but also could increase costs. Specialty societies try to balance benefits and costs when they develop guidelines for when in the course of a patient's illness they should be referred for specialty care. Appointment availability and insurance coverage also influence the timing of referral.

End-stage renal disease (ESRD) is the final stage of chronic kidney disease (CKD), a chronic and progressive illness which affected over 700,000 patients in the US and cost $33.9 billion in 2015 (System 2018) . While patients become eligible for Medicare after being diagnosed with ESRD, the care of these patients prior to reaching the end-stage of the disease is not covered by Medicare, leaving many individuals unable to afford preventive care. Studies have shown that patients who see nephrologists prior to being diagnosed with ESRD (i.e. before their kidneys completely fail) tend to have better outcomes than patients who do not see a nephrologist until ESRD diagnosis (Jungers, Massy et al. 2001, McClellan, Wasse et al. 2009, Maripuri, Ikizler et al. 2013, Plantinga, Kim et al. 2014, Gillespie, Morgenstern et al. 2015, Hao, Lovasik et al. 2015, Norris, Williams et al. 2017). Jungers et al. found that patients who received

between 6 and 35 months of pre-dialysis nephrology care were at a 27% lower risk of death than patients with <6 months of pre-dialysis nephrology care(Jungers, Massy et al. 2001). Maripuri et al. found that seeing a nephrologist at least 6 months prior to esrd start was associated with 21% lower likelihood of death and a 45% increased likelihood of receiving a kidney transplant(Maripuri, Ikizler et al. 2013). Gillespie et al found that 12+ months of pre-ESRD nephrology care was associated with a ~40% decrease in 1-yr mortality when compared to no care and that a 10% increase in the proportion of patients receiving >12 months of pre-ESRD care at the state level was associated with a 9.3% decrease in mortality(Gillespie, Morgenstern et al. 2015). Another study found pre-ESRD nephrology care to be associated with higher likelihood of AVF, treatment with an erythropoietin-stimulating agent, pre-treatment dietary counseling, and guideline-appropriate hemoglobin and albumin levels (McClellan, Wasse et al. 2009). They also tend to receive more education about their disease and their treatment options (Mehrotra, Marsh et al. 2005, Patzer, Amaral et al. 2012, Patzer, Sayed et al. 2013, Gillespie, Morgenstern et al. 2015). Earlier referral to a nephrologist is associated with higher likelihood of beginning dialysis with a permanent access which is associated with lower rates of access-related morbidity (Allon, Dinwiddie et al. 2011) as well as lower mortality and higher likelihood of receiving a transplant(Maripuri, Ikizler et al. 2013). There is a large body of evidence supporting the benefits of referral to a nephrologist for CKD patients which served to motivate the 2012 KDIGO guidelines (KDIGO 2013). While there are no RCTs addressing this issue, it would likely be impossible to have one approved due to ethical concerns. However, pre-ESRD nephrology care is significantly lower than guidelines recommend; approximately 36% of incident ESRD cases in 2015 having received little or no pre-ESRD nephrology care (Arora,

Obrador et al. 1999, Obrador, Ruthazer et al. 1999, Maripuri, Ikizler et al. 2013, Yan, Cheung et al. 2013, Gillespie, Morgenstern et al. 2015, System 2018).

In 2002 the National Kidney Foundation–Kidney Disease Outcomes Quality Initiative (NKF-KDOQI) issued guidelines recommending that "consultation and/or co-management with a kidney disease care team is advisable during Stage 3, and referral to a nephrologist in Stage 4 is recommended"(National Kidney 2002). At that time late referral to a nephrologist was defined as a referral within 3 months of ESRD start. In subsequent years, many studies were published showing consistently better outcomes for patients with early referral to nephrologists (lower mortality, less hospitalization, earlier dialysis access placement, etc.) and KDIGO's meta-analysis of 27 longitudinal cohort studies found that these association were not explained by differences in prevalence of diabetes mellitus, previous CAD, BP control, serum phosphate, and serum albumin (KDIGO 2013). This body of evidence led KDIGO to revise the 2002 recommendations and, in particular, to recommend a minimum of a year of pre-ESRD nephrology care in what would end up becoming the 2012 KDIGO Clinical Practice Guideline for the Evaluation and Management of CKD. These new guidelines recommended that CKD patients should receive at least 12 months of pre-ESRD nephrology care (Inker, Astor et al. 2014). This recommendation is graded 1B (According to UpToDate: "A Grade 1B recommendation is a strong recommendation and applies to most patients. Clinicians should follow a strong recommendation unless a clear and compelling rationale for an alternative approach is present)" which is the strongest recommendation possible without a random control trial, which is likely impossible in this context due to ethical concerns. These guidelines were published in Kidney International Supplements on January 1, 2013 and have since been cited over 240 times.

Insurance is an important factor in a patient's access to care. Providers prefer to see patients with insurance, meaning Medicaid expansion should improve access to care for previously uninsured patients. However, Medicaid has historically reimbursed providers at a lower rate than Medicare(Zuckerman, McFeeters et al. 2004, Zuckerman, Williams et al. 2009, Decker 2012, Mabry, Gurien et al. 2016) or employer-based insurance plans (Decker 2009). This means that providers have less financial incentive to see a Medicaid patient than to see a patient with other forms of insurance. Studies looking at reimbursement rates have found that physicians are more likely to take new patients as the reimbursement for seeing them increases (Zuckerman, McFeeters et al. 2004, Decker 2012, Decker 2013) and that Medicaid beneficiaries are less likely to visit the ED when fees for outpatient services are increased, suggesting that higher reimbursement is linked to increased access to outpatient services(Decker 2009).

The Affordable Care Act (ACA) intended to expand Medicaid to cover a larger range of individuals than had been previously covered. The ACA was passed in 2010 and seven states (CA, CO, CT, DC, MN, NJ, WA) expanded Medicaid from 2010-2012, while 20 states (including DC) expanded in 2014 and 6 states have expanded since 2014 (KFF State Health Facts 2018). The Supreme Court case National Federation of Independent Business (NFIB) v. Sebelius determined that the federal government could not force states to expand Medicaid, and 18 states had yet to expand as of 2016. While Medicaid expansions should increase demand for services, sudden increases in demand could hinder the ability of Medicaid patients to access services if there are not enough providers to meet the demand for appointments.

As the US population grows older, the demand for services is increasing faster than our medical education system can increase supply (Professions 2008, Mehrotra, Shaffer et al. 2011, Grover and Niecko-Najjum 2013, Markit 2017) leading to concerns of a physician shortage. A

shortage of physicians, in our case nephrologists, would reduce the potential positive impact of Medicaid expansion. Evidence of such a shortage would likely come in the form of crowding out of uninsured patients. If such a shortage occurred in response to Medicaid expansion, it would suggest that we may have reached the limits of availability of nephrology care. There is some disagreement in the literature about the extent to which predicted shortages have actually materialized, which means that additional evidence suggesting a shortage, or lack thereof, would be valuable.

In this study we estimate the impact of Medicaid expansion and the 2012 KDIGO guideline change on rates of receipt of nephrology care among incident ESRD patients. There have been two significant recent developments regarding this patient population which may impact both access to, and guideline concordance of, specialist care. First, the ACA resulted in Medicaid expansion in 33 states (including DC) between 2010 and 2016, potentially benefitting a large portion of the CKD population who may now qualify for coverage. Second, during the period that states were expanding Medicaid under the ACA, guidelines for pre-ESRD nephrology care changed. We examine the Medicaid expansion and change in guidelines to study the role of insurance in getting access to specialist care, whether those with Medicaid access get differential access to guideline concordant specialist care, and the resultant short-term health impacts of having access to specialists.

2.2 Data

The United States Renal Data System (USRSDS) is a national database that collects information about the ESRD population in the US. For the purposes of this study, we are particularly interested in the 2728 form which is filled out to document each patient's ESRD

diagnosis, demographics, and their treatment leading up to that point. Prior to 2005, pre-ESRD nephrology was not included on the 2728 form. There was some noticeable lag time between the form changing and it being regularly filled out and therefore we use USRDS data from 2006 through 2016 (thereby excluding the transition period). We are interested in all incident ESRD patients during this time period with a 2728 form (N=1,453,473). Various sub-analyses have smaller samples restricted by either expansion category or year. The outcomes of interest are the source of insurance for those entering the ESRD system, the receipt of appropriate pre-ESRD nephrology care, access type used for first dialysis, the presence of a maturing fistula or graft, and waitlisting at 1 year from ESRD start.

2.2.1 Study Variables

The 2728 form collects information about pre-ESRD nephrology and categorizes the answers into <6 months, 6-12 months, and >12 months. For this reason, we are unable to examine care that is less than 6 months prior to ESRD start because it is not distinguishable from the receipt of no care. Therefore, we use 6 months as the cut-off for appropriate care prior to the 2012 guideline and 12 months as the cut-off for appropriate care after the guideline change. Furthermore, although the new guidelines are referred to as the 2012 KDIGO guidelines, they were being worked on and discussed from 2009-2012 and the final version was not published until January of 2013(KDIGO 2013). For this reason, we consider the guidelines to have been issued at the start of 2013 despite the fact that the evidence supporting the new recommendations was both available and being openly discussed in the nephrology community prior to the final publication. We are also interested in demographic characteristics (race/ethnicity, sex, BMI, age,

and insurance status), comorbidities (Hypertension, Arteriosclerotic Heart Disease, Congestive Heart Failure, Peripheral Vascular Disease, Diabetes), and lab values (GFR, HBA1C).

2.2.2 Limitations

Studies on the impact of nephrology care on patient outcomes vary in how they define pre-ESRD nephrology care. Some define pre-ESRD care as any care (Prakash, Rodriguez et al. 2010), more than 6 (McClellan, Wasse et al. 2009, Maripuri, Ikizler et al. 2013) or 12 (Yan, Cheung et al. 2013, Slinin, Guo et al. 2014, Yan, Cheung et al. 2015) months, and some use other lengths of time(Arora, Obrador et al. 1999, Mehrotra, Marsh et al. 2005). This also makes it hard to compare rates of pre-ESRD care across studies, but it consistently reported that pre-ESRD nephrology is not received by everyone who would benefit from it (McClellan, Wasse et al. 2009, Prakash, Rodriguez et al. 2010, Hao, Lovasik et al. 2015, Yan, Cheung et al. 2015). We focus on receipt of 12+ months of pre-ESRD care which is consistent with current guidelines but may limit comparability to previous studies.

Although reporting on 2728 forms is not perfect, a recent study found a reasonable degree (70%) of agreement between claims data and 2728 reporting of pre-ESRD nephrology care when dichotomized at more or less than 12 months (Kim, Desai et al. 2012). Kim et al. acknowledge that their study is limited by the fact that they used Medicare claims and therefore could not study individuals who lacked Medicare before ESRD start. To the extent that older patients are more prone to misstate treatment history, our sample is likely to be at least as accurate as the sample used by Kim et al.

Using a standardized date to look at the impact of Medicaid expansion as we do in our main analyses may obscure effects seen in the states that expanded outside of 2014 but should

provide a useful estimate of the average effect of the policy on the national level. Furthermore, our Medicaid-only analyses seek to address the extent to which Early expansion differed from Late expansion.

2.3 Methods

To determine how expansion impacted insurance coverage, we compared the proportions of patients in each insurance category before and after expansion at the state level (among states that expanded in the study period). We use multinomial logit to compare the likelihood of being in each insurance group coverage pre- and post-expansion. We also graphed the rates of receipt of pre-ESRD nephrology care over time, stratified by insurance types to examine whether Medicaid beneficiaries diverged from trends seen in other groups. We also graph the likelihood of receiving 12+ months of pre-ESRD nephrology among Medicaid patients in states that expanded Early (2010-2012) to states that expanded Late (2014) or never (no expansion from 2010-2014). We treat states that expanded after 2014 as never states both because we are interested in the overlapping policy effects from 2010-2014 and because, as seen in Figure 2.2, Late and Never states had already converged by the end of 2014.

2.3.1 Medicaid Patients

First we examine the impact of Medicaid expansion using Ordinary Least Squares (OLS) looking at only Medicaid patients and controlling for time trends, state fixed effects, and demographic characteristics (race, sex). In order to isolate the effect of expansion we look at a period of 1 year prior to expansion and 1 year after expansion. For Early states, we analyze 2009-2013 because those states expanded between 2010 and 2012. For Late states, we analyze

2013-2014 because those states expanded in January 2014. We then examine all Medicaid patients from 2009-2015 (using state-specific expansion dates) to find the overall impact associated with expansion.

Next, we use OLS to examine Medicaid patients in the period surrounding the guideline change (2012-2013), using the same controls as with the previous model. We again examine Early and Late expanders separately before running the analysis with all Medicaid patients.

2.3.2 Full Sample

We examine the impact of Medicaid expansion on the full sample of incident ESRD patients from 2008-2014 patients using OLS and state-specific expansion dates along with the aforementioned controls. We then estimate the impact of the guideline change in the full sample in a similar fashion.

Next, we use a difference in differences model to estimate the impact that Medicaid expansion had on the different insurance groups (Medicaid, Medicare, private, VA, other). For this model, we need a consistent expansion date so that we can make comparable pre/post groups and for this reason we use January 1, 2014 as the standardized expansion date because it was the date that was used by the majority of expansion states. We include data from 2006-2016 in these analyses. Finally, we use our difference in differences model to estimate the impact that the guideline change had on the different insurance groups (Medicaid, Medicare, private, VA, other). By analyzing our sample in a variety of ways we are able to develop a clearer picture of what occurred in the wake of these overlapping policy changes (expansion and guideline change).

We use OLS analysis to determine if the likelihood of starting dialysis with a permanent access (fistula or graft), or the likelihood of starting dialysis with a maturing fistula or graft was

impacted by expansion. We similarly used OLS to examine the impact of expansion on the likelihood of being waitlisted within a year of ESRD start.

Sensitivity analyses were performed to test the robustness of our finding to the inclusion of various comorbidities and were found to produce similar results to the analyses reported (see appendix).

2.4 Results

We present summary statistics in Table 2.1 describing the full sample as well as expansion and non-expansion states, before and after the guideline change (2013). Non-expansion states had higher proportions of black and Hispanic ESRD patients than expansion states (Table 2.1). Hypertension has increased in both expansion and non-expansion states since 2013, while other comorbidities such as CHF, ASHD, and PVD have all been declining. The proportion of patients covered by Medicaid went up in expansion states and down in non-expansion states. The proportion uninsured patients went down in all states, but the decline was larger in expansion states (9.4% to 4.2% vs 15.0% to 9.6%).

Medicaid expansion led to a larger percentage of ESRD patients covered by Medicaid. Almost all states who expanded Medicaid (87%) had a larger percentage of ESRD patients covered by Medicaid after expanding compared to prior to expanding. Our multinomial logit results show that, compared to a base outcome of private insurance, expansion was associated with a decreased risk ratio of being uninsured (95% CI: 0.54-0.57) and an increased risk ratio of having Medicaid coverage (95% CI: 1.16-1.19) (Table 2.4).

2.4.1 Medicaid

Expansion was associated with a decrease in the likelihood of receiving 12+ months of pre-ESRD care of 3 percentage points ($p<0.001$) in early expansion states. Expansion is not significantly associated with the likelihood of pre-ESRD care ($p=0.32$) in late expansion states. When we examine all Medicaid patients together, we find again that expansion is not significantly associated with likelihood of pre-ESRD care ($p=0.99$).

Examining the effect of the guideline change on Medicaid patients provides quite different results. Early states saw a 1.7 percentage point increase in the likelihood of pre-ESRD care ($p<0.01$) while Late states saw an increase of 1.4 percentage points ($p=0.01$). Overall, Medicaid patients saw an increase of 1.2 percentage points in the likelihood of pre-ESRD care associated with the guideline change ($p<0.001$).

2.4.2 Full Sample

Medicaid coverage was consistently associated with a higher likelihood of receiving 12+ months of pre-ESRD care compared to no insurance and a lower likelihood compared to employer-based insurance or Medicare (Figure 2.1). There are no clear changes around expansion (2010-12 or 2014) but all insured patients saw increased likelihood of pre-ESRD care from before to after the 2012 guideline change while uninsured patients saw a decreased likelihood.

Using OLS to examine the full sample of incident ESRD patients using state-specific expansion dates, we find that expansion was not associated with likelihood of pre-ESRD care ($p=0.71$). We found that the guideline change was associated with an increase of 1 percentage point in the likelihood of pre-ESRD care among all patients ($p<0.001$).

Using our difference in differences model with a standardized expansion date to examine the full sample from 2006-2016 we find that expansion was associated with an increase in the likelihood of receiving 12+ months of pre-ESRD care for all insurance groups: 5.6, 7.2, 7.1, 6.9 percentage points for Medicaid, Medicare, Private, and VA, respectively (all $p<0.001$). Notably, Medicaid patients saw the smallest increase associated with expansion. Using the same model to examine the guideline change, we find similar increases in the likelihood of pre-ESRD care for all insurance groups: 5.7, 7.5, 7.8, 7.6 percentage points for Medicaid, Medicare, Private, and VA, respectively (all $p<0.001$). While Medicaid patients again saw the smallest increase, all insurance groups saw a larger increase associated with the guideline change than with expansion.

While all insured groups improved over the study period, the gap between Medicaid beneficiaries and other insured patients (Medicare or privately insured) became wider over the period that states were expanding Medicaid (Table 2.3). Furthermore, our difference-in-differences analysis around the 2013 guideline change shows that the proportion of patients receiving pre-ESRD nephrology care increased in all insured groups.

The likelihood of starting dialysis with a permanent access (fistula or graft) was not impacted by expansion, nor was the likelihood of starting dialysis with a maturing fistula or graft. Expansion was associated with an increase of 0.02 percentage points in the likelihood of being waitlisted within a year of ESRD start ($p= 0.011$). The likelihood of being waitlisted with a year of dialysis start increased from 6.8% in the pre-period to 8.8% in the post-period.

2.5 Discussion

Our results show that expansion led to more individuals being covered by Medicaid, which was the goal of expansion, but also that the quality of care received by Medicaid

beneficiaries seems to have slightly declined relative to the trajectory seen in other insurance groups. We also find that the 2013 guideline change appears to have made a significant improvement in the pre-ESRD care received by all insured patients. Pre-ESRD care improved among all insured patients which is consistent with the implementation of the 2013 guideline change. Therefore, we believe that the observed increases in receipt of pre-ESRD nephrology have been caused by changing guidelines and not Medicaid expansion.

Expansion has slowed the improvement of pre-ESRD care in Medicaid beneficiaries, but has not caused the upward trend to reverse direction. Such a bending of the curve suggests that while coverage expansion was partially successful, some factors remain which are slowing the rate of improvement. There are two likely factors to consider; either patients or providers are likely the limiting factor. Given that Medicaid expansion tended to expand coverage to individuals who are wealthier than previous beneficiaries, it stands to reason that those who acquired care in the expansion would be at least as able to take advantage of their new coverage as pre-existing beneficiaries. This suggests that the limiting factor is likely physician related and this is potentially evidence that we are facing a shortage of nephrology care. This is consistent with previous literature that has shown the supply of nephrology care declining as the prevalence of CKD has risen (Parker, Ibrahim et al. 2011, Berns, Ellison et al. 2014, Sharif, Elsayed et al. 2016).

We see more patients covered under Medicaid and we see them getting treated similarly to the smaller number of patients previously covered, which suggests that there must be some supply of nephrology care that is now being allocated to Medicaid patients. CMS has increasingly pushed for payment reform in nephrology with the goal of achieving better care at lower cost (Lockridge 2004, Fishbane, Miller et al. 2012, Watnick, Weiner et al. 2012, Maddux,

McMurray et al. 2013, Jones and Hostetter 2015, Weiner and Watnick 2017) but this creates incentives for providers to cherry-pick the best patients (Tangri, Tighiouart et al. 2011). If nephrologists are incentivized to pick patients who are more likely to adhere to their recommendations, we would expect individuals without insurance to be selected against and our results suggest this is in fact happening.

While receipt of pre-ESRD nephrology care has increased over time, we do not see evidence that Medicaid expansion was responsible for improving access to pre-ESRD care for Medicaid patients. Meanwhile, our results show that the gap between Medicaid beneficiaries and patients with other insurance types grew over the period that states were expanding Medicaid. However, Medicaid expansion was associated with a higher percentage of Medicaid patients being waitlisted within a year of ESRD start. The fact that the KDIGO guideline change in 2013 appears to have made a larger impact than Medicaid expansion is not surprising given that the guidelines recommended more than doubling the amount of pre-ESRD care for all patients, in all states while Medicaid expansion only expanded coverage to a small subset of the population, in some states.

The data in Figure 2.2 indicate that Medicaid patients in late expansion states had already seen their receipt of pre-ESRD care converge to the level of non-expansion states, prior to the expansion of Medicaid in those states. This suggests that the increased rate of pre-ESRD care receipt was not caused by Medicaid expansion, but rather predated it. This supports our finding that expansion did not improve the care of incident ESRD patients with Medicaid. Furthermore, our difference-in-differences analysis around the 2013 guideline change shows that all insured patients saw an increased likelihood of receiving 12+ months of pre-ESRD nephrology care. This

evidence suggests that improved care for insured patients is a result of changing guidelines, rather than Medicaid expansion.

The United States is in the early stages of a well-documented shortage of physicians and it is not surprising that nephrologists seem to also be in short supply. Interest in the specialty appears to be on the decline despite growing demand (Parker, Ibrahim et al. 2011, Berns, Ellison et al. 2014, Sharif, Elsayed et al. 2016) .Our medical education system is designed in such a way that it is impossible to increase physician supply in a short time period, due to the long periods of education and training between college and independent practice. As we face the prospect of an aging population it is important that efforts be made to address the shortage of doctors in order to facilitate guideline-concordant care.

The concern of crowding out is further supported by our observation that while all insured patients saw an increased likelihood of receiving 12+ months of pre-ESRD nephrology care, uninsured patients saw a decreased likelihood. The fact that the gap between the care received by the uninsured and that received by Medicare beneficiaries grows over this period, as does the gap between Medicaid beneficiaries and Medicare beneficiaries suggests that we do not have the supply of nephrologists needed to provide all patients with guideline-concordant care. Our results show all insured patients getting more pre-ESRD care after the guideline change which suggests that the crowding out seen in the uninsured population is likely due to the guidelines rather than Medicaid expansion.

Given the existing concerns about the supply of physicians, it is important to illuminate areas of care in which the supply available seems unable to meet the current demand. This study provides evidence that there may be significant benefits to expanding insurance coverage, but also that the current supply of nephrologists is likely unable to meet the needs of the roughly

15% of American adults who suffer from some stage of CKD (System 2018). Expanding coverage among lower-income individuals is likely to have additional benefits downstream as a growing body of evidence supports the importance of intervening early in chronic conditions, but these benefits will not be fully realized if there are not enough physicians treat beneficiaries. ESRD is the terminal stage of a very costly chronic condition. CMS ends up spending billions of dollars each year covering patients whose kidneys fail and require dialysis or kidney transplantation. Fortunately, our results suggest that nephrologists are relatively responsive to changes in practice guidelines. Expanding coverage to low income patients, who are at higher risk of developing ESRD, is important because it may allow us to substitute relatively cheaper preventive care for costly renal replacement therapy.

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Table 2.1: Summary Statistics of incident ESRD patients from USRDS data (2006-2016)

	Full Sample (2006-2016) N=1,453,473	Expansion States (2006-2012) N=578,615	Expansion States (2013-2016) N=285,471	Non-Expansion States (2006-2012) N=388,521	Non-Expansion States (2013-2016) N=200,866
N (%)					
White	836,001 (65.94)	348,441 (68.25)	172,408 (68.84)	206,045 (61.62)	109,107 (63.29)
Black	354,940 (28.00)	123,502 (24.19)	57,574 (22.99)	116,700 (34.90)	57,164 (33.16)
Other Race	76,824 (6.06)	38,617 (7.56)	20,463 (8.17)	11,618 (3.47)	6,126 (3.55)
Hispanic	185,708 (14.65)	68,055 (13.33)	35,026 (13.99)	54,158 (16.20)	28,469 (16.51)
Female	541,467 (42.71)	217,439 (42.59)	103,526 (41.34)	146,550 (43.83)	73,952 (42.90)
Hypertension	1,092,682 (86.19)	430,393 (84.30)	217,557 (86.87)	291,732 (87.25)	153,000 (88.75)
Arteriosclerotic Heart Disease	228,047 (17.99)	104,177 (20.40)	37,585 (15.01)	62,875 (18.80)	23,410 (13.58)
Congestive Heart Failure	378,474	159,417	71,983	99,893	47,181

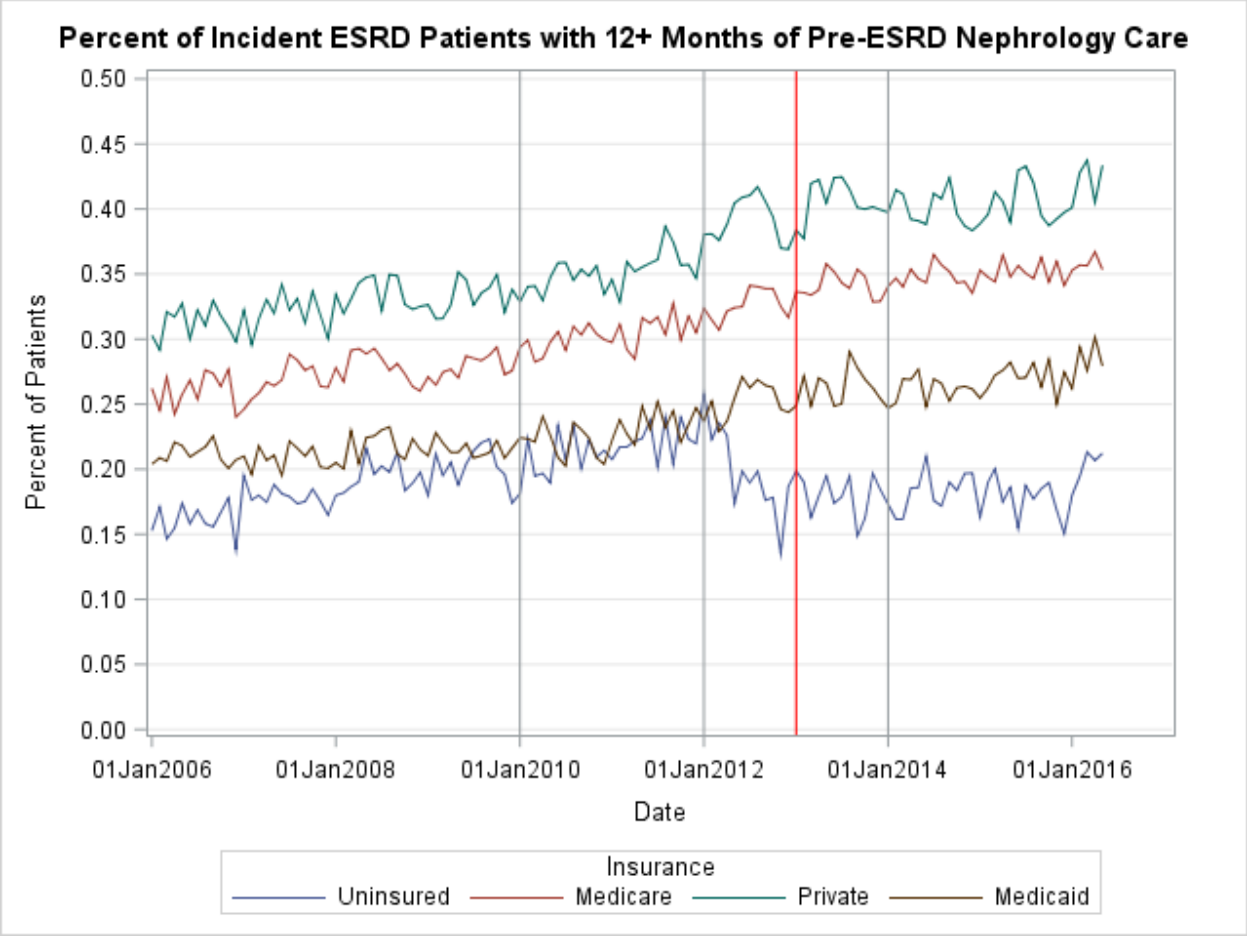
	(29.85)	(31.22)	(28.74)	(29.88)	(27.37)
Peripheral Vascular Disease	154,609 (12.20)	64,605 (12.65)	25,231 (10.07)	45,795 (13.70)	18,978 (11.01)
Private Insurance	291,034 (22.96)	126,729 (24.82)	49,986 (19.96)	81,346 (24.33)	32,973 (19.13)
Medicare	425,801 (33.59)	152,508 (29.87)	98,987 (39.52)	102,748 (30.73)	71,558 (41.51)
Medicaid	326,584 (25.76)	139,165 (27.26)	73,419 (29.32)	76,587 (22.91)	37,413 (21.70)
No Insurance	125,213 (9.88)	48,137 (9.43)	10,444 (4.17)	50,009 (14.96)	16,623 (9.64)
Other Insurance	75,532 (5.96)	35,894 (7.03)	13,220 (5.28)	16,762 (5.01)	9,656 (5.60)
VA Insurance	23,601 (1.86)	8,127 (1.59)	4,389 (1.75)	6,911 (2.07)	4,174 (2.42)
Diabetes	686,310 (54.14)	264,679 (51.84)	139,783 (55.81)	181,740 (54.35)	100,108 (58.07)
No Pre-ESRD[1] Nephrology	658,227 (51.92)	281,412 (55.12)	122,503 (48.91)	168,646 (50.44)	85,666 (49.69)
6-12 Months Pre-ESRD Nephrology	243,814 (19.23)	97,291 (19.06)	46,008 (18.37)	68,690 (20.54)	31,825 (18.46)

[1] End-stage renal disease

12+ Months Pre-ESRD Nephrology	365,724 (28.85)	131,857 (25.83)	81,934 (32.72)	97,027 (29.02)	54,906 (31.85)
Mean (Standard Deviation)					
BMI[2]	29.22 (7.97)	28.92 (7.93)	29.33 (7.91)	29.33 (8.03)	29.77 (8.04)
Age at Incidence	61.19 (16.57)	61.67 (16.92)	62.15 (16.27)	60.06 (16.53)	60.59 (15.91)
GFR (MDRD)[3]	11.75 (5.36)	12.06 (5.46)	11.88 (5.35)	11.40 (5.28)	11.34 (5.15)
HBA1C[4]	7.37 (26.75)	7.27 (34.78)	7.68 (18.60)	7.37 (7.03)	7.48 (12.37)

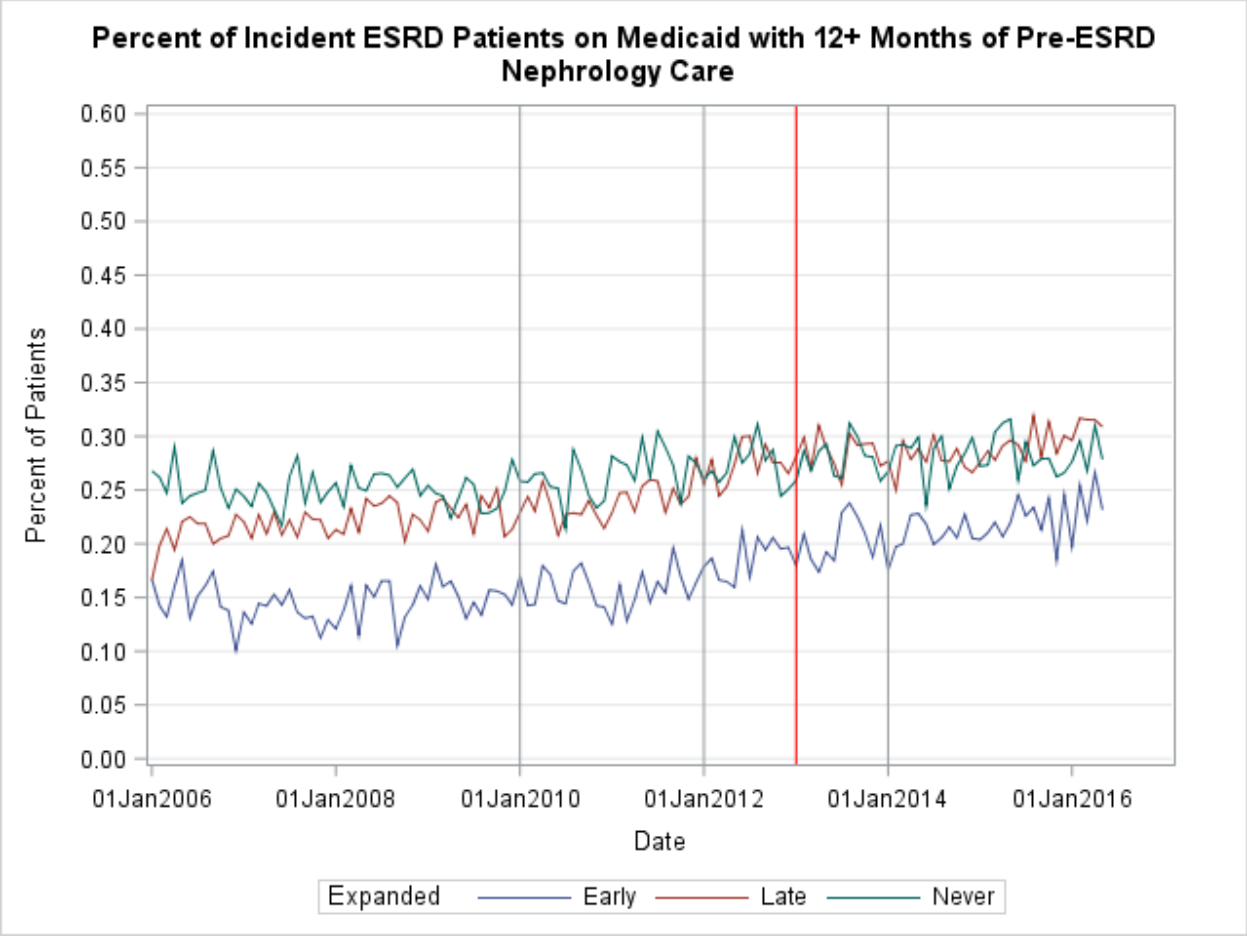
[2] Body-Mass Index
[3] Glomerular filtration rate, calculated using the Modification of Diet in Renal Disease equation
[4] Glycated hemoglobin, aka hemoglobin A1c

Figure 2.1



Vertical lines at 2010 and 2012 indicate period of Early expansion. Vertical line at 2014 indicates late expansion. Red vertical line indicates publishing of 2012 KDIGO guidelines.

Figure 2.2



Vertical lines at 2010 and 2012 indicate period of Early expansion. Vertical line at 2014 indicates late expansion. Red vertical line indicates publishing of 2012 KDIGO guidelines.

Table 2.2: Ordinary Least Squares Results – Estimating the Impact of Medicaid Expansion and the KDIGO Guideline Change on Medicaid Patients

Results for Medicaid Patients Only							
		Early Expansion States		**Late Expansion States**		**All States**	
Years	**Policy Examined**	Coefficient (Standard Error)	P-Value	Coefficient (Standard Error)	P-Value	Coefficient (Standard Error)	P-Value
2009-2013	Post Expansion	-0.030 (0.007)	<.0001				
2012-2013	Post Guideline Change	0.017 (0.006)	0.007				
2013-2014	Post Expansion			0.013 (0.013)	0.323		
2012-2013	Post Guideline Change			0.014 (0.006)	0.011		
2009-2015	Post Expansion					0.000 (0.003)	0.987
2012-2013	Post Guideline Change					0.012 (0.003)	0.001

All above analyses include controls for state fixed effects, time trends, race, and sex (data not shown).

Table 2.3: Difference-in-Differences Results – Estimation of the Impact of Medicaid Expansion and the KDIGO Guideline Change on Different Insurance Groups (2006-2016)

	Medicaid Expansion		**Guideline Change**	
Post (implementation indicator)	-0.059 (0.004)	<0.0001	-0.050 (0.003)	<0.0001
Post*Medicaid	0.055 (0.004)	<0.0001	0.057 (0.003)	<0.0001
Post*Medicare	0.072 (0.004)	<0.0001	0.075 (0.003)	<0.0001
Post*Private	0.071 (0.004)	<0.0001	0.078 (0.004)	<0.0001
Post*VA	0.069 (0.008)	<0.0001	0.076 (0.008)	<0.0001

All above analyses include controls for state fixed effects, time trends, race, and sex (data not shown).

Table 2.4 Multinomial Logit Results – Relative Risk Ratios Examining Insurance Type Following Medicaid Expansion

Insurance	RRR	Std. Err.	z	P>|z|	[95% CI]	
Medicare (Reference Group)						
Uninsured	0.557781	0.007033	-46.3	0	0.544165	0.571737
Other Insurance	0.905526	0.011898	-7.55	0	0.882504	0.929148
VA	0.846358	0.020087	-7.03	0	0.807889	0.886658
Private Insurance	1.025152	0.008765	2.91	0.004	1.008116	1.042475
Medicaid	1.17649	0.009266	20.64	0	1.158468	1.194792

Chapter 3: Variation in Living Donor Kidney Transplantation and the Impact of Medicaid Expansion

3.1 Introduction:

End-stage renal disease is the final stage of chronic kidney disease (CKD), a chronic and progressive illness which affected over 700,000 patients in the US and cost $33.9 billion in 2015 (System 2018). Living donor kidney transplant is the preferred treatment for patients with end-stage renal disease but continues to be significantly less common than deceased donor kidney transplant. End-stage renal disease patients require dialysis or transplantation(Goodman WG 2005). In 2015, 70.2% of prevalent ESRD patients were on dialysis while only 29.6% had a functioning kidney transplant(ADR). Dialysis is quite common despite it being more expensive, riskier for the patient, and providing a lower quality of life compared to transplantation (Whiting, Kiberd et al. 2004, Goodman WG 2005, Tonelli, Wiebe et al. 2011). While deceased donor kidney transplant is preferable for most patients when compared to dialysis, receiving a kidney from a living donor has been established as the optimal treatment for patients (Waterman, Rodrigue et al. 2010, Friedewald and Reese 2012).

The process of receiving a living donor kidney transplant differs from that of receiving a deceased donor kidney transplant in that a patient hoping to receive a living donor kidney transplant generally must find a willing donor, while deceased donor kidney transplant recipients only need to wait once they have gotten cleared to be waitlisted at a kidney transplant center.

Variation in living donor kidney transplant rates across the country have been observed for years, but the factors driving such variation are not entirely understood. Previous work has found that individuals with lower SES and/or minorities tend to have both worse access to healthcare and are less knowledgeable about end-stage renal disease and their various treatment options, including living donor kidney transplant (Patzer, Amaral et al. 2009, Axelrod, Dzebisashvili et al. 2010, Saunders, Cagney et al. 2010, Patzer, Perryman et al. 2012, Mohan, Mutell et al. 2014).

In 2015 there were 18,021 kidney transplants in the US, 5,672 of which were living donor kidney transplants(System 2018). Living donor kidney transplants accounted for just over 30% of total kidney transplants. A 2010 study found that patients living in areas in the top quartile of socioeconomic status (SES) were 76% more likely to receive a living donor kidney transplant than those in the lowest quartile(Axelrod, Dzebisashvili et al. 2010). Another study found that this SES-related disparity grew from 1999 to 2010(Gill, Dong et al. 2015), and SES appears to have a greater impact on black patients' likelihood of living donor kidney transplant than white patients(Gill, Dong et al. 2013). For this reason, improved insurance coverage may be especially impactful for minority patients. Medicaid Expansion increased in enrollment of over 15 million individuals by 2016, with expansion-related enrollment making up ~20% of total Medicaid enrollment in 2016 (Foundation 2016).

The Affordable Care Act (ACA) intended to encourage all states in the US to expand Medicaid to cover a larger range of individuals than had been previously covered. While the ACA was passed in 2010, seven states (CA, CO, CT, DC, MN, NJ, WA) expanded from 2010-2012, and 33 states (including DC) had expanded by 2016 (KFF State Health Facts 2018). 18 states have yet to expand after the Supreme Court case National Federation of Independent

Business (NFIB) v. Sebelius determined that the federal government could not force states to expand Medicaid. Medicaid expansion was intended to increase the number of insured individuals and thereby improve access to care.

While Medicaid Expansion sought to increase insurance coverage, it is not fully understood how this influx of insured patients may have impacted demand for, and rates of, kidney transplantation. Living donor kidney transplant is the preferred treatment option for most end-stage renal disease patients but is not the treatment that most end-stage renal disease patients receive. Typically, living donor kidney transplant recipients are younger, have higher SES, and are less likely to be minorities. Medicaid expansion provided insurance to a group of individuals who occupy an unusual rung on the economic ladder, in that they are better off than prior Medicaid beneficiaries, but still worse off relative to most privately insured patients. This means that we may see an increase number of patients diagnosed with end-stage renal disease or CKD who would want a living donor kidney transplant but may lack the resources to acquire one.

Living donation is less common among minorities and low SES patients (Axelrod, Dzebisashvili et al. 2010, Waterman, Rodrigue et al. 2010, Mohan, Mutell et al. 2014, Hart, Smith et al. 2017), which means that newly insured patients may realize their eligibility for a living donor kidney transplant only to be unable to find a willing and/or able donor. If Medicaid expansion expanded coverage to patients with below average understanding of their treatment options, then it seems likely that such patients would be less likely to understand the options available to them and therefore less likely to find a living donor. To the extent that Expansion leads to increasing numbers of patients being recognized as potential transplant recipients, we may see a decrease in the apparent living donor kidney transplant rate caused by an increasing

denominator (eligible recipients) that is not likely to be counteracted by an increase in living donations. Most living donor kidney transplants occur early on in a patient's course of disease; thus the entire waitlist may be an inappropriate comparison group when looking for changes in living donor kidney transplantation. For this reason, we analyze the likelihood of living donor kidney transplant within one year of waitlisting, rather than include the entire waitlist.

In this study we describe variation in living donor kidney transplant rates and estimate the impact that Medicaid expansion had on patients' likelihood of receiving a living donor kidney transplant. First, we examined living donor kidney transplantation rates at the transplant facility level to illuminate both the extent to which variation in living donor kidney transplantation exists among the >240 kidney transplant centers in the nation as well as to examine what transplant center-level factors may be driving variation in living donor kidney transplant rates. Second, we graph living donor kidney transplantation rates over time at the region level to determine if there are regional trends in living donor kidney transplantation rates. Third, we examine the impact that Medicaid Expansion had on living donor kidney transplantation rates by comparing states based on expansion status. Finally, because the majority of patients who receive a living donor kidney transplant are transplanted soon after listing, our main analysis examines the impact of Medicaid expansion on the likelihood of living donor kidney transplant within 1 year of waitlisting.

3.2 Methods:

3.2.1 Study Population and Data Source

We examined kidney transplant waitlisting events occurring from January 2008 through December 2016 within the United Network for Organ Sharing standard analytic file. When an

individual is waitlisted this creates a record, i.e. a waitlisting event, with a unique identifier, separate from the patient identifier. Patients listed a second time would receive an additional waitlisting event with an identifier different from their first instance of waitlisting.

We selected adult patients listed only for kidney transplant, rather than for multi-organ transplants, (N=405,288). We removed patients who left the list before 2008 or were listed after 2016 (N=371,487). When examining how likelihood of living donor kidney transplant varies based on states' expansion status we included all adult patients who were on the waitlist at any point during our study period (N=371,487). For our graph of center level living donor kidney transplant rates in 2016, we restricted our sample to centers with at least 10 patients on the waitlist in a given year (N=206) because facilities with fewer patients tend to be outliers when considering living donor kidney transplant rates. For our patient-level analysis we further restrict our sample by taking the first listing for any patients listed more than once (N=314,124) and then removing patients who were not on the waitlist for at least 1 day and those who did not have either at least 390 days of follow-up or a kidney transplant within 390 days of listing to get our final sample of N=296,013.

3.2.2 Study Variables

This data includes all patients waitlisted for a kidney transplant in the US and includes demographic and geographic information about patients as well as key treatment information. This provides us with the ability to calculate the rate of living donor kidney transplant among waitlisted patients while also accounting for a range of demographic and clinical characteristics: state of residence, most recent BMI, most recent CPRA, Race/Ethnicity (Non-Hispanic Black,

Hispanic, Non-Hispanic Other), age at waitlisting, blood type, sex, and diabetes. The listing center is included which allows us to look at center-level variation in living donor kidney transplant rates and the state of residence is also included which allows us to examine variation in state policies such as Medicaid expansion.

The main outcome of interest was receipt of a living donor kidney transplant among patients waitlisted within the past year. The main exposure was Medicaid expansion, defined as whether an individual resided in a state that had expanded Medicaid at the time of waitlisting. We examined the impact of Medicaid expansion at both the state and individual levels. For state level analyses we grouped states by timing of expansion: early (expanded 2010-2012), late (expanded 2014-2016), and never (did not expand in our study period). Our focus was on how the likelihood of receiving a living donor kidney transplant varied across transplant centers, UNOS regions, and states, and how likelihood of living donor kidney transplant was impacted by Medicaid expansion.

3.2.3 Statistical Analysis

We graphed the distribution of living donor kidney transplant rates at the transplant center level among prevalent waitlisted patients in 2016 in order to examine the current level of variation across centers, including only centers with at least 10 waitlisted patients (N=206). We examined what potential transplant center factors may drive differences in living donor kidney transplant using bivariable Ordinary Least Squares (deceased donor kidney transplant rates, total transplant rates, percent black patients, average patient age at waitlisting). Examining the association between deceased donor kidney transplant and total transplant rates and living donor kidney transplant rates, at the center level, will illuminate whether higher living donor kidney

transplant rates are related to higher center volume . Next, we examined variation across UNOS regions by graphing the average living donor kidney transplant rate in each region, in each year of our study. This allows us to examine change over time within a given region, variation across regions within a given year, and to see how regional rates change relative to other regions over time. We then graphed living donor kidney transplant rates across states groups by expansion categories: Early (expanded 2010-2012), Late (expanded 2014-2016), and Never (did not expand in our study period). We use a difference in difference analysis to examine whether each period of expansion (Early/Late) was associated with a change in the relationship between expansion states and non-expansion states.

We also examine the likelihood of living donor kidney transplant within 1 year (13 months) of listing, at the patient level using multivariable Ordinary Least Squares. To do this, we take a patient's waitlisting date and examine whether they received a living donor kidney transplant within 390 days of their listing date. This allows us to examine the group of patients who are most likely to be at risk of living donor kidney transplant and to control for a variety of demographic factors (age, sex, race, state, date of waitlisting, diabetes, BMI, CPRA) in order to get a more precise estimate of the impact that Medicaid expansion has had on waitlisted patients. We clustered standard errors at the state level, because Medicaid expansion differs from state to state and a given transplant center may treat patients from multiple states with different expansion policies.

3.3 Results:

States that expanded Medicaid had higher percentages of white, Hispanic and other patients but a lower percentage of black patients than non-Expansion states (Table 3.1). Diabetes, BMI,

and age at waitlisting increased in both groups, while CPRA declined. The number of patients on the waitlist increased from 2008 to 2016 in both groups.

The distribution of living donor kidney transplant rates (Figure 3.1) suggests that while most centers performed relatively low rates of living donor kidney transplants, some centers vastly outperform others (Range: 0-19.3% of waitlisted patients in 2016). The mean yearly rate of living donor kidney transplants at a transplant center in 2016 was 3.8/100 waitlisted patients.

The results of our center-level analysis (Table 3.2) found that the rate of LDKTtxs was positively correlated with both the rate of deceased donor kidney transplant and the rate of total Txs (both $p<0.001$). The percentage of waitlisted patients at a given center that were black was negatively associated with living donor kidney transplant rates ($p<0.001$). Average age of patients at waitlisting at a center was not associated with living donor kidney transplant rates ($p=0.896$).

Our graph of UNOS region averages (Figure 3.2) shows that centers in region 1 average roughly twice the rate of living donor kidney transplants as those in regions 3 or 11 over our study period. There is more variation across regions within a given year than within regions over time, suggesting that despite the overall downward trend in living donor kidney transplant rates, the relative positioning of regions remains fairly stable. Figure 3.2 shows all regions see living donor kidney transplant rates trending downward, and Figure 3.3 shows that this is true when looking at states by when/whether they expanded Medicaid. Figure 3.3 shows that while all expansion groups are trending downwards, Late expansion states consistently had the highest rates of living donor kidney transplant while Early and Never expansion states follow a similar trajectory prior to Early expansion and then diverge. Late and Never states seemed to be diverging prior to Late expansion but converge slightly afterwards. This is confirmed by our

difference in difference results seen in Table 3.3. We compare Early expanding state to Never states, considering the periods of 2008-2011 and 2012-2016, and see that while both groups saw a decline from pre to post, Early states declined ~ 0.2 percentage points relative to Never states. We conduct a similar analysis comparing Late and Never states before and after 2014. We find that Late states declined ~0.3 percentage points relative to Never states.

When we examine the likelihood of receiving a living donor kidney transplant at the patient level using a model controlling only for listing date, we find that expansion is associated with a decrease in the likelihood of living donor kidney transplant within the first year of 1.9 percentage points ($p<0.0001$). When we add in demographic controls and cluster standard errors at the state level we find similar results (Table 3.4): -2.3 ($p<0.001$) percentage points. Nonwhite patients and females were also less likely to receive a living donor kidney transplant: -10.9 percentage points for blacks, -7.1 percentage points for Hispanics, -8.7 percentage points for other racial groups, and -1.1 for females (all significant at $p<0.0001$). Age at waitlisting and diabetes were also negatively associated with living donor kidney transplant: -0.2 and -3.4 percentage points, respectively (both significant at $p<0.0001$).

3.4 Discussion:

The rate of living donor kidney transplants performed at a transplant center in 2016 varied considerably across the more than 200 transplant centers in the nation who saw at least 10 waitlisted patients. Furthermore, this variation can also be seen across UNOS regions and the large variability has been a consistent fact in the US over our study period. Living donor kidney transplant rates are higher at higher volume transplant centers which may reflect differences in practice patterns but may also be related to differing patient populations and/or preferences.

Living donor kidney transplant rates are unsurprisingly lower at centers with higher proportions of black patients. This is to be expected because black patients are far less likely to receive living donor kidney transplants than white patients.

Our results show that Medicaid expansion was associated with a decline in the rate of living donor kidney transplant among waitlisted patients, but this should be interpreted cautiously. Expansion intended to increase access to care for disadvantaged individuals which, while an important goal, would not necessarily lead to an increase in living donor kidney transplant rates. Those individuals who gained coverage as a result of expansion are less likely than average to have the support network or resources necessary to find a living donor. This means that we should see the increased number of patients eligible for a living donor kidney transplant as an indication of improving access, while the decrease in living donor kidney transplant rates is likely a mechanical result of increasing the denominator of eligible patients without doing much to the numerator of living donor kidney transplant recipients. The fact that Medicaid expansion is associated with a decrease in LKDTx rates is consistent with the idea that expansion increased insurance coverage of relatively disadvantaged individuals. This finding suggests that there are many patients and/or providers who would benefit from additional educational interventions and efforts to encourage living donor kidney transplant.

Regional variation in LDKT suggests that initiatives to encourage living donation may be beneficial, especially in regions that are lagging behind in living donor kidney transplant. The fact that regional variation appears relatively stable over time suggests that there may be underlying factors driving this variation that have yet to be addressed. While it is not well understood what factors drive this variation, it is clear that many regions have room for

improvement. Within-region variation is also significant which suggests that localized factors are important.

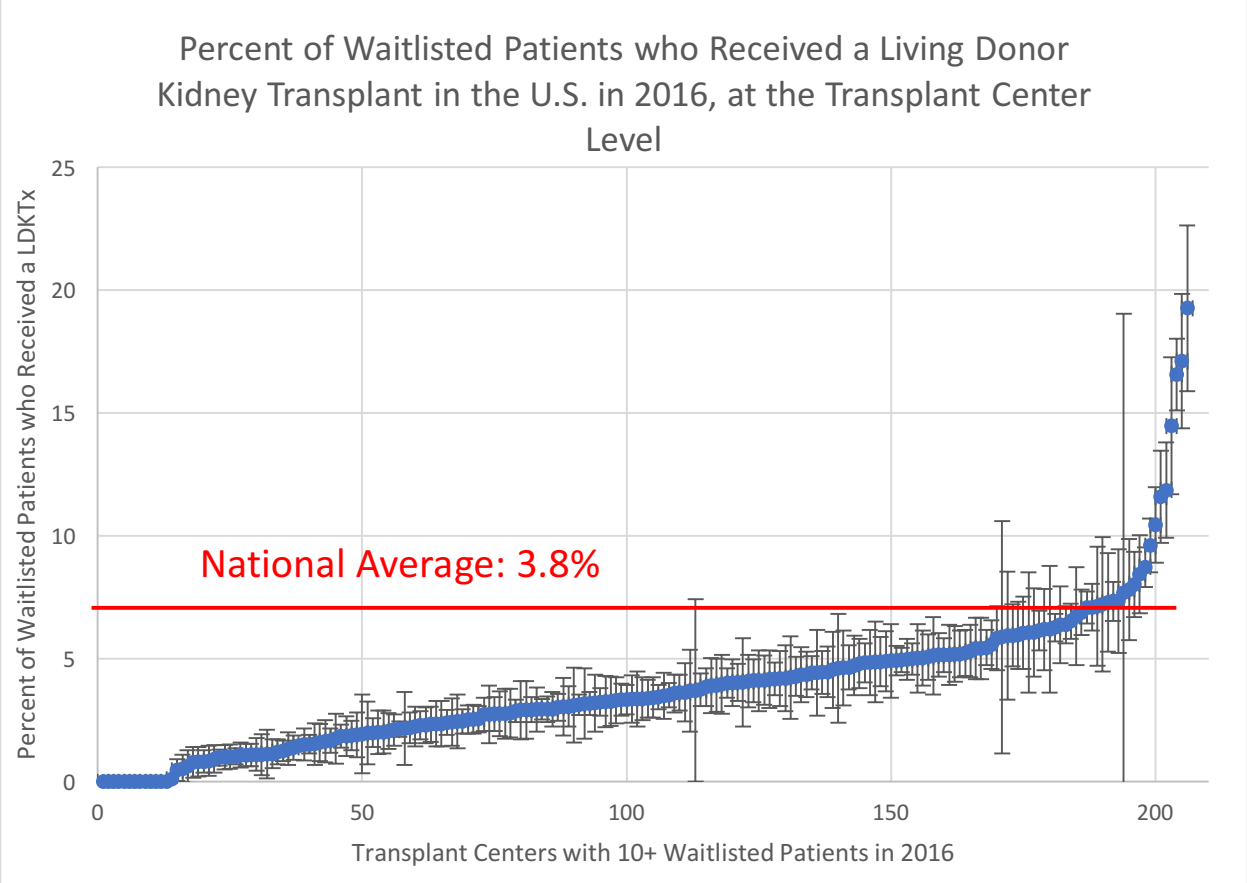
Medicaid expansion has changed the health insurance landscape across the country and it is important to understand the impact that is has had on kidney transplantation. Living donor kidney transplant is the preferred treatment for end-stage renal disease patients and this study suggests that increased insurance coverage is not enough to improve access to this life-saving treatment for low SES individuals in the US. The large amount of variation seen across transplant centers is a cause for concern when we consider the goal of equitable treatment for patients across the nation. However, such variation also serves as a reminder that there remains much room for improvement in the treatment of end-stage renal disease patients. This is an issue that is likely to increase in importance as our end-stage renal disease population continues to grow by around 20,000 individuals per year (USRDS ADR).

Table 3.1 (Descriptive Statistics)

	2008 Full Sample (N=92,760)	**2008 Expansion States (N=62,197)**	**2008 Non-Expansion States (N=30,563)**	**2016 Full Sample (N= 111951)**	**2016 Expansion States (N= 72096)**	**2016 Non-Expansion States (N= 39855)**
Race/Ethnicity, n (%)						
Non-Hispanic White	37,067 (37.96)	25,801 (41.48)	11,266 (36.87)	41,588 (37.15)	28,024 (38.88)	13,564 (34.03)
Non-Hispanic Black	31,527 (33.99)	18,608 (29.92)	12,919 (42.27)	36326 (32.45)	19447 (26.97)	16879 (42.35)

Hispanic	16,002 (17.25)	10,866 (17.47)	5,136 (16.80)	22362 (19.97)	15050 (20.87)	7312 (18.35)
Non-Hispanic Other	8,164 (8.80)	6,922 (11.13)	1,242 (4.06)	11675 (10.43)	9575 (13.28)	2100 (5.27)
Blood Type, n (%)						
A	27,486 (29.63)	18,572 (29.86)	8,914 (29.17)	32936 (29.42)	21560 (29.90)	11376 (28.54)
B	14,738 (15.89)	9,972 (16.03)	4,766 (15.59)	17799 (15.90)	11337 (15.72)	6462 (16.21)
AB	2,914 (3.14)	2,041 (3.28)	873 (2.86)	3298 (2.95)	2210 (3.07)	1088 (2.73)
O	47,622 (51.34)	31,612 (50.83)	16,010 (52.38)	57,918 (51.73)	36,989 (51.31)	20,929 (52.52)
Female, n (%)	38,404 (41.40)	25,328 (40.72)	13,076 (42.78)	43920 (39.23)	28077 (38.94)	15843 (39.75)
Diabetes, n (%)	35,427 (38.19)	23,932 (38.48)	11,495 (37.61)	50341 (44.97)	32446 (45.00)	17895 (44.90)
BMI, mean (SD)	28.26 (5.83)	28.19 (5.91)	28.38 (5.66)	29.16 (5.67)	29.03 (5.74)	29.39 (5.54)
CPRA, mean (SD)	23.31 (36.89)	22.21 (36.17)	25.55 (38.23)	20.52 (33.94)	19.80 (33.40)	21.83 (34.88)
Age at Waitlisting, mean (SD)	49.87 (13.07)	50.37 (13.11)	48.83 (12.92)	51.53 (12.76)	51.88 (12.80)	50.90 (12.68)

Figure 3.1 Percent of Waitlisted Patients Who Received a Living Donor Kidney Transplant in the US in 2016, at the Transplant Center Level



Vertical bars represent 95% confidence intervals

Table 3.2 Bi-Variable OLS Results: estimating the association between living donor kidney transplant and various facility-level characteristics

Bi-Variable OLS Results: estimating the association between living donor kidney transplant and various facility-level characteristics					
	Coefficient	SE	P-value	95% CI	
Deceased Donor Kidney Transplant Rate	0.082	0.010	0.000	0.061	0.102
Proportion of Waitlisted Patients that are Black	-0.047	0.003	0.000	-0.053	-0.041
Average Age at Listing	-0.000	0.000 203	0.896	-0.000	0.000
Total Tx Rate	0.213	0.008	0.000	0.198	0.228

Figure 3.2

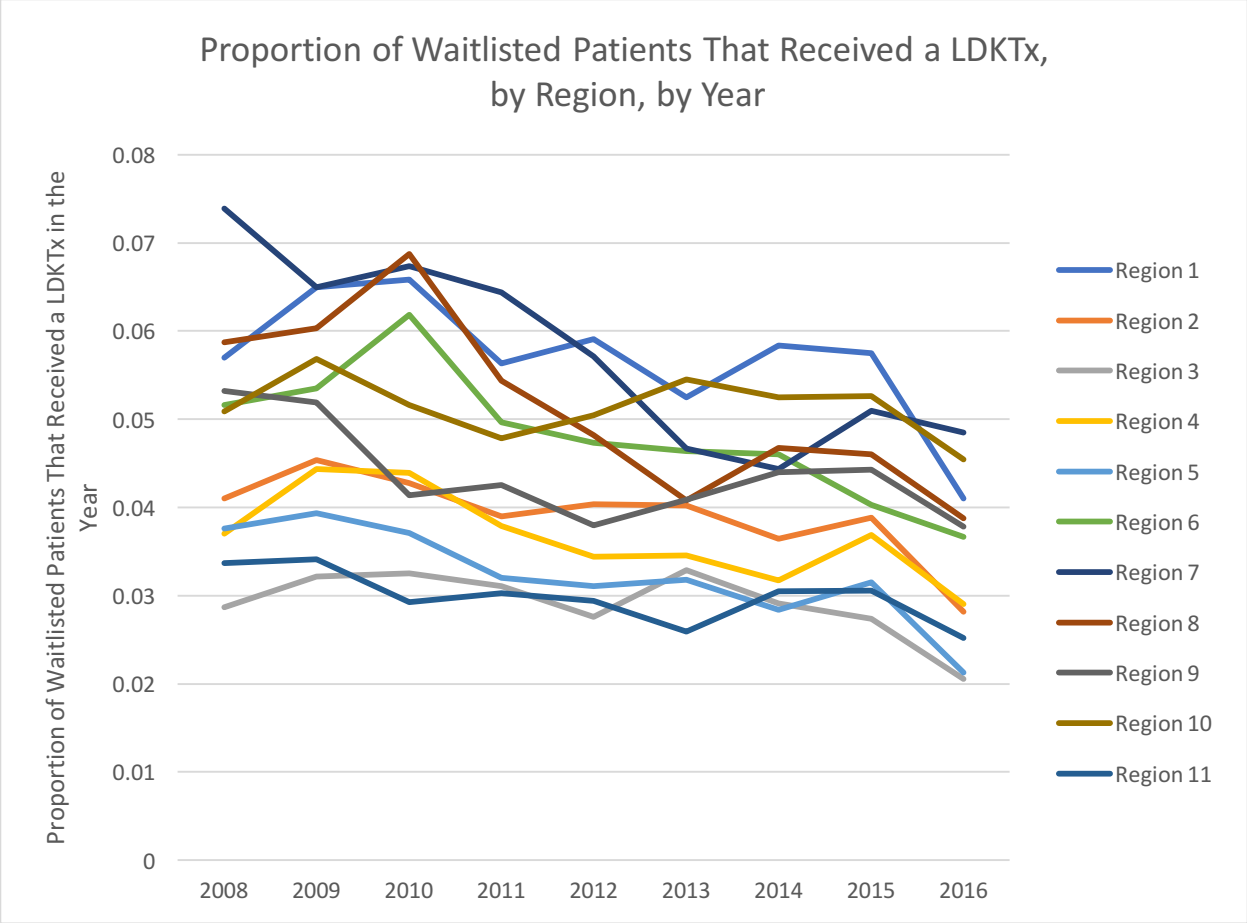
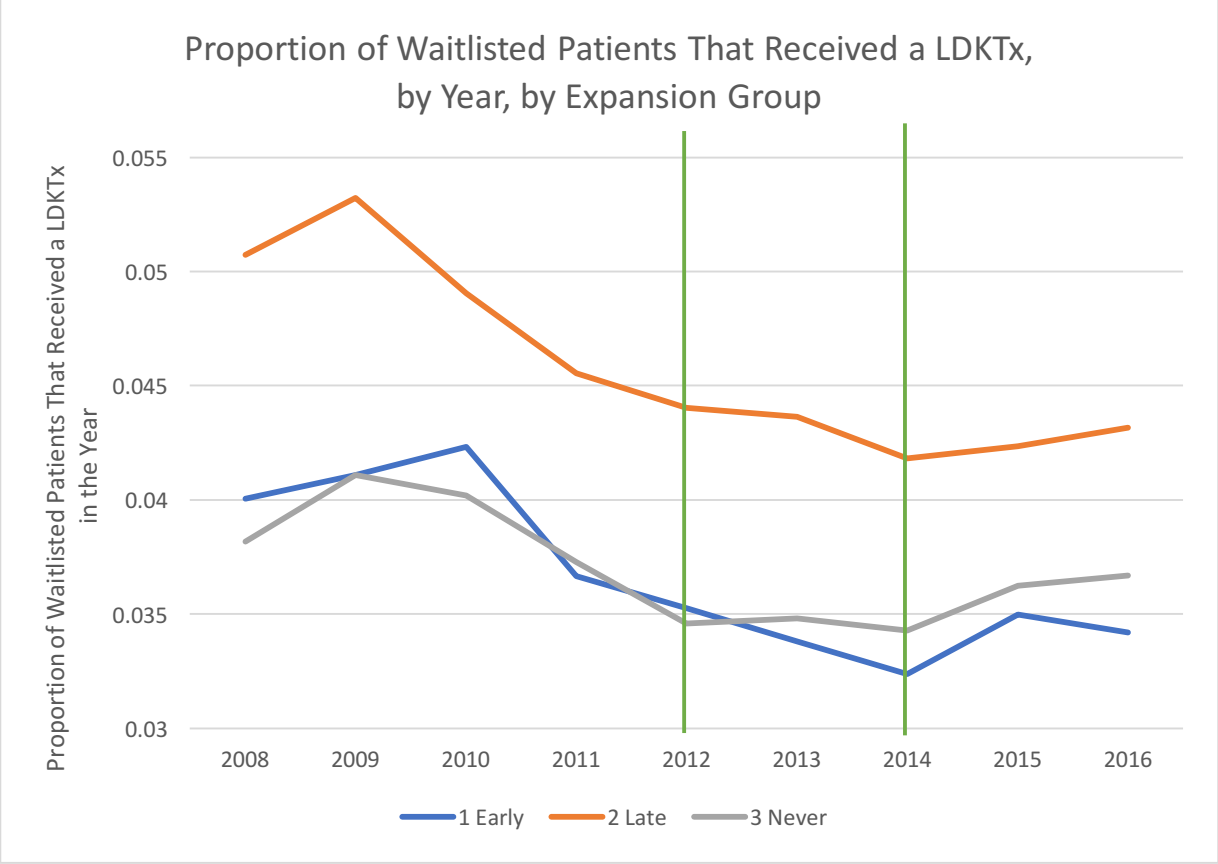

Proportion of Waitlisted Patients That Received a LDKTx, by Region, by Year
Proportion of Waitlisted Patients That Received a LDKTx in the Year
0.08
0.07
0.06
0.05
0.04
0.03
0.02
0.01
0
2008
2009
2010
2011
2012
2013
2014
2015
2016
Region 1
Region 2
Region 3
Region 4
Region 5
Region 6
Region 7
Region 8
Region 9
Region 10
Region 11

Figure 3.3: Proportion of Waitlisted Patients That Received a Living donor kidney transplant, by Year, by Expansion Group



Early Expansion ends at 2012, indicated by the first green line. Late Expansion occurs at the second green line in 2014.

Table 3.3 Difference-in-Difference Analysis of Living Donor Kidney Transplant Rates in Expansion vs Non-Expansion States

Expansion Status	**2008-2011**	**2012-2016**	**Post-Pre**	**D-D**
Never	0.039	0.035	-0.004	
Early	0.040	0.034	-0.006	-0.002**
	2008-2013	**2014-2016**	**Post-Pre**	**D-D**
Never	0.038	0.036	-0.002	
Late	0.048	0.042	-0.005	-0.003**

* = P<0.1, ** = P<0.05

Here we see that, relative to states that do not expand Medicaid, we see both Early and Late expansion states see rates of living donor kidney transplant declining faster than those in states that never expand.

Table 3.4 The Impact of Medicaid Expansion on the Likelihood of Receiving a Living Donor Kidney Transplant Within 1 Year of Waitlisting

Parameter	**Estimate (Standard Error)**	**P-value**
Waitlisted In State That Has Expanded (Y/N)	-0.023 (0.005)	<0.001
Most Recent BMI[5]	-0.002 (0.000)	<0.001
Most Recent CPRA[6]	-0.001 (0.000)	<0.001
Race/Ethnicity		
Non-Hispanic Black	-0.109 (0.004)	<0.001
Hispanic	-0.071 (0.004)	<0.001
Non-Hispanic Other	-0.087 (0.005)	<0.001
Age at Waitlisting	-0.002 (0.000)	<0.001
Blood Type		
A	0.023	<0.001

[5] Body Mass Index
[6] Calculated Panel-Reactive Antibody

	(0.002)	
B	0.010 (0.001)	<0.001
AB	0.025 (0.003)	<0.001
Female	0.011 (0.002)	<0.001
Diabetes	-0.034 (0.002)	<0.001
Waitlisting Date	0.000 (0.000)	<0.001

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Chapter 4: The Interaction Between the New Kidney Allocation System and Medicaid Expansion on Access to Living Donor Kidney Transplantation

4.1 Introduction

End-stage renal disease (ESRD) is the final stage of chronic kidney disease (CKD), a chronic and progressive illness which affected over 700,000 patients in the US and cost $33.9 billion in 2015 (System 2018). While patients become eligible for Medicare after being diagnosed with ESRD, the care of these patients prior to reaching the end-stage of the disease is not covered by Medicare, leaving many individuals unable to afford preventive care. Studies have shown that patients who see nephrologists prior to being diagnosed with ESRD (i.e. before their kidneys completely fail) tend to receive more education about their disease and their treatment options (Mehrotra, Marsh et al. 2005, Patzer, Amaral et al. 2012, Patzer, Sayed et al. 2013, Gillespie, Morgenstern et al. 2015). Earlier referral to a nephrologist is associated with higher likelihood of

receiving a transplant (Maripuri, Ikizler et al. 2013). For this reason, insurance coverage may be influential in whether a patient receives a living donor kidney transplant (LDKTx).

The Affordable Care Act (ACA) intended to expand Medicaid to cover a larger range of individuals than had been previously covered. The ACA was passed in 2010 and seven states (CA, CO, CT, DC, MN, NJ, WA) expanded Medicaid from 2010-2012, while 20 states (including DC) expanded in 2014 and 6 states have expanded since 2014 (KFF State Health Facts 2018). The Supreme Court case National Federation of Independent Business (NFIB) v. Sebelius determined that the federal government could not force states to expand Medicaid, and 18 states had yet to expand as of 2016. While Medicaid expansion should increase demand for services, it is not clear whether the supply of LDKTx will grow proportionately.

Medicaid expansion aimed to improve access to care by providing millions of low-SES Americans with health insurance. (PAPER 1) as well as others (Sommers, Baicker et al. 2012, Boudreaux, Barath et al. 2018, Brown, Tilford et al. 2018, Nikpay, Tebbs et al. 2018) have shown that more individuals have in fact received coverage since some states expanded Medicaid. The question remains as to how much this increased population of insured individuals will impact patterns of care across the country.

The Medicaid population has historically had a significantly larger proportion of non-whites than the overall population. In 2016, the US was 76.9% white(Bureau 2016), while whites made up only 43% of Medicaid beneficiaries(Foundation 2016). If Medicaid Expansion has increased coverage to a group that looks similar demographically to the pre-existing Medicaid beneficiaries, then expansion has a large potential to impact the care of minority patients.

KAS had the intended effect of reducing disparities in access to deceased donor kidney transplant (DDKTx) nationwide (Melanson, Hockenberry et al. 2017). It led to white and non-

white patients having similar likelihood of receiving a DDKTx once they had reached the kidney waitlist. Medicaid Expansion had the potential to increase access to the waitlist. Paper 1 showed that expansion led to increased nephrology care prior to ESRD start and such an increase may very well lead to more patients making it through the complicated and lengthy process required to be added to the waitlist.

While many papers have examined the impact of KAS on DDKTx(Colovai, Ajaimy et al. 2017, Hahn, Mackey et al. 2017, Hart, Gustafson et al. 2017, Hickey, Zheng et al. 2017, Melanson, Hockenberry et al. 2017), which was its intended target, the indirect impact it may have had on LDKTx remains unknown. LDKTx is the preferred treatment for ESRD but requires more resources and effort to acquire a willing donor. Patients who receive increased priority for a DDKTx may feel less inclined to bother searching for a living donor and therefore KAS may indirectly impact LDKTx rates. A given patient will receive either a living or a deceased kidney for a given transplant and therefore LDKTx and DDKTx likely act as substitutes. For this reason, we expect that changes in the allocation of DDKTx will impact the demand for LDKTx via a substitution effect(NELSON 2003, HOWARD 2011, Crost B 2012, FERNANDEZ, HOWARD et al. 2012, SCHNIER, MERION et al. 2018).

Non-white patients have historically received far fewer LDKTxs than white patients(System 2018). KAS Increased receipt of a DDKTx for many minority patients and therefore we may see groups with low LDKTx rates becoming even less likely to receive LDKTxs. For this reason, it is important to understand the effects that these policies have had both individually and in combination. Both policies aimed to benefit traditionally disadvantaged groups and, to the extent that those groups overlap, they likely played a role in how effective the other policy was.

4.2 Methods

We examined kidney transplant waitlisting events occurring from January 2008 through December 2016 within the United Network for Organ Sharing standard analytic file. We selected adult patients listed only for kidney transplant, rather than for multi-organ transplants, (N=405,288). We removed patients who left the list before 2008 or were listed after 2016 (N=371,487). We kept only a patients initial waitlisting event (N=314,124). We then excluded patients who were transplanted prior to listing and those who had less than 1 year of follow-up without a transplant, leaving our final cohort of N=296,013 waitlisting events for kidney transplant. We categorized patients as non-Hispanic white, non-Hispanic black, Hispanic, and other non-Hispanic patients.

When considering the impact that these policies may have, it is important to understand the racial makeup of the states that did or did not expand Medicaid. If expansion and non-expansion states are facing parallel trends in terms of racial composition, we should be able to get accurate estimates of the policies effects. Non-parallel trends could potentially bias our results. For this reason, we compare the racial makeup of expansion states to that of non-expansion states by looking at their respective ESRD populations (from USRDS), waitlisted populations (from UNOS), and their total population (from publicly available CPS data).

Our first model includes indicators for both Medicaid Expansion and KAS, as well as interactions between KAS and different racial/ethnic groups. This model also includes controls for state fixed effects, secular trends, and patient characteristics (BMI, CPRA, age at waitlisting, sex, diabetes). We use this model to estimate the impact of these two policies on the likelihood of receiving a LDKTx ever (for this outcome we use the sample prior to restricting based on

follow up time or time to tx), receiving a LDKTx within a year of listing, and the likelihood of receiving a DDKTx within a year of listing. These models also include controls for state fixed effects, secular trends, and patient characteristics (BMI, CPRA, age at waitlisting, sex, blood type, diabetes).

We estimate the impact of both policy changes on the likelihood of receiving a LDKTx within one year using both a triple interaction model (examining the interaction between Medicaid Expansion, KAS, and race) and stratified analyses looking at each racial group separately. These models also include controls for state fixed effects, secular trends, and patient characteristics (BMI, CPRA, age at waitlisting, sex, blood type, diabetes).

We estimate the impact of both policy changes on the likelihood of receiving a LDKTx within one year among Medicaid beneficiaries using a triple interaction model. This model also includes controls for state fixed effects, secular trends, and patient characteristics (BMI, CPRA, age at waitlisting, sex, blood type, diabetes).

4.3 Results

Whether we compare the racial makeup of expansion states to that of non-expansion states by looking at their respective ESRD populations (from USRDS), waitlisted populations (from UNOS), or their total population (from US Census), we find consistently that expansion states were less diverse than non-expansion states. Figure 4.1 shows trends in racial composition over the period of 2011-2014 from the US Census and shows that while expansion and non-expansions differ in their racial make-up, the difference appears consistent over the period of time leading up to implementation of both Medicaid Expansion and the new KAS.

Expansion states contained more white patients than non-expansion states both pre- and post-KAS: 44 vs 39% pre-KAS and 45 vs 40% post-KAS (Table 4.1). Correspondingly, expansion states also had fewer black patients than non-expansion states in both periods: 27 vs 39% pre-KAS and 24 vs 37% post KAS. Expansion states did have slightly more Hispanic patients than non-expansion states (17.4 vs 17.3% pre-KAS and 19.7 vs 18.2 post-KAS) and roughly double the proportion of other racial groups seen in non-expansion states (11 vs 4% pre-KAS and 12 vs 6% post-KAS). Other covariates were largely similar across expansion and non-expansion states (Table 4.1).

Medicaid expansion was associated with a decreased likelihood of receiving a LDKTx both within one year and ever (Table 4.2), -1.9 and -2.8 percentage points, respectively (both $p<0.001$). KAS was associated with a decrease in the likelihood of LDKTx ever for black (2.7 percentage points), Hispanic (3 percentage points) and other races (2.5 percentage points), all $p<0.001$. KAS was associated with a decreased likelihood of LDKTx within one year of 4.2, 3.2, and 3.2 percentage points for black, Hispanic, and other patients (all $p<0.001$). Medicaid expansion was non associated with the likelihood of receiving a DDKTx within one year ($p=0.943$). KAS had a positive impact on the likelihood of DDKTx within one year for all non-white patients: 4.8, 3.1, and 1.8 percentage points for black ($p<0.001$), Hispanic ($p=0.011$), and others ($p=0.099$), respectively.

Our triple interaction model (Table 4.3) using our full sample shows that being nonwhite is associated with a decreased likelihood of LDKTx ($p<0.001$). KAS had a negative impact on the likelihood of LDKTx for all nonwhite patients ($p<0.001$ for blacks and others, $p=0.02$ for Hispanics). Medicaid Expansion was associated with a decreased likelihood of LDKTx for all non-white patients as well ($p<0.01$). Our triple interaction term showed that being nonwhite and

listed post-KAS and in an expansion state was associated with an increased likelihood of LDKTx (relative to nonwhite patients post-KAS in non-expansion states), and this effect was statistically significant for black ($p<0.001$) and other ($p=0.052$) patients, but not for Hispanic patients ($p=0.176$).

Our stratified models (Table 4.3) show that Medicaid expansion was consistently associated with a decreased likelihood of LDKTx within one year: 3.4, 0.8, and 3.4 for white ($p<0.001$), black ($p=0.021$), and Hispanic ($p<0.001$) patients, respectively. KAS was associated with decrease of 4.6 percentage points for white patients ($p<0.001$), 1.7 percentage points for black patients ($p<0.001$) and 2.6 percentage points for Hispanic patients ($p=0.022$). The interaction of Medicaid expansion and KAS had a positive effect on the likelihood of LDKTx within one year for both white ($p=0.239$) and black ($p=0.176$) patients. These effects are similar in magnitude: 1.2 and 0.9 percentage points, respectively.

Our triple interaction model looking at Medicaid beneficiaries only (Table 4.4) shows that non-white race remains highly significant and associated with decreased likelihood of LDKTx within one year (all $p<0.01$). Among Medicaid beneficiaries, all interaction terms lose statistical significance ($p>0.15$).

4.4 Discussion

Medicaid Expansion and the new KAS are both associated with a decreased likelihood of receiving a LDKTx. This is an unintended consequence of these policies but it is important to understand when discussing how these policies have impacted patients. Policies are necessarily implemented without a full understanding of how they may interact with the rest of the health

policy landscape but it is crucial to study such interactions in order to determine how policies can be improved.

Medicaid Expansion has been successful in increasing the number of patients that have health insurance, but our results show that this is not leading to increased rates of LDKTx. While insurance is a necessary first step, it is important to understand the ways in which insurance alone is not sufficient to achieve equitable health care. The fact that we do not see declines in likelihood of LDKTx among Medicaid beneficiaries as a result of expansion suggests that Medicaid Expansion has succeeded in providing a similar quality of care to a larger group of patients.

The KAS made notable improvements in reducing racial disparities in access to DDKTx among waitlisted patients. At the same time, our results suggest that KAS was also associated with a decreased likelihood of receiving an LDKTx among minority patients. This is likely attributable to the fact that minority patients who received increased priority for a DDKTx may now see a LDKTx as a less desirable option. Acquiring a living donor requires both a sizeable amount of effort as well as potentially causing a larger emotional burden for patients who request donations from family or friends. Patients may choose to avoid the emotional or logistical work if they feel likely to receive a DDKTx but this is likely suboptimal for both the individual patient as well as the health care system as a whole. LDKTx has been consistently shown to produce better outcomes when compared to DDKTx and it is important that providers continue to encourage LDKTx among all eligible patients.

While DDKTx is a suboptimal treatment compared LDKTx, it remains preferable to remaining on dialysis. For this reason, shifting deceased kidneys to minority patients rather than white patients may result in improving net outcomes among ESRD patients. White patients have

historically gotten the vast majority of LDKTx and therefore it seems likely that white patients will, on average, be more able to substitute towards LDKTx after receiving a DDKTx becomes less likely. At the same time, minorities are much less likely to be able to acquire a living donor and therefore may not be as able to substitute LDKTx for DDKTx. This means that allocating more deceased kidneys to minorities has the potential to benefit patients who are unlikely to receive a living donor without having a large negative effect on white patients who have more ability to acquire a living donor.

Stratified models show both white and black patients see a positive effect on likelihood of LDKTx from being post-KAS in an expansion state. Though these effects are not statistically significant, they are likely due to the fact that KAS had a stronger impact on DDKTx in non-expansion states. Non-expansion states have larger populations of non-white patients, meaning KAS changed allocation more than in states with less diverse populations. This means that the negative impact of KAS on likelihood of LDKTx was lessened in states that expanded compared to states that did not. The lessening of a negative effect results in the positive coefficient.

Our triple-interaction model looking at just Medicaid patients finds that no covariates were significantly associated with likelihood of LDKTx other than the race variables. This is consistent with the idea that Medicaid expanded coverage to more people, but that Medicaid coverage is still suboptimal compared to care received by other insured patients.

We have historically seen the ESRD population growing at a faster rate than deceased donation which has led to a worsening shortage of organs(System 2018). LDKTx has the potential not only to provide the recipients with better outcomes, but also to lessen the strain on the DDKTx allocation system. It is important to keep in mind that as we improve access to care for low SES and minority patients, we want to avoid funneling such patients towards lower-

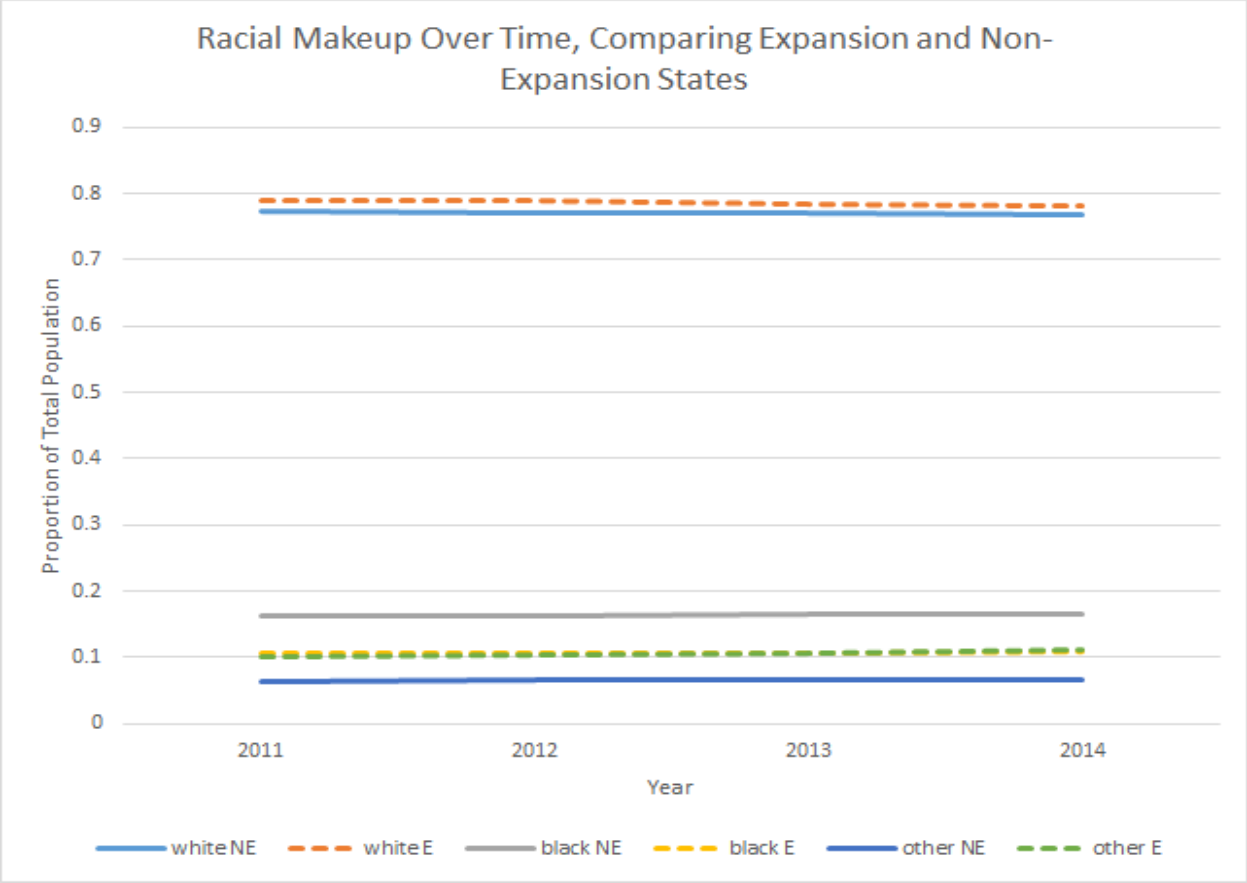
quality care. White patients have historically received far more LDKTxs than other racial groups and our results suggest that recent policies are not working to address this disparity. Living donation is voluntary which makes it less amenable to policy changes. For this reason, it is crucial that efforts continue to work to encourage and promote LDKTx, to both patients and providers, as the preferred treatment option for ESRD.

Table 4.1

	Pre-KAS Full Sample (N=244,549)	**Pre-KAS Expansion States (N=158,256)**	**Pre-KAS Non-Expansion States (N=86,293)**	**Post-KAS Full Sample (N=51,464)**	**Post-KAS Expansion States (N=32,661)**	**Post-KAS Non-Expansion States (N=18,803)**
Race/Ethnicity, n (%)						
Non-Hispanic White	103,810 (42.45)	69,839 (44.14)	33,971 (39.37)	21,999 (42.75)	14,563 (44.59)	7,436 (39.55)

Non-Hispanic Black	76,697 (31.36)	43,161 (27.27)	33,536 (38.86)	14,627 (28.42)	7,737 (23.69)	6,890 (36.64)
Hispanic	42,530 (17.39)	27,604 (17.44)	14,926 (17.30)	9,855 (19.15)	6,442 (19.72)	3,413 (18.15)
Non-Hispanic Other	21,512 (8.80)	17,652 (11.15)	3,860 (4.47)	4,983 (9.68)	3,919 (12.00)	1,064 (5.66)
Blood Type, n (%)						
A	77,916 (31.86)	50,926 (32.18)	26,990 (31.28)	17,023 (33.08)	10,923 (33.44)	6,100 (32.44)
B	36,969 (15.12)	24,098 (15.23)	12,871 (14.92)	7,476 (14.53)	4,750 (14.54)	2,726 (14.50)
AB	8,948 (3.66)	6,045 (3.82)	2,903 (3.36)	2,033 (3.95)	1,327 (4.06)	706 (3.75)
O	120,716 (49.36)	77,187 (48.77)	43,529 (50.44)	24,932 (48.44)	15,661 (47.96)	9,271 (49.31)
Female, n (%)	97,830 (40.00)	62,564 (39.53)	35,266 (40.87)	19,479 (37.85)	12,176 (37.28)	7,303 (38.84)
Diabetes, n (%)	101,502 (41.51)	65,632 (41.47)	35,870 (41.57)	22,584 (43.88)	14,394 (44.07)	8,190 (43.56)
BMI, mean (SD)	28.64 (5.72)	28.54 (5.79)	28.81 (5.60)	28.97 (5.50)	28.87 (5.57)	29.13 (5.35)
CPRA, mean (SD)	20.92 (34.75)	20.11 (34.20)	22.42 (35.70)	17.71 (31.40)	16.70 (30.58)	19.46 (32.70)
Age at Waitlisting, mean (SD)	51.05 (13.15)	51.48 (13.18)	50.26 (13.06)	52.06 (13.14)	52.34 (13.15)	51.56 (13.11)

Figure 4.1 Racial Makeup Over Time, Comparing Expansion and Non-Expansion States



This figure does not include data for Hispanics because the CPS data separates race and ethnicity, meaning Hispanic individuals are included in whichever racial group they identify themselves as.

Table 4.2: The Impact of Medicaid Expansion and KAS on the Likelihood of Receiving a KTx

	y= LDKTx ever		y= LDKTx within 1 year of listing		y= DDKTx within 1 year of listing	
	Estimate	**Pr > |t|**	**Estimate**	**Pr > |t|**	**Estimate**	**Pr > |t|**
Impact of Medicaid Expansion	-0.028	<0.001	-0.019	<0.001	-0.005	0.943
Impact of KAS	-0.035	<0.001	-0.005	0.332	0.004	0.490
Non-Hispanic Black	-0.135	<0.001	-0.102	<0.001	0.001	0.763
Hispanic	-0.077	<0.001	-0.065	<0.001	0.005	0.417
Non-Hispanic Other	-0.098	<0.001	-0.081	<0.001	-0.010	<0.001
KAS*Black	-0.027	<0.001	-0.042	<0.001	0.048	<0.001
KAS*Hispanic	-0.030	<0.001	-0.032	<0.001	0.031	0.011
KAS*other	-0.025	<0.001	-0.032	<0.001	0.018	0.099

These models also include controls for state fixed effects, secular trends, and patient characteristics (BMI, CPRA, age at waitlisting, sex, blood type, diabetes).

Table 4.3: Triple-Interaction vs Stratified Models

Examining the Impact of Medicaid Expansion and KAS on the Likelihood of LDKTx Within 1 Year of Listing

	Triple Interaction Model Using full sample		White		Black		Hispanic	
Parameter	**Estimate**	**Pr > |t|**	**Estimate**	**Pr > |t|**	**Estimate**	**Pr > |t|**	**Estimate**	**Pr > |t|**
Impact of Medicaid Expansion	-0.004	0. 620	-0.034	<0.001	-0.008	0.021	-0.034	<0.001
Impact of KAS	-0.004	0.594	-0.046	<0.001	-0.017	<0.001	-0.026	0.022
Expansion*KAS	-0.016	0.091	0.012	0.239	0.009	0.176	-0.004	0.743
Non-Hispanic Black	-0.099	<0.001						
Hispanic	-0.060	<0.001						
Non-Hispanic Other	-0.079	<0.001						
KAS*Black	-0.053	<0.001						
KAS*Hispanic	-0.026	0.020						
KAS*other	-0.039	<0.001						
Expansion*Black	-0.032	0.003						
Expansion*Hispanic	-0.034	<0.001						
Expansion*other	-0.018	0.003						
Expansion*KAS*Black	0.049	<0.001						

Expansion*KAS*Hispanic	0.017	0.176						
Expansion*KAS*Other	0.024	0.052						

These models also include controls for state fixed effects, secular trends, and patient characteristics (BMI, CPRA, age at waitlisting, sex, blood type, diabetes).

Table 4.4: Model examining triple interaction using only Medicaid patients

Parameter	Estimate	Pr > |t|
Impact of Medicaid Expansion	-0.012	0.509
Impact of KAS	-0.005	0.840
Expansion*KAS	-0.000	0.998
Expansion*KAS*Black	0.031	0.354
Expansion*KAS*Hispanic	-0.015	0.732
Expansion*KAS*Other	0.000	0.994
Non-Hispanic Black	-0.061	<0.001
Hispanic	-0.026	0.002
Non-Hispanic Other	-0.043	<0.001
Expansion*Black	-0.012	0.462
Expansion*Hispanic	-0.011	0.561
Expansion*other	-0.009	0.585
KAS*Black	-0.034	0.159

KAS*Hispanic	0.009	0.807
KAS*other	-0.006	0.838

This model also includes controls for state fixed effects, secular trends, and patient characteristics (BMI, CPRA, age at waitlisting, sex, blood type, diabetes).

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Chapter 5: Conclusions

5.1 CKD, ESRD, and Nephrology Care

Chronic Kidney Disease represents a large and growing public health concern in the United States and will continue to play a large role in our health care system. ESRD affected over 700,000 patients in the US and cost $33.9 billion in 2015 (System 2018). Medicare has covered ESRD patients for decades but it has become increasingly clear that earlier intervention is crucial both for the sake of patients and the federal budget. LDKTx is the preferred treatment for patients with ESRD but continues to be significantly less common than DDKTx. Encouraging LDKTx is both beneficial for the recipients of living donations and for the organ allocation system as a whole which has been unable to supply sufficient deceased kidneys to meet demand. A large and growing body of evidence suggests earlier referral to nephrologists provides significant benefits to patients.

5.2 Main Findings

5.2.1 The 2014 Kidney Allocation System

The KAS made significant improvements in reducing racial disparities in access to DDKTx among waitlisted patients. At the same time, our results suggest that KAS was also associated with a decreased likelihood of receiving an LDKTx among minority patients. This is likely attributable to the fact that minority patients who received increased priority for a DDKTx may now see a LDKTx as a less desirable option. Acquiring a living donor requires both a sizeable amount of effort as well as potentially causing a larger emotional burden for patients who request donations from family or friends. Patients may choose to avoid the emotional or logistical work if they feel likely to receive a DDKTx but this is likely suboptimal for both the individual patient as well as the health care system as a whole. As the ESRD population grows and the DDKTx pool fails to keep pace, LDKTx offers significant potential to increase the number of transplants performed in the US. LDKTx has been consistently shown to produce better outcomes when compared to DDKTx and it is important that providers continue to encourage LDKTx among all eligible patients.

While DDKTx is a suboptimal treatment compared LDKTx, it remains preferable to remaining on dialysis. For this reason, shifting deceased kidneys to minority patients rather than white patients may result in improving net outcomes among ESRD patients. White patients have historically gotten the vast majority of LDKTx and therefore it seems likely that white patients will, on average, be more able to substitute towards LDKTx after receiving a DDKTx becomes less likely. At the same time, minorities are much less likely to be able to acquire a living donor and therefore may not be as able to substitute LDKTx for DDKTx. This means that allocating more deceased kidneys to minorities has the potential to benefit patients who are unlikely to receive a living donor without having a large negative effect on white patients who have more ability to acquire a living donor.

5.2.2 The 2012 Kidney Disease Improving Global Outcomes Guidelines

The United States is in the early stages of a well-documented shortage of physicians and it is not surprising that nephrologists seem to also be in short supply. Interest in the specialty appears to be on the decline despite growing demand (Parker, Ibrahim et al. 2011, Berns, Ellison et al. 2014, Sharif, Elsayed et al. 2016). Our medical education system is designed in such a way that it is impossible to increase physician supply in a short time period, due to the long periods of education and training between college and independent practice. As we face the prospect of an aging population it is important that efforts be made to address the shortage of doctors in order to facilitate guideline-concordant care.

The concern of crowding out is further supported by our observation that while all insured patients saw an increased likelihood of receiving 12+ months of pre-ESRD nephrology care, uninsured patients saw a decreased likelihood. The fact that the gap between the care received by the uninsured and that received by Medicare beneficiaries grows over this period, as does the gap between Medicaid beneficiaries and Medicare beneficiaries suggests that we may not have the supply of nephrologists needed to provide all patients with guideline-concordant care. Our results show all insured patients getting more pre-ESRD care after the guideline change which suggests that the crowding out seen in the uninsured population is likely due to the guidelines rather than Medicaid expansion.

Given the existing concerns about the supply of physicians, it is important to illuminate areas of care in which the supply available seems unable to meet the current demand. This study provides evidence that there may be significant benefits to expanding insurance coverage, but also that the current supply of nephrologists is likely unable to meet the needs of the roughly

15% of American adults who suffer from some stage of CKD(System 2018). Expanding coverage among lower-income individuals is likely to have additional benefits downstream as a growing body of evidence supports the importance of intervening early in chronic conditions, but these benefits will not be fully realized if there are not enough physicians treat beneficiaries. ESRD is the terminal stage of a very costly chronic condition. CMS ends up spending billions of dollars each year covering patients whose kidneys fail and require dialysis or kidney transplantation. Fortunately, our results suggest that nephrologists are relatively responsive to changes in practice guidelines. Expanding coverage to low income patients, who are at higher risk of developing ESRD, may allow us to substitute relatively cheaper preventive care for costly renal replacement therapy.

5.2.3 Medicaid Expansion

Medicaid expansion has changed the health insurance landscape across the country and it is important to understand the impact that is has had on the care of patients with kidney disease. Expansion led to more individuals being covered by Medicaid, which was the goal of expansion, but the likelihood of receiving appropriate pre-ESRD care among Medicaid beneficiaries seems to have declined relative to the trajectory seen in other insurance groups. LDKTx is the preferred treatment for ESRD patients and this study suggests that increased insurance coverage is not enough to improve access to this life-saving treatment for low SES individuals in the US. The large amount of variation seen across transplant centers is a cause for concern when we consider the goal of equitable treatment for patients across the nation. However, such variation also serves as a reminder that there remains much room for improvement in the treatment of ESRD patients.

This is an issue that is likely to increase in importance as our ESRD population continues to grow by around 20,000 individuals per year (System 2018).

Medicaid Expansion was associated with a decreased likelihood of receiving a LDKTx. This is an unintended consequence but it is important to understand when discussing how this policy impacted patients. Policies are necessarily implemented without a full understanding of how they may interact with the rest of the health policy landscape but it is crucial to study such interactions in order to determine how policies can be improved. Medicaid Expansion has been successful in increasing the number of patients that have health insurance, but our results show that this is not leading to increased rates of LDKTx. While insurance is a necessary first step, it is important to understand the ways in which insurance alone is not sufficient to achieve equitable health care.

We have historically seen the ESRD population growing at a faster rate than deceased donation which has led to a worsening shortage of organs(System 2018). LDKTx has the potential not only to provide the recipients with better outcomes, but also to lessen the strain on the DDKTx allocation system. It is important to keep in mind that as we improve access to care for low SES and minority patients, we want to avoid funneling such patients towards lower-quality care. White patients have historically received far more LDKTxs than other racial groups and our results suggest that recent policies are not working to address this disparity. Living donation is voluntary which makes it less amenable to policy changes. For this reason, it is crucial that efforts continue to work to encourage and promote LDKTx, to both patients and providers, as the preferred treatment option for ESRD.

5.3 Conclusions

These studies have shown that polices to improve insurance coverage are not sufficient to ensure equitable care. Medicaid expansion covered more patients but, without increased reimbursement, beneficiaries remain likely to receive care of a lower quality than that received by patients with private insurance or Medicare. It will be valuable to continue studying the effects of Medicaid expansion because there may be additional effects that we have missed due to the limited follow-up data available at this time.

The 2014 Kidney Allocation System made many changes to allocation and significantly reduced disparities in deceased donor transplant. However, it appears to have inadvertently reduced incentives to pursue living donor transplantation, especially among minorities. This is concerning from an equity perspective in that we appear to have made it easier for minorities to get sub-optimal treatment. Improving equity in allocation necessarily requires tradeoffs when we are dealing with a small number of kidneys relative to the large number of potential recipients. In our attempts to fix one disparity, we want to be careful that we do not end up funneling minorities and/or low-SES patients towards suboptimal care. LDKTx remains the preferred treatment for the majority of ESRD patients and efforts to encourage all patients to pursue LDKTx are likely to be beneficial.

Chronic Kidney Disease continues to affect millions of Americans and to cost billions of dollars a year for both public and private payers. As health care costs continue to rise, pressure to intervene earlier in the disease process increases. This patient population represents an opportunity to capitalize on the decades of research into preventive care and to improve the lives of patients while also avoiding potential costs looming in the future.

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